

INTERNATIONAL

Supported Employment Consortium

For the Competitive Employment of People with Severe Disabilities

Personal Assistance in the Workplace: A Customer-Directed Guide

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Reference

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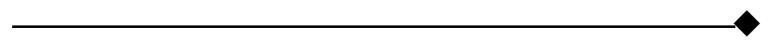
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DEDICATION

The Rehabilitation Research and Training Center on Workplace Supports proudly dedicates this Guide to Personal Assistance Services in the Workplace to Judy Huemann, the current Assistant Secretary to the Office of Special Education and Rehabilitation Programs. Ms. Huemann became well-known as a leader in promoting personal assistance services to enable people with the most significant disabilities to live in the community. Judy used these services herself to both live in her community and to work as the Executive Director of the Berkley, California Center for Independent Living, and at the World Institute on Disability. She co-authored a monograph titled “Attending to America” that documented the value of consumer-directed PAS and its cost-effectiveness. This manual is still being used by many states. Shortly after her Presidential appointment in 1993, Judy began hiring people with significant disabilities who utilized PAS as a workplace support. Her leadership helped to demonstrate the value of PAS not only as a support that enables people to live successfully in their community but also to maintain meaningful careers at the highest level of the Federal Government. Judy Huemann has set a standard that other employers can follow in the provision of PAS as a reasonable accommodation to promote the employment of people with significant disabilities.



ABOUT THE AUTHORS

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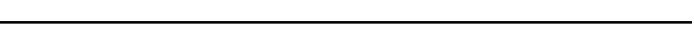
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Ed Turner has thirty-two years experience providing a variety of services to students and adults with different types of disabilities. He has been a Special Education teacher, independent living service provider, an assistant administrator for a gubernatorial board, and a camp director serving children and adults with mental retardation. He currently works as a Training Associate for RRTC-VCU. Ed has utilized PAS as a workplace support in his last three professional position spanning twenty-two years. Here at RRTC, he has provided leadership in research projects on PAS and has written numerous articles related to the findings.

Susan Webb has had a disability for 26 years. She is a Certified Professional in Human Resources (PHR) and was appointed to U.S. Architectural and Transportation Barriers Compliance Board in 1988 by President Reagan. She chaired the Board's task force in development of the ADA Accessibility Guidelines. She served as Executive Director of Arizona Bridge to Independent Living for 8 1/2 years and as a NCIL Board Member from 1966-1999. Twelve years with AT&T, 10 years of that as

a Senior Account Executive. She currently serves as a member of the Arizona Legislative Task Force on Welfare Reform, is President of the Arizona Association of Temporary & Staffing Services, and is an appointee to the Work Incentives Advisory Panel mandated by the Ticket to Work and Work Incentives Improvement Act. Susan started her own company in March, 2000 to provide return-to-work services using IL philosophy and peer mentoring methodology for mothers with disabilities or who have children with disabilities .

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INTRODUCTION

by: Paul Wehman

Historically, personal assistance services have been viewed as an essential way of supporting individuals with physical disabilities in their independent living. The use of personal assistance services has been an important extension of empowering individuals with disabilities to live at home and to move about the community with a greater degree of independence. Without personal assistance services, thousands of people with physical and other significant disabilities would be confined to institutionalized nursing home environments or other segregated living situations that were predicated on the need for group care. Fortunately over the last two decades, there has been both a philosophical and programmatic move away from institutional living arrangements, and an understanding that a personal assistant can play a critically vital role in allowing for improved quality of community living for many people with significant disabilities.

Unfortunately, a myriad of problems is holding back the expansion of personal assistance services. First, there is a scarcity of personnel who are willing and able to fulfill this personal care attendant role. Remember, personal assistants have responsibilities for the lives in their hands, and if they are indifferent or not trained properly in how to perform their duties, particularly in a crisis situation, it can be the difference between life and death. The second problem is that there are very few well developed training programs for guiding people who wish to become competent personal assistants. The third and perhaps the most significant obstacle has been the lack of a clear stream of funding from the state or federal government in helping to underwrite the costs of personal care services as a genuine long-term support priority. It is reasonable to argue that if the federal government is going to pay for wheelchairs, respirators, cochlear implants, job coaches, and other types of long-term support services and devices, public funding for the use of personal assistants to help people enjoy a better quality of life and reduce institutionalization would also be a good investment. To date, this critical shortage of skilled personal care attendants, the lack of quality training resources, and the limited funding available for personal care services are primary obstacles that have made independent living more difficult for people with significant disabilities. Congressional and Presidential

approval of the Medicaid Community Attendant and Supports Act (MiCASSA) and effective implementation by states of the Medicaid Buy-In provision of the Ticket to Work and Work Incentives Improvement Act of 1999 would help to reduce these obstacles.

In this consumer guide, however, we extend our thinking beyond only home and community living to address the role of a personal assistant in the workplace. Although modern medicine and contemporary rehabilitation, as well as families and friends, have helped individuals with disabilities become individually empowered at home, employment must not be left out. In fact, one could very reasonably argue that returning to a previous job, entering new employment, starting a business, or telecommuting are all important elements of closing the rehabilitation loop for people who have suffered serious injuries or experienced significant and/or life changing disabilities. Living with independence at home is vital. Moving about the community is essential, but productive work provides that final stage of fulfillment and meaningfulness that home living by itself cannot provide. This is especially true for younger Americans with disabilities, full of energy and excitement and looking forward to making an impact on the world around them.

Consider for example the young man in the recent movie Remember the Titans who was a star defensive linebacker and larger than life in many of his actions as he struggled to overcome discrimination and improve his athletic prowess. When this young man was in a severe car accident that left him paralyzed, he was the same person— but was he? In reality, he was very much the same person except that he had lost the use of his legs and needed the aid of a personal assistant for him to extend his life in a similar way but with different outcomes. This young man was able to go on and become a star in the Olympics, despite the fact that he used a wheelchair and the services of a personal assistant.

What we hope to accomplish with this guide book is an understanding of the premise that personal assistants are absolutely crucial, not only at home, not only in the community, but also in the workplace. Employers have learned to accept employment specialists and job coaches for short term periods, and they will also accept competent and well trained personal assistants who can help individuals with a disability with critical functions that are necessary in their work performance. For example, in our own Center that is made up predominantly of people without disabilities, some employees have very significant disabilities, such as cerebral palsy. These individuals are highly intelligent and very motivated but in some cases are unable to handle utensils. Therefore,

for these individuals, the services of a personal assistant are used to enhance their ability to get their job done with a maximum of productivity and efficiency. In other cases, personal assistants assist an extremely intelligent and highly motivated individual complete work tasks by operating equipment that the employee with a disability is physically unable to operate. In short, personal assistants in the workplace, as well as in a home environment, should be seen as what they are— **an important extension or support** that enables the person with the disability to be all that she or he can be.

There is really nothing new or radical about this idea philosophically. Virtually all people at some point in their work tenure need help or support. It may be a special type of chair; it may be a different type of schedule; it may be help within the Employee Assistance Program: there really is no end to the different types of assistance that good employers will make available for employees who have shown themselves to be good workers. Yes, the concept of a personal assistant is different, but when you get past the issue of funding, does it really matter? If the employee being supported by a personal assistant effectively and efficiently delivers products or services valuable to the employer, than why not utilize the personal support mechanism?

In this guide, we lay out for the reader strategies for making extension of the personal assistant into the workplace a reality. These strategies emphasize the primary role and responsibility of the person who utilizes these services to hire, train, guide, and supervise the personal assistant. These strategies also involve accurate assessments of the need for personal assistance services at the workplace, careful consideration of the employer's critical involvement in planning for these services, access to needed funding, and consideration of resources such as assistive technology to help with needed workplace supports. We believe that personal assistants have proven themselves over and over again to be viable reasonable accommodations; failure to use this resource when appropriate to the functions of the job discriminates against potential employees who have a disability. It is accepted that a personal assistant can help an individual live with independence at home and move with freedom about the community. Why then should there be any doubt that a personal assistant can help that same person with a significant disability earn a living wage and be more productive in the work place? The answer to this question is simple: the personal assistant can work just as effectively in the workplace as elsewhere in the community.

American society has not come to grips with the value and power of a personal assistant model that is flexible and individualized and has depth in its capacity and available labor pool. Right now, this model is all too frequently a vision and a dream, not a reality, for many individuals with significant disabilities who utilize and depend on the support of a personal assistant. It is our fervent hope that this consumer guide will be one small step in the direction of making personal assistance services a routinely available and accepted workplace accommodation in the years ahead.



USING PERSONAL ASSISTANCE AS A WORKPLACE SUPPORT

by: Ed Turner

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.

Although the business community may consider the ADA definition a fair concession, it presents many challenges to employees with more significant disabilities.

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
-

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.
-

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

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.

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 someone 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.

USING A SELF-ASSESSMENT IN FINDING THE RIGHT PERSONAL ASSISTANT

by: Ed Turner

◆ INTRODUCTION

Finding a qualified workplace personal assistant (PA) begins with the employee with a disability doing a self-assessment. The self-assessment will help identify the employee's support needs and will assist in determining the qualifications to look for when recruiting a workplace PA. Determining the qualifications for a workplace PA is most essential. The employee needs to know how well the PA applicant can perform the skills needed to assist in completing the job tasks. In recruiting a workplace PA, it is important for the employee to find someone who would be interested and capable of assisting in completing work tasks in the most efficient manner.

When an employee with a disability decides to request a workplace PA as a reasonable accommodation for employment, a self assessment becomes a valuable tool in negotiating with an employer for personal assistance services (PAS). The assessment will help determine the level of work-related PAS needed by the employee with a disability and will ultimately assist in finding the PA with the necessary skills.

◆ COMPLETING AN OBJECTIVE SELF-ASSESSMENT

The entire self-assessment process should be driven by the employee with the disability. The employee understands his/her own skills and abilities and can best determine what supports will work most effectively. When completing the self-assessment, the employee should consider three basic factors. First, what are the essential functions of the job and what are the most efficient ways to accomplish these functions? Second, which functions can be accomplished by using assistive technology? Thirdly, which functions can be best done through the assistance of another individual with the necessary skills?

In assessing ways to efficiently accomplish the essential functions of the job, employees should focus the self-assessment on what is needed to increase their productivity and effectiveness. For example, an employee who has limited finger dexterity would find word processing, filing, keeping

the workstation organized, and dialing the telephone difficult. This employee will probably want to recruit a PA who has good motor skills and basic filing skills to assist with these tasks. In this case, it is the employee with a disability who has the responsibility to know what needs to be written, how files should be setup, and how the workstation needs to be organized.

In most cases, employees with disabilities will know their skills, abilities, and support needs. However, it may be advisable to consult with a rehabilitation engineer, vocational professional, Employment Specialist, or the job-site supervisor to make sure all support needs are addressed in the self-assessment. If an employee feels intimidated by having these professionals involved in the self-assessment process, he/she can get a friend to serve as a mentor in this process. Having the support of a mentor or friend is a best practice for ensuring all support needs have been addressed. Nevertheless, it is vital that the employee with a disability is in charge of the self-assessment process.

It is important that the employee and the individuals assisting with the self-assessment systematically identify workplace support needs. In researching material for this chapter, it was difficult to come up with an assessment instrument designed to measure the need for a workplace PA. Most instruments found have been developed for determining the need for assistance in the home setting. A simple checklist can serve as an effective assessment format. This checklist should include such factors as essential functions of the job, how those functions will be accomplished, any assistive devices that may assist in accomplishing these functions, tasks that require human assistance, and estimated times this type of assistance will be needed. For example, a training associate with a significant disability that affects his finger dexterity, coordination, and ability to verbally communicate has requested a workplace PA as a job accommodation. His employer has agreed to provide the services of a workplace PA to assist with job duty tasks. The table on the following page is an example of the checklist he used to justify his needs for a workplace PA. A self assessment checklist form for the reader's use is provided in Appendix 1 at the end of this Guide.

Using this checklist gives the employee with a disability a graphic picture of personal support needs and the accommodations that will best meet those needs. The checklist is also an effective tool in showing employers how the use of assistive technology and a workplace PA can help improve the employee's efficiency. In addition, the list can give the employee a clear picture of the skills needed by the PA. Having

**SELF-ASSESSMENT
CHECKLIST:**

- ✓ **Essential functions of the job;**
 - ✓ **How functions will be accomplished;**
 - ✓ **Assistive devices used;**
 - ✓ **Tasks needing Personal Assistance; and**
 - ✓ **Estimated time PAS needed.**
-

this picture in mind will enable the employee to develop a recruitment strategy and will help in identifying the best applicants for the workplace personal assistant position. The checklist can also be used by the employee in writing an ad to begin the process of recruiting the workplace PA. In addition, the same information can be used to describe the job description that will specifically outline the duties and responsibilities for a workplace personal assistant.

Self-Assessment Checklist for a Training Associate

| ESSENTIAL FUNCTION | HOW FUNCTION WILL BE ACCOMPLISHED | ASSISTIVE DEVICES USED | TASKS NEEDING PERSONAL ASSISTANCE | ESTIMATED PAS TIME NEEDED |
|---|--|---|--|---------------------------|
| Develop training materials, reports, related correspondence | Assistance from a workplace personal assistant | Appropriate computer software | Word processing skills in a timely manner | 12 hrs wk. |
| Acquire speakers and coordinate trainings | Assistance from a workplace personal assistant | Telephone with speaker device | Assistance with dialing phone, recording dates, maintain phone data base | 5 hrs wk. |
| Track training outcomes | Assistance from a workplace personal assistant | Appropriate computer software / telephone with speaker device | Assistance with dialing phone numbers | 2 hrs wk. |
| Prepare and participate in presentations | Assistance from a workplace personal assistant | Appropriate computer software | Word processing, power point skills in a timely manner | 3 hrs wk. |
| Represent company at national meetings | Assistance from a workplace personal assistant | Appropriate computer software | Word processing, personal grooming, travel assistance | As needed |
| Coordinate activities across various projects | Assistance from a workplace personal assistant | Appropriate computer software / telephone with speaker device | Word processing, power point skills in a timely manner | 5 hrs wk. |
| Necessary systems advocacy | Assistance from a workplace personal assistant | Appropriate computer software / telephone with speaker device | Word processing, power point skills in a timely manner | As needed |

◆ RECRUITING A WORKPLACE PERSONAL ASSISTANT

The recruitment process involves developing an effective ad, screening appropriate applicants, using effective interviewing techniques, and weighing all the factors before making a final selection. Once again, the employee needs to be in charge of this process. In writing the recruitment ad, the employee should give basic information such as the type of job, a brief explanation of needed skills, and that the applicant will be working for a person with a disability. At this initial stage, it is not important for the employee to give specifics about his/her disability.

The objective of the ad is to find the most qualified person for the job. The ad should be concise with no more than fifty words and be placed in strategic locations and/or publications to attract qualified applicants. For example, an employee working in an academic environment should target recruitment efforts to people who have the necessary skills required in an academic setting. Some likely locations to post the ad might be on bulletin boards around campus or in newsletters which are read by both faculty and students. Other employees who are in different careers can look at their own workplace environments and determine where to post the ad to receive high readership. The table below contains suggestions on where to post an ad for a PA. Additional suggestions for recruiting a workplace PA are presented in Chapter 3.

Options for PA Recruitment Ads

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 co-workers 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 Yellow-pages of your local phonebook for home care services.



Check with health care profession schools for students who are seeking practical experience.

Check with local colleges for business interns interested in serving as personal assistants while learning about the business.



Advertise in a business newsletter

◆ SCREENING APPLICANTS

As soon as enough applications for the position are received, the employee should begin the screening process. Usually, the initial screening is handled by the employee, and no representative from the company's management or human resource area needs to be involved. However, the employee should make certain there is no company or agency policy to the contrary. Also, the employee should check to see if the employment entity has a policy requiring the workplace PA to fill out an employment application. This is a recommended procedure for best practice.

Most often, the initial screening is conducted by phone by the employee with a disability. By asking a few basic questions, the employee can determine which applicants have the basic skills to merit a face-to-face interview. At this stage, the employee should focus on applicants who have the necessary skills to assist in performing the essential functions of the job. For example, if the employee's job involves word processing, data entry, and other clerical tasks, applicants should be quizzed as to their proficiency in these areas. Hopefully, during this initial screening process, two or three applicants will be determined to have the necessary skills to meet the employee's basic support needs. If so, the employee can then move to the next stage, which is interviewing finalists to become a workplace personal assistant.

◆ INTERVIEWING APPLICANTS

In interviewing applicants, the employee with a disability should be the primary person conducting the interview with two or three other team members. The employee should develop between five and seven questions to ask prior to the interview. The employee can use the job description to come up with the interview questions. An example job description for a workplace PA is contained in Appendix 2 of this guide. The questions should evolve around skills needed, the employee's personal preferences in how tasks are to be accomplished, and the applicant's experience in a work environment. At least one question should be designed in such a way as to gain an understanding of the applicant's feeling about working with and for an employee with a disability. The way the applicant responds to this question should be a determining factor in giving the applicant further consideration. No matter how skilled or unskilled the person may appear to be, if the applicant is having a problem relating to working for an employee with a disability,

Sometimes it might be better to give a person who has less skills more consideration if the individual has a positive attitude about working for a person with a disability. A person can always be trained in the appropriate work skills, but it will be difficult to change negative attitudes.

the employment relationship will not work. Sometimes it might be better to give a person who has less skills more consideration if the individual has a positive attitude about working for a person with a disability. A person can always be trained in the appropriate work skills, but it will be difficult to change negative attitudes.

It is recommended that the interview be held in the employee's work environment. If the employee decides to do a skills test using a word processor or other types of equipment, it can be incorporated into the interview process with no difficulty. Also, with the interview being conducted at the workplace, it gives the employee an opportunity to observe the applicant's behavior and mannerisms. The employee can also observe the applicant's dress attire, which may be another consideration in some work environments. After interviewing all perspective applicants, the employee should have a good idea which applicant is the best candidate for becoming a workplace PA.

◆ **HIRING THE WORKPLACE PERSONAL ASSISTANT** —————

Once the interviews are completed, if the supervisor was not part of the interview team, the employee should consult with the immediate supervisor at the job site before making the job offer. This supervisor will be interacting with the workplace PA and, therefore, this consultation is only a common courtesy. All hiring decisions should be in writing indicating why the candidate was selected. This paperwork should be shared with the supervisor to promote a good working relationship among all concerned.

Following a positive interview, the employee should wait 24 hours before making a job offer to the successful applicant. This allows the employee time to mull over everything that was said during the interview and perhaps raise some new questions that need to be asked prior to hiring the applicant. It also gives the company time to check out the applicant's past work history, references, and background.

Once the employee is comfortable with the final decision, the job offer is now ready to be made. The offer can be made over the telephone. However, a pre-employment meeting should be scheduled to clarify final details and to iron out any problems or concerns either person may have. This meeting may also produce a written document that can be called "an employment agreement or contract". This agreement should outline the workplace PA's responsibilities and the employee's obligations to that person. It should also stipulate how the salary will

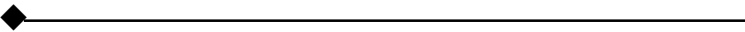
be paid and when. This is especially important if the employee plans to pay a portion of that salary in addition to what the employer will pay. The agreement should also list the terms of employment such as vacation days, sick days, quarterly or semiannual performance evaluations, reasons for immediate termination, and causes for lay-offs. Once this agreement is developed, it needs to be reviewed, agreed to, and signed by both the employee, the workplace PA and the employer.

The performance evaluation is a very important tool that gives the employee an opportunity to identify any modifications or additions to the support plan. The evaluation also gives the workplace PA the opportunity to cite any needs for additional training based on the changing support needs of the employee. The evaluation provides the opportunity to share problems or concerns either may be having. The evaluation should not be used as an instrument to discipline but rather a gage to be used to improve the working relationship.

The performance evaluation can be a part of the employment agreement. An example of an employment agreement for a workplace PA is found in the Appendix.

◆ SUMMARY

This chapter contains a blueprint to assist the employee with a disability find the most qualified workplace personal assistant. As noted, the whole process needs to be driven by the employee who will be using this vital support. However, during the initial stage of completing the self-assessment, the employee should seriously consider seeking the advice of the most appropriate rehabilitation professional to make certain all support needs are being addressed. It is the self-assessment that will determine the needed qualifications of the applicants who will be recruited to become the employee's workplace personal assistant. The employee should have the final decision on the selection of qualified candidates to serve as a workplace PA.



TRAINING A PERSON WITH A DISABILITY TO USE PAS

by: Jeanette Strong

◆ RECRUITMENT TIPS

Recruitment of personal assistants (PA) is an ongoing process for many persons with disabilities. Because of low pay, lack of benefits (in most cases) and few chances for promotion, turnover of PAs can be quite high. By casting a wide net, qualified applicants may be found who become longer-lasting assistants.

ADVERTISING FOR A PA

How to advertise is as important as where to advertise. When writing ads, be brief and to the point. If any inducements such as higher pay are being offered, emphasize that in the first line of the ad. Do not include your home address to insure safety and to avoid having people show up to check on the job. Interview applicants at your place of employment.

ADVERTISEMENT GUIDELINES

Give the following information:

- ▶ **brief description of duties (without being too technical);**
- ▶ **your telephone number;**
- ▶ **work hours required; and**
- ▶ **experience or qualifications (driver's license, medical certification, skills specific to helping employee at the workplace, etc.)**

There are numerous places to look for personal assistant applicants. Here are some examples:

1. **Agencies for persons with disabilities** -- Most independent living centers offer information and referral services and have a registry of potential personal care assistants. Some referrals will have experience working as PAs for persons with disabilities; however, it is up to the employee to screen applicants and train the PA.
2. **Classified ads in local or college newspapers or shoppers** -- Many persons with disabilities feel that placing classified ads is the best way to recruit assistants. Contact your local newspapers and compare prices. Keep your message short and to the point.

WHERE TO LOOK FOR PAs

- ▶ Agencies for people with disabilities,
- ▶ Classified ads,
- ▶ Bulletin boards,
- ▶ Colleges,
- ▶ Employment office,
- ▶ Senior citizen groups, and
- ▶ Word of mouth

3. **Bulletin boards: college dorms or libraries, laundromats, apartments, YMCA/YWCAs, etc.** -- Posting on bulletin boards is a great, free way to recruit PAs. If possible, post your ad at your place of employment. Write or type the ad clearly in print large enough to be seen from a distance.
4. **Colleges and universities** -- Personal assistant work can be well suited to college students' schedules. Post your ad on their bulletin boards, advertise in their newspaper, or call the college placement office to ask for referrals. Colleges that train health care professionals (occupational and physical therapists, nurses, etc.) can be a source of applicants.
5. **Local employment office (Workforce Development, Manpower)** -- Many people who are out of work check for available jobs at an employment office. Call your local employment office and ask to list your job opportunity.
6. **Senior Citizen groups** -- Some individuals have reported that they have found PAs through local agencies that find jobs for retired senior citizens. These agencies differ from city to city. Call your local Council on Aging, Association of Retired Persons, or other senior citizen groups to locate the appropriate agency in your area.
7. **Word of mouth** -- Get referrals from friends, relatives or other disabled peers. Peers using PAs can recommend good assistants.
8. **Other places to advertise** -- Newsletters from hospitals & civic organizations • Church bulletins: Call your minister or rabbi to post an ad • Other community groups (social, political, volunteer or civic) may have a pool of applicants, or may be able refer you • Support groups for persons with disabilities.

SAMPLE ADS THAT FOLLOW GUIDELINES

- ▶ **Blind man wishes to hire reader/driver for paperwork and errands. Must have own vehicle. Call Pat @ 123-4567.**
- ▶ **Wanted: personal care assistant for male with a disability needing assistance at work. Call Elvis @ 123-4567.**

SAMPLE ADS THAT DO NOT FOLLOW GUIDELINES

- ▶ **Minimum wage position, no benefits. Evenings and weekends required. Must be able to operate Hoyer lift. Call 123-4567.**
- ▶ **Caregiver needed immediately to care for CP adult. Minimum wage. Medically trained only need apply. Call 123-4567.**

Contracts are an important management tool. They specify employee behaviors and set up clear guidelines that outline the responsibilities of both the employer and employee. The employee may need to develop an employment contract to clarify duties. A written contract makes it easier to maintain an effective and long lasting working relationship with the workplace PA. A contract should include:

- ▶ **duties in specific areas;**
- ▶ **the number of hours and schedule;**
- ▶ **wages: hourly, by job, mileage rate;**
- ▶ **supervisor;**
- ▶ **2 weeks notice, for leave;**
- ▶ **confidentiality requirements;**
- ▶ **limits on work behavior, absenteeism, tardiness, phone usage, and dress code;**
- ▶ **notice for emergencies;**
- ▶ **social limits (i.e., smoking, alcohol use, swearing);**
- ▶ **contract employee status; and**
- ▶ **signatures, dated.**

PAY RATES

Pay rates vary from company to company, consumer to consumer, and task to task. For a guideline of competitive rates, your local independent living center should be consulted. Some employers give a raise for satisfactory performance on an anniversary date. Some give bonus pay or paid time off for perfect attendance. Others reward longevity or superior performance by paying tuition for expanded training for the personal assistant. When a company and an employee are sharing the salary of the PA, raises and rewards should be planned together.

Compensation can vary depending on the task, experience/skill level of the PA, and the time of day the PA is needed. A pay differential for evening work or more difficult tasks may encourage assistants to perform tasks in a timely manner. People who hire drivers pay a mileage rate only while the individual is being driven somewhere. Mileage rates vary, as do hourly rates. Don't be afraid to negotiate.

A completed sample contract is presented on the following page. It is meant to only serve as a guide because contracts must fit individual circumstances.

◆ **MANAGING A PERSONAL ASSISTANT** _____

The training program is a critical component in personal assistance management. Management skills contribute to continued success in hiring, training, and retaining reliable, conscientious PAs. In the event that a PA does not stay, a well managed working relationship will give valuable skills for future hiring or supervising situations.

Attempt to create an environment where the PA's best traits will flourish. While it may not be easy to establish good communication, time invested in this process will pay off with a PA who is motivated.

Personal assistance management may seem complicated, but with some planning and perseverance, it can be accomplished. Remember: other persons with disabilities have been effectively hiring and managing personal assistants for years. Be ready to communicate job activities to the PA along with the time of day specific tasks are to be completed. Everyone learns differently, so do not rely on only one method of training. Do not end up on the floor because an assumption was made that the assistant knows how to do a transfer.

Periodically during the training, take time to stop and ask the assistant questions to assess understanding of the procedures. Do not expect a PA to be able to perform routines the first time. Setting up a good working relationship with the assistant starts with making expectations clearly understood from the beginning. The training period is the time to lay important ground rules for necessary behaviors and to set the tone for the relationship. The process of training someone involves patience and the ability to break tasks down into small, easily understood units that can be communicated to another person.

FEEDBACK/CONSTRUCTIVE CRITICISM _____

The most important part of managing assistants is providing feedback—both praise and constructive criticism. Research has shown that job performance improves and remains high when employees receive positive feedback on jobs they perform well. The training period gives ample opportunity to solve small problems before they become too big. Feedback makes the assistant aware of his/her performance and needed adjustments. Constructive feedback guidelines are as follows:

1. Give feedback as soon as a problem occurs. Prompt feedback lets the PA know how he/she is doing after an activity.
2. Be specific. Explain the parts of the task that were done well, what needs improvement, and how to improve performance.
3. Don't bring up incidents from the past. Deal with issues as they occur. Focus on the performance, not the person or personality.
4. Give feedback to provide information, not to criticize. Coach, don't command.

SAMPLE CONTRACT: This is a legally binding document. Be sure you understand everything in this contract BEFORE you sign it.

The assistant will perform the following services for the person with a disability. Activities include, but are not limited to: preparing for work, workplace activities of daily living, equipment set up, communication assistance, mobility assistance, office duties, transportation.

Assistant will be supervised by and is wholly responsible to the person with a disability.

Assistant will respect the confidentiality of the person with a disability.

Assistant will complete duties by the agreed-upon time.

Three absences without prior notification and/or three tardies will result in termination.

Assistant will work Monday through Friday from 7:30 am to 5:00 pm on days when the person with a disability regularly reports to his/her place of employment. (Excludes state holidays.)

Assistant will take breaks with the person with a disability and will have an unpaid lunch hour that will be taken before or after the person with a disability's lunch time.

The person with a disability will pay the assistant an hourly wage of \$8.00 semi-monthly on the 15th and the last day of the month.

Transportation with or for the person with a disability will be reimbursed at the rate of \$.30 per mile if the assistant uses his/her own vehicle. The assistant agrees to use the employer's vehicle ONLY for business purposes.

Salary does **not** include paid vacation or sick leave.

In an emergency, the person with a disability and the assistant will notify the other as soon as possible.

Assistant will be notified three times of unacceptable behavior before being terminated, unless such behavior endangers the person with a disability's health or safety, in which case the assistant will be terminated without notice.

Each party will give two weeks notice before terminating this contract.

The assistant is working as an independent contractor and is solely responsible for keeping adequate records and making tax and other payments related to contract. Assistant acknowledges that no money will be withheld by the employer for payment of assistant's local, state, or federal taxes.

Signature of the person with a disability _____ Date _____

Signature of the assistant _____ Date _____

5. Balance praise and criticism. Give as much praise as possible. The assistant is often making valuable contributions; mention those first.
6. Rehearse your message; before delivering it.

FEEDBACK

- | | |
|---|---------------------------------|
| ▶ Give feedback promptly. | ▶ Coach, don't command. |
| ▶ Be specific. | ▶ Balance praise and criticism. |
| ▶ Don't bring up incidents from the past. | ▶ REHEARSE |
-

POSITIVE REINFORCEMENT

Honest appreciation of services rendered is valued by everyone. The more specific the praise, the greater the impact.

It can be difficult to give negative feedback. Try hard to think about the consequences of not giving feedback. Generally, that translates to unmet workplace needs and sloppy or incomplete work being accepted from the assistant. A work supervisor may see these problems as reflection of the employee's inability to perform the duties of the job.

No one learns by hearing "You did a terrible job!" If the PA performs only one part of a task incorrectly, it is a good to mention first what was done correctly. Point out positive aspects as well as areas that need improvement.

EXAMPLES OF POSITIVE REINFORCEMENT STATEMENTS

- ▶ "I really appreciate all your hard work."
 - ▶ "You did a great job taking notes in the meeting. They will be very helpful."
 - ▶ "You did a good job taking notes. Next time don't gossip with Mary."
-

SCHEDULING PA WORK HOURS

Scheduling is an important employee management skill. Not only are there numerous ways to make schedules, each can be customized to meet individual needs. While these schedules may seem like a lot of paperwork, they contribute to a good working relationship with a workplace PA. Well planned schedules insure effective coverage of needed areas of assistance and make it easier to explain the position to a new PA or applicant. Careful preplanning can maximize assistant services and promote a smooth functioning work relationship.

Sloppy or incomplete work from a PA may be seen by a supervisor as poor job performance by the employee.

In making a schedule, first consider how often tasks need to be done, (daily, several times a week, once a week, or only require occasional attention). Then estimate how long each task will take. Tasks that require longer periods of time can be scheduled on alternate days.

Schedules can be arranged to meet learning style, personality, or paperwork needs. Some can serve as a time sheet to tally assistant hours. Others provide for the concise communication of specific details of the position duties and activities. Use the scheduling approach that will be most effective for the situation.

A simple task list arranges duties as they occur throughout the day. A narrative style allows for an informal description of daily activities. Activities can be also arranged in a daily grid. Samples of a service area schedule and schedule grid are provided on the following page.

MAKING SCHEDULES

- ▶ **How long does each task take?**
- ▶ **How often does the task need to be done?**
- ▶ **Group tasks together.**

TASK LISTS

- ▶ **Schedule: weekdays 7:00 - 8:00 a.m. prepare for work, 8:00 -9:00 a.m. transport, 9:00 - 11:30 a.m. office duties, lunch and personal care, return at 5:00 - 6:00 p.m. for transport home.**
- ▶ **Personal assistance: medication, transfers, bathing, minimal grooming and hygiene.**
- ▶ **Office duties: filing, taking meeting notes, equipment set-up, paperwork, business transportation as needed.**

EXAMPLE OF A NARRATIVE SCHEDULE

I have MS and use an electric chair. I need assistance getting up in the morning and getting ready for work. A PA should arrive at my house at 7:00 a.m. to enable me to be ready and leave by 8:00 a.m. The PA would drive me to work. From that point until noon the PA would need to be involved with my office duties by taking notes, filing, and performing general clerical duties. After assisting me with lunch, the PA would then be free until it is time to pick me up at 4:30 p.m. The PA will then transport me home and prepare a light meal for dinner. This schedule involves wheelchair assistance and minimal business travel. An occasional overnight is required.

◆ SERVICE AREA SCHEDULE

| <i>Service Area</i> | <i>Hours per Week</i> | <i>Schedule</i> | <i>Comments</i> |
|-----------------------------|-----------------------|------------------------|---|
| prepare for work, transport | 5 | 7 - 8 a.m. | minimal assistance required |
| workplace personal cares | 5 | 8 - 9 a.m. | medication 2 x daily, assist with lunch |
| equipment set-up | 3 | beginning & end of day | maintenance as needed |
| mobility assistance | 5 | as needed | meetings, business travel |
| office duties | 5 | mostly p.m. | paperwork, filing, taking meeting notes |

◆ SCHEDULE GRID

| | <i>Monday</i> | <i>Tuesday</i> | <i>Wednesday</i> | <i>Thursday</i> | <i>Friday</i> |
|---------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Prepare for Work: | | | | | |
| Dressing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bathing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Transfers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hygiene | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Transportation to and from work | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Office Duties: | | | | | |
| Typing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Filing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Taking Notes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mailings | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Equipment Set-Up | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mobility Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

CLARIFYING ON-THE-JOB RELATIONSHIPS

Just like some people hire someone to clean their home, change their oil, or cook their food, persons with disabilities hire PAs to assist with daily living activities. Persons with disabilities direct the actions of their PA, even in cases where they do not directly pay for their services or hold the power to fire.

Personal assistants perform a variety of services in the workplace that may include:

- ▶ **Daily workplace activities: assisting with beverages or food, assisting with lunch, grooming, administering medication.**
- ▶ **Equipment set up: technical/electrical equipment such as a wheelchair, closed circuit TV, etc.**
- ▶ **Communication assistance: answer phone calls, interpret for person with hearing or speech impairment.**
- ▶ **Mobility assistance: guide to meetings, restrooms, etc.**
- ▶ **Office duties: copying, filing, dictating, handling paperwork, taking notes in meetings, reading documents, opening mail, entering data, keeping workspace organized, preparing mailings.**
- ▶ **Transportation: take to and from work.**
- ▶ **Business travel: make arrangements, handle paperwork, provide transportation, provide guide services on business trips.**

A good working relationship between the assistant and the employee receiving PA services includes a clear delineation of the PA's duties. It involves a clear understanding of accountability. For example, in a situation where an insurance company is the employer, the PA would likely be accountable to the employee with a disability for specifics related to the job and to the insurance company's human resource department for overall conduct.

◆ CONDUCTING SEMI-ANNUAL PERFORMANCE REVIEWS —

Setting up a schedule for regular evaluations provides an opportunity to reward good performance and improve poor behaviors. A two-

day trial period provides both parties with an opportunity to determine if the relationship is going to work. The first evaluation can be done at 90 days, then six months, and finally once a year. During an evaluation, ask for the PA's input on what parts of the job he/she likes or dislikes, and suggestions to improve service. An example of a Personal Assistant Evaluation Form is on the following page.

Some people who employ personal assistants do not complete a formal performance review. Instead, they handle problems as they occur.

“I have found it necessary to formally lay out expectations, but have not done a performance review.” Mark Jones

“I don't do regular reviews with my assistants, but if there is a problem, we talk about it.” Marsha Williams

◆ RESOLVING DISPUTES

HANDLING CONFLICT

Handling conflict is an important management skill that involves compromise and negotiation. Don't remain silent if the PA's behavior is less than satisfactory. Personal assistants who quit usually identify a lack of communication as the primary reason for leaving. Assistants who are not satisfied with their position cannot reflect positively to co-workers, supervisors, or customers. Here are sample ways to diplomatically resolve conflicts:

1. Describe the actions: Don't label, accuse or insult. Avoid making it a personal issue.
2. Define the conflict as a mutual problem to be solved, not as a win/lose struggle.
3. Be specific in defining the conflict and give possible solutions.
4. Discipline tactfully. Maintain a constructive dialogue rather than communication that causes resentment and defensiveness. Tactful discipline is fair, private, and without anger.

LISTENING SKILLS

Employing active listening skills, can result in improved management skills on and off the job.

- ▶ Listen consciously without interrupting.
- ▶ Don't think of what to say next. If the listener is focused on a reply, concentration is taken away from the speaker.
- ▶ Hold discussions in a quiet space at a time when the PA is most capable of communicating.
- ▶ Provide truthful, accurate information to the receiver. Don't make promises that can't be kept.
- ▶ It is up to the employee to modify his/her listening behavior, not the PA.

◆ ASSISTANT EVALUATION FORM

Name of Assistant: _____ Date: _____

| | | | | | | |
|---|---------------|---|---|---|---|--------------|
| 1. Arrives for work when scheduled | almost always | 1 | 2 | 3 | 4 | almost never |
| 2. Follows directions | almost always | 1 | 2 | 3 | 4 | almost never |
| 3. Maintains open communication | almost always | 1 | 2 | 3 | 4 | almost never |
| 4. Treats consumer respectfully | almost always | 1 | 2 | 3 | 4 | almost never |
| 5. Respects consumer's preferences | almost always | 1 | 2 | 3 | 4 | almost never |
| 6. Maintains confidentiality | almost always | 1 | 2 | 3 | 4 | almost never |
| 7. Conscientiously performs routines | almost always | 1 | 2 | 3 | 4 | almost never |
| 8. Handles constructive criticism well | almost always | 1 | 2 | 3 | 4 | almost never |
| 9. Does quality work | almost always | 1 | 2 | 3 | 4 | almost never |
| 10. Shows initiative in handling problems | almost always | 1 | 2 | 3 | 4 | almost never |

Comments: _____

The values, habits, and personalities of the assistant may positively or negatively define the work relationship. Conflict can arise if values are not shared or respected. Prior to making an offer of employment, decide if the PA can be a smoker, someone who drinks socially, someone who curses, or someone with strong political beliefs. These values or habits can interfere with establishing a work relationship. By setting limits on certain social behaviors, problems can be forestalled as an effective and longer lasting working relationship is built.

HOW TO TERMINATE AN ASSISTANT

Specialists in personnel management suggest never firing an assistant in anger. However, if the assistant's behavior endangers health or safety, the assistant should be terminated without notice. Before termination, think through the reasons for dismissal and what backup arrangements can be put in place. Reasons for dismissal might include:

STEPS TO BETTER LISTENING

- ▶ **paraphrase,**
- ▶ **maintain eye contact,**
- ▶ **ask relevant questions,**
- ▶ **remain calm & non-judgmental, and**
- ▶ **offer reasonable options.**

-
- ▶ **drug or alcohol abuse,**
 - ▶ **physical abuse,**
 - ▶ **sexual harassment,**
 - ▶ **general misconduct: insubordination, breach of contract, unauthorized property use, etc.**
 - ▶ **poor performance: repeated warnings about incorrect procedures, excessive tardiness, or absenteeism.**
-

Except in cases where health or safety is endangered, there is a responsibility to give the assistant two weeks notice prior to terminating his/her services. If consistent feedback has been given about problems all along, termination should not come as a surprise. Questions to ask when considering termination include:

-
- ▶ **Does the assistant follow directions?**
 - ▶ **Does the assistant interfere with daily activities?**
 - ▶ **Does the assistant reflect negatively on the business?**
 - ▶ **Does the assistant consistently show up late or not show up at all without notification?**
-

Ending the relationship with an assistant can be the opportunity to improve personal management skills by evaluating what worked and what needed improving. When an assistant resigns, conduct an exit

interview to determine what the assistant felt was good and bad about the position and solicit recommendations on how to make improvements. The exit interview may help determine and correct problems before they cause irreparable damage in the next PA working relationship.

Once an assistant has been hired, it is impossible to project how long they will stay. There is no benchmark that represents an official guide to a PA's longevity. Many aides are in transition from one state of life to another. The successful management of your personal and workplace needs is an ongoing process that will usually be in a state of change. Don't get discouraged when things don't work out. Personal assistant management is a delicate balance of authority, responsibility, and friendship that must be fine tuned as situations change. The bottom line must be safety, physical and mental health, and independence.

◆ DETERMINING THE CAPABILITIES OF A NEW PA —————

New personal assistants should be screened for work-related experience, not just for those skills necessary to get ready for work or transporting to and from work. The assistant who does a good job at home may not be the best person to select for work-related duties. Keep in mind the skills needed in the workplace and hire accordingly. Having a specific set of job duties in mind will assist in hiring and training a personal assistant at work. A personal assistant who does not have good office skills may still be useful at home and/or to keep on a list of emergency backup workplace assistants.

In recruiting a PA for workplace support, look for standard business behaviors: professionalism, good communication skills, respect for authority, and specific job-related tasks such as typing or note-taking skills. Make it clear to the assistant that she/he reflects on the agency or business. One employee always directs his assistant to not violate office confidentiality with "What you see or hear here, stays here."

The level of experience and training can vary considerably among candidates. To determine the capabilities of a potential PA, a skills assessment may include:

- ▶ **Work related history in individual, agency or institutional settings,**
- ▶ **educational history in health care related areas including diplomas, degrees, certifications or related training and course work,**

(continued)

In recruiting a PA for workplace support, look for standard business behaviors.

- ▶ background in providing support to persons with disabilities,
- ▶ communications skills (verbal and non-verbal) and active listening skills,
- ▶ ability to provide mobility assistance,
- ▶ familiarity with adaptive equipment: hearing aids, low vision aids, wheelchairs, braces, computer access equipment CCTVs, refreshable Braille, Relay devices, TTYs, etc.,
- ▶ ability to safely maneuver wheelchairs on steps, ramps and curbs, and
- ▶ background in basic first aid, CPR.

◆ UNDERSTANDING FEDERAL & STATE REPORTING REQUIREMENTS

An employer of a PA must generally withhold income taxes, pay social security and Medicare taxes, and pay unemployment taxes on wages paid to an *employee*, unless the PA, works for an *independent contractor*.

When the employee shares in the salary of the PA the following requirements should be set:

- ▶ the worker must follow your instructions about when and how to work,
- ▶ you control the details of how the work is done,
- ▶ you provide the training, and
- ▶ you set the hours and schedule.

Training of a PA by an experienced employee is an indication that the employer wants the services performed in a particular method or manner. The existence of a continuing relationship between a PA and the person for whom the individual performs services is a factor tending to indicate the existence of an employer-employee relationship. This type of relationship is considered permanent if recurring work is contemplated, even if the services are performed on a part-time basis, are seasonal, or the person actually works only a short time.

An *employee* is usually paid by the hour, week, or month; payment on a commission or job basis customary occurs when the PA is an *independent contractor*.

The right to fire is an important factor, indicating that the person possessing the right is an employer. *Independent contractors*, on the other hand, cannot be fired as long as they produce results which measure up to their contract specifications.

A personal assistant is generally considered an *independent contractor* if:

- ▶ **you pay them by the job (not by the hour),**
- ▶ **you do not provide benefits,**
- ▶ **the relationship is for a short period of time (not indefinitely),
or**
- ▶ **they work for more than one person, (not just you).**

Independent contractors ordinarily use their own methods and receive very limited training from the purchasers of their services.

If a person works for a number of people or firms at the same time, it usually indicates an independent status because in these cases, the worker is usually free from control by the people or firms. It is possible, however, that a person may work for a number of people or firms and still be an employee of one or all of them. Most consumers of PAS reported that their employer paid the withholding taxes since the personal assistant was considered an employee of the business. Some PAs had recently changed from independent contractor status where they had been responsible for withholding their own taxes and were reimbursed for expenses.

◆ SUMMARY

Learning how to effectively use a workplace personal assistant will enable more persons with disabilities to be successful in employment and to obtain positions more in keeping with their true potentials. The material presented in this chapter is drawn from the suggestions of many persons with disabilities who use personal assistants. These individuals include a woman in a wheelchair who uses a two day trial period technique with potential PAs. The voice of the man who is blind talking about the importance of professional behaviors is represented in the material, as is the man in a wheelchair who uses varying pay rates on weekends. These successful persons with disabilities manage their personal assistants, drivers, readers, and attendants. Their techniques are

gained from personal experience, creative solutions, and learning the hard way how to navigate the mine field of assistant security issues.

Some persons with disabilities enjoy a long working relationship with the personal assistants they employ. The PAs themselves benefit from the association with an employer who offers a wider range of life experiences and enlarged work situations beyond what the PAs might have gained on their own. This synergy is an enlightening aspect of a situation that on the surface may appear to be a simple employer/employee relationship. A successful relationship between an employee with a disability and the workplace personal assistant will aide each in looking beyond disability and towards a more successful use of all the capabilities of both individuals.

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WORKPLACE PERSONAL ASSISTANT SERVICES: EMPLOYERS PERSPECTIVE

by: J. Michael Barcus & Pamela Targett

◆ INTRODUCTION

As discussed in Chapter One of this guide, there are many different definitions of Personal Assistance Services. However, many employers are most familiar with the definition from the Presidential Committee on Employment of People with Disabilities. The Presidential Committee's Job Accommodation Network (JAN) describes Personal Assistance Services as "people" or "devices" that assist a person with a physical, sensory, or cognitive disability with tasks that the person would perform for her or himself if she or he did not have a disability (Presidential Committee on Employment of People with Disabilities, 1997). The Presidential Committee on Employment of People with Disabilities states that work-related PAS may include:

- ▶ **filing;**
- ▶ **retrieving work materials that are out of reach;**
- ▶ **providing travel assistance for an employee with a mobility impairment;**
- ▶ **assisting and employee with a cognitive disability with planning or decision making;**
- ▶ **reading material to an employee with a visual impairment;**
- ▶ **providing a sign language interpreter during staff meetings to accommodate an employee with a hearing impairment**

PAS may take the form of adjustments to an employee's work schedule, a co-worker assigned to assist a worker with a disability with a specific job related function, modification to the employee's work station, or the hiring of a workplace personal assistant.

◆ WHY EMPLOYERS SHOULD CONSIDER PAS AS A REASONABLE ACCOMMODATION

The same forces that are driving our strong economy are also creating one of the greatest challenges faced by today's employers: low unemploy-

The same forces that are driving our strong economy are also creating one of the greatest challenges faced by today's employers: low unemployment. Thus, many employers are turning to the large and untapped labor pool of employees with disabilities.

ment. Thus, many employers are turning to the large and untapped labor pool of employees with disabilities. The use of PAS as a reasonable accommodation is new to many businesses. In the workplace, PAS is considered a reasonable accommodation to enable an employee to perform the essential functions of the job. According to Section 1630.9 of the Americans with Disabilities Act (ADA) Handbook, the employer's obligation to make a reasonable accommodation is a form of non-discrimination.

SECTION 1630.9 -- NOT MAKING REASONABLE ACCOMMODATION

- (a) It is unlawful for a covered entity not to make reasonable accommodations to the known physical or mental limitations of an otherwise qualified applicant or employee with a disability, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the operation of its business.**
- (b) It is unlawful for a covered entity to deny employment opportunities to an otherwise qualified job applicant or employee with a disability based on the need of such covered entity to make reasonable accommodation to such individuals' physical or mental impairments.**
- (c) A covered entity shall not be excused from the requirements of this part because of any failure to receive technical assistance authorized by Section 506 of the ADA, including any failure in the development or dissemination of any technical assistance manual authorized by that Act.**
- (d) A qualified individual with a disability is not required to accept an accommodation, aid, service, opportunity or benefit which such qualified individual chooses to accept. However, if such individual rejects a reasonable accommodation, aid, service, opportunity or benefit that is necessary to enable the individual to perform the essential functions of the position held or desired, and cannot, as a result of that rejection, perform the essential functions of the position, the individual will not be considered a qualified individual with a disability.**

From: A Technical Assistance Manual of the Provisions of Title I. Equal Employment Opportunity Commission

If an adjustment or modification specifically assists the individual in performing the duties of a particular job, it may be considered a type of reasonable accommodation (ADA Handbook, 1992). For instance, an employer may provide an individual who is blind with a workplace personal assistant to act as a sighted guide on business trips. However, if a modification assists the individual throughout his or her daily activities, on or off the job, it is considered a “personal” item that the employer is not required to provide. An employer does not have to provide an employee with a workplace personal assistant for personal needs such as grooming, eating, or personal hygiene unless such non-job related supports are provided to employees without disabilities (EEOC Title I Technical Assistant Manual, 1992). Daily living activities on or off the job are not the responsibility of the employer.

◆ **WORK SITE MODIFICATIONS AND ASSISTIVE TECHNOLOGY AS A REASONABLE ACCOMMODATION**

Work site modifications through use of adapted equipment or alterations to the workplace often make it possible for a qualified person with a disability to do the same job as everyone else. For example, the use of the telephone at work for the workers with normal hearing is seldom an issue. However, for the worker unable to hear clearly or to hear at all, using the phone to take accurate information or to place an emergency call can be an issue. To improve hearing on the telephone, many types of assistive devices are available. The following are a few examples:

- ▶ ***Amplified Telephone*** -- Amplified telephones with frequency response selections can help the person with moderate to severe hearing disability. These systems are more costly (usually several hundred dollars) and may not work with multi-line phone systems.
- ▶ ***“In-Line” Amplifier*** -- Small, inexpensive “in-line” amplifiers give minimal amplification but are often adequate for the user with a mild to moderate hearing disability. This type of amplifier is connected between the body of the standard telephone and the receiver.
- ▶ ***Portable Amplifier*** -- Another inexpensive, but often completely adequate phone amplifier is the portable amplifier

(continued)

that attaches to the receiver of the standard telephone. The portable phone amplifier, can be easily carried in a pocket or purse and is powered by either an AA battery or a hearing aid battery. This type of phone amplifier is also useful for the person with a mild to moderate hearing disability. It can be used on single or multi-line telephones.

Work site modifications may include special equipment, facility modifications, and/or adjustments to work schedules or job duties. For example, an employee with quadriplegia uses a personal computer to develop office procedures and operation manuals. To increase productivity, her employer purchased a voice dictation program that enables her to operate her personal computer for research, e-mail, report writing, and data collection. Another employee who is blind has to prepare memos, briefs and technical reports using a variety of resources such as books, newspapers, and Internet materials. His employer purchased a print reader to assist him in accessing these products.

Some employers are afraid that work site modifications for workers with disabilities will be expensive and therefore prohibitive for many businesses. Research from JAN shows that accommodations don't have to be costly: 80% of job accommodations suggested by JAN cost less than \$500 (Job Accommodation Network, June 14, 2000). In a recent survey of 42 companies, Virginia Commonwealth University found that 80% of human resource representatives indicate costs are an insignificant barrier to hiring or advancing persons with disabilities (Darlene Unger, Personal Communication, October 12, 2000). Table 1 on the following page includes examples of the use of work site modifications and assistive devices in the workplace.

◆ USE OF A “WORKPLACE PERSONAL ASSISTANT” AS A REASONABLE ACCOMMODATION

If a person has a visual, hearing, speech, or mobility impairment, the accommodation that enables the individual to work may be a person, known as a workplace personal assistant (WPA). Most employees do not require a PA; yet, for those individuals who do need these services, they can make the difference between employment and unemployment. Hiring individuals to assist employees with disabilities to perform their jobs is considered a reasonable accommodation. Providing a PA for certain job-related functions may include qualified readers or

A bookstore needed a cashier for the afternoon rush; it hired an individual who has a spinal cord injury. Since the store had a workstation that was low enough for him to use, only a few changes were made to his cashier station.

- First, a hook was added to hold bags for packaging customer purchases. This allows the cashier to get bags easily without having to bend over.
- Next, several shelves were removed so he could maneuver behind the counter, and the phone was lowered to within his reach.
- The Cashier cannot use his fingers, so he was given a few simple tools. A short dowel was inserted into a cuff, which allows him to pull money out of the drawer and to push numbers on his keyboard. A change belt was mounted on the counter in front of him so he could handle coins more easily. He pushes down the buttons at the top to get the exact amount of a customer's change.

A business found that it never had enough promotional materials to meet customer demand. When requests were made to the company, the response time was slow. A young man with cerebral palsy was hired to put together sales binders and fill customer requests. To make it easier to compile the binders, the most frequently used materials were placed into two "lazy Susan" filing systems that sit on his desk.

- Other important information is filed on shelves with the least used materials located on the higher shelves.
- A co-worker assists him when he needs to reach these materials.
- A simple box was built for his wheelchair so he can move materials from one area of the office to another.
- Since he could not use a standard hole punch, an electric one was purchased from an office supply store. This low cost accommodation allows him to punch holes using only one hand.

A woman was hired by a university card service to perform customer service duties. She takes pictures of students, faculty, and staff using a computerized photographing system. To make the job accessible, her camera was moved from the floor to a table at her workstation.

- She was unable to use a standard mouse; it was replaced with a trackball. A trackball is simply an upside down mouse that allows you to move the cursor with one finger.
- She was unable to handle money to balance her cash drawer. A phone call to a local bank to inquire about purchasing a currency counter resulted in the acquisition of one from surplus at no cost.

In the business community, the current view is that a personal attendant is to be provided as a reasonable accommodation for job related functions only.

sign language interpreters. It can also include a personal assistant to serve as a travel attendant for an employee who uses an electric wheelchair to assist on business trips. Table 2 on the following page provides sample PA job functions for readers, interpreters/transliterators and personal attendants. Table 3 on page 44 shows examples, taken from the Presidential Committee's Job Accommodation Network (JAN), of the use of PAs that employers have provided for their employees with disabilities.

It is important to note that professionals who provide reader and interpreter/transliterator services usually do not refer to themselves as a personal assistant or WPA. The classification of readers and interpreters/transliterators as a personal assistant service is a business perspective driven by the EEOC's interpretation of the ADA. For example, when asked what personal assistant services are provided to employees with disabilities, representatives from IBM, Unum/Provident, and SunTrust Bank indicated they routinely provide personal assistants such as readers and interpreters (Jon Ehret, March 17, 2000; Susan Olson, April 17, 2000; and Meg O'Connell, April 11, 2000). However, with the exception of Unum/Provident, it was indicated that these businesses had no experience in providing personal assistants in the workplace for their employees.

In the business community, the current view is that a personal attendant is to be provided as a reasonable accommodation for job related functions only. In the disability field, a personal assistant is viewed as a person who assists people who have Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADLs) deficiencies with their personal care or other daily activities (Dautel & Frieden, 1999). Activities of Daily Living are considered basic self-care functions such as bathing, dressing, and using the toilet. Instrumental Activities of Daily Living refer to tasks that require physical dexterity, strength, speech, hearing, vision, memory, and cognitive reasoning. Examples of IADLs include: cooking, cleaning shopping, doing laundry, using a telephone, and paying bills.

The disability rights movement has pushed for the utilization of personal assistants who provide assistance with ADL and IADL to people with disabilities throughout the community, including the workplace. However, at this time, an employer does not have to provide an employee with a WPA for personal needs such as grooming, eating, or personal hygiene (EEOC Title I Technical Assistant Manual, 1992). It is important to note that there is nothing in the law that prohibits an

employer from paying for personal attendant services if they choose to do so. For example, Unum/Provident has an Attendant Service Policy that subsidizes the cost of personal attendant service to employees who need these services in order to work (Susan Olson, Personal/Communication, April 17, 2000). The Unum/Provident Attendant Service Policy includes eating, bathrooming, hygiene and job specific assistance.

◆ TABLE 2 -- SAMPLE JOB FUNCTIONS FOR WORKPLACE PERSONAL ASSISTANTS —

Reader

- Assist an employee with a disability with reading:
 - resource and reference materials
 - technical materials in specialized areas
 - field reports, surveys, and other documents
 - legislation
 - regulations
 - policies
 - incoming correspondence
- Identify significant information and/or issues in incoming correspondence as per directions from the employee with a disability.
- Highlight and condense pertinent information as per directions from the employee with a disability.

**Interpreter/
Transliterater**

- Interpret spoken words using the communication mode of the deaf or hearing impaired individual, either a manual code for English or American Sign Language, to facilitate communication between hearing and hearing impaired employees.
- Interpret manual code for English or American Sign Language to spoken words for hearing individuals to facilitate communication between hearing and hearing-impaired employees.
- Transliterate spoken words to manual coded English/pidgin signed English to facilitate communication between hearing and hearing impaired employees.
- Transliterate manual coded English/pidgin signed English to spoken words to facilitate communication between hearing and hearing impaired employees.

◆ TABLE 3 -- EXAMPLES OF THE USE OF WORKPLACE PERSONAL ASSISTANTS

A state agency maintenance mechanic had difficulties climbing stairs and carrying materials. The job was restructured so that this individual always worked in a team with another mechanic.

- ◆ ***The co-worker was easily able to carry the equipment and do the required lifting on the job while this worker performed other necessary tasks.***

Because the facility had no elevator, the worker was assigned only to jobs on the first floor.

A college professor with physical limitations resulting from a stroke was assigned a...

- ◆ ***student worker to assist with transport of materials to and from classes.***

The cost was minimal as the worker was already assigned to the Department and performed other duties.

An engineer who uses a wheelchair worked in a manufacturing company that required employees to move around the facility inspecting buildings by climbing and crawling into small spaces. They worked in teams.

- ◆ ***A member of the team videotaped the areas that this worker could not access. The engineer used the videotape to gather pertinent information.***

A proofreader, who uses a wheelchair, in a publishing company was not able to transport materials from an inaccessible location to her workstation. She was provided a low file cabinet and drawer unit to help her access the necessary materials placed within her reach. This area was periodically stocked for her by co-workers.

- ◆ ***Materials that were housed elsewhere were brought to her on a daily basis by co-workers who were also obtaining or returning their own materials.***

- ◆ ***A federal agency employed two full-time sign language interpreters to accommodate communication needs of numerous deaf employees.***

Having interpreters on staff eliminated the need to contract out for this service. This eliminated the need to schedule interpreters in advance, allowing for impromptu meetings. In addition, these interpreters were familiar with the agency's vocabulary, protocols, and individuals, therefore enabling them to perform their duties better.

An insurance company program analyst who is deaf had to communicate with frequently others. The person worked with a team, but team members rotated throughout various projects.

- ◆ ***An interpreter was hired to facilitate communication between this worker and other team members.***

A private school employed a counselor who is blind. Accommodations included providing a screen reader and voice synthesizer for computer activities.

- ◆ ***A part-time support service assistant for completing handwritten paperwork and reading print materials.***

A health care service case manager who is blind was provided a driver to assist them in making home visits.

- ◆ ***The same driver also was used for other driving needs of the health care facility. As often as possible, trips were scheduled so that the driver was transporting this individual and meeting other needs at the same time.***

From the Presidential Committee on Employment of People with Disabilities, 1997
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In general, it is the employer's responsibility to provide a workplace personal assistant for job related functions and the employee's responsibility to provide a PA for personal needs. Employers often have no previous experience with providing a Workplace Personal Assistant and may not realize that providing a WPA can be easy to implement and inexpensive. Some common employer questions are addressed below.

I am concerned about the cost of providing a WPA. Often times cost is minimal; however, if the cost of the service is expensive, then employers should inquire about financial assistance available to either pay or help pay for the service. This might include assistance from state and local vocational rehabilitation agencies or tax incentives from the Internal Revenue Service, like the tax credit to small businesses who provide job accommodations. Also, employers must give the applicant/employee the opportunity to pay a portion of an accommodation that proves undue hardship for the business. In some cases, the applicant/employee may be able to write off the cost for the service by using a Social Security Work Incentive (see Chapter Seven on funding).

I believe this would be disruptive to my place of business. Keep in mind that in some instances, the provision of WPA may not require another employee to be hired. In many cases, a co-worker can quickly and effectively assist the employee with whatever is needed. If indeed a WPA would be needed on a consistent basis, then the employer needs to keep in mind that the WPA would be an employee and therefore is required to follow workplace policies like any other employee.

Employees should take care of their own personal care needs. Employers are not required to pay services not related to enabling the person to complete essential job functions. WPAs are not paid to take care of an employee's personal needs while at work. If an individual needs assistance eating or going to the restroom while at work it is up to them to make necessary arrangements and get their employer's permission to allow the PA on the premises to assist in such a way.

◆ **EMPLOYEE'S RESPONSIBILITY TO REQUEST WPA** —————

According to the Americans with Disabilities Act, it is generally the responsibility of the applicant/employee to inform the employer that an accommodation is needed. This request may be made verbally or in

writing. After the employer is informed that a WPA may be needed, given that the person requesting WPA satisfies the job-related requirements of the position, the employer should share a job description with the individual. The applicant would then have a chance to review the job functions fully and provide a more complete explanation of the role of the WPA.

◆ **WHAT SHOULD AN EMPLOYER DO FOLLOWING A REQUEST?**

A job applicant or an employee with a disability may request a workplace accommodation at any time during employment. There are several considerations when determining reasonable accommodation requests, including the demands of the job, the employee's skills and functional limitations, available technology, and cost. After the employer and employee agree that a workplace accommodation is needed, they should determine an appropriate accommodation. The following process may be helpful when determining the use of a Workplace Personal Assistant as a reasonable accommodation.

According to the Americans with Disabilities Act, it is generally the responsibility of the applicant/employee to inform the employer that an accommodation is needed. This request may be made verbally or in writing.

- ▶ **Identify the employee's Personal Assistance Services needs.**
 - Use job descriptions and job analyses to identify the essential functions of the job;
 - With the employee who has the disability, identify the employee's functional limitations and potential accommodations;
 - Consult with rehabilitation professionals, if needed.
- ▶ **Select and provide the Personal Assistance Service(s) that is/are most appropriate.**
 - With the employee, select Personal Assistance Services that are effective, reliable, easy to use, and readily available for the employee;
 - If equipment is used, the employee should try the product or piece of equipment prior to purchase (it is best, if possible, to try the product, modification, or equipment on the job);
 - If a person is used, the employee should direct the selection of the personal assistant.
- ▶ **Examine the Personal Assistance Service(s) utilized to see if it enables the employee to complete the necessary work task(s).**

(continued)

- ▶ **Evaluate regularly the Personal Assistance Services to ensure effectiveness.**
- ▶ **Provide regular follow-up. If needed, modify the Personal Assistance Services plan as necessary.**

When a request is made for a Workplace Personal Assistant or other Personal Assistance Services, employers should test the “reasonableness” of the accommodation. First, the employer and the employee need to identify the job functions that require Personal Assistant Services. Next, a variety of Personal Assistant Services should be identified that may reduce or remove the barrier and increase productivity. Finally, in partnership with the employee, the employer should implement the most appropriate accommodation with the least economic impact.

An employer is only required to offer an effective accommodation; it may not be the “best” accommodation in the eyes of the applicant or employee. For example, a customer service representative may want a personal attendant to come in daily to help respond to written correspondence, but the employer may either decide that having the WPA there once a week is enough to get the job done or may ask another worker to assist the person on a scheduled basis. If the employer decides that the WPA request as an accommodation presents undue hardship, then another alternative accommodation should be considered. Undue hardship is determined on an individual basis using the following criteria: the cost, overall financial resources of the business, and the type of operation of the employer. If the alternatives are deemed “unreasonable”, then the individual who made the request must be given a chance to pay for a portion of the service.

◆ **PROVIDING A WORKPLACE PERSONAL ASSISTANT AS A REASONABLE ACCOMMODATION**

When applying for a job, an applicant with a significant disability may need assistance to complete an application or a pre-employment test. For example, an employer may provide a reader to assist someone with a visual impairment with completing a job application or a pre-employment test. A WPA may also be needed to “assist” an employee with performing certain job functions. In this case, the WPA assists with, but does not perform, essential job functions. For example, a reader may be needed on a daily basis to help a customer service repre-

sentative who has a visual impairment and limited use of his/her hands to perform the essential job function of responding to *written correspondence*. This might include performing a job-related function like *reading written letters aloud* to the employee and/or *typing a response* dictated by the employee. Workplace personal assistants may also be needed to allow an employee to participate in or enjoy equal benefits and privileges of the job. For example, a driver may be hired from time to time to transport an employee to the annual company picnic or holiday celebration.

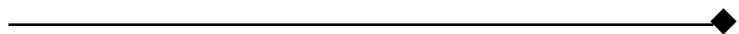
As illustrated previously in Table 3, sometimes a person outside of the company is hired to provide assistance, while at other times a co-worker may provide the assistance needed. For example, a major manufacturing corporation in Richmond, Virginia temporarily employed three sign language interpreters through the Virginia Department for the Deaf and Hard of Hearing (VDDHH) to accommodate the communication needs of employees who are deaf during the company's annual shareholders meeting. In another situation, which illustrates the use of existing workplace supports, a human resource assistant with a bank assisted an applicant (who could not write) complete a job application.

◆ SUMMARY

People with disabilities remain a largely untapped labor source. If greater numbers of people with disabilities are going to access employment, increased understanding and use of PAS is needed. The role and function of PAS in the workplace provides an important tool to employers for increasing access to individuals with significant disabilities as a major labor pool. Individuals with disabilities, employers, and rehabilitation professionals must expand their understanding of the benefits of PAS. Before large numbers of employees can begin accessing this support, additional regulatory clarification must be given to define the supports considered to be personal in nature and potentially funded by Medicare or other funding sources (Brooke, Revell, and Wehman, 2000).

To address the need for personal assistance services, the disability rights movement has pushed for a fundamental change in Federal and State long-term care policies (Dautel & Friedan, 1999). Current efforts are focused on the passage of The Medicaid Community Attendant Services and Supports Act (MiCASSA) to establish a national program of community-based attendant services and supports for people with disabilities, regardless of age or disability (ADAPT, 2000). Once

these important issues are addressed, it is hoped that employees with significant disabilities will expand their work opportunities. A chief business benefit will be dedicated, dependable, and productive employees.



◆ 50

KEYS TO BEING AN EFFECTIVE WORKPLACE PERSONAL ASSISTANT

by: John Barrett

Personal assistants (PAs) and their ability to effectively provide essential supports at the workplace are extremely important to the employment success for employees with a disability who utilize personal assistant services (PAS). Employees with disabilities who use PAS to live successfully in the community need similar supports at work. The expansion of the use of PAS at the workplace has created a unique set of challenges for PAs because there are tremendous differences between providing this type of support in a business environment as compared to a home environment. These potential differences between the home and the workplace involve both the wide variety of potential work-related personal assistance services that the PA may provide, as well as and also changes in the relationship between the PA and the employee with a disability receiving PAS.

For example, there is usually less formality in the home environment than may be required in a business setting. A good workplace PA must recognize and understand the role differences across settings and adapt accordingly. Almost always in the workplace setting, the PA will be directed by the employee with a disability and employer instead of a professional home health care agency. This shift in supervision will be a big difference for PAs who have only provided PAS through an agency and have been accountable primarily to that agency.

This chapter will describe some “do’s and don’ts” that a workplace PA should adhere to when providing support in the workplace. It will address some of the particular requirements and expectations for the PA to work effectively within the workplace culture, including how to assist the employee with a disability receiving PA support meet job performance demands. It will review attributes and competencies of an effective workplace PA. Finally, the chapter will offer suggestions on how the PA can remain unobtrusive while providing the level of support needed by the employee, perhaps the most important attribute of a good PA in the workplace.

Providing PA services in the workplace can be a new and exciting career opportunity. Workplace PAs can have the satisfaction of assisting a person with a significant disability be successful on the job while also learning valuable new skills that will enhance their own employability. These skills can range from simple tasks, such as arranging the work site to facili-

There are both obvious and some subtle differences between providing PAS in a business environment and providing it in the home. In the workplace, the relationship between the PA and the employee must be more formal in nature than in the home setting.

tate the productivity of an entry level employee, to more complex tasks involved in assisting a college researcher. Having the opportunity to learn different skills will make being a workplace PA an exciting and rewarding career in the new millennium.

There are both obvious and subtle differences between providing PAS in a business environment and providing it in the home. In the workplace, the relationship between the PA and the employee must be more formal in nature than in the home setting. Here are some best practice examples that workplace PAs should follow when providing on-the-job support.

- ▶ **Ask the employee about workplace dress codes and other pertinent rules or regulations. The Personal Assistant should dress and act in a manner fitting to the work environment.**
- ▶ **Do not exhibit any inappropriate behavior that will reflect negatively on the employee receiving your support. Do not get involved in conflicts that may be occurring between the employee and co-workers or among the co-workers. Do not participate in any conversations that may involve gossip about the employee you are supporting.**
- ▶ **Do not discuss services personal in nature with other co-workers or the employee's supervisor. This would be a breach of confidentiality, which is the quickest way for the Personal Assistant to lose credibility with the employee. Once the Personal Assistant has lost the employee's trust it will be difficult to regain, and could lead to the PAs' employment being terminated.**

DEALING WITH DISTRACTIONS AT THE WORKPLACE

There are many distractions in a workplace environment that do not exist in the home setting. Unlike the home environment, the workplace is filled with different personalities that may cause a PA to lose focus on workplace duties. These distracting personalities may include the employee's co-workers and supervisors. For example, a very loud and talkative co-worker trying to drum up a conversation with a person near to where the PA is working can be very distracting. A supervisor who tries to give the PA other duties not directly involved in providing PAS can also be very distracting. Other distractions at the work place might include multi-cubicle work stations, sharing an office with another employee, noisy environments, or stressful situations.

Examples of stressful situations include jobs that have short deadlines, fast-paced jobs, constantly changing priorities, and/or short-notice business trips where travel arrangements and needed accommodations must be planned quickly. These distractions can result in a loss of privacy in the provision of PAS, a breakdown in effective PAS routines, a temporary change in PA support needs, and a need to adjust the provision of PAS to unfamiliar locations and situations. A resourceful workplace PA will constantly strive to assure that these and other distractions do not interfere with providing effective PAS.

MAINTAINING PROFESSIONAL RELATIONSHIPS

Personal assistants must recognize the importance of maintaining a professional relationship with the employee and employee's supervisor while in the workplace. In most situations with the employee/PA relationship, the employee with a disability is the PA's primary supervisor. The PA has a primary responsibility to support and report directly to the employee with a disability. The PA should avoid becoming a "go-for" person for other employees and/or the employee's supervisor. Although the compliant "go-for" role might make the PA popular around the office, it will interfere with the PA effectively performing his/her primary duties, thus causing a loss of the productivity by the employee with a disability. In situations where the PA feels that the duties being assigned or requests being made by co-workers and/or a supervisor distract from the effective provision of PAS, the PA should let the person she/he supports know of the problem. The final responsibility for resolving this type of job interference lies with the employee with a disability.

ESTABLISHING AN EFFECTIVE WORK ROUTINE

Workplace PAs should follow common sense approaches to providing PAS in the workplace. For example, when the employee pauses to chat with colleagues, it is alright for the PA to interact and be friendly with other co-workers. However, when the employee is ready to resume the job tasks of the day, the PA must get back to supporting that person. It is really important for the PA to negotiate with the employee about times when support is not needed and then schedule personal breaks accordingly. For example, perhaps the employee makes telephone calls during certain times of the day and may not need PAS at those times, thus providing an excellent opportunity for the PA to take a personal break. Knowing the best times to take breaks will come as the relationship develops and the PA learns the employee's work routine.

An effective workplace PA understands fully the support needs of the employee being assisted, can adapt to routines and various personalities in the work environment, and can keep focus on whatever task the employee is involved in despite multiple distractions. To be effective, the workplace PA should be familiar with the employee's job tasks and production requirements in terms of quantity, quality, and timeliness of outputs. There are a number of personal attributes that are key to being an effective workplace PA. These attributes are highlighted in the next Section.

◆ ATTRIBUTES & COMPETENCIES OF AN EFFECTIVE WORKPLACE PERSONAL ASSISTANT

ATTRIBUTES

Five core attributes of an effective workplace PA are reliability, punctuality, loyalty, honesty, and a commitment to effective communication with the employee receiving support. All are the building blocks of a successful long-term employee/PA relationship.

Five core attributes of an effective workplace PA are reliability, punctuality, loyalty, honesty, and a commitment to effective communication with the employee receiving support. All are the building blocks of a successful long-term employee/PA relationship. It is very important for the employee with a disability to know that the PA's support will be readily available at the time it is needed. A good workplace PA understands that the employee relies on the PA to get the job done in a timely and reliable manner. Being on the job at the appointed time is a must for the workplace PA.

Loyalty to the employee is another key attribute of a good workplace PA. Showing loyalty may include the PA's willingness to stay late on occasion to assist the employee complete a job that may have an immediate due date. Maintaining loyalty by avoiding doing anything that might cause the employee to question the PA's faithfulness is key to building a long-term working relationship. Also, PA being honest with the employee will make the relationship stronger. Demonstrating a commitment to reliability, punctuality, loyalty, and honesty will increase the PA's value to both the employee and the employer. These attributes will not only assure a long-term successful working relationship for the PA with the employee, but also will increase the Personal Assistant's overall value to the entire organization. It is important to remember that the longer the relationship, the more the PA's salary is likely to increase over time.

Clear communication is another essential attribute for a good working relationship between the employee and the workplace PA. Effective communication requires a commitment to a two-way exchange of

information. For example, even though it is the responsibility of the employee to provide guidance to the PA about how tasks should be done, the PA should make certain that the employee's instructions are understood. The PA should never assume that he/she knows the best way to provide support or understands the employee's wishes. Making assumptions can lead to problems for both the PA and the employee. The PA must remember that the employee is responsible for the outcome of tasks to be performed on-the-job and should clarify any unclear instructions before proceeding with a support task. In more long-term relationships, the PA learns to understand what needs to be done without always being told. An experienced PA can work independently sometimes (such as setting-up the work area for a upcoming task, for example) while the employee is elsewhere or involved in another activity.

Commitment to reliability, punctuality, loyalty, honesty, and clear communication are the qualities of an effective workplace PA. These attributes will facilitate the development of a good working relationship between the PA and the employee.

PERFORMANCE AREAS

The workplace Personal Assistant must have skills necessary to assist the employee receiving support to complete job tasks. For example, if the employee has a job involving the development of correspondence, training materials, and/or other documents, the PA should possess some knowledge of basic letter writing and word processing. If the PA is supporting a person with a visual impairment, the PA's ability to read competently is extremely important. When supporting a person with a hearing impairment, the PA should know sign language in order to communicate with the employee and to assist him/her in communicating with the supervisor and other co-workers. If the PA is supporting an employee with a cognitive disability, good judgement and decision-making skills are needed in helping the employee make good decisions. A good example of a PA prompt for an employee with a cognitive disability to accommodate possible memory challenges is a suggestion five minutes before the close of the work day that it is time to clean up the work space and set it up for the first task of the next work day. However, no matter what the disability of the employee receiving support, the PA should treat that individual as his/her supervisor.

It is very important that a PA be honest with the employee about the skills and knowledge he/she has or does not have. In most cases, the employee is looking for good attributes such as reliability and de-

pendability from a PA and will make sure the PA receives the necessary training for job specific tasks. However, the workplace PA should have a basic set of skills in key performance areas that support the employee in completing core job tasks. PAs who are not truthful about their skills and abilities will not only potentially lose their job, they may also cause the employee's job loss as well and can cause employers to take a dim view of future requests for PAS as a workplace accommodation.

A summary presentation of core attributes and performance areas of an effective workplace PA are listed in the Table below.

◆ TABLE 1 -- WORKPLACE PERSONAL ASSISTANT COMPETENCIES & ATTRIBUTES —

| Performance Areas | Description | Attributes |
|---|---|---|
| <i>HAS NECESSARY SKILLS</i> | Has skills to perform necessary job tasks | <u>Punctual</u> -- will always be on time |
| <i>KNOWS HOW TO BE UNOBTRUSIVE ON THE JOB</i> | Provides necessary support without drawing attention to his/her self | <u>Dependable & Reliable</u> -- will always show up for work |
| <i>IS PROFESSIONAL AT ALL TIMES</i> | Exhibits professional behavior at all times and remains focused on the tasks of the employee | <u>Right Personality & Temperament</u> -- is content to provide support in background without sharing spotlight |
| <i>KEEPS CONFIDENTIALITY</i> | Never discusses personal issues of the employee with others | <u>Loyalty</u> -- is loyal to the employee and respects him/her |
| <i>KNOWS WHAT TO DO WITHOUT SUPERVISION</i> | Can follow through on certain tasks while employee is in meetings | <u>Team Player</u> -- will do whatever is necessary to help the employee get the job done |
| <i>WILLING TO BE TRAINED TO DO NEW TASKS</i> | Is eager to learn new things as employee's responsibilities change | <u>Highly Focused</u> -- does not let other things distract him/her |
| <i>HAS A GENERAL KNOWLEDGE OF DIFFERENT DISABILITIES</i> | Knows what employee might expect | <u>Patience</u> -- has the ability to take time to listen and take direction from the employee |
| <i>WILLING TO BE FLEXIBLE</i> | Can change from one task to another as the employee's priorities change; can adapt to employee's working schedule | <u>Honest</u> -- Will let employee know problems with doing particular jobs |

THE IMPORTANCE OF THE PERSONAL ASSISTANT BEING UNOBTUSIVE IN THE WORKPLACE

Providing PAS as a workplace support places the Personal Assistant in a relatively new public situation as compared to the more familiar home environment. Therefore, it is important to focus on the PA remaining unobtrusive while providing supports as a key attribute of an effective workplace PA. An unobtrusive PA almost fades into the background, leaving the employee as the focal point and leaving no confusion about who is getting the job done. Maintaining focus on the employee, not the PA, sends a positive message to co-workers and supervisors and reduces the chances that possible conflicts will develop between the employee and the PA. The ability to achieve this level of unobtrusiveness takes real skill and attention on the part of the workplace PA.

In a workplace PAS situation, some co-workers and supervisors may have the misconception that two people are doing the same job. The workplace PA must help prevent this misconception, which can become a problem for the PA and the employee. For example, the PA should avoid becoming involved when the employee is having a discussion with the supervisor about how a particular job task needs to be done, unless the employee requests input. After the discussion is over and the supervisor has left, it is very appropriate for the PA to offer suggestions to the employee in private. This approach also keeps the PA from being put in the middle of awkward situations and encourages the supervisor to deal directly with the employee who has a disability. If the supervisor tries to solicit the PA's input directly, the PA should politely remind the supervisor that she/he is there to support the preferences of the person with the disability and should defer to the judgment of that individual. These tips will facilitate the workplace PA remaining unobtrusive while earning the respect of the employee, co-workers, and supervisors.

◆ SUMMARY

In time, the use of PAS at the workplace will increase substantially employment opportunities for private PAS providers. However, it is critically important that Personal Assistants adjust to the unique requirements of different business environments. Workplace PAs must have a high self-esteem and know their value to the employee without needing the gratification of sharing the spotlight. This willingness to remain in the background takes a unique and unselfish person who is

very comfortable in a supporting role and is gratified by the success of the employee. It comes in-part from the PA establishing a very good working relationship with the employee with a disability.

As the new economy seeks to fill critical labor shortages, it is becoming quite apparent that the role of a PA in the workplace will become just as vital to a person with a significant disability as providing PA support in the home. Over the next decade, the refinement and recognition of the critical supports provided by the workplace PA will add a new dimension to addressing the employment support needs and expanding the employment opportunities of many individuals with a disability. It will also expand the work experiences, skills, and potential job satisfaction of PAs. My own experience as a workplace PA is both rewarding and very fulfilling. I have had the opportunity to travel and participate in national conferences, and I have received training and gained valuable experience in how to better support my employer on his job. The opportunity to provide PAS at the workplace is a mutually beneficial experience for both my employer and myself.

WORKPLACE PERSONAL ASSISTANCE SERVICES AND ASSISTIVE TECHNOLOGY

by: Wendy Strobel & Jennifer Todd McDonough

Independence and efficiency are important factors in today's workplace. Many of the accommodations made on the job are aimed at increasing autonomy and productivity. For many people with disabilities, workplace personal assistant services (PAS) are a valuable accommodation in performing job tasks. However, PAS alone may not always be the most practical solution. Assistive technology (AT) is a viable complement and/or alternative to a personal assistant for many who are seeking to become more efficient and independent in completing their job requirements. While assistive technology certainly will not replace the personal assistant, it can sometimes serve to reduce the number of hours that the personal assistant is needed on the job site.

The following is an example of how assistive technology can complement the workplace personal assistant. John works for a heat exchange manufacturing plant and is responsible for assembling three types of sales binders. The material used for the binders was located on an eight foot high shelving unit and was arranged in no particular order. John, who uses a wheelchair, was unable to access much of the material on his own because it was stacked above his reach. To rectify this problem, John asked his personal assistant to aid him in identifying the most frequently used material. This information was placed on a "lazy Susan" file added to the corner of John's desk. Less frequently used material was placed within his reach on the shelving unit; infrequently used material was placed on the higher shelves. John could now perform many of the functions of the binding task independent of the assistance of his PA. In this situation, John utilized his personal assistant on the job and a simple assistive accommodation (the lazy Susan) to increase his autonomy and productivity on the job. John continued to use his personal assistant for other job tasks.

John had a distinct choice in this situation: continue to depend on a personal assistant or seek technology that could reduce costs to his employer, increase his independence, and improve his efficiency. Potentially, prospective assistive technology (AT) users will be presented with similar choices in their jobs. The choices that individuals make will vary depending on their knowledge of AT services. In order to make an informed choice

over how best to complete job tasks, the prospective AT user must develop some competencies regarding the options available. These competencies include:

◆ IMPORTANT COMPETENCIES OF POTENTIAL AT USERS —

Awareness of Technology

Gather information on the types and features of AT.

Awareness of Disability

Identify the strengths you can capitalize on and the limitations for which you need to compensate.

Awareness of Job Tasks

Identify the essential functions of the job and the tasks AT will need to assist you in accomplishing.

Awareness of Training

Determine how the device operates and who can instruct both the user and co-workers.

Awareness of Maintenance Options

Gather information on the AT to be implemented and evaluate its durability, maintenance, and repair schedules.

Awareness of Funding Option

Determine who is responsible for paying for a device and identify potential sources of funds for the purchase of AT.

BENEFITS OF AT

- ▶ **Increased Independence**
- ▶ **Reduction of PA hours**
- ▶ **Increased Efficiency**
- ▶ **Increased Productivity**

A potential AT user must consider the environment in which the assistive technology will be used. Small differences, such as variations in the noise level at the job site, can have a large impact on the effectiveness of technology. If office equipment is shared amongst co-workers, the changes made for one person cannot adversely impact another's ability to perform the job. Therefore, it is imperative that supervisors be consulted on the AT interventions that will be applied. Also, cost is sometimes an issue in obtaining AT at work. As a result, a prospective AT user should be aware of potential funding sources. In addition, one must also consider the training, maintenance, and repair of AT implemented on a job site. This chapter will discuss these and other critical issues related to the application of assistive technology in the workplace.

The potential user must have an understanding of AT to apply it effectively in the workplace. The legal definition of AT is “ any device, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (PL 100-407 [2(b) (1)]).” This broad definition is appropriate because of the varied nature of AT applications. Assistive technology can be “high tech”, which refers to equipment that is expensive and frequently has a computer component. Examples of such equipment include a voice activated software system, an augmentative communication device, and an electric wheelchair. “Low technology” is generally more easily obtained and less expensive. (Cook and Hussey, 1995). The range of low tech devices includes everything from Velcro to an electric stapler.

As consumers of assistive technology, it is important to have an idea of the types of equipment that are available in today’s marketplace. Often times, creativity plays a large role in the equipment selected for any given situation. Sometimes the simplest interventions can make a world of difference. For example, Andy, who was responsible for opening mail and entering billing information into a computer, found it extremely difficult to turn on his equipment in the morning. To turn on an electric letter opener, a computer, and a monitor took him about 10 minutes. The simple solution identified was the addition of a power strip that all devices were plugged in to. Fastened with velcro inside a top drawer, he only had to pull open the drawer and flip one switch, reducing the time for completing this task from 10 minutes to 1. Thinking outside of the box allowed Andy to become more efficient and effective in this seemingly simple task for the cost of about \$10.

Researching assistive technology is an important step in the identification of a piece of assistive technology. In any given situation where a technological intervention may be beneficial, there may be many solutions. If the prospective user has a clear understanding of the options available, he/she is able to choose the device(s) that best fits the situation. Perceived stigmas associated with using AT may play a lead role in guiding a person’s decision. A user must be comfortable with the technology selected, or it will be abandoned.

IMPACT OF DISABILITY AND ENVIRONMENT ON ASSISTIVE TECHNOLOGY

The type of assistive technology used in a situation will vary greatly depending on the nature of a person's disability. An evaluator or prospective user should take into account the individual's skills that can be maximized through the use of technology. For example, a person with poor motor control (except for his foot) is given a wheelchair that can be operated using the foot. Would this be effective for everyone? No, but in this person's case, it is the most effective method of control. In a job situation, a similar foot activated switch could be used to select letters on an on-screen keyboard or to control a mouse.

Environment also plays a key role in the identification of AT. The situation specific nature of assistive technology discourages the "prescription" of technology in a medical or rehabilitation setting away from the job site where the AT will be used. Imagine that during a training period in a rehabilitation facility, Alice is taught to use a speaker phone to answer calls. It is quiet in the facility and people tend to offer her privacy when she is on the phone. When she returns to work, her office is a three walled cubicle with numerous co-workers working and conversing nearby. A speaker phone would make it difficult to impossible to have private conversations. While the speaker phone is functional, it is not practical for Alice's work setting. If too little consideration is given to the environment in which it will be used, assistive technology will most likely be ineffective.

A visit to the work environment will not only provide the information necessary to ensure that the technology will best meet a person's needs, it will also provide other valuable information. For example, a visit to Randy's work site at a book store revealed options for AT devices that neither he nor his coworkers had thought to utilize. Randy has worked for 3 years as a cashier. Recently, his responsibilities were increased to include work in the office phoning customers to let them know their orders had arrived. His job coach visited the job site and noticed that Randy was having trouble holding the phone receiver. She suggested he try an adapted receiver that had a hook on the back of the receiver. The hook made lifting and holding the receiver easier. An alternative adaptation was a headset that only required him to push a button to answer a phone, leaving his hands free.

AT should be introduced in a way that will not adversely affect the performance of others in the work place. In many offices, equipment is shared. Therefore, the technology must either be optional or

functional for everyone performing a particular job function. An example is a data room at a research agency. Here, an employee with a disability uses an Anthelices keyboard at a shared workstation. This device is a keyboard that uses enlarged print overlays. Its function, in this case, is to provide a bigger target area for the keys. Because it is substantially different from a traditional keyboard, some co-workers do not find it easy or comfortable to use. To accommodate the co-workers, a riser with a sliding tray is used to store a traditional keyboard. To use the standard keyboard, the co-worker simply pulls out the tray.

AT introduced for an employee with a disability will be utilized frequently by other people in the office. For example, a money counter is introduced to a work setting that requires a person with poor motor control to count from a cash register drawer containing approximately \$300. Instead of counting bills individually, this machine counts stacks of bills using a feeder. Use of this device allows for a significant increase in the speed of this task for everyone. Another example involves Sarah, who works for a university taking pictures for identification cards. For her to use the camera and computer, she needs to use a mouse. A standard mouse is hard for her to manipulate, so a trackball mouse is introduced, resulting in Sarah being much faster in navigating the computer screen. Her supervisor found that the trackball mouse works better for all of the office employees and therefore purchased a trackball mouse for each work station.

ASSISTIVE TECHNOLOGY AND THE JOB SITE STRATEGIES

On a job site, it is also important to consider the supervisor's approval for a piece of assistive technology. An employer, in considering a recommendation for AT, must analyze the implications of the AT application on the overall operation of the business. In one case, Julie, who is unable to move her arms, needs to take messages. A recording system for the phone would require no effort on Julie's part to use. When this AT intervention is suggested to Julie's employer, Ms. Thomas, she voices concerns regarding the privacy of her customers and the legality of recording conversations. The employer's concerns had not been considered by Julie or the rehabilitation professional in suggesting the recording system. As an alternative, a tape recorder is suggested where Julie can verbally record the information she needs to retain. The information is gathered in a traditional message format in which the caller provides the information and Julie repeats it onto the tape recorder. The cost for this low tech device is minimal, as is the effort needed to imple-

ment it. Also, customers have been impressed with Julie's conscientiousness in getting the correct information. Most importantly, the employer feels that her concerns were addressed appropriately and that Julie is performing her job effectively and efficiently.

SELECTING AND UTILIZING ASSISTIVE TECHNOLOGY AT THE WORKPLACE

The durability of a piece of technology is also an important consideration when implementing AT on the job site. If a piece of equipment is to be used on a regular basis, it must be durable. The durability of a device can be determined in a number of ways. The most effective source of this information is often talking to other people who are using the same or similar devices. What problems have they had with the AT? When repairs were needed, did a technician come to the job site? If yes, how long did it take? Was a loaner provided during the repair period? Also, an AT user must also consider what regular maintenance a device will require. If maintenance is required on a regular basis, can a schedule be devised so that other work tasks can be scheduled during this period?

The cost of Assistive Technology must also be addressed. Cost can be a major factor in determining what type of AT will be implemented on a job site. According to a survey done by the Job Accommodation Network (2000), 80% of accommodations cost less than \$500. Therefore, the majority of accommodations are relatively inexpensive. The ADA mandates that employers with more than 25 employees pay for reasonable accommodations. In the event that an employer is unable or not required to pay for an accommodation, other options may be considered. If an accommodation is considered durable medical equipment, such as a wheelchair or a scooter, funding may be provided by either private insurance or Medicaid. Also, The Tech Act has established Technical Assistance Projects that are operated throughout the country; some offer loan programs for assistive technology. Information on these programs can be obtained from the Rehabilitation Engineering Society of North America (RESNA).

Other funding sources for AT include Social Security Work Incentives, Vocational Rehabilitation agencies, and private foundations. The government offers tax credit to small business, known as the Disabled Access Tax Credit (IR Code Section 44), that allows small businesses who earned \$1 million or less in gross receipts in the previous year or had 30 or fewer full-time employees to deduct a variety of disability

According to a survey done by the Job Accommodation Network (2000), 80% of accommodations cost less than \$500. Therefore, the majority of accommodations are relatively inexpensive.

related costs, including the purchase of adaptive equipment (US Chamber of Commerce and VCU RRTC, 2000). The Assistive Technology Resource information provided at the end of this chapter contains information that can be helpful in the acquisition of assistive technology.

Training on AT devices is essential to their successful use. The employee utilizing the AT requires training on the device in order to complete job tasks as independently as possible. Co-workers and personal assistants should also be trained in the event that regular maintenance or trouble shooting is required. Co-workers must understand how the device is used in the event that they are asked to use the device when the primary user is not available. Training can be provided by an assistive technology vendor, a rehabilitation engineer, an occupational therapist, a physical therapist, a speech therapist, a job coach, an assistive technology practitioner, or a co-worker who is familiar with its use. In order for an AT user to truly benefit from the devices introduced, training must be comprehensive and readily available. For example, Julie, whose use of a tape recorder to dictate messages was discussed earlier in this chapter, needed to input addresses into a mailing list database. In order to perform this task, Julie's job coach installed Drag and Dictate, a voice recognition word processing software, onto her computer and worked with Julie to train her on how to use the software effectively.

◆ SUMMARY

A potential user of assistive technology should have a working knowledge of the types of AT that may be beneficial. This knowledge can be gained through the Internet, talking with other AT users, shopping at an office supply or computer store, or talking with professionals. For example, the Job Accommodation Network (JAN) offers support over the phone to AT users who would like advice on what technology may be effective for a given situation in the workplace.

It is imperative that a prospective AT user has a working knowledge of the AT system and an in-depth knowledge of the job duties that will be performed. This information will empower a prospective AT user to have an intelligent conversation about what technology might be beneficial and what the device would be the most comfortable to use. Also, a piece of technology does not have to be high tech to be effective. Inexpensive, low tech items are often the most practical and easily applied solutions. However, AT is not a cure all. While technology offers

many effective options to assist a person with job tasks, it cannot complete a job for a person with a disability. The employee must be qualified for a position and be able to perform the job duties with accommodation, including the possible use of personal assistant at the workplace. AT can supplement and reinforce the current skills and abilities of a user and can complement other accommodations .

◆ ASSISTIVE TECHNOLOGY RESOURCES

WEB SITES

<http://janweb.icdi.wvu.edu/> – The Job Accommodation Network (JAN) is not a job placement service, but an international toll-free consulting service that provides information about job accommodations and the employability of people with disabilities.

<http://www.resna.org/> – Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is an interdisciplinary association for the advancement of rehabilitation and assistive technologies (AT).

<http://codi.buffalo.edu/assistiv.htm> – Cornucopia of Disability Information (CODI) serves as a community resource for consumers and professionals by providing disability information in a wide variety of areas. This website provides a variety of links to assistive technology resource web pages.

<http://www.latech.edu/tech/dss/dsstech.html> – Louisiana Tech University Center for Biomedical Engineering and Rehabilitation Science assistive technology web links

http://trace.wise.edu/world/computer_access/ – The Trace Center is currently working on ways to make standard information technologies and telecommunications systems more accessible and usable by people with disabilities. This web page lists accessible computer and software features provided by a variety of manufacturers.

<http://java.sun.com/products/jfc/accessibility.html> – Assistive Technology Defined (on-line document).

<http://www.ataccess.org/> – Provides location information for the Alliance for Technology Access regional centers. The Alliance assists individuals with disabilities access technology, mainly through computer resources.

<http://www.abledata.com> – A national database of information on more than 17,000 products that are currently available for people with disabilities.

<http://www.mindspring.com/~ncatp/mitat.htm> – Maintaining Independence Through Assistive Technology (on-line document)

<http://www.cns.state.va.us/atlfa/whats at.htm> – Assistive Technology Loan Fund Authority - The ATLFA makes loans and loan guarantees to people with disabilities for equipment and technology that increase independence, quality of life and employment opportunities.

<http://www.vcu.edu/rrtcweb/techlink/iandr/links/art/assis.html> – Transition from School to Work: Facilitating Employment Using Assistive Technology and Supports (on-line document). This article describes one strategy for facilitating competitive employment by providing community-based training experiences, assistive technology, and other workplace supports in real work environments within the student's education program.

<http://www.blvd.com/> – The Boulevard is a resource directory of disability products and services for the disabled, elderly, care giver and healthcare professional.

<http://www.vats.org> – Virginia Assistive Technology System (VATS) is a statewide systems change project committed to improving the quality of life for all Virginians by increasing awareness and accessibility.

<http://www.staples.com/> – Staples Office Supply home page lists a variety of products that can increase an individuals productivity and effectiveness in their work environment.

<http://www.officemax.com> – Office Max home page lists a variety of products that can increase an individuals productivity and effectiveness in their work environment.

<http://www.closingthegap.com> – Closing The Gap, Inc. is an organization that focuses on computer technology for people with special needs through its bi-monthly newspaper, annual international conference and extensive web site.

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FUNDING OPTIONS AND OPPORTUNITIES FOR PERSONAL ASSISTANCE SERVICES AT THE WORKPLACE

by: Valerie Brooke

Previous chapters have discussed some of the challenges associated with finding an appropriate and reliable personal assistant. While most individuals with significant disabilities will not require the support of another person to accomplish routine daily living activities, these personal assistance services (PAS) are critically important for those who do. Once the potential new employee finds the right individual to provide personal assistance services, building a long-term relationship is most important for establishing high quality, consistent, and reliable care. Knowing how to access a range of financial options for supporting these services is key to building this successful relationship with a personal assistant. This chapter highlights information on possible funding options and provides a detailed explanation of how Social Security Work Incentives can be used for accessing workplace personal assistant services. The table on the following page highlights a variety of possible funding options with a brief description of each resource.

◆ POSSIBLE FUNDING OPTIONS

When thinking about possible funding options for a workplace PAS, the most obvious resource is the business and/or employer. Yet, in order for the business to be legally liable for providing a PAS, specific criterion must be met according to the Americans with Disabilities Act (ADA). These criterion are: 1) the applicant must disclose his or her disability during the interview process, 2) the business must have fifteen or more employees to be subject to ADA regulations, 3) the PAS must be needed to complete the essential functions of the job, and 4) payment of the PAS must not create an undue hardship for the business. When the employer is not an option for securing payment for workplace PAS, other potential funding options do exist. An excellent funding source for PAS can be found in state government programs.

State-based funding options for PAS are varied and may look very different from state-to-state. The state Vocational Rehabilitation (VR) agency is one possible funding option for those individuals with disabilities who utilize VR services while pursuing employment. If available, these funds

◆ **FUNDING OPTIONS FOR WORKPLACE PERSONAL ASSISTANCE SERVICES**

Employers

Under the Americans with Disabilities Act (ADA), an employer can be responsible for providing PAS as a reasonable accommodation if necessary criterion are met.

State Vocational Rehabilitation

Several state vocational rehabilitation programs (VR) have well developed programs that fund personal assistant services for individuals with significant disabilities who qualify for VR services. Typically, the PAS must be required for the individual to participate in the Individual Plan for Employment that will specifically outline plans for achieving employment outcomes.

State Medicaid-Funded Waiver Programs

In many states across the country, PAS can be obtained through Medicaid funded waiver programs. Generally, access to these services is determined by a state's office of medical assistance services. Medicaid Waiver programs will have strict eligibility criterion that must be met for participation.

Impairment Related Work Expense (IRWE)

The purpose of an IRWE as an incentive is to enable individuals with disabilities to recover some of the costs of the expense incurred to support their work as a result of their disability. PAS would be an allowable cost under the IRWE program.

Plans for Achieving Self Support

This Supplemental Security Income (SSI) work incentive allows a person to set aside income and/or resources that he/she have (or will have in the near future) to be used to achieve a specific work goal. PAS would be considered an allowable service.

When the employer is not an option for covering the cost of workplace PAS, other potential funding options do exist.

would be accessed through the VR counselor assigned to the potential employee's case. The customer and the counselor would jointly complete an Individual Plan for Employment (IPE) that specifically outlines plans for achieving an employment outcome by using a PAS.

Another possible state-based option is the state's Medicaid Waiver program. Information regarding a state's Medicaid Waiver program can be accessed through a state office of medical assistance. Within each state, there exist specific eligibility criterion and guidelines for use of the Medicaid Waiver. Generally, these guidelines will require the applicant to document the presence of limitations resulting from a disability that require the services potentially available from the Medicaid Waiver for the individual to live in the community (as compared to an institutional setting). A financial needs test for Medicaid eligibility is also generally required. It is important to note that the specific state Medicaid Waiver program for which the individual is eligible must include workplace PAS as an allowable service for PAS to be funded through the Waiver.

The Social Security Administration (SSA) can be another important funding option for PAS. SSA has long recognized that some major disincentives to employment exist within its disability benefit system. Beginning in the early 1970s, a broad range of programs and work incentives for individuals receiving Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were developed. Over the years since their inception, most of these incentives have been adjusted and redefined in an ongoing effort to increase their effectiveness and ultimately their usage. Today, while there is a full range of work incentives for beneficiaries, the results of these incentives in promoting employment has been limited for Social Security Disability beneficiaries.

The two major SSA work incentives that can be used to purchase PAS are Plans for Achieving Self Support (PASS) for SSI recipients and Impairment Related Work Expense (IRWE) for SSI and SSDI beneficiaries. The table on the following page highlights some of the advantages for initiating a PASS or IRWE.

◆ GENERAL PASS PLAN REQUIREMENTS

A Plan for Achieving Self Support (PASS) allows a person with a disability to set aside income and/or resources for a specific period of time to realize a work goal. Any person who receives SSI benefits, or receives SSDI and could qualify for SSI, can have a plan. There is no limit to the number of successful PASS plans a person receives .

◆ SSA WORK INCENTIVES FOR PURCHASING PERSONAL ASSISTANCE SERVICES (PAS) AND OTHER WORK SUPPORTS

**PLANS FOR ACHIEVING SELF-SUPPORT
PASS**

**IMPAIRMENT RELATED WORK EXPENSE
IRWE**

DEFINITION

A **PASS** enables an individual to set aside income and resources to purchase goods or resources, including Personal Assistance Services, that will help the person achieve a vocational goal.

An **IRWE** enables a person with a disability to recover expenses incurred as a result of his/her disability. The expenditure must be needed to support work activities and related to the person's disability.

ACQUIRING PERSONAL ASSISTANT SERVICES

A PASS will make it possible for an individual to hire a workplace personal assistant to provide as workplace support for accomplishing activities of daily living and/or essential functions of the job.

An IRWE can be used for a variety of workplace supports to include personal assistant services, purchase of assistive technology, special transportation services, and job coaching support.

WORK INCENTIVE PROGRAM CRITERION

The PASS must include the following five components 1) individualized obtainable vocational goal; 2) time frame for meeting the goals; 3) identification of resources and the amount of income or resources to be set aside; 4) explanation of how the money will be used; and 5) a written plan.

An IRWE must contain a the following four components: 1) information indicating that expenses are directly related to work, 2) documentation of cost paid by the individual with a disability; 3) records of expenses paid during months of employment, and 4) indication that expenses are reasonable.

EFFECTS ON BENEFITS

Income and resources set aside in a PASS are not counted in determining SSI eligibility or in calculating the amount of SSI benefit. PASS can assist in supporting a new employee to:

- ▶ qualify for SSI,
- ▶ maintain current SSI payment, or
- ▶ increase SSI benefits

An IRWE enables SSI recipients to recover some of the expenses incurred as a result of a disability to support their work. For SSI recipients, deducting the cost of the IRWE from gross wages increases the amount of the SSI check. For SSDI beneficiaries, deducting an IRWE may keep gross monthly earnings below Substantial Gainful Activity (SGA) level and thereby maintain SSDI eligibility.

BASIC REQUIREMENTS

There are essentially ten basic requirements for setting up a PASS Plan. It will be important to follow each requirement to achieve success. The plan must include the following:

- ▶ **Increase the person's self-support/self-reliance and decrease reliance on the Social Security system.**
- ▶ **Be designed specifically for the person.**
- ▶ **Be in writing.**
- ▶ **Have a specific work goal that the person is capable of performing (unless there is evidence to the contrary, SSA PASS Specialists will presume an occupational goal to be feasible and a PASS to be viable).**
- ▶ **Have a specific time frame for reaching the goal.**
- ▶ **Show what money and other resources received will be used to reach the goal.**
- ▶ **Show how the money and resources will be used.**
- ▶ **Show how the money set aside will be kept identifiable from other funds.**
- ▶ **Be approved by the Social Security Administration.**
- ▶ **Be reviewed periodically to assure compliance.**

LIKELY CANDIDATES FOR A PASS

If an individual has never had a PASS Plan, a good place to begin is to determine if he/she will be a likely candidate. The following seven profiles are individuals who would benefit from a PASS Plan.

Resources in Excess of Allowable Limits -- Individuals who do not have earned or unearned income and have not qualified for SSI in the past (due to resources in excess of the resource limit - generally defined as over \$2,000 in non-excluded resources.) Establishing a PASS allows individuals to set aside resources to achieve vocational goals and, as a result, they may qualify for SSI.

Unearned Income Only -- Individuals with unearned income only (SSDI, SSDAC, railroad pension checks, parental subsidies/gifts, etc.) can establish a PASS to exclude income (use all or part of the income to pay for PASS expenses) and establish SSI/Medicaid eligibility.

Earned Income Only -- Individuals who have earned income only can set aside earnings in a PASS and begin receiving SSI checks and Medicaid.

Both Earned and Unearned Income -- Individuals who have earned income and unearned income can set aside their wages, Title II (SSDI) payments, or both to establish SSI/Medicaid benefits.

Earned Income and Receiving SSI/Medicaid -- Individuals who have earned income and are receiving SSI checks can set the earnings aside in a PASS to prevent reduction of their SSI checks.

Earned Income (in the future) and Receiving SSI/Medicaid -- Individuals who have SSI only, but will begin working in the near future, can establish a PASS to set aside new wages starting with the first month of employment. The SSI check will only be reduced by the amount of countable income not excluded by the PASS.

In School or Training -- Potential PASS candidates having income/resources including those individuals in school or training programs, currently receiving services from rehabilitation agencies, or interested in rehabilitation and becoming self-supporting.

PASS APPROVAL REQUIREMENTS

The PASS approval requirements are not long or difficult. However, it is important to remember that careful attention must be paid to each area. For example, having an occupation goal and milestone step without a clear timetable for success will not be approved.

- 1. Feasible Occupational Goal** -- Although SSA must assume that the occupational goal is feasible for the person and that it will generally raise the ability of the person to become more self-supporting, the agency requires information regarding the proposed vocational goals. Needed information includes job title (or if self-employed, the type of business), age of the person, any prior work history, education and training, and type of disability. The PASS must also indicate current earnings after the PASS has been completed.
- 2. Interval Steps/Milestones** -- The PASS should include specific time frames/milestones that document a person's progress toward achieving his/her stated PASS goal. These should be criterion-based statements (e.g., begins school/job coaching, hired for job, etc.) that show the steps to goal achievement.
- 3. Definable Timetable** -- Specific time frames for meeting vocational goals must be established within the PASS. Provide schedules for meeting the vocational goals, indicating the month and year it is expected to begin and end.

4. **Income/Resources to be Set Aside** -- Plans must state the sources and amount of income or resources to be set aside (earnings, benefit supports, savings accounts, etc.). The sources and amounts must be adequate to achieve the goals, but cannot be excessive. Separate accounts for PASS monies (checking accounts) provide excellent verification of PASS savings and expenditures.
5. **Expenditures** -- The PASS must state how the money set aside will be spent to achieve the occupational goal. A list must be included of monthly planned expenditures, grouped or categorized with an explanation of their connection to the occupational goal. Expenses must be reasonable to be approved. Cost estimates for goods and services should indicate how the cost was calculated.
6. **Organization** -- The PASS must be in writing, but there is no mandatory format. Forms are available to assist applicants.
7. **Deferred Expenses** -- Not all expenses may be allowed at the beginning of the PASS. In some cases, approval of certain goods and services may be contingent on the successful completion of milestones that justify the expense.

EXAMPLES OF POSSIBLE PASS EXPENDITURES

The PASS Work Incentive will fund any goods/services that will enable a person to become more self-sufficient. In many instances, due to the availability of funding through the PASS, paying for items must be prioritized as to their relative importance in the person's employment plan.

- ▶ **Equipment, supplies, operating capital, and inventory required to establish a business;**
- ▶ **Any cost associated with an educational or occupational training program, including tutoring, counseling, etc.;**
- ▶ **Attendant care, personal assistance services;**
- ▶ **Child care;**
- ▶ **Equipment or tools, either specific to the individual's condition or designed for general use;**
- ▶ **Uniforms, specialized clothing (including dress business clothing), safety equipment;**
- ▶ **Least costly alternatives for transportation including:**
 - **public transportation and common carriers**
 - **hire of private or commercial carriers**
 - **purchase of a private vehicle;**

(continued)

- ▶ Dues and publications for academic or professional purposes;
- ▶ Operational or access modifications to buildings or vehicles to accommodate disability; and
- ▶ Licenses, certifications, and permits necessary for employment.

◆ **IMPAIRED RELATED WORK EXPENSES (IRWE)** —————

IRWEs enable SSI recipients to recover some of the expenses incurred as a result of their disability to support their work, and they allow SSDI/SSDAC beneficiaries to decrease reliance on SSDI benefits. The IRWE is much easier to apply for than PASS plans.

For the SSI recipient, deducting the cost of the IRWE from monthly gross wages increases the amount of SSI check benefit that he/she receives. For Title II (SSDI) beneficiaries, deducting an IRWE may keep gross monthly earnings below SGA, thus allowing them to maintain Title II eligibility.

AN IRWE DEDUCTION MUST MEET THE FOLLOWING CRITERIA

- ▶ Expenses must be directly related to enabling the person to work;
- ▶ Individuals, because of a severe physical or mental barrier, need the items or services to be employed or maintain employment;
- ▶ Costs must be paid directly by the person and not be reimbursable from other sources;
- ▶ Expenses must be paid in a month in which the person is working; and
- ▶ Expenses must be reasonable.

DEDUCTIBLE IRWE EXPENSES INCLUDE

- ▶ Supported employment services that further self-sufficiency;
- ▶ Work-related attendant care services, used to prepare to go to work and/or in the workplace; services can be performed by family

(continued)

members who can prove that caregiver suffers economically due to performing the service;

- ▶ Transportation costs, i.e., vehicle modification to get to work, SSA approved mileage expenses for travel to and from work, cost of drivers or taxi services;
- ▶ Medical devices, wheelchairs, pacemakers, respirators, etc., that allow someone to work;
- ▶ Prosthetics to enable employment;
- ▶ Residential modifications, either interior (if the person works from the home), or exterior (modifications to enable access to public thoroughways or transportation);
- ▶ Routine drugs or medical services to reduce the effects of the disability;
- ▶ Diagnostic procedures related to evaluation, control, or treatment of disabling condition;
- ▶ Prescribed non-medical appliances and devices essential for controlling the disabling condition at home or work (e.g., air filtering equipment);
- ▶ Cost of expendable medical supplies; and
- ▶ Cost of service dogs, such as dog food, licenses, and veterinary services.

BUSINESS CASE STUDY: USING AN SSI WORK INCENTIVE FOR PERSONAL ASSISTANT SERVICES

Mary Ellen is a middle-aged woman who lives independently with the support of a personal assistant. Mary Ellen has been employed as an office receptionist for two months and is earning a gross monthly salary of \$1,150. In addition to her salary, Mary Ellen receives SSI benefits. Her total countable income is in excess of SSA's Federal Benefit Rate (FBR) of **\$512.00**, and Mary Ellen anticipates that she will no longer financially qualify for SSI benefits. The presenting problem for Mary Ellen is that she needs the support of a workplace personal assistant during key points of her work day to maintain employment. Mary Ellen continues to have the following work related monthly expenses:

| | |
|---|--------------|
| ▶ Personal Assistant Services (10 hours a month @ \$30 per hour medical certification, etc.) | \$300 |
| ▶ Special Transportation Services | \$90 |
| ▶ TOTAL WORK RELATED MONTHLY EXPENSES | \$490 |

Mary Ellen's Benefits Planner met with her to demonstrate how SSA's IRWE work incentive could be used to pay for the work related expenses described above. She can potentially receive up to one-half of the IRWE through an increase in SSI cash benefits because of where the IRWE exclusion is applied in the SSI Formula. In Mary Ellen's case, the example below illustrates how the IRWE will affect her SSI cash benefit.

| | | |
|----------------|---------------------------------|-------------------------|
| STEP 1. | Gross Earned Income | \$1,150.00 |
| | General Income Exclusion | <u>-\$20.00</u> |
| | TOTAL | \$1,130.00 |
| STEP 2. | Earned Income Exclusion | <u>-\$65.00</u> |
| | TOTAL | \$1,065.00 |
| STEP 3. | IRWE | <u>-\$490.00</u> |
| | TOTAL | \$575.00 |
| STEP 4. | Divide by 2 | <u>2</u> |
| | TOTAL COUNTABLE INCOME | \$287.50 |
| STEP 5. | Federal Benefit Rate | \$512.00 |
| | Total Countable Income | <u>-287.50</u> |
| | SSI | \$224.50 |
| STEP 6. | Gross Earned Income | \$1,150.00 |
| | SSI | <u>+ 224.50</u> |
| | TOTAL INCOME | \$1,374.50 |
| | IRWE | <u>- 490.00</u> |
| | TOTAL USABLE INCOME | \$ 884.50 |

It will be important for Mary Ellen to keep accurate records of her IRWE, as well as all of her correspondence with SSA. Mary Ellen's Benefits Planner recommended that she develop a Social Security notebook that would identify SSA contact names, date of contact, and information obtained. Moreover, Mary Ellen must know her rights and understand that she has the right to appeal any and all decisions made by SSA, including eligibility decisions. If an appeal is made and won, the

decision will be retroactive from the date of the appeal. Therefore, even if a beneficiary is counseled that she/he does not stand a chance of winning the appeal, it is wise to make a formal application of appeal and to keep on trying, even if the appeal is not won on the first attempt.

◆ OTHER NOTABLE SSA PROGRAMS

BLIND WORK EXPENSE (BWE)

Blind Work Expense differs significantly from other SSA Work Incentive Programs. A BWE allowable expense needs only to be work-related expenses incurred by the person.

Effective January 1, 1999, the monthly substantial gainful activity (SGA) amount for persons receiving Social Security disability benefits based on blindness is \$1,100. This is a \$50/month increase over the 1998 amount. The nonblind SGA amount remains at \$700/month.

It is important to remember that since 1997, the blind SGA amount is no longer tied to the over-age 65 retirement earnings test. That amount will rise significantly over the next four years, based on legislation signed in March, 1996, until it reaches \$30,000 per year in 2002.

Although de-coupled from the retirement earnings test, the blind SGA amount continues by law to be adjusted annually based on the national average wage index.

STUDENT EARNED INCOME EXCLUSION (SEIE)

The SEIE is a Title XVI work incentive that allows people under age 22, who regularly attend school, to exclude up to \$400 of earned income per month (or up to a maximum of \$1,620 per year). This exclusion is applied before any other exclusion.

“Regularly attending school” means that the person takes one or more courses of study and attends classes:

- ▶ **In a college or a university for eight hours per week; or**
- ▶ **In grades 7-12 for 12 hours per week; or**
- ▶ **In a training course to prepare for employment for 12 hours per week (15 hours per week if the course involves shop practice); or**
- ▶ **For less time than indicated above for reasons beyond the student’s control, such as illness.**

Reporting SEIE to the SSA Claims Representative

The following information must be reported to the SSA claims representative for SEIE:

- ▶ **Whether the student was regularly attending school in at least one month of the current calendar quarter or he/she expects to attend school for at least one month in the next calendar quarter; and**
- ▶ **The amount of the student's earned income.**

SECTION 301

Section 301 provides for a continuation of SSI and/or Title II benefits to people who have medically recovered but are participating in an approved vocational rehabilitation (VR) program if:

- ▶ **They are participating in an approved VR program (school, job development, coaching, situational assessments, site evaluations, etc.) at the time that their disability ceases; and**
- ▶ **SSA has determined that the person's continued participation in the VR program will increase the likelihood of permanent removal from the disability benefit rolls.**

◆ **SUMMARY**

This chapter describes several options for funding personal assistant services. It is important that each individual exploring funding options understands that many PAS resources are unique to each specific state. Local Independent Living Centers and brain injury support groups can be valuable supports in helping to identify state specific PAS resources. For SSI and SSDI recipients, the Social Security work incentives remain a valuable option. The Social Security Administration continues to improve its work incentives program to assist individuals with significant disabilities achieve the employment goals that they seek. On December 17, 1999, the President signed into law the Ticket to Work and Work Incentive Improvement Act of 1999 (TWWIIA). This law is designed to: 1) increase beneficiaries choice in obtaining rehabilitation and vocational choices; 2) remove barriers that require people with dis-

abilities to choose between health coverage and work; and 3) increase work opportunities while decreasing dependence on public benefit. Many of these programs will be rolled-out over the coming years. It is important for interested participants to carefully monitor the Social Security Administration's web site at www.ssa.gov. This web site will always provide the most up to date information related to all of SSA's work incentive program.

INDEPENDENT LIVING AND EMPLOYMENT SERVICES: EQUAL PATHS TO COMMUNITY INTEGRATION

by: Susan Webb

◆ OVERVIEW OF FEDERAL LAWS THAT SUPPORT COMMUNITY INTEGRATION

For many persons with significant disability, the availability of Personal Assistance Services is the most critical factor for determining whether an individual lives in an institution or in the community. Even in communities where PAS is available to enable an individual to live in his or her own home or apartment, the cost is often so prohibitive that institutionalization is the only option. Clearly, employment that leads to economic independence is the primary key to community integration for people with significant disabilities. Unfortunately, public policy has been slow to offer programs that encourage employment for people with significant disabilities who need PAS. During the past two decades, however, public policy changes are helping people with even the most significant needs become employed without fear of losing their safety net of social supports.

Paving the way for these system changes was the Rehabilitation Act of 1973. This Act established a new, more aggressive national system of Vocational Rehabilitation. The main thrust of this program was employment for persons with significant disabilities. Few people worked in the Vocational Rehabilitation system, however, who personally experienced a significant disability of their own. Consequently, many individuals with significant disabilities were “deemed” to be unemployable by virtue of the severity of their disability.

A small group of advocates from Berkeley, California is generally credited with beginning what became the “Independent Living Movement”. Frustrated by a feeling of powerlessness and limited choice in Vocational Rehabilitation, this small group started the first Center for Independent Living (CIL) in Berkeley, California. In 1978, when the Rehabilitation Act came before Congress for reauthorization, Title VII was added to establish a number of Independent Living Programs designed around the theory that if people became more independent, they would become more employable.

Today, there are more than 450 such Centers around the country with staffs and Boards of Directors where individuals with significant disabilities hold the majority of board seats. The 1978 Rehabilitation Act

Building upon the concepts embodied, debated and upheld in the Rehabilitation Act, the ADA extended civil rights protections to persons with a disability against discriminatory treatment by the private sector.

Amendments required these Centers to be community-based non-profit corporations offering four core services: 1) Individual and Systems Advocacy; 2) Information and Referral; 3) Independent Living Skills Instruction and; 4) Peer Mentoring and Support. In addition to the four core services, CILs are involved in additional programs to meet local consumer needs such as Personal Assistance Services. Some CILs offer PAS directly through the Center. Others provide consumer training and referral for using PAS. A menu of related services include such offerings as: 1) accessible housing search and/or home modifications; 2) advocacy services to mentor individuals living in nursing homes to move into community living arrangements; 3) job training, placement and accommodations; and 4) transportation services including bus training, van modifications and, carpool matches. Consistent with the consumer control and choice philosophy embodied by the Rehabilitation Act, advocacy has emerged as perhaps the most important element of programs offered by CILs in changing public policy toward empowerment.

In addition to Title VII, the Rehabilitation Act Amendments added Sections 501-504. These short but powerful provisions opened a whole new world of civil rights protections for individuals with disabilities. Section 504 in particular prohibited discrimination by any Federally funded program and required these programs to deliver services and programs to persons with disabilities in the most integrated setting. Universities, court rooms, employers receiving federal contracts, even prisons, were required to ensure that persons with disabilities have access to participation. For the next decade, these civil rights protections enhanced awareness of persons with disabilities as equal citizens.

On July 26, 1990, President George Bush signed into law perhaps the most historic civil rights legislation ever enacted on behalf of persons with disabilities: The Americans with Disabilities Act of 1990 (ADA). Building upon the concepts embodied, debated and upheld in the Rehabilitation Act, the ADA extended civil rights protections to persons with a disability against discriminatory treatment by the private sector. The ADA protects qualified individuals with disabilities from discrimination in employment, public programs, public and private transportation, public accommodations (e.g. banks, theaters, hotels, restaurants, retail stores, etc.) and communications. Title I of the ADA delineates the requirements for employers to ensure non-discrimination in recruiting, hiring, testing, placing, retaining and promoting qualified individuals with disabilities who, with or without a reasonable accommodation, can perform the essential functions of the job.

Ten years post-ADA, the unemployment rate among people with disabilities remains a staggering 70%. As comprehensive as the ADA provisions are, there is still one major element missing: healthcare coverage, including prescription drugs and PAS. Healthcare coverage for approximately 10 million Americans with disabilities is currently linked to remaining on public assistance, primarily Medicare and Medicaid. Under current public policy, an individual with a disability who leaves cash entitlements also eventually loses healthcare coverage. When an employer provides healthcare coverage to its employees with disabilities, the ADA requires that the insurance be provided equally to employees with disabilities.¹ However, private health insurance does not include PAS as a covered benefit.²

In 1996, recognizing that many individuals with disabilities need healthcare coverage, including PAS, to be able to work, a grassroots movement emerged to change the Social Security Disability system. Massive amounts of research by the National Academy of Social Insurance, the General Accounting Office, the Social Security Administration, the National Council on Disability and various universities provided the data taken to Congress and the White House to develop legislation to remove the disincentives that so pervasively discouraged work. Concurrently, another group worked to introduce legislation to change the long term care system so that PAS would be available nationally to all who need it to be independent, including in employment.

In December, 1999 the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) was signed into law by President Clinton. This new initiative changes the Social Security Disability program to encourage beneficiaries to return to work. TWWIIA extends Medicare coverage for up to eight years post-employment regardless of income and allows states to implement a Medicaid Buy-In on a premium share basis. SSDI/SSI beneficiaries will be given a “ticket” to deposit with an employment services provider of his or her choice for help in preparing for, finding and retaining employment. Benefits planning and

¹ One notable inequity that exists is the issue of mental health parity. The ADA requires employers who provide health insurance to provide the same insurance to employees with disabilities. However, there is no requirement that the coverage provided to all employees is adequate for all employees' health care needs. Many employer-provided health plans significantly limit coverage for mental health services. The ADA does not prohibit this type of underwriting, even though it has been challenged many times in the courts.

² Many employers offer Long Term Care Insurance coverage. However, such coverage is offered separate from health insurance and refers to employees who typically can no longer work. Individuals with pre-existing conditions, even those with disabilities who do not use PAS at the time of the application for coverage, are usually denied coverage by the insurance carrier.

assistance counselors will be established nationally to ensure that beneficiaries have accurate and timely information on how to use the work incentives. Other provisions allow for work attempts without triggering a Continuing Disability Review and expedited re-entry if a work attempt fails. The new law also requires the Social Security Administration (SSA) to conduct demonstration projects to determine whether the SSDI program will encourage work more if beneficiaries could lose \$1 in cash benefits for each \$2 earned.³

The TWWIIA Medicaid Buy-In, in those states that opt to implement it, would allow individuals who are significantly disabled and utilize PAS to work without fear of an inordinate amount of his or her income being used to pay for PAS services. However, some states have limited PAS availability to many of its citizens. A grassroots movement to introduce and pass legislation to guarantee PAS availability is currently making its way through Congress.⁴

◆ INDEPENDENT LIVING & EMPLOYMENT SERVICE PROVIDERS AS PARTNERS

The Ticket to Work and Work Incentives Improvement Act of 1999 promises to return millions of Americans to the work force by offering consumers with disabilities a “ticket” to deposit with approved employment services providers. These providers will be part of an employment network or series of networks designed specifically to assist Social Security Disability (SSD) beneficiaries. Centers for Independent Living can either partner with these employment services providers or can become providers themselves. The TWWIIA legislation is very broad and comprehensive in encouraging providers who offer an array of services to apply to the SSA as a “ticket-taker”. Employers themselves can actually become ticket takers if they provide job skills training and other supports for SSD beneficiaries. There are a number of ways these partnerships can work. The following examples are not an exhaustive list. As the regulations are developed for implementing TWWIIA, additional creative solutions are expected to emerge.

³ Current law allows an SSA beneficiary to earn up to \$700 per month (more for individuals who are blind) without losing cash benefits. This is sometimes referred to as the “earnings cliff.” It is widely known that many individuals limit work to keep earnings below this level. The “2 for 1 offset” demonstration projects are designed to evaluate whether such a plan would increase employment by offering a “ramp” off benefits instead of the earnings cliff.

⁴ The Medicaid Community Attendant Services and Supports Act (MiCASSA) has been introduced in the U.S. Senate as S. 1935 by Senators Harkins and Specter.

1. **CILs as Providers** -- A CIL may apply directly to the SSA to be an employment services provider. Many CILs offer services beyond the four core services⁵. By virtue of being community-based, CILs must be responsive to local community needs. For that reason, some CILs provide PAS directly while others provide information and referral to other agencies who provide PAS. Likewise, some CILs offer employment services and/or benefits counseling. It is rare that a CIL is not in collaborative relationships with other organizations. An individual CIL could conceivably become an employment network to coordinate and subcontract to other providers of service. Multiple CILs within the same state could join together as an employment network to provide statewide, urban, and rural employment services.
2. **CILs and State Vocational Rehabilitation** -- Many CILs are contracted by their state Vocational Rehabilitation Department to provide independent living and employment services. Under the current system, VR is reimbursed from the Social Security Trust Fund for whatever expenditures they invest in an SSDI beneficiary who returns to work. In some states, those trust fund reimbursements are used to establish and maintain CILs who are not funded with Federal Title VII funds. Under the new TWWIIA, state VR systems have a choice of whether to continue the current reimbursement payment system or to shift to an outcome and/or milestone payment structure. The new payment options under TWWIIA have potential to increase Trust Funds coming into a state; however, the new shift to milestone/outcome-based payments could conceivably force CILs currently funded by VR Trust Fund reimbursements to reconsider and become a ticket taker themselves to maintain or increase their base funding.
3. **CILs and Projects with Industry** -- Projects With Industry (PWI) are community-based employment services providers established by Title VI of the Rehabilitation Act. Although, PWI providers are generally separate entities, some CILs have PWI programs. A partnership opportunity exists with the CIL offering consumers services such as peer mentoring, independent living skills instruction (bus training, budgeting, etc.), self-advocacy training, benefits counseling, home modifications, and PAS. After a consumer achieves his or her goals for independence, PWI providers can then effectively provide job readiness, skills training, job development, job placement, etc. that are typically not provided by CILs.
4. **CILs and DD Providers** -- Partnerships between CILs and those who provide services to individuals with developmental disabilities (DD) are emerging as the DD community begins to adopt such concepts as “self-determination” and “People First”. Sheltered workshops

(continued)

⁵Core services required by Title VII of the Rehabilitation Act are 1) Information & Referral; 2) Individual & Systems Advocacy; 3) Peer Mentoring & Support; 4) Independent Living Skills Instruction.

By establishing relationships with employers and staffing agencies, CILs also increase their credibility when advocating for improved access and when garnering support for changes in public policy.

group homes and institutions of the past are giving way to programs that offer greater opportunity for community integration. Individuals with developmental disabilities are more likely to find work in non-segregated settings, often with on-the-job supports such as job coaching, mentoring and PAS. Partnerships between CILs and Parent Training and Information Centers (PTIs) are effective in transitioning young people with disabilities from school to work. CILs can offer advocacy services to help families resolve conflicts with schools and other social systems.

5. **CILs and One-Stop Career Centers** -- One-Stop Career Centers were established as part of the Workforce Investment Act. They are designed to provide comprehensive job readiness, search, and placement services to individuals who may qualify for one or more training and employment programs. Anyone can drop in to a One-Stop and independently use the resources located there. Counseling and comprehensive job search assistance is available to those who need it. The Vocational Rehabilitation system is now incorporated into the Workforce Investment Act. Partnerships between VR and other one-stop programs are being developed so that individuals with disabilities are served equally by such centers. CILs can be effective advocates by: 1) ensuring that the one-stop centers know about services available through CILs; 2) encouraging consumers with disabilities to be appointed to the state and local Workforce Investment Boards; 3) referring/accompanying consumers to the one-stop centers to use their resources; and 4) monitoring the one-stops to be certain they are offering individuals with disabilities appropriate and integrated services.
6. **CILs and Employers/Staffing Agencies** -- Employers and staffing agencies are finding it increasingly challenging to recruit employees with the necessary skills and work ethic. The expanding job pool and shrinking workforce have left a significant void in the available pool of potential employees. Recent economic expansion and global competition only exacerbate the problem of finding enough people to get the job done. CILs can offer qualified individuals with disabilities to expand the labor force. By establishing relationships with employers and staffing agencies, CILs also increase their credibility when advocating for improved access and when garnering support for changes in public policy. Possible funding sources to operate a job placement program can be contracts with State VR, United Way, Projects with Industry, Division of Developmental Disability, and eventually the Ticket to Work program. The Society for Human Resource Management and the American Staffing Association are excellent national resources for CILs to obtain contact information to join local chapters.
7. **CILs and Long-Term Disability Insurance Carriers** -- More than 40% of individuals applying for Social Security Disability benefits

are doing so as a requirement for receiving cash payments from an employer's long-term disability policy. Back injury, stress disorder and repetitive motion syndrome are conditions that result in employees leaving work on disability benefits. Larger insurance carriers have aggressive return-to-work programs; however, they are often based upon the "medical model" that focuses on incapacity rather than capacity. Beneficiaries who ultimately receive Social Security Disability benefits generally never return to work. Consequently, employees with disabilities who have excellent skills, good work ethics and want to work are relegated to lower standards of living and become trapped by entitlements. CILs can establish relationships with Long-term Disability insurance carriers to use the independent living model for return to work supports. CILs can charge an hourly fee-for-service to build upon capacity and accommodation of these valuable employees rather than incapacity and public benefit programs. Such fee-for-service programs can generate unrestricted funding for CILs to use for advocacy activity or anything needed to strengthen its programs and operation.

8. **CILs and Welfare-to-Work Programs:** According the recent statistics from the University of Kansas, 55% of families receiving Temporary Assistance to Needy Families (TANF) have disabilities.⁶ Often, these are mild mental retardation or learning disabilities that are not even identified. These families frequently feel frustrated by continual failure when, in fact, a cognitive limitation could be the reason for their failure. The comprehensive, holistic methods used by CILs to enhance quality of life and independence can be very effective in working with these families toward self-sufficiency. Partnerships between the CILs, welfare agencies and the one-stop career centers can be a truly dynamic opportunity to change people's lives. The CIL's peer mentoring and advocacy programs are proving to be effective supports for families who may have limited self-advocacy skills and self-esteem.

◆ EMPOWERING CONSUMERS TO NAVIGATE FEDERAL REGULATIONS

USE OF THE INTERNET

The advent of the internet has brought significant empowerment to the desktop of consumers with disabilities. Historically, the lack of transportation and accessible, affordable communications have restricted the ability of people with disabilities to congregate sufficiently to influence public policy to the same extent as other stakeholders within the

⁶National Technical Assist Center on Welfare Reform (Winter, 1999). Welfare policy and disability. 1(2): University of Kansas, Lawrence, KS.

community. Grass roots organizations such as ADAPT⁷ have expended significant effort just accumulating the donations necessary to travel to Washington, D.C. or other places across the nation to advocate for available in-home personal assistance services. Organizations such as ADAPT are even more effective today with the availability of e-mail as a vehicle for communicating and organizing their cause.

The internet is valuable in increasing the numbers of grass roots advocates and improving their knowledge and advocacy skills. New regulations published in the *Federal Register* literally appear on computer listserves within minutes of their announcement. Proposed rules open for public comment are disseminated the same way. Organizations such as National Council on Independent Living (NCIL), Disability Rights Education and Defense Fund (DREDF), National Parent Network (NPND) and other interest groups not only disseminate the rules and proposed rules, but also their recommended responses to the rules. As such, Federal agencies responsible for promulgating rules receive more and better comments from a more diverse public than ever before.

Another important aspect of internet communications is that it engenders solidarity and self-confidence. A consumer who may have been isolated in the past, believing he or she is the only one experiencing a given situation, finds through the internet that many, others are having the same problem. The internet lends a new opportunity for effective peer mentoring and support, a core service of Centers for Independent Living. People with disabilities in rural communities or belonging to certain minority groups can communicate effectively and experience camaraderie through the internet, even though they may have never met face-to-face.

WHAT TO DO WITH THE INFORMATION

Once consumers have the information, they need to know how to use it. CILs and Protection and Advocacy (P&A) organizations typically offer courses in self-advocacy. These courses often include information about how a bill becomes law and the subsequent regulatory process. However, it is difficult to effectively use this information without hands-on practice. Reading laws and regulations is not very exciting work; generally the text of laws and regulations are best used as references when searching for some particular information about an issue.

⁷ Americans Disabled for Attendant Programs Today (formerly Americans Disabled for Accessible Public Transportation) has long been recognized as a “militant” group of grass roots advocates who “climb” the stairs of the Capitol, chain themselves to buses and routinely get arrested for civil disobedience to increase awareness of disability oppression.

Navigating a law or regulation can be challenging without help, no matter how skilled and experienced a consumer becomes. Federal regulations are promulgated by the Federal agency responsible for its implementation and enforcement. Usually these agencies have websites and/or toll-free numbers to request interpretive guidance on a particular regulation. For example, a consumer who needs information on the Social Security Work Incentives can go to the internet at www.ssa.gov to get information on the regulations

USING LAWS AND REGULATIONS FOR PROBLEM

Unfortunately, disability culture has a long way to go to become credible in the eyes of “professionals”. American culture still has a great deal of paternalism deeply entrenched relative to disability. Non-disabled people, especially those with limited experience around people with disabilities, often want to take care of individuals with disabilities and believe they are being helpful and compassionate in doing so.⁸ Even as more people with disabilities enter the professions, acceptance as equals is difficult to achieve. For this reason, using laws and regulations is often a “buddy” process. Effective advocacy using laws and regulations takes more than one person; usually a group is needed to be taken seriously. For this reason, it is often faster and easier to take a personal issue to a formal or informal support group to resolve it.

For example, several years ago a consumer who uses crutches visited a Motor Vehicle Division (MVD) office on his lunch hour to renew his expiring driver’s license. The clerk informed him that it would be necessary for him to take the written test and a road test for his renewal. When he questioned why this was the case as he had a safe record and nothing had changed since his last renewal, the clerk told him it was because he was “not normal” and the state regulations required such tests. He left without renewing his license and asked for help from his local CIL. The CIL director, incensed about such a clearly discriminatory policy, called one of the MVD’s attorneys and explained this to be a violation of Title II of the ADA. The attorney argued that the MVD had a responsibility under state law to ensure that only safe drivers receive driver’s licenses. Of course, the assumption that a driver with a disability has a greater burden of proof than a non-disabled driver, was clearly the flaw in the attorney’s logic. What ensued was nearly two years and

⁸One of the most recent chronicles of the history of the civil rights movement as it relates to disability culture is a book by Joseph P. Shapiro, *No Pity*. Shapiro examines various pockets of disability culture and how advocates struggle to achieve equality within a society that still sees disability as a pitiable circumstance.

the work of 43 advocacy agencies and individuals to get the state regulations changed to eliminate this discriminatory practice. Had the individual consumer simply succumbed to the discriminatory policy, no changes would have taken place and others would have continued to be subjected to the practice. However, because this consumer had some sense of his civil rights and where to go for peer support, the landscape improved not only for him but for those others who would also seek the same public service.

Recent shifts in public policy toward empowerment and consumer choice have opened significantly improved opportunities for people with even the most significant disabilities to enjoy life more than ever. The ADA borrowed from the history of the Rehabilitation Act to ensure equal access to all facets of community life, including employment. More recently, the Workforce Investment Act, the Ticket to Work and Work Incentives Improvement Act, and appointment of individuals with disabilities to key policy making positions within the Federal government, have all served to bring greater hope for a bright future for millions of disempowered and discouraged Americans. With a strong economy and a renewed sophistication within the disability culture, no American with a disability should be left out in pursuit of the American dream.

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APPENDIX

◆ SAMPLE JOB DESCRIPTION

OPTION 1

Person needed to be a workplace personal assistant for an employee with a disability in an Academic environment. Casual attire is suitable for office work but more business like attire will be required for meetings and training assignments that will take place outside of the office. Some of the duties of the assistant will include word processing, keeping employee's workstation organized, assisting employee with retrieving and responding to e-mails, filing, assistance with telephone calls, and some traveling will be necessary.

Additional duties may be assigned in the future to accommodate any changes in the employee's work scope and job responsibilities. In this case, training will be made available to the assistant to prepare him/her to assume any necessary additional duties. The salary will be paid partially by the employee's employer and by the employee and will be negotiated by the assistant.

OPTION 2

The primary duty of a workplace personal assistant is to support an employee with a disability in an academic environment. That employee will be the primary supervisor of the workplace personal assistant. Most duties are clerical in nature. Some of the necessary skills needed are having a basic knowledge of word processing programs, data entry programs, how to build and maintain telephone data base, and how to assist the employee they are assisting with correspondence or reports on an as needed basis. In addition to these, the workplace personal assistant will be responsible for handling all administrative paperwork at training events out in the field.

The employer and employee will compensate the workplace personal assistant a maximum of thirty-two hours per week. The employer's portion will be for twenty hours a week to assist the employee with all tasks that are specifically related to work. The employee will compensate the workplace personal assistant an additional twelve hours a week for assisting with chores which are considered a personal nature.

The successful applicant needs to be prepared to accompany the employee on overnight business trips. On these trips, the workplace personal assistant will assist with such chores as dressing/undressing, providing support at mealtime, and minimal assistance with personal hygiene. The employer or the employee will reimburse the workplace personal assistant for all work-related expenses on business trips.

Agreement between Edmond Turner, Employer, and John C. Barrett, Personal Assistant (PA).

- PA will work five (5) days a week. PA will work one (1) day at home (either Monday or Friday) and four (4) days in the office.
- PA will be paid once monthly.
- PA will receive two (2) weeks paid vacation per year.
- PA will have one (1) sick day per month.
- PA will give two (2) weeks notice of leave.
- PA will keep dwelling clean, do laundry, prepare meals, and do grocery shopping.
- PA will pay for own long distance telephone calls.
- PA will assist employer with dressing and grooming.
- PA will travel with employer on business trips, to meetings, and other functions to assist employer.
- PA will perform other duties as needed by employer.
- Employer agrees to pay PA's expenses at social functions, if business related.
- Employer agrees to pay PA once monthly and for any other services deemed necessary.
- Employer agrees to pay half of PA's van repairs.
- Employer agrees to give two (2) weeks notice of termination of PA.
- Employer agrees to pay half of the purchase price on a 1999 Ford van, lift equipment/controls, and automatic tie downs. Vehicle will be jointly used by employer and personal assistant.
- Employer agrees to do as much as possible for himself independently.

Signatures:

Employer: _____ Date: _____

Personal Assistant: _____ Date: _____

Self assessment

◆ WORKPLACE PERSONAL ASSISTANT SELF-ASSESSMENT FORM _____

| Essential Job Functions | How Function will be Accomplished by PA | Assistive Devices Needed | Tasks Needing Assistance | Estimated Time Assistance Needed |
|-------------------------|---|--------------------------|--------------------------|----------------------------------|
| | | | | |

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