

# INTRODUCTION

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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.

