

Personnel Management Manual: Achieving Independence Through Personal Assistance



Accessibility and community integration consultants dedicated to supporting the spirit of independent living and enabling people with disabilities to access the best that life can offer.

Written by

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Edited by
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PLEASE HELP ME KEEP THIS MANUAL UP-TO-DATE

This manual is a living document and, as such, is meant to be functional.

I welcome hearing from you concerning your experiences, suggestions and ideas that could improve the manual. While I may not be able to respond to all comments and suggestions, I will certainly try, and I will take them all to heart and make certain they are included in upcoming editions. All proceeds from this manual are a donation to the non-profit corporation Help-Your-Self inc. and used to provide free copies of the manual to individuals with disabilities who otherwise could not afford them.

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Thank you for your input!

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DEDICATION

This book is dedicated to the strong people that taught me what it takes to survive and strive as a quadriplegic woman.

Thank you to Dr. Russler, Sybille, and Dr. Mandalca for keeping me alive, and for your in-depth knowledge about people with disabilities, your dedication to genuinely helping people, and your wisdom.

ABOUT HELP-YOUR-SELF INC.

Help-Your-Self inc.® is a 501(c)(3) non-profit corporation dedicated to enhancing accessibility for people with disabilities. We are above all committed to helping people help themselves to become self-sufficient, lead productive lives, and improve and maintain a life style of their choice. We provide tools and services to enable community integration, reduce barriers that cause handicaps, and educate to prevent injuries.

Donations are welcome and tax deductible.

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PRINCIPALS AND PHILOSOPHY OF THIS MANUAL

“Independence is not measured by the quality of tasks we can perform without assistance, but the quality of life we can have with help.”

– World Institute on Disability, Berkley, CA

“Whereas you may choose to think that having to use a personal attendant robs you of your independence, in reality having a personal attendant may be your means of living your life the way you want.”

– Erica Nash

INTRODUCTION

The goals of this manual are to help people with disabilities learn to live independently and teach PAs how to assist them, so they can achieve that independence.

Personal Attendant

A Personal Attendant (PA), or Attendant, typically provides assistance with tasks and chores that persons with disabilities are unable to perform themselves. These tasks vary from individual to individual.

For some people with disabilities, attendant care is a necessary element of everyday living. The person with a disability may be assisted in performing or need everyday activities performed by the PA. These activities range from personal hygiene, bathing, dressing, shopping, and housekeeping to assistance with work or school. The efficiency of your PA affects the quality of your life. Only a good PA can help you achieve independent living. Although effective attendant care is the most important factor to achieving independent living, it is also often a problem and a struggle.

Traditionally, attendants were hired by outside agencies that required them to be trained and supervised by a nurse or doctor. Today, more people hire and train attendants privately.

Independent Living

This manual is based upon an independent living philosophy – the idea that people with disabilities should be in control of support services that assist them in achieving independent living.

In the 1970s, a group of students with disabilities in Berkeley, Calif., realized they knew as much, if not more, about their attendant needs than the medical personnel. The students felt that if they were to live independently, they should be responsible for hiring, training, and supervising their attendants. Due to the lack of existing programs, they created their own, and from their hard work and effort, the Independent Living (IL) movement was born.

One of the beauties of the IL philosophy is “consumer control also means consumer choice.” It is up to you to determine if you want total control of your attendant services or if you need some assistance from an agency. You might prefer to hire a PA on your own, search with the assistance of a nursing agency, or have a nursing agency provide you a PA. You can decide whether to train them yourself or hire someone with extensive medical experience.

The Manual

What I suggest and recommend in this manual has worked well for other people with disabilities and for me as well. After reading this manual, you may wish to adopt all the procedures or only some of them. Keep in mind, however, that the suggestions and concepts I outline are designed to work well as a whole, but you may also benefit from using individual sections. You will feel confident that you are hiring the correct person, you can manage how they assist you, your particular needs are met the way you want them to be, and you have a healthy and happy relationship with your PA.

This manual will teach you how to assess your own needs and how to find, hire, train and supervise a PA. You will learn how to write a Personal Needs Assessment, Job Description, Personal Schedule, and Work Agreement/Contract. This manual will provide you with tips about hiring, interviewing, and communicating with your PA, as these items are important when hiring and supervising your attendants. You will also learn how to find legal advice when necessary.

Generally, most of us have had little or no experience as an employer or supervisor. When you hire an attendant, you become a boss, and you enter the complex world of business management. In the business world, there are basic employee management skills that apply whether the worker is a store clerk, a factory worker, or an attendant in your home. This manual will supply you with business management concepts as they apply to the PA-employer relationship and indicate how they will benefit you.

The manual only suggests how you can train and manage your attendant. It does not plan your routine, measure your requirements, or arrange your schedule. These are decisions that you must make. This manual will serve as a guide to make your decisions easier in finding and living with an attendant effectively.

The challenges lie not only in finding, training, and interacting with PAs, but also learning how to communicate in a positive way, to keep your PA involved and willing to remain in your employ. It is certainly not an easy task. Proper communication and personnel management skills are tasks that people with disabilities stumble with, yet they are crucial tools that need to be mastered. In this manual, you will find the knowledge other people with disabilities and I have gained from years of experience, frustrations and accomplishments that led to these recommendations.

In addition, all too often, individuals who want to assist people with disabilities do not receive the type of training that enables them to help their client achieve true independence. PAs are usually prepared to handle seating transfers, bathing and other medical needs. However they are not taught the psychology of care, nor interpersonal skills. They often lack insight into how people with disabilities perceive independence. Without this knowledge, PAs can feel overwhelmed by their job. This contributes to the frequent turnover of personnel, and can easily cause an individual with disabilities to lose self esteem and lower their expectations of independence.

This manual goes beyond basic instruction and teaches tools that will empower people with disabilities. It is designed to be helpful to individuals with disabilities, family members, caregivers, hospitals, ILCs, teaching institutions, nursing agencies, and community centers.

Funding

You may be asking yourself how you can find funding to pay for your PAs. It is a challenge to locate funding; however, financial resources are available from the private sector and the state and Federal governments. Which funds are available to you, where to find them, and how to request the funds, are resources that are offered in this manual as well.

Most people with disabilities need to rely on state funds, which can be quite limited. All too often, PAs leave their positions because the financial compensation offered to them through state funding is too low. Having said that, I must point out that it is important for you to recognize and always remember that PAs do not engage in this line of work just for the money. Because of this, a congenial relationship is necessary. When your financial resources are limited, it is important to offer your PA other reasons and incentives, beyond financial, to stay. In this manual, I suggest to you a variety of incentives that others and I have used to motivate PAs.

Screening

For your safety, it is imperative that you thoroughly screen applications. However, even with thorough screening, it is still possible to end up with a dishonest attendant. This occurs rarely. Independence comes with risks and responsibilities that I feel are worth the price. In this manual, I offer dos and don'ts and some possible solutions on how to handle difficult circumstances during the screening process.

I hope you find this manual helpful.

Erica Nash

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1.

THE ROLE OF A PERSONAL ATTENDANT

“It is up to you, the individual with the disability, to communicate that your attendant is not your babysitter, but rather your means of living your life independently.”

A Personal Attendant (PA) is paid to provide services for persons with disabilities. These services may involve personal care assistance, help with household chores, or both. Attendants assist you in completing Activities of Daily Living (ADLs) that may be too difficult and/or too time consuming and exhausting for you to perform on your own. The PA's role is to provide the assistance that enables a person with disabilities to live more independently.

Able-bodied people hire individuals to perform ADLs, but the employee is not referred to as a PA; they are maids, laundresses, valets, cooks, butlers, drivers, gardeners, and secretaries. A wealthy person is considered fortunate to be able to afford such personal help and care. However, a disabled person is considered "dependent" on such care.

Do not let social construction affect you. The terms "dependent" and "independent" are relative to class and consciousness. If we continue to think of a disability as a pitiful state, then everything about the life of a disabled person is perceived as pitiful and not luxurious nor envied.

Attendants should not be viewed as parents, servants, medical personnel, or personal friends. Although relationships can develop between people with disabilities and their caregivers, it is necessary to define and maintain the fine line that separates the work from the personal relationship.

Whose responsibility is it to insure that the PA meets all your needs? The answer depends upon how involved you want to become with your own care, how much attention you want your PA to pay to your instructions, and how well you are able to instruct your PA.

If you are accustomed to having your needs assessed and fulfilled by parents or a nursing staff, you will have to learn to regard your PA differently. When living on your own, first and foremost, you need to define your own needs. Only then, will you be able to instruct your PA on what tasks to perform and how to perform them.

You have the option to choose what you would like to instruct and how you train your PA. It is your responsibility to prioritize your needs and instruct your PA in detail on the steps related to completing those tasks to your satisfaction. After training, you can insist that those instructions be followed.

You will need to consider your entire routine. There are many other details of your daily life and care that I recommend you carefully consider before approaching your PA with requests for assistance.

There will be many tasks that you need or want your PA to do as you direct them through the task. Therefore, it is necessary to alleviate some of the pressure that constant instruction applies on your PA. In matters that you feel do not need supervision or control, allow your PA the freedom of choice. I have found it helpful to explain how I like tasks to be done by supervising the task the first time to ensure that the end result is indeed what I want. After that, I allow my PA to accomplish those tasks without supervision.

You may find yourself frustrated at the lack of control you have and be emotionally tied-up by trying to accomplish tasks yourself that you can no longer perform because of your disability. This could be a conflict between your need to have control over your environment and the way the environment around you is evolving. The way your environment evolves after a trauma, injury, or disabling condition will not be the same as it was prior to the event.

Try not to confuse control issues with concern about how the laundry is done, how your kitchen is cleaned, how your vehicle is driven, etc. If you are pleased with the end result, you need not control how it was achieved. However, in instances where the manner in which the task was performed can cause injury or damage (e.g., reckless driving), you need to be concerned.

Prior to your injury, folding clothes and washing dishes may have played a part in your self worth. It is possible for you now to find other aspects of your life that can replace the function that those activities had in the building of your self esteem. You could be spending an incredible amount of energy by being frustrated, angry, resentful, and controlling. Try to put that energy to better use.

The PA is an assistant, not a servant. It is easy to fall into the routine of daily living and lose sight of this important concept. At all times, mutual respect and consideration must be maintained within the relationship. I can tell you from experience, without a doubt, that mutual respect is necessary in order for you to receive the type of care, concern, and attention you would like from your PA. You should be flexible and have the ability to work around your needs to accommodate the PA and vice versa. This is a concept that I have taught at many seminars, and the feedback I have received over the years confirms that this is the most important factor in achieving good personal care and a good relationship with your PA. Unless there is a spirit of respect, people will not be free to learn, think, change, or grow in assisting you and attending to your needs.

There are many ways to define disabled, and there are many ways people react toward a person with a disability. These responses are not dictated by human nature; they are socially constructed. Personal Assistants respond to people with disabilities in a variety of ways that may not seem logical, justified, or fair. But, such is life in our society.

It is difficult for people to see and meet other people's needs when it interferes with their own needs. As long as you are aware of this human characteristic, you can avoid being hurt by people's responses and reactions.

Generally speaking, people bring baggage along with them that at times clouds their ability to understand that people with disabilities can indeed live independently. Although there are many examples, I offer the following. People's perceptions can often lead them to think of your PA as your companion or babysitter. It is up to you, the individual with the disability, to communicate that your attendant is not your babysitter, but rather your means of living your life independently. If you help people become conscious of your needs, you will be less frustrated at their perhaps improper reaction to your circumstances.

Attendants can become companions, but the process of developing such a relationship takes a long time. Be aware that due to close contact between you and your attendant, developing a friendship, and sometimes even more intimacy, is often a consequence.

Maintaining both a work and personal relationship at the same time is more complicated than keeping your relationships separate. If the work relationship is burdened by your friendship, I recommend that you talk about the issues and consequences together.

Under these circumstances, you must decide how to continue and define the work relationship. One choice you have is to terminate one type of a relationship and continue only with the other. Most people find it more difficult to terminate a friendship than an employer/employee contract. This is a decision that depends on compatibility and personality and should be mutually decided. To maintain both a personal and work relationship at the same time is extremely difficult. However, maintaining both relationships can sometimes work.

2.

ATTENDANT CHARACTER TYPES

“You will simply have to choose the characteristic that best compliments your own needs and personality.”

There are many types of attendants. After years of living with, hiring, training, and firing PAs, you will learn to recognize these characteristics very quickly. Until then, keep the following personality outline in mind while you conduct interviews. Try to recognize what sort of characteristics might be hidden in the person sitting across the table. These characteristics are neither negative nor positive. Any one of these characteristics might be right for you. You will simply have to choose the characteristic that best compliments your own needs and personality.

The Nurse: A person who has developed their own medical techniques and refuses to do a task any other way. The disabled person no longer directs their care as they are being directed. This PA will be knowledgeable about your safety, hygiene and able to prevent medical problems, which could allow you to feel confident and secure.

The Mother: A person who feels that it is their moral responsibility to take care of the disabled individual. They are nurturing and attentive. The PA may be too affectionate, might sweetly hover over you and pat you on the head, and will always want to know what you are doing and why. However, you might feel that this PA is trustworthy and may offer you the nurturing attention that you are accustomed to or feel you need.

The Best Friend/Companion: A person who allows no privacy to the disabled person. They tamper with, manipulate, and interfere with the individual's social life, potentially trying to keep the individual from having other social relationships. This attendant expects to be included in all social activities planned by the disabled individual. They, indeed, would be hurt if they were left out. However, such a PA might offer you acceptance and stability and turn out to be your best friend.

The Over-protector: A person whose credo is "I know what's best for you." This PA may try to prevent the disabled person from taking even the most minor risks, thus encouraging a dependent relationship. This PA, however, might also force you to believe in yourself more and encourage you to become more independent and strive for your life goals.

The Good Samaritan: This PA's primary objective is to make herself/himself feel needed. This person's credo might be "You've suffered enough already. Let me take care of you." This attendant will do more for you than is necessary. This could be a good quality, but you might also feel you are being treated like a child.

The Addict: A PA who abuses alcohol, drugs or medications. These attendants may do a good job when they are not “spaced out.” They are usually unreliable and/or inconsistent in behavior.

The Preacher: A PA who insists on imposing their religious beliefs upon the disabled person. I know of some PAs who have attempted to perform their duties through prayer. They generally would not respect the disabled person’s rights, beliefs, and values. However, if you are a very religious person, this PA might help you create the type of living environment you would enjoy.

The Assertive Personality: A PA who states their feelings and needs in an aggressive manner. Their bold and direct approach can be overpowering. However, if you have patience and a strong personality yourself, this could be exactly what you want.

It is wishful thinking that the perfect personality match is on the other side of the table during an interview. You will probably focus on the candidate’s positive qualities and discount their negative ones. It is necessary to look at all of an individual’s characteristics, both positive and negative. You should look for someone who is naturally caring and confident. The most overqualified individual can be just what you are seeking or the seemingly most unqualified person can prove to be your best candidate. Ultimately, the perfect match is very dependent on your own personality.

3.

DIFFERENCES BETWEEN 'AGENCY-DIRECTED' AND 'SELF-DIRECTED' PERSONAL CARE

“Many people with disabilities find that agency-directed care does not meet their individual needs.”

Traditionally, attendants were hired by an agency that required all attendants to be trained and supervised by a registered nurse. Some state agencies still require that attendants receive Home Health Aid (HHA) certification. This arrangement is called agency-directed personal care. However, many people with disabilities find that agency-directed care does not meet their individual needs. Your insurance company may determine the amount of hours of care you receive.

Private agencies usually provide a minimum of 4 hours of services in a single block of time. However, a person who requires only 1–2 hours of assistance in the morning and the same amount of hours in the evening (two blocks of time) would be subject to paying extra for hours not used.

Using an agency as an attendant-provider might mean giving up some of the freedom of your lifestyle. For example, agencies may not provide attendants if you require them to stay out late at night. Self-directed care requires that you learn how to hire, train, manage, and terminate employment of your PA. My aim is to assist you in this process.

Agency-directed

Advantages

- The agency is responsible for making sure that you have an attendant.
- The agency interviews, checks references, and performs a criminal background check on all applicants.
- The agency provides back-up care if your attendant calls in sick.
- The agency might offer benefits.
- If you decide to go on vacation without your attendant, you are not burdened with the expense of maintaining a salaried attendant while you are away.
- Agencies withhold payroll taxes and submit them to the IRS, so you are not responsible for that task.

Disadvantages

- Persons with disabilities have no choice in the selection of their attendant.
- The attendant does what the agency directs them to do, which may contrast with what you want them to do.
- Some agencies might not have good back-up arrangements due to lack of staff or disorganization.

- If you complain about your attendant to the agency, your complaints might be brushed off as “whining.”
- Agencies approach personal assistance from a medical point of view where the consumer is a patient, not an individual, and certainly not capable of being in charge.

Self-directed

Advantages

- You are in charge.
- You set the rules.
- You can hire whom you like.
- You have greater flexibility in scheduling.
- If your attendant doesn't do a job to your satisfaction, you can fire them.
- You can alter your reward system.
- You can encourage specific behavior from your attendant.

Disadvantages

- You must arrange your own back-up and emergency care.
- You must calculate withholding taxes and report them to the IRS (computer software is available to assist you).
- It is very time consuming to place ads, conduct interviews, arrange schedules, and train attendants.
- You must train and supervise your attendants, which is very demanding of your time, patience, health, and finances.