

## THE BASICS OF PAS

### DIFFERING DEFINITIONS

Before getting into too much depth regarding finding and managing your own PAS, it's important to have a basic understanding of the varying definitions of PAS, knowledge of commonly used terms, and a grasp of the common legal issues that arise surrounding the issue of PAS.

The term “**personal assistance services**” has become the more preferred term in the disability community to refer to someone, or several people, who assist a person with a disability in performing certain tasks during the course of the day that s/he cannot perform on his/her own. Other terms are still used, such as personal assistant (PA), Personal Care Assistant (PCA), or Attendant. While it may seem confusing, it is important to understand the use and meaning of the term PAS as there are subtle differences in various programs and settings that can affect eligibility for programs, funding, and specific services.

The World Institute on Disability defines PAS as “assistance, under maximum feasible user control, with tasks that maintain well-being, comfort, safety, personal appearance, and interactions within the community and society as a whole” (Holt, Chambless & Hammond, 2006). In general, PAS is used by persons with disabilities to perform tasks that the person would perform for him/herself if s/he did not have a disability. It can include tasks that range from reading, communication, and performing manual tasks (e.g., turning pages) to bathing, eating, toileting, personal hygiene, and dressing (Silverstein, 2003).

Another way to think about PAS, especially for Medicaid program eligibility purposes, is as a “range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do for themselves if they did not have a disability.” Assistance may be hands-on (actually performing a task for an individual) or cueing so that the person performs the task by him/herself. Such assistance most often relates to performance of activities of daily living

(ADLs) and instrumental activities of daily living (IADLs) (State Medicaid Manual, Section 4460).

And to push the definition even further, the Rehabilitation Act and the Ticket to Work and Work Incentives Improvement

Act define PAS as “a range of services provided by one or more persons designed to assist an individual with a disability to perform daily living activities on or off the job that the individual would typically perform if the individual did not have a disability. Such services shall be designed to increase the individual's control in life and ability to perform everyday activities on or off the job” (Ticket to Work and Work Incentives Improvement Act, 42 USC 1320b-22(b)(2)(B)(ii); 34 CFR 361.5(39) and the Rehabilitation Act, 34 CFR 361.5(39)).

However, over the last several years, legislation floating (and dying) in Congress designed to create a comprehensive national PAS system has consistently used the following more specific definition of PAS: “...tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair, or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation laundering, and long-term heavy cleaning and repairs; 4) infant and child-related tasks such as bathing, diapering, and feeding; 5) cognitive or life management activities such as money management, planning, and decision making; 6) security-related services such as interpreting for people with hearing or speech difficulties and reading for people with visual disabilities” (Glazier, 2001).



## UNDERSTANDING KEY TERMS

In the realm of PAS, certain terms are critical to understand in order to protect your civil rights. Here are some key terms you need to know:

- **Activities of Daily Living:** These are things you do every day such as dressing, grooming, bathing, eating, positioning, transferring, and toileting.
- **Health-Related Functions:** Services that must be delegated or assigned by a licensed health care professional, such as a nurse or doctor. Health-related functions are usually required to be provided under the direction of a qualified professional (QP) or a doctor. Examples of health-related functions are special skin care, non-sterile catheter care, tube feedings, and respiratory assistance.
- **Home Health Agency:** Home health agencies usually have a license from the Department of Health or other disability-related department and are Medicare certified. These agencies typically provide skilled nursing visits, home health aide visits, occupational and physical therapy (OT/PT) visits, as well as PAS.
- **Instrumental Activities of Daily Living:** These activities include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.
- **Major Bodily Functions:** These include but are not limited to the operation of a major bodily function, including but not limited to, functions of immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.
- **Major Life Activities:** Caring for oneself, performing mental tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.
- **Personal Care Provider Organizations:** Sometimes called “PCA Agencies.” These are community-based organizations or agencies that only provide PAS.
- **Reasonable Accommodation:** A modification or adjustment to a job that enables a qualified individual with a disability to perform the job functions and thus enjoy equal employment benefits and privileges.
- **Workplace Personal Assistance Services:** Workplace PAS comprises task-related assistance at work, including readers, interpreters, and help with lifting or reaching. Non-essential tasks may also be re-assigned to co-workers. Workplace PAS might include personal care-related assistance such as helping someone with eating, drinking, or using the restroom while at the job site (Krause, 2007).

## DISTINGUISHING BETWEEN JOB-RELATED AND PERSONAL PAS

The Americans with Disabilities Act (ADA) of 1990 is a civil rights law that bans discrimination on the basis of disability. Under the ADA, an employer with 15 or more employees must make reasonable accommodation for an otherwise qualified applicant or employee unless the employer can demonstrate the accommodation would impose an undue hardship on the operation of the business (29 CFR 1630.9(a)). A qualified person with a disability must meet the skill, experience, education, and other job-related requirements (of a position held or desired) and—with or without reasonable accommodation—be able to perform the essential functions of a job (29 CFR 1630.2(m)).

Thus, the ADA requires employers to provide PAS to an applicant or employee with a disability so long as the services are job related and not primarily for personal benefit. Job related assistance in the performance of such tasks as reading, communication, the performance of nonessential manual tasks, and business-related travel may be considered

reasonable accommodations. Assistance with tasks such as eating, toileting, dressing, and personal hygiene are primarily personal in nature and generally are not considered reasonable accommodations (Silverstein, 2003, p. 2). Assistive technologies such as closed caption television, text messaging, screen magnification, and reaching devices complement work-related PAS. However, assistive technologies are not workplace PAS (DOL/ODEP (2006), p. 3).

These lines can become very blurry, especially if an employer provides personal care as a part of workplace PAS. It is important to know the rules and the legal interpretations. Since the provision of some PAS is at the discretion of the employer, it is always a good idea to communicate directly with your supervisor about specific PAS workplace needs.

According to the Equal Employment Opportunity Commission (EEOC), reasonable accommodation under the ADA can include providing work-related personal assistance to help an employee with a disability perform marginal job functions. The EEOC includes the following example in its ADA Technical Assistance Manual: "Some other accommodations that may be appropriate include . . . providing a personal assistant for certain job-related functions, such as a page turner for a person who has no hands, or a travel assistant to act as a sighted guide to assist a blind employee on an occasional business trip" (EEOC, 1992).

Use of the term PAS to describe readers and interpreters and people helping to carry out tasks at work is often confusing, because PAS is so commonly thought to be mostly about someone helping provide personal care (Stoddard & Kraus, 2006). It is important for employees with disabilities to understand what workplace PAS (WPAS) is and is not. A workplace personal assistant does not perform the job duties or take care of daily personal needs. The employer is not responsible for providing this type of service.

A workplace personal assistant only provides assistance with the actual job tasks in order to increase the efficiency and productivity of an employee with a disability (Turner, 2007).

The distinction is mainly driven by this factor: who is responsible for providing and funding WPAS. While the employer most often covers task-related WPAS, personal care-related tasks are left to the employee. Business travel is a commonly highlighted exception. When an employee requiring WPAS needs to travel for work, the employer may need to consider providing assistance both for personal care-related tasks and WPAS for the employee during travel.

The EEOC clarifies that employers are not required to pay for or arrange personal care-related assistance in the workplace, since such accommodations are related to meeting an individual's personal needs. Employers must, however, consider both allowing employees with disabilities to bring their personal assistants into the workplace and providing space for ensuring the employee's personal needs (i.e., eating, drinking, toileting, etc.) are met.

The EEOC also notes that employers may choose to go beyond the requirements of the ADA when providing job assistants. For example, "supported employment" programs may provide free job coaches and other assistance to enable individuals with significant disabilities to learn and/or to progress in jobs. These programs typically require a range of modifications and adjustments to customary employment practices. Some of these modifications may also be required by the ADA as reasonable accommodations (EEOC, 1992).

## TRANSITIONING TO LIVING INDEPENDENTLY

### CLAIRE'S STORY

As she approached high school graduation, Claire began looking at different colleges. "I was pushing away from having my parents as my main caregivers," she says. "It was kind of a scary thing, but I wanted to be out on my own."

Perhaps you've reached a place in life when you're ready to be more independent and even live on your own. Some of us are fortunate enough to have friends or relatives around the same age who have been through the process before: they're living on their own, paying their rent, managing their bills, and maintaining their own place.

If so, begin by asking them what it takes to be more independent. Chances are that the positive experiences, such as meeting new people, having more freedom, and learning new things, have been balanced with a number of challenges (i.e., bad roommate situations, conflicts with apartment managers, and the difficulty of learning to manage a household). Nevertheless, don't let these realities deter you from pursuing and achieving your goal of independence. Making any sort of life change has both its drawbacks and benefits.

It's important to make an informed decision. This requires some serious needs assessment, targeted research, and personal and financial planning for anyone. You may face the additional consideration of needing to find your own PAS.

In addition to talking to both friends and family, take some time to assess your own needs. Be honest and realistic with yourself, and consider the type of living situation that suits you best: living on your own or with roommates. Think about how you will pay for food, utilities, and other essentials. Take into account your transportation needs as well as your personal assistance requirements. It may be helpful to involve your friends and family in the evaluation process to ensure you consider a variety of perspectives.

### JEFF'S STORY

"We have had to 'wing it' as Jeff moved from childhood to adolescence to young adulthood," Jeff's mom, Raechelle, confides. "At each stage, Jeff had different needs," she says. "Right now we are trying to figure out how to pass the torch of responsibility (for PAS) to Jeff." Raechelle and her husband are concerned about what will happen to Jeff when they are no longer available to help him choose and direct personal assistants. They want him to be as independent as possible but lack guidance on how to make that happen.

Drafting a list of key considerations/issues to address will help you gain a better understanding of the areas that need some attention if you are to live on your own and take charge of your own PAS. They may include the following:

**Your personal care needs** (i.e., dressing, grooming, personal care and hygiene, housekeeping, meal preparation, transportation, companionship, medical issues, etc.);

**When you will need assistance and for how long:** this would include the amount of time you will need assistance each day and during which periods of the day (i.e., morning, evening, 24 hours, etc.);

**Personal assistant preferences:** what characteristics might an assistant have that will make you most comfortable (i.e., gender, age, ethnicity, disability, language, reading and communication skills, citizenship status, personal hygiene, patience, compassion, strength, ability to listen, talkative, nonsmoker, etc.); and,

## CLAIRE'S STORY

Claire currently has a roommate who helps with a variety of tasks. "I have a roommate who is more like a friend although she does some of my personal care," says Claire. "Sometimes she cooks meals for dinner, but not always." The amount of time her roommate assists her varies at times. Occasionally, she assists Claire in the restroom. "I find that if I drink coffee or alcohol I need to go to the bathroom more," Claire offers, "so I have to limit my drinking."

**Knowledge, skills, and abilities** to address difficult issues with your personal assistant(s) (i.e., money management, time management, conflict, romance, sexuality, etc.).

Taking some time to consider your personal preferences and needs in the beginning will go a long way in helping you effectively recruit, interview, hire, and manage your personal assistant services in the future. On the pages that follow are some checklists and tools meant to help guide you in thinking through these important topics. Keep in mind that these are only examples, and that many community programs that assist people with disabilities (such as independent living centers and community rehabilitation programs) also may have helpful planning tools and tips. The *Additional Resources* section at the end of the toolkit provides links to locate such community-based organizations.



## THINKING OUTSIDE THE BOX: SERVICE DOGS

The tools to help people with disabilities live independently don't just come in the form of other people or services. Over the last 20 years, a growing number of people with disabilities have come to rely on animals, such as dogs, monkeys, and ponies, for assistance. Since space is limited, the discussion here will focus on dogs. But before considering whether a dog might help you be more independent, it's important to make the distinction between assistance dogs and service dogs.

**Service Dog:** A dog that works for individuals with disabilities other than blindness or deafness. They are trained to perform a wide variety of tasks including but not limited to: pulling a wheelchair, bracing, retrieving, alerting to a medical crisis, and providing assistance in a medical crisis (Assistance Dogs International, 2009).

**Assistance Dog:** A generic term for a guide, hearing, or service dog specifically trained to do more than one task to



mitigate the effects of an individual's disability. The presence of a dog for protection, personal defense, or comfort does not qualify that dog as an assistance dog (Assistance Dogs International, 2009).

Maybe the idea of having a dog help you pick up

things or pull off your socks appeals to you. If you're an animal lover, the thought of being able to take a dog nearly everywhere might seem too good to be true. But, there is a difference between the idea of a service dog and the actual responsibility of a live animal. Service dogs are specially trained, but they are still dogs. They are not machines, and they cannot be put on the shelf. Responsible dog ownership takes time and energy. A service dog increases independence, but also requires sacrifices and adjustments.

While it is perfectly okay to have assistance in caring for a service dog, the human partner should take an active and primary role in making sure the dog's needs are met. For the bonding of a team to take place, the human partner needs to be the most important person in the dog's life. This means making time to exercise, groom, and even play with the dog. It's important to take an active role in the day-to-day activities, so when you're alone the dog will recognize your leadership and respond.

### **Being Realistic in Your Expectations**

If you are exploring getting a service dog, there are some questions you need to be able to answer for yourself.

### **Would you consider yourself a "dog person"?**

It's highly likely that a service dog would spend more time with you than any personal assistant or family member.

Given the dog's responsibilities, this means the dog will likely sleep next to you, pick up things with its mouth, and need to be walked regularly. It also means that your clothes and your living space will regularly be covered in dog hair. So, if dog slobber and animal fur are anywhere on your list of pet peeves, you may want to rethink the idea of getting a service dog.

### **What types of things would a service dog do for you?**

Make sure that your expectations are realistic. For example, perhaps you're considering having a service dog to help you get around campus in your manual wheelchair. It's important to know these dogs cannot pull a wheelchair entirely on their own. In order for the dog to perform the skill, the individual must be able to move the chair somewhat.

While the general public may consider getting a dog for protection, keep in mind service dogs are not trained to be protective. In addition, while many organizations teach service dogs basic and specialized commands, working effectively as a team requires hours of ongoing training that help the dog learn new skills and review those previously learned.

### **Do you have the financial resources to provide for basic needs of the dog (i.e., food, veterinary bills, and grooming costs)?**

Many organizations that train service dogs will extensively screen applicants to ensure they have the need for a dog, the resources to care for the animal, and the time necessary to maintain the animal's skills and well-being. These organizations often recognize that individuals with disabilities may receive financial assistance from other sources. This factor alone will not preclude an individual from being eligible for a service dog. Whether you receive assistance or not, it's important to seriously consider the cost involved in caring for an animal.

## **Do you have someone who could serve as a training assistant?**

Some agencies require that you bring a training assistant with you when you get the dog. If not, it's still important to consider having someone who could help if you run into problems teaching the dog new skills and strengthening existing commands. The organization may provide support to recipients, but sometimes an informal assistant can also be helpful—especially if you find that you need basic assistance on a regular basis.

## **Are you prepared to be completely responsible for the life, health, safety, care, and needs of a living being?**

This animal will be your responsibility 24 hours a day, 7 days a week, 365 days a year.

## **Choosing a Program**

Not all assistance dog programs are created equally. Programs vary widely in terms of training philosophies, structure of the training process, the source of potential service dogs, and cost for potential recipients. It's in your best interest to do as much research as possible to see what works best for you and your situation. The first step to getting a service dog is finding a reputable program with skilled trainers and a proven track record. Programs vary in terms of their structure and cost to recipients. Potential recipients typically must complete an application and screening process before being placed on a waiting list for a service dog. The waiting time for a service dog can be as long as two to four years, depending on the organization, their training methods, and the types of dogs selected for training.

If the dog is trained through a specific program or organization, it is likely that some basic training will occur before you train with the dog. Depending on the structure of the program, basic training can last anywhere from six months

to a year and a half. Following basic training, recipients are usually invited to a training class—usually several weeks in length—to learn the commands and handling skills needed for working with a service dog.

## **Shelter Dogs Versus Specially-Bred Dogs**

Some people believe it's more beneficial to train dogs selected from the local shelters. Although there are practices in place for evaluating these animals' potential for service work, it is impossible to know for certain whether something in the animal's background may lead to irrational or inappropriate behavior later (i.e., biting someone who approaches them too quickly or being overly frightened by noises or activity such as a car backfiring).

## **HANNAH'S STORY**

"Upon leaving team training, I had my serious doubts as to whether I had made the right decision. I had even talked with the trainers about not taking Max home, because he wasn't responding as I thought he should. The trainers reassured me Max knew the commands and would perform them well. I just needed to relax and give him time. Sounds easy enough, right??? Maybe for someone who is not a perfectionist, but I wanted Max to do things well, and do them right the first time, without having to repeat commands. What I had to realize was that Max was not a robot. Our relationship depended on more than just what Max could do for me. It really depended on really loving one another. The trainer's homework assignment for me as I left training was to go have fun with your dog. For someone who likes cut and dry instructions, this seemed crazy. But I'm here to tell you that it worked. Although my high expectations for Max have not changed, I have realized that he is not perfect and neither am I."



Programs that breed and train their own dogs spend months, even years, evaluating the animal's temperament, physical health, and overall work ethic. Oftentimes, if an animal is not suited for service work, this is determined well before a potential recipient enters the picture. Be wary of an agency that promises too much too soon. Also, take time to ask questions about the program's certification. Assistance Dogs International (ADI) is a nonprofit organization that helps develop standards for various types of working animals, such as therapy dogs, companion animals, guide dogs, and service animals. Organizations and programs accredited by ADI have met certain standards.

According to ADI, the number of shelter dogs that are viable as hearing and service dogs is exaggerated by some organizations. The organization explains that selection of a dog is critical and much more involved than it first may seem.

"A Service Dog candidate should be between 18 months to 2 years old. A younger dog will not show its adult temperament and will not have adult bone structure for hip/shoulder/elbow x-rays. Older than two reduces the amount of time the dog will be able to work....This will eliminate 60 to 80 percent of the dogs in the shelter. Dog size and inappropriate breeds will eliminate another 10 to 20 percent. Temperament tests

will eliminate many more. In general, during a visit to the shelter only 1 to 5 percent of the dogs might qualify. Fifty percent of the dogs selected will have...health problems that will then disqualify them" (ADI, 2009).

### **Considering Costs**

Most organizations will charge a minimal fee or no fee at all for the dog, despite the fact that it may cost up to \$50,000 to raise and train a prospective service dog. Other organizations and private trainers will expect potential recipients to cover some costs. If you apply to and are accepted by a provider organization that belongs to Assistance Dogs United Campaign, you can apply to receive a voucher that pays the cost of your dog.

While there may be no fee for the dog, you may be required to pay an application fee. In addition, you may be asked to cover your travel and lodging expenses while in training. Some organizations have facilities for potential recipients to stay in, while others may have arrangements with hotels and restaurants in their area. Keep in mind there will also be long-term costs of maintaining your dog's health, such as annual shots, food, and potential grooming costs (e.g., trimming your dog's nails).

## **ESTABLISHING A PLAN**

We all have areas and skills in which we can grow. Think about what you want to learn or need to know before moving out on your own or taking more responsibility for your personal care needs. As the example below illustrates, it may be doing a task around the house. It could also include such goals as developing and maintaining a budget, learning to use public transportation, or strengthening your personal advocacy skills. The following pages provide an example goal and the resources, activities and steps necessary to achieve it, as well as a blank form for you to use in determining your own goals.



## Goals for Living Independently (Sample)

### Goal #1: Learning how to do laundry

#### People to Help Me Reach that Goal:

*Mom and my friend, Janet*

#### Resources to Help Me Reach that Goal:

*The back of the laundry detergent container and the inside lid of the washing machine*

#### Planned Completion Date:

*August 2009*

#### Activities to Reaching that Goal:

- *Learning to sort clothing and read clothing labels*
- *Understanding appropriate settings on the washing machine for different types of clothing*
- *Learning the different settings on the dryer*
- *Knowing how to iron different types of clothing*

#### Target Dates for Completing Interim Activities:

- *Learning to sort clothing and read clothing labels—June 16*
- *Understanding appropriate settings on the washing machine for different types of clothing - June 30*
- *Learning different settings on the dryer - July 5*
- *Knowing how to iron different types of clothing—July 25*

#### Notes on Your Progress:

*June 5 - had some trouble sorting laundry and accidentally put a pink shirt with white pants. July 19 - learned today how to iron a button-down shirt.... did most of it myself, with only a little bit of help from my mom.*

## Goals for Living Independently Worksheet

Goal:

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People to Help Me Reach that Goal:

Resources to Help Me Reach that Goal:

Planned Completion Date:

Activities to Reaching that Goal:

Target Dates for Completing Interim Activities:

Notes on Your Progress:

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## Independent Living Checklist

While moving out on your own can be exciting, it requires a whole new level of responsibility. Being more independent means taking an active role in your health and wellness, personal care, job training, school work, and other areas of your life.

Below are some questions to ask yourself to see whether you are prepared to live more independently. You may not be able to answer “yes” (or “always”) to every question listed, but you should be familiar with where to go for assistance.

### Overall Independence

- Do you have any savings?  Yes  No
- Do you have a source of steady income?  Yes  No
- Are you contributing to the household income (e.g., paying rent, utilities, etc.)?  Yes  No
- Are you able to get from place to place independently?  Yes  No
- Do you have a place to live or have you begun looking for one?  Yes  No

### Social Supports and Staying Emotionally Healthy

- Do you have friends that you spend time with on a regular basis?  Yes  No
- Do you regularly communicate with family and friends?  Yes  No
- Is there at least one person you talk to when you feel sad, nervous, or things aren't going well?  Yes  No
- Are you familiar with the common symptoms of depression?  Yes  No
- Do you seek help from others when you experience those symptoms?  Yes  No
- What are your hobbies? Or, what do you enjoy doing?

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- Do you regularly make time for these activities?  Yes  No

### Staying Physically Healthy

- If you take medications, do you know the name, dosage, reason, and potential side effects for each prescription?  Yes  No
- Do you take your medication as prescribed and without being prompted?  Yes  No
- Have you taken time to learn about the options available for preventing pregnancy, HIV/AIDS, and sexually transmitted diseases?  Yes  No
-