We Choose Independence!
**What are the important issues facing people who use Personal Assistance Services (PAS)?**

- People who use PAS have a right to expect safe, quality services from a system that is accountable to those that use the service.

- People who use PAS need workers. There should be adequate funding in the state PAS system to ensure that users have the services they need.

- People who use PAS know what they need. The training curriculum for workers should be created and presented by PAS users whenever possible.

- PAS should be guided and directed by the choices, preferences, needs and desires of the individual who uses the service.

- People who use PAS should have access to voluntary training about hiring and supervising employees, and how to manage their own services.

- People who use PAS should have services that are flexible and available.

- Everyone has the right to fully participate in the community of their choice.

- State rules should allow people to use their PAS to assist with parenting tasks and assistance when looking for employment.
We Choose Independence!

Introduction
Living at home in the community of your choice is a big part of the American Dream. For millions of older adults and people with disabilities, the only thing preventing them from fulfilling that dream is the need for assistance with one or more tasks such as bathing, dressing, eating, using the bathroom, or moving from a wheelchair to a bed.

A few decades ago, it was almost unheard of for people with disabilities to choose where they lived. Often they were sent to institutions and their care was provided en masse. Nursing homes, psychiatric hospitals and “schools” for people with cognitive and sensory disabilities were the accepted destinations.

Over the years, however, things have changed. People with disabilities are speaking out against being institutionalized and demand the same rights as others; the right to live where they choose, the right to participate in their community, the right to make decisions for themselves. This alternative to institutions is called Independent Living.

People with disabilities, however, often face unique barriers related to achieving independence. That is where Personal Assistance Services come in.

What are Personal Assistance Services (PAS)?
PAS is a simple concept. One or more people assist a person with a disability to perform everyday tasks. Services are managed and directed by the person who uses them, in his or her own home. PAS can include assistance with eating, dressing, bathing, getting in and out of bed, planning a budget, or reading the mail aloud. The service is sometimes called attendant care, personal care, chore service, respite, Medicaid Personal Care, or COPES.

PAS is a tool that allows more freedom. Freedom to get out of bed in the morning; freedom to eat the foods that you like, when you like; freedom to decide what activities to be involved in; freedom to live independently.

Who uses PAS?
People who use PAS may have a physical, sensory, psychiatric or intellectual disability.

They are the employer and are in charge of hiring, training and supervising the workers. However, throughout most of history, people with disabilities have been treated as being incapable. Sometimes this old-fashioned attitude persists. PAS workers are sometimes guilty of treating their boss like a child or as if they were incompetent. Similarly, people who use PAS sometimes feel dependent on a worker, and being treated as helpless reinforces those insecure feelings. Both of these dynamics compromise a healthy working relationship.

Changing the Dynamics
There are many ways that these outdated patterns are changing. More people with disabilities live in the community and are taking control of their lives. Workers are
becoming more professional and have made significant gains in earning power and benefits. The PAS system itself, administered by the state, is attempting to find new, more respectful ways to work with PAS users.

**PAS Users: The Independent Living Movement**

People with disabilities are demanding the right to make their own decisions. By standing up for their rights, they created a worldwide movement to promote Independent Living.

PAS is an important tool that helps older adults and people with disabilities become more independent. Not only do PAS users get assistance with important tasks that they could not otherwise do on their own, PAS users learn how to hire, fire, supervise, and train workers.

**PAS Workers: Higher Wages, Building Careers**

Workers – and PAS users – have long asked that wages and benefits be increased. Over the past five years, workers have made impressive strides. In Washington State, independent providers of PAS have formed a union (SEIU Local 775) and through collective bargaining have achieved higher wages, health insurance, and a strong voice at the state legislature.

**State PAS System: New Freedom**

Although the PAS user hires and supervises the worker, the state Department of Social and Health Services (DSHS) administers the PAS system. DSHS issues the paychecks for workers and establishes regulations that govern the program.

One innovative program being piloted by the agency is called *New Freedom*. For many years, older adults and people with disabilities have had the option of selecting their own PAS worker. They have not, however, had the flexibility to purchase goods and services specific to their individual needs. Under the *New Freedom* program, older adults and people with disabilities will be able to buy products and services (using Medicaid funds) related to their disability that help them live in their community.*

**Meet Six Pioneers in the Independent Living Movement**

On the following pages are the stories of six Washington residents who are living the ideals of the Independent Living movement. They are all pioneers in discovering how to overcome barriers and become important members of their communities.

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* For more information on the New Freedom program, contact Rosemary Biggins or Patty McDonald at 1-800-422-3263 or e-mail, NewFreedom@dshs.wa.gov.
Barbara L. from Spokane Valley, WA

People who use PAS should expect good customer service and a system that is accountable.

Barbara L. has what is often described as “complex medical issues.” She needs a PAS worker to help with most activities of daily living: getting in and out of bed using her special lift (see picture); cooking meals and clean up; general housework; getting dressed; and using the bathroom.

Barbara does not want to live in a nursing home. She loves her house and is active in the community, including serving on the board of a statewide non-profit agency. She hires an independent provider as well as using an agency to find her PAS workers.

Barbara is a cheerful person with an active mind and a strong sense of justice. She appreciates that her PAS allows her to stay at home and be a part of her community, but she worries about the lack of customer service and accountability in the state PAS system.

“My heart’s desire is to clean this industry up before I leave this earth,” she sighed. Barbara relies on a Hoyer lift to get her in and out of bed. It is not easy to operate the lift, and when used incorrectly, it can be extremely dangerous. After an incident
in which she nearly fell, her agency admitted that they didn’t know how to train workers on safe operation of the lift.

Worried about her safety and the well-being of others, Barbara offered free training to agency staff on the operation of the lift.

Barbara’s outgoing personality helps her get along with her workers. “I try to pull the best out of everybody,” she says with a grin. “The more you get to know them, the better it gets!” But then her expression darkens, and she whispers, “sometimes workers just don’t want to be here. Sometimes if they are angry, I won’t ask them to use the lift even if I have to go to the bathroom.” Other times, Barbara has had workers who submitted time sheets listing hours they didn’t work.

“I’m labeled as a troublemaker because I stand up for myself.”

When incidents such as this occur, Barbara calls the agency to tell them about the problem she is having with a worker. She has not always been happy with the agency’s response when she calls with a complaint. Barbara says that she tries not to call them unless there is a serious problem, but nevertheless, she is “labeled as a troublemaker because I stand up for myself.”

Barbara never felt quite so vulnerable, however, as the time one of her workers hit her. After the worker left, she called the agency. Although the worker did not return, the agency never responded to Barbara and nobody came to investigate the assault.

**PAS users have a right to expect safe, quality services from a system that is accountable to those that use the service.**
Susan C. from Soap Lake, WA

People who use PAS need workers. There should be adequate funding in the state PAS system to ensure that users have the services they need.

Susan C. is a quietly confident single mother who continually finds ways to be the person she wants to be. Lots of things help Susan maintain her independence: her wheelchair allows her to be mobile and get around town; her relationship with her daughter brings personal satisfaction and a sense of family; and her PAS helps her be self-sufficient.

When you first talk with Susan, you have to lean forward a little bit to hear her. She's not shy, just soft-spoken. After listening to her for a while, you realize that you are talking with a self-assured, competent woman who has learned that to get what you want, you need to be assertive, but not necessarily loud.

Susan and her worker have been together for a long time and have developed a great working relationship. “It wasn’t always perfect between us,” Susan says thoughtfully, “but over time we have learned to work together and care about each other.” In fact, the two are very close. Susan’s worker has three children, which has often made scheduling difficult. The bond between them helps them work through difficult situations.

Susan’s worker used to work nearly full time, but changes in the state PAS system have led to reductions in service hours for many users, including Susan. She reports that her hours have been cut by over 60%, and that has been hard on both her and her worker. With significantly fewer hours of PAS, Susan has had to give up many of
the things she was previously able to do. To make matters worse, her worker has had to find a second job – complicating the already difficult job of coordinating schedules.

“Workers need more money,” fumes Susan. “They can’t make a living on the small number of hours I get.” It has been difficult for many PAS users the past few years. Workers have received some hourly wage increases, which has been applauded by workers and PAS users alike. However, as the wages went up, many people found that their service hours went down.

“Maybe this booklet will help people understand how important these services are for people.”

The Legislature controls the funding for the PAS system. There are many groups, including Project PAS-Port for Change, who advocate in Olympia for the system to be better funded. One advocate said that it is a “great thing that workers are receiving better pay and are starting to receive benefits. However, it doesn’t help the workers or the PAS users if there isn’t enough funding to pay for the services that help keep people out of nursing homes.”

Susan is worried about the future of PAS in the state. She has already lost some of her independence with the loss of many of her PAS hours. She is doing what she can to keep busy and make the most of things. She also hopes that greater public awareness will prompt lawmakers to provide more funding for PAS. “Maybe this booklet will help people understand how important these services are for people.”

There should be adequate funding of the PAS system. Eligibility for services should be based on functional need.
Ray E. from Wenatchee, WA

People who use PAS know what they need. The training curriculum for workers should be created and presented by PAS users whenever possible.

Ray E. lives with his service dog, Duchess, and uses PAS workers from a local agency. Ray is proud to say he is 70 years young and he and Duchess are quite a pair. Duchess is a happy-go-lucky companion who is also a well-trained service animal. Ray relies on Duchess and his PAS workers to perform many tasks he can no longer do himself.

Ray likes to get on with the business of his life and not spend a lot of time dealing with people who tell him he can’t do things. Because Ray, it turns out, can do quite a lot that others didn’t think he could.

Ray’s approach to life has served him well when training his workers on what he needs. Like most PAS users, Ray has learned that the training received by new workers does not address his specific needs. In many cases, workers come to work even before they take the state’s Basics of Caregiving class. “There just isn’t enough good training for the workers,” says Ray, gently shaking his head.

Ray has learned he gets the best workers when he trains them himself. Every time a new worker arrives at Ray’s house, it offers a new challenge.

Although some workers have received some basic training, Ray is the person who can best communicate what he does – and does not – need from his PAS. Each worker has their own strengths and weaknesses, and Ray takes pride in
communicating his needs clearly. At times, workers have told Ray that they know what is best for him, but Ray is a confident fellow and has no trouble establishing who is the boss in his home.

Over the years, Ray has learned how to tell his workers what he needs clearly without coming across as overbearing. Learning to train and supervise employees has given him an understanding of the responsibilities of being an employer and has ensured he receives the services he needs. He would like to see training programs created by people with disabilities because they know best how to describe their requirements.

“I had a worker who tried to tell me how to spend my money, how to live my life. I fired him.”

Looking to the future, Ray is optimistic. He has developed a good rapport with his current worker and enjoys her company. He smiles when he says, “my current caregiver is really good. She’s a good employee and has become a friend.”

When asked how he learned how to be a good boss, Ray acknowledges that it has not always been easy and that he has needed to fire a number of workers over the years. He doesn’t like firing people, but he is willing to do so when the need arises. “I had a worker who tried to tell me how to spend my money, how to live my life. I fired him.” He says this without rancor or bitterness; it was just something that needed to be done.

Because he knows what he needs from his workers, Ray is able to handle any situation that comes up. The agency that provides his employees is anxious to keep him happy, his employees enjoy working for him, and Ray and Duchess look forward to a bright future. More PAS users would benefit if training programs were developed and presented by people who use PAS.

PAS should be guided and directed by the choices, expressed interests, needs, and desires of the individual who uses the service.
Kate S. from Sequim, WA

People who use PAS should have access to voluntary training about hiring and supervising employees, and how to manage their own services.

Kate S. is a firecracker. The former Sequim city councilwoman is a rolling ball of energy that comes at you from all sides. She has a flair for language that can sometimes leave you gasping for breath. She is eloquent and accomplished, funny and effervescent. She also needs a PAS worker so that she can do all the things that come roiling into her head.

“I have done a lot of things in my life,” declares Kate, “but one of the hardest was learning to be a good employer.” Kate has accomplished a lot in her life and has used PAS for many years. But she readily admits that it was difficult to learn how to be a boss.

It is never easy to hire someone. There are a lot of things to be considered. For example, how do you review applications and resumes to determine which people you should interview? When you interview someone you have never met, where should you meet to be sure you are safe? What questions should you ask the people you interview, and what answers should you be listening for? How do you check up on references?

Many employers learn this process over years of experience, and they have to go through some bad employees in the process. The stakes are higher for people with disabilities, however. Kate explains, “it’s not as if a bad hire will mean a bit of
inconvenience like it does for a businessperson. This is my life we are talking about!” Indeed, hiring the wrong person to provide intimate tasks inside your own home can be a dangerous situation. There will be nobody to help if the new employee is not honest or is violent.

Many people who need to hire PAS workers have never been in a business setting before, much less gone through the process of hiring someone. And yet, in order to have the most independence, they need to hire someone to help them. There is virtually no training available for PAS users to learn to be a good boss.

“I have learned, through some horrible mistakes and frightening situations, how to establish a good, working relationship. But a lot of people out there end up with bad workers or worse. If they could learn some skills, they could be safer.”

The need for training doesn’t end when a worker is hired. Good employers learn how to supervise and motivate employees, and how to establish a good business relationship. This can be particularly hard in a PAS situation, because the nature of the tasks can be so personal.

“I have been fortunate,” declares Kate. “I have learned, through some horrible mistakes and frightening situations, how to establish a good, working relationship. But a lot of people out there end up with bad workers or worse. If they could learn some skills, they could be safer.”

PAS users should have access to training that helps build the skills they need to be good employers.
Shelly M. from Medical Lake, WA

People who use PAS should have services that are flexible and available.

Nobody would describe Shelly M. as helpless. She has learned to confront all of life’s challenges with energy, humor and grace. Shelly and her constant companion and service dog, Oreo, ricochet through their lives with a burning purpose – to live their lives fully, passionately and independently.

Sometimes Shelly is described as being “wheelchair-bound,” but that is not an accurate description. When she is in her chair, she and Oreo are a whirlwind. If they are not setting out for a meeting, they are trekking across the state to attend Independent Living rallies. She is not bound to her wheelchair; it is a tool that allows her more freedom and self-sufficiency.

Nevertheless, Shelly needs a PAS worker to help her exercise her independence. She has used workers for many tasks, including assistance getting in and out of her wheelchair, her bed, or the bathroom. When nobody shows up to do the work, Shelly can be stuck without access to food, water, or a way to call for help. Unfortunately, this has happened to her several times and it can be a frightening experience.

Shelly uses an agency to hire PAS workers, but she has not always had a good experience with them. The agency wants to establish a schedule for a full month in advance and is not flexible when Shelly needs to make changes. Shelly is frustrated that the agency frequently asks her to be flexible with scheduling, but is not able to
accommodate a change in Shelly’s plans. A doctor’s appointment, a meeting or an errand throws the schedule into turmoil.

One holiday weekend, the agency told Shelly that no workers were available. Shelly was left alone for two days.

Shelly has had workers who claimed hours they never worked, broke her personal items, burned her carpet with an iron, and some that “hollered and cursed at me.”

“One worker accidentally dropped me from the lift because they hadn’t been trained how to use it. But the worst was when nobody showed up and I was abandoned without food or water.”

“I value the caregivers I have, because they help me continue to do things in the community.”

She has tried to hire her own worker by using the state’s Independent Provider Referral Registry. The registry is a new service that allows PAS users to examine a listing of workers in their area, and what their qualifications are. The new program has great promise for PAS users. Unfortunately for Shelly, she has been unable to find workers willing to come to her out-of-the way location.

Shelly is not one to wallow in self-pity, however. She is active in the state Independent Living movement and volunteers at several organizations around town. She is often seen rolling down the street with Oreo by her side, and is cheerfully determined to change the PAS system by ensuring that services are more flexible. “I value the caregivers I have, because they help me continue to do things in the community.”

People who use PAS expect services that meet their needs and are flexible.
Patrick S. from Tacoma, WA

People who use PAS want to live, work, play, and participate in their own community.

Patrick S. is a philosopher at heart and an incurable optimist. He enthusiastically points out, "just because someone has a disability, it doesn’t mean that they can’t be a productive citizen in the community, the state, or the country."

Patrick takes his own philosophy seriously, and has many ambitions for his life. “For the last five years I worked at a daycare center for kids – I loved that!” Even though he was laid off when the center had to downsize, Patrick gained experience and skills working with children. “I want to have my own kids some day.”

Patrick has developed quite a taste for independence. When he was 20, he was placed in a facility with other people with disabilities. Institutional living was not much of a life, but Patrick made the most of it. “I’m a people person,” he beams, “if you treat people right, things work out.” After five years in the facility, Patrick moved out, and eventually found his own place. “Living in my own apartment is much better,” he says, “it’s difficult sometimes, but I wouldn’t change it.”

Patrick would like to get married and have children and is working toward that goal. Parenting will present particular challenges for Patrick, because his PAS workers are not allowed to help with parenting tasks. Nevertheless, Patrick is focused on how to make things happen, rather than concentrating on the barriers. “I’m sure there will be some roadblocks when I get to that point. Marriage and being a parent is not easy, but some things are worth the risk, and marriage is one of them.”
Patrick has had the same PAS worker for many years, and has become more self-sufficient with his worker’s assistance. They have a system of scheduling that works well for both of them. When Patrick needs assistance, he calls his worker and leaves a voicemail message, saying when he wants her to come to his apartment. She will call back when she gets Patrick’s message and either confirm the time or reschedule. “It works pretty well,” says Patrick, “even if there is a time conflict, one of my friends from church can help out.”

“I want more than just a nine-to-five job. I want a career that I enjoy and have control over.”

Patrick’s sunny disposition and outgoing personality have allowed him to build up a large circle of friends that provide a support network. Without them, Patrick would find it more difficult to participate in his community.

After being laid off from the daycare center, Patrick has been looking non-stop for another job. It has not been easy, because many employers look at Patrick and see only that he has a disability. “I’ve been looking for almost two years,” he lamented. When employers see someone with a disability, “they go by appearance and they don’t know how valuable that person could be as an employee.”

Patrick is disappointed with his unsuccessful search for work, but he is still determined to find a job – employment that will give him satisfaction and fulfillment. It is hard work looking for a job, and Patrick wishes that his PAS worker could help him with some of the tasks needed to seek work. Unfortunately, that kind of assistance is not allowed under state rules. Patrick is undaunted, however. He is concentrating on building a career for himself. “I want more that just a nine-to-five job. I want a career that I enjoy and have control over.”

State rules should allow people to use their PAS to assist with parenting tasks and assistance when looking for employment.
Summary
Personal Assistance Services (PAS) enable people with disabilities to live independently in their own homes, take part in their community, and live the American Dream. PAS gives people with disabilities and older adults an alternative to living in a nursing home or other institutional setting - a choice to live a life of dignity and independence.

PAS programs, however, are experiencing serious problems. Many of these problems have existed for decades and are not easy to fix. Advocates – such as those you met in this document - are committed to improving the system by working with the State Legislature, DSHS, and others to make the changes necessary to keep Personal Assistance Service programs growing and improving.

People with disabilities choose to live the American Dream. They choose independence.

Project PAS-Port for Change
Project PAS-Port for Change is a statewide organization made up of people who use Personal Assistance Services (PAS). PAS-Port advocates for people who use PAS through legislative and other systemic advocacy.

For more information about the organization or to receive the PAS-Port newsletter, contact PAS-Port, c/o DRW at the address or phone numbers listed on the back cover.

Disability Rights Washington
Disability Rights Washington (DRW) formerly known as Washington Protection & Advocacy System advocates for and protects the rights of individuals with disabilities in Washington State. DRW is a member of the National Disability Rights Network. A substantial portion of the DRW budget is federally funded.
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