Acknowledgements

The publication and distribution of this document is made possible through the Research and Training Center on Public Policy in Independent Living (NIDRR grant #H133B00006-92), a joint project with the World Institute on Disability, InfoUse, and The Western Consortium for Public Health, University of California. The editors would like to acknowledge the time and effort of the contributing authors, as well as the staff of the World Institute on Disability. The content of these essays are the personal experiences and opinions of the authors, and do not represent the policies of NIDRR. Endorsement by the federal government should not be assumed.
# Table of Contents

## Introduction

<table>
<thead>
<tr>
<th>Introductory Letter</th>
<th>iii</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Assistance Services: A Personal and Political Perspective</td>
<td>1</td>
</tr>
<tr>
<td>Tony Young</td>
<td></td>
</tr>
<tr>
<td>To My Other Bodies</td>
<td>4</td>
</tr>
<tr>
<td>Connie Panzarino</td>
<td></td>
</tr>
<tr>
<td>Personal Perspectives on the Importance of PAS</td>
<td>6</td>
</tr>
<tr>
<td>Julie Weissman</td>
<td></td>
</tr>
</tbody>
</table>

## PAS and the Family

| Thinking Differently about Developing Personal Assistance Support | 15 |
| Jeffrey L. Strully and Cindy Strully | |
| How Personal Assistance Services Affected My Life and My Daughters' Lives | 19 |
| Leah Welch | |
| The Influence of PAS on a Mother/Daughter Relationship | 23 |
| Donna Robb | |
| Personal Assistance Services For People With Mental Retardation: One Person's Perspective | 26 |
| Martha E. Ford | |
| PAS From a Teenage Perspective | 31 |
| Sascha Bittner | |
| Personal Perspectives on PAS: Gay and Lesbian Issues | 36 |
| Connie Panzarino | |
| PAS Values and Issues Guiding Effective Services For Multicultural Persons With Disabilities | 39 |
| Emeka Nwokegi | |
PAS and Specific Disabilities

PAS for People with Cognitive Disabilities
Beverly Evans, Connie Martinez, and Tom Hopkins ......................... 43

PAS Issues for the Blind Community
Sharon Gold .................................................. 52

Personal Assistance Communication Services and Technologies
for Individuals Who Are Deaf or Hard of Hearing
Ed Rogers
Kate Seelman .................................................. 60

PAS and Persons With AIDS
Gary Harmon .................................................. 64

PAS for People With Psychiatric Disabilities
Lorelee Stewart ................................................ 67

PAS and Head Injury
Sherry Watson .................................................. 72

Living Without a Live-In: PAS in my Life as a Respirator User
Alana R. Theriault .............................................. 76
September, 1992

Dear Reader,

All of us at the Research and Training Center on Public Policy in Independent Living (RTC/PPIL) are extremely pleased to present this document to you. The World Institute on Disability (WID) has been studying Personal Assistance Services (PAS) for the past decade. Outcomes of this pursuit have included the pioneering document Attending to America; case studies of various state programs, detailed in several publications available from WID; and model legislation, including the Personal Assistance for Independent Living Act (PAIL) of 1989.

With the inception of the RTC/PPIL in 1990, these PAS efforts have intensified. In the fall of 1991 WID sponsored the symposium "Empowerment Strategies for the Development of a National Personal Assistance Services System". Representatives from over 40 states and 10 countries assembled at this Symposium, the first of its kind held in the U.S., to discuss PAS issues and refine strategies for addressing them. As a precursor to the Symposium, participants were asked to describe what PAS meant to them on a personal level. Their responses were the basis of this document.

WID has defined PAS as one person assisting another with tasks the individual would normally do for themselves if he or she did not have a disability. These tasks may include personal maintenance and hygiene, such as dressing, bathing and catheter care; mobility assistance, such as transferring to and from bed or wheelchair; household maintenance, including cooking, cleaning and childcare; cognitive assistance, such as money handling and budget planning; and communications access, including interpreting and reading.

The essays that comprise this manuscript represent a wide range of experience with PAS as it relates to many different kinds of disabilities and life situations. But the document is not meant to be definitive; it is not representative of every PAS need for every group or individual. There is even some disagreement on the definition of PAS (most clearly seen in the discussion on PAS for the Deaf and Hard of Hearing, where technological aids and devices are included in the definition of PAS). But on one issue everyone agrees: Personal Assistance Services are essential for independent living.

PAS is a highly-charged personal issue, as well as a crucial political concern. Due to the personal nature of the essays, we tried to maintain the writers' distinctive voices as much as possible, without sacrificing clarity. The purpose of Personal Perspectives on Personal Assistance Services is to present a sampling of personal perspectives in light of the national movement for implementation of a Personal Assistance Services system.

We would very much like to have your response to this effort. Would you please use the evaluation form provided at the back of this monograph and let us know what you think.

Sincerely,

Steven E. Brown, Ph.D.
Training Director, RTC/PPIL
Personal Assistance Services: A Personal and Political Perspective

Tony Young

I don't like to talk about my personal assistance (PA) needs and arrangements in public. I like it even less when I write about them in articles, book introductions, and similar pieces. It is not enjoyable for me to expose this private part of myself to others; to offer up my failures as an example of how things are; to tell people how much money I earn, how I go to the bathroom, and who has abused me lately. Yet, I do these unpleasant things all the time. Why do I and the other authors of this book subject ourselves to this pain, and why are you being asked to subject yourself to the same torture by talking about your PA needs?

It's all politics. Pure and simple, politics.

But, you (should) ask, what do personal stories have to do with politics? The political process is used to equitably allocate scarce financial resources among competing yet equally viable needs of society, right? Isn't this done on a rational basis, using accurate, timely information as the determining factor in resource allocation?

Wake up and smell the coffee. The political process in more akin to a Roman gladiatorial contest than to a debating meet. The winners in this arena are the ones who are willing to get bloody while fighting for what they believe in. I assure you of this: the battle for a national PAS program will be a long and bloody one. Compared to enacting a PA program, passing the Americans with Disabilities Act was easy.

There is a straightforward explanation behind the relative difficulties of these two tasks: everyone knows what civil rights are; nobody knows what personal assistance services are.

---

1 Tony Young is the director of the job training partnership program at the National Association of Rehabilitation Facilities. He has been a PAS user for 22 years, which has enabled him to earn a degree in business administration, direct a center for independent living, start his own consulting business, and participate actively in national disability policy development and advocacy.
Civil rights have been a part of the American political process since the beginning of the process itself. Our Constitution is based on the foundation of "life, liberty, and the pursuit of happiness." The very first modification to that hallowed document was in the form of ten specific guarantees of individual rights. Limited at first to white males, these rights have been extended to all members of American society. However, this did not happen without great struggle and sacrifice by those who did not have these rights.

The struggle for civil rights was one of persons who were disenfranchised working to get what others were born with and took for granted. In a way, so will be the struggle for PA. It is significantly different, however, that we will need to help both policy makers and the public understand what it is we want, and why we need it.

What we want from a national PA program is, in essence, freedom. The freedom to do what we want to do, when we want to do it. This may be to go to work, to get an education, to go to the park, to cook dinner, to go to the bathroom, to read a newspaper, to write a letter, or to go out on a date. People who do not have disabilities, and many people who do have disabilities, are free to perform these everyday activities at their will. People who need PA are not. Yet, this freedom of self-directed activity is so familiar to people who do not need PA that they rarely ever think about it as a freedom.

If they had to think about these things, and plan ahead to do some of them, and to do some only when other people beyond their control were available to help, and forego others entirely, their lives would be different. It is up to someone to show them what this lifestyle means.

It is, of course, up to those of us who need the services to communicate this message. If we truly want a national PA program, we must communicate to the decision makers in the political process what it is we want, why we need it, and frankly, what benefit it will provide for the society as a whole.

It is fair to say that PA has not simply influenced my lifestyle; it has enabled me to have a lifestyle. Without the education, employment, mobility, and freedom of choice PAS has brought to my life, I would have a bleak existence and an even bleaker future. Consider
the differences before and after PA:

Before PA I spent the majority of my time watching television and sleeping. I watched television because it was my only companion, as I was unable to get out to see friends and meet new people. I slept to escape the boredom of watching television. There were many, many days when I never got out of bed because my family did not have the time or the energy to help me in both the mornings and the evenings, especially after working all day. The days when I did get up were short days, partly because I had to do so between work schedules, and partly because I didn't get up enough to build up any endurance. Even though I never worried about getting my basic needs met, there wasn't much more to my life than eating meals and watching television.

After PA I have a job and a career, an active social life, an active advocacy life, and the reasonable expectation that they will continue. I find myself thinking of the future in terms of the next few years instead of the next few days. There is the potential of marriage, a home of my own, and a family of my own. I find myself now living in a world of potential rather than a world of despondency. I no longer fear that I will inevitably spend many years in a nursing home or other institution. I plan to devote considerable time and energy to keep this feeling.

Consequently, a large portion of this time will be spent talking about my personal assistance needs and arrangements in public, and some more will be spent writing about them in articles, book introductions, and similar pieces. I live in a political world, where the major road to change is through a political process.

Let the games begin!
To My Other Bodies
by Connie Panzarino

It's strange
this relationship,--relationships.
you are each my hands, my feet,
sometimes my eyes, and mouth to interpret clearer
speech.

There have been so many of you in my life
I lose count.
Can't remember
your name
the face.
I see you years later
in a crowd
at the beach,
and Body says, "I know you well,"
while Mind shouts, "No! I don't remember.
Not-a-lover-not-a-friend, but who?"

I spend more time with you than with my lover.
Our boundaries blur with painful necessity
as I know when you are hungry, but saying you're not,
or constipated, or doubting yourself,
and you suffer my medical abuses as if they were your own,
Just as you know my everything
from my love of chocolate, my bank balance, and what
brand of tuna I buy
to how my twisted body must be placed at night so

---

2 Concetta (Connie) Panzarino is a forty-four-year-old lesbian with a neuromuscular progressive disease. She holds a Master’s degree in Art Therapy from New York University, is a practicing Registered Art Therapist working with both men and women survivors of physical and sexual abuse, lectures nationwide on the subjects of disability, homophobia, sexism, and the ethics of genetic engineering, and is a professional artist and writer. Connie uses daily full-time assistant services to run the household, write, paint, see her clients, and cook in the Italian gourmet style that she loves.
that we both get a good night's sleep,
and how I need you to wash my labia
    my hair,
    my teeth
but need you to be invisible,
so I can feel alone
    at dinner with my lover while you feed me;
invincible,
so you never get sick and
get me sick,
and always on time for your workshift.

I pay, but it's never enough to compete with
    Burger King,
    or MacDonalds,
but it's all I have.
It's all THEY will give
    a person with a disability to pay a personal assistant.

Why do you do it?
    I know your friends think this job is weird.
    People at Woolworth's think you're all my daughters,
as a way to rationalize your attentiveness to my every move,
    or normalize the closeness they see between us.

you personal assistants are a crazy bunch
    with precious humor and the insight to know
that crips are far more interesting than Big Macs,
and that sometimes
    we must cross a boundary or risk climbing over a fence
to realize our fullest sense of self
as it is reflected in those around us.
Personal Perspectives on the Importance of PAS

Julie Weissman³, Intern
The Research and Training Center on Public Policy in Independent Living
at the World Institute on Disability

The first international symposium on Personal Assistance Services (PAS), sponsored by the World Institute on Disability in the fall of 1991, brought together disabled advocates selected from over 40 states to address state and national PAS system reforms. Participants were asked "what has been the impact of PAS in your life?". Their responses, as well as my own observations, form the basis of the following essay.

I am a 26 year old woman with cerebral palsy currently working as school teacher and an intern at the World Institute on Disability. I receive nine hours of PAS daily through the California In-Home Supportive Services program, which pays providers at minimum wage and offers no benefits other than social security. Since the program allows me to hire individual providers, I decide who works for me, when they work, and what they do. The total number of hours of PAS I am allocated by no means meets all my needs. It's also very difficult to find someone willing to provide PAS at this pay scale. However, I consider myself fortunate to be receiving PAS through this program, because most publicly funded programs in the country use private agencies, which end up making most of the decisions on how people get served.

Personal assistance is a broad category of support services, which vary according to the needs, abilities, desires, and circumstances of the individual. Candace Low, a deaf PAS consumer and advocate from Oklahoma who uses interpreter services, observes, "The meaning of personal assistance is as unique as the individual who utilizes the service." Different disability groups may need different types of PAS. For example, a person who is deaf or hard of hearing may use interpreter services to communicate with people who don't know sign language or are difficult to lipread, while someone who has a physical disability may need assistance with physical tasks like dressing, bathing, and eating. A person who has a cognitive disability may need assistance with things like money management, while a

---
³Julie Weissman is a twenty-six year old woman who has used personal assistant services for the past eight years. She has taught independent living skills to both high school and college aged people. For the past year Julie has worked with the Research and Training Center at the World Institute on Disability.
Personal Perspectives on the Importance of PAS
Julie Weissman3, Intern
The Research and Training Center on Public Policy in Independent Living
at the World Institute on Disability

The first international symposium on Personal Assistance Services (PAS), sponsored by the World Institute on Disability in the fall of 1991, brought together disabled advocates selected from over 40 states to address state and national PAS system reforms. Participants were asked "what has been the impact of PAS in your life?". Their responses, as well as my own observations, form the basis of the following essay.

I am a 26 year old woman with cerebral palsy currently working as school teacher and an intern at the World Institute on Disability. I receive nine hours of PAS daily through the California In-Home Supportive Services program, which pays providers at minimum wage and offers no benefits other than social security. Since the program allows me to hire individual providers, I decide who works for me, when they work, and what they do. The total number of hours of PAS I am allocated by no means meets all my needs. It's also very difficult to find someone willing to provide PAS at this pay scale. However, I consider myself fortunate to be receiving PAS through this program, because most publicly funded programs in the country use private agencies, which end up making most of the decisions on how people get served.

Personal assistance is a broad category of support services, which vary according to the needs, abilities, desires, and circumstances of the individual. Candace Low, a deaf PAS consumer and advocate from Oklahoma who uses interpreter services, observes, "The meaning of personal assistance is as unique as the individual who utilizes the service." Different disability groups may need different types of PAS. For example, a person who is deaf or hard of hearing may use interpreter services to communicate with people who don't know sign language or are difficult to lipread, while someone who has a physical disability may need assistance with physical tasks like dressing, bathing, and eating. A person who has a cognitive disability may need assistance with things like money management, while a

3Julie Weissman is a twenty-six year old woman who has used personal assistant services for the past eight years. She has taught independent living skills to both high school and college aged people. For the past year Julie has worked with the Research and Training Center at the World Institute on Disability.
independently. However, her mother, who was working at the Berkeley Center for Independent Living, decided it would be a good idea for Chloe and the rest of the family if they began using PAS sooner rather than later. Today, Chloe's attendants get her up in the morning, take her to places she wants to go during the day, and sometimes put her to bed. She does not have to rely on her parents, and this has made her much more capable and competent in her decision making, within the limits of her disability and age. With this assistance, both of her parents can hold full time jobs, and spend time with their other daughter without worrying about Chloe's needs. However, resources for most families remain very limited, and over 70% of PAS continues to be done by unpaid family members. Young people have a tough time growing up under such conditions.

In places where PAS is available, disabled people often make the transition from family providers to paid PAS in their late teens. Without proper supports, this can be a very difficult time for a young person. Brian Atwell, a parent from Kansas, recalls his son's first year away at college:

There was absolutely no physical, monetary or emotional assistance and we were nearly at rope's end before he started school at a 2-year college. This small college had never had a wheelchair student full-time live on campus who needed the help of a PA. The first man to try to help with dressing, etc., quit after 2 days and 1 night. I heard our son say, "I guess I won't be able to go to college--no one wants to work for me." Further into his first year--he was heard to complain of having to sit in his wheelchair till 2 a.m. because his attendant "forgot to come" or was "on a date".

In contrast, I received support and training at the University of California at Berkeley. When I moved from my parents' house into an integrated dormitory, there was a program to teach me independent living skills. One of the first things I learned was how to hire and train my own attendants. The people I interviewed were recruited by the attendant referral office on campus, but I interviewed and hired my own workers. If my attendant did not show up, I called the back-up attendants who were hired by the university.

By the time I moved out of the dorm, I was confident with my attendant management skills. Now, as a resident of Berkeley with my own apartment, I still have access to many community resources for personal assistance services. When I need to hire a new attendant, I call the Berkeley Center for Independent Living for a list of people who are looking for
work. Additionally, the City of Berkeley runs an emergency attendant service program. If an attendant does not come to work, I just call for back-up. Within an hour an experienced attendant is at my door.

Most disabled people face much more of a struggle in gaining their independence. Carolyn Newcombe, a disabled advocate with cerebral palsy from Connecticut, recalls, "growing up, I was led to believe I would live in an institution for most of my life." Historically, parents of significantly disabled children were often led to believe that institutions were the only option. People growing up in such institutions faced enormous barriers in attempting to gain independence. Parents who went against the conventional wisdom of institutional placement were often worried about what would happen when they were no longer able to help their children. Nursing homes and state hospitals always loomed on the horizon. But because of community-based PAS, Newcombe and others are living a life they never thought possible: "With the use of personal assistance services I'm able to live in my own apartment, be employed and do things I enjoy doing."

Disabled parents face a different set of PAS issues. They may need physical assistance with their child as well as assistance with their own personal and household services. Inadequate services have forced some disabled couples to challenge state authorities for the right to raise their own children.

In the absence of other alternatives, disabled parents often must use their children as attendants. Elaine Zwicker, a parent and an advocate from the Center for Accessible Living in Kentucky, explains her own situation:

...my PAS needs are met by my daughter, a college student who has a toddler and also a half-time job. I am therefore dependent upon her spare time and energy to assist me. I am also placed in the position of espousing independence from family assistance while being forced by circumstances to use it myself. The situation is unfair to both of us...

PAS needs can place tremendous strains on marriages and other important relationships. Bettye Watts, a disabled advocate from Arkansas, recalls the pressures her PAS needs placed on herself and her family after her injury: "The increased reliance on my husband to help with activities which I formerly performed independently has become a continual challenge of my private life and to my self-esteem, my motivation level and hence my ability to effectively interact both at home and in the work place."
Henry Claypool, a PAS consumer and advocate from Colorado, observes, "Interpersonal relationships have taken on a different meaning since I have been using PAS." Like Henry's, my social life has improved since I began using PAS. I do not have to rely on my friends for personal activities like dressing or toileting. We can go out and just have fun. If they do decide to help me, it is a joint decision. I have the freedom to form many types of relationships. I do not need my friends to do everyday activities.

PAS is an essential part of employment for those of us with significant disabilities. However, most people who need PAS to work cannot receive it. Most programs are tied to ridiculously low income limits, and the threat of losing government support keeps most PAS consumers from even attempting to enter the job market. This is probably one reason why almost 70% of people with disabilities are unemployed. Patty Arndt McKelvey, a disabled advocate from Oregon, describes the common dilemma consumers face:

_Faced with the disincentive of lost benefits, I chose to do volunteer work for many years. When I chose to accept gainful employment I did so knowing I would eliminate my eligibility for attendant care services through the state Medicaid system. The transition has been frightening and a struggle for the first six months. At the same time I knew I reached a "do or die" point in my life. I have been fortunate that my salary has just covered my PAS expenses and that I have had no "unexpected" dilemmas having to choose between employment or state-paid benefits._

Once a significantly disabled person decides to work, he or she will need personal assistance services on and off the job to maintain that employment. Simply being at work on time is impossible without adequate personal assistance services. Stephen Johnson, an advocate from Virginia, observes:

_Personal assistance services have a direct effect on my livelihood. I need to be at work on time and when traveling, I am dependent on a personal assistant. Having a good personal assistant could mean the difference in being to work on time and making very important meetings out of town. It can be extremely frustrating and jeopardize employment and job-related activities when personal assistance is ineffective._

The World Institute on Disability is one of the few organizations which has a budget for employee PAS needs. I use my attendant to make phone calls, use the fax machine, and for filing. In addition, she feeds me lunch and assists me in the bathroom. Without these services, I wouldn't be able to work outside my home.

People with disabilities have unique needs, goals, values, and lifestyles, just like
people without disabilities. Current PAS systems are rarely flexible enough to accommodate these differences, but efforts are being made to reform these systems. At a recent Congressional hearing on PAS, Judy Heumann, the vice president of WID, testified,

*I was raised to live the American dream of equal opportunity. I always thought that meant getting a well-paying job, getting married, owning a nice house and a car, and going on vacations. But how can I reach that dream of equal opportunity without the assistance I need? For me and people like me the American dream will begin to be achieved when we can drink when we want, go to the bathroom when we want, and get out of bed when we want.*

Increasingly, disabled advocates are defining PAS as a basic civil and human right. The following essays address the importance of PAS from a wide range of perspectives. In an effort to maintain the individuality of each essay, the editors did not make any major revisions to their content. The first group of essays focuses on the role of PAS within the family structure, while the second group addresses issues of PAS as they relate to specific disabilities. People with different disabilities, sexual orientations, and ages articulate their struggles to receive and effectively use this basic right:

**Jeff and Cindy Strully** discuss the role of PAS in the life of their developmentally disabled daughter, advocating an integrated approach to personal assistance. They refuse to label their daughter, arguing instead that their daughter should be considered a unique individual with a unique set of needs and desires. People participate in all aspects of her life, but she dictates the terms of these relationships.

**Leah Welch** describes PAS as a vital part of a disabled parent's life. The lack of appropriate assistance in her case led to tremendous pressures on her entire family. The stress of providing PAS to family members is also discussed by **Donna Rob**, the older daughter of Leah Welch. She depicts the difficulties involved in taking on responsibilities beyond her years and their negative impact on her development, especially with regard to her peer relationships.

**Martha E. Ford** discusses the situation of her brother, Jud, who is mentally retarded. While they were growing up, her whole family assisted in providing his PAS needs, which allowed him to be integrated into all community and family events. However, as the siblings left home, there were fewer people to help with Jud's PAS needs, and the family made the painful decision to put him in an institution. She tells about a recent family event at which
Jud received adequate PAS, illustrating the possibilities of his functioning in the community which such assistance provides.

**Sascha Bittner** is a 19 year old woman who has cerebral palsy. She is living at home with her parents who provide her PAS. Like most young adults, Sasha wants to gain independence from her family. However, her needs make it difficult to achieve this. Sasha writes about how her family is coping with her transition from childhood to adulthood.

**Connie Panzarino** is a lesbian with a neuro-muscular progressive disease which allows her movement of only her right thumb and some facial muscles. As a member of two minority groups, she faces discrimination on many fronts. Connie describes how this ignorance has prevented her from receiving adequate PAS. She believes that with sufficient funding, she could develop a system which would meet all her needs.

**Emeka Nwokeji** is a Nigerian living in the U.S. who writes of the various cultural and ethnic factors which affect the lives of people with disabilities and their potential to access services.

**Beverly Evans, Connie Martinez, and Tom Hopkins** speak to the need to expand PAS to include services which enable people with cognitive disabilities to participate in the community. They demonstrate how a "partnership with another person who helps in perceiving, explaining, and understanding the world while at the same time fostering informed choice and self-confidence" can lead to an active and productive life.

**Sharon Gold** outlines six principles for establishing a PAS system to serve people who are blind. She emphasizes the importance of tailoring these services to the needs of the individual. Sharon stresses the fact that PAS can be abused and warns against providing services which could be done independently, or with assistive technology.

**Ed Rogers** and **Kate Seelman** describe the unique blend of personal assistance and technologies which allow deaf and hard of hearing individuals to communicate. They outline the variety of communication services available to people who are deaf or hard of hearing. Some of these services do not technically qualify as personal assistance. (Telecaptioning, for example, does not involve any direct help from another individual.)
Others, like the relay service, expand our current concept of PAS.

**Gary Harmon**, a featured speaker at the PAS Symposium, describes his experience as a person with AIDS in need of PAS. His physical and emotional needs are inadequately met by an under-funded and uncoordinated PAS system. Gary pleads for people with various disabilities to come together and work to improve the situation for everyone.

As a person who has a psychiatric disability, **Lorelee Stuart** writes from the perspective of someone who is often excluded from receiving PAS. Loralee argues that current mental health services, which function according to the medical model, do not foster independence for people in her situation. Using her own experiences, she demonstrates how pain and cost can be minimized by using attendants during times of crisis.

Like people who have psychiatric disabilities, people who have traumatic brain injury are frequently excluded from discussions of PAS. **Sherry Watson** illustrates with examples from her own life how important other people can be in coping with the effects of head injury.

**Alana Theriault**, a respirator user, describes how she maintains her privacy while receiving the extensive personal assistance she needs. She rejects the conventional belief that respirator users must have live-in assistance. Instead, Alana has developed an extensive emergency system which she can activate in times of crisis.
PAS and the Family
Thinking Differently about Developing Personal Assistance Support

Jeffrey L. Strully and Cindy Strully

My wife and I are parents of three individuals who all present unique personal challenges. Our middle "child" has started college this year as a freshman at Colorado State University. Shawntell is a person who is truly gifted. However, she needs lots of assistance in order to have a decent quality of life. This assistance and support come from three levels:

* family involvement
* friends
* integration facilitator

There are two major life defining areas for Shawntell. The first has to do with things such as dressing, eating, going to the bathroom, getting places and providing support so that she does not become isolated, dependent or segregated. These daily activities require direct support and assistance for our daughter. Someone must be present and involved in order for these things to be accomplished. Sometimes the people who are involved are paid to perform a certain function and at other times friends are around to help her out.

The second major life area has to do with connections with a circle of friends and the community. Without facilitation from a third person, Shawntell's day would be controlled by the human service empire. She would experience life as a client within the system. She would be "handled" by developmental disabilities professionals, vendors, providers, and a host of others who would be labeled as counselors, skill trainers, teachers, paraprofessionals, etc.

That is not what we envision for Shawntell nor is it what she envisions for herself. What we envision for Shawntell and what she envisions for herself is a life filled with rich diversity, fun, friends, and exciting adventures. Shawntell is looking forward to moving into her own place with people she chooses to be with. She is looking forward to attending CSU,

---

4 Jeffrey L. Strully is the father of three young people who require supports to live valued lives in the community. He has been involved with people with developmental disabilities and their families for over twenty-three years, and lectured throughout North America on issues of empowerment, friendship, inclusion, and leadership. He currently serves as Executive Director of the Association for Community Living in Colorado, a not-for-profit agency working to build caring, competent communities.
meeting new people and travelling. She is looking forward to a life that is exciting and rewarding.

While accomplishing tasks of daily living is very important, from our point of view these are secondary to the need to get Shawntell known and connected in the community. It has been our experience over the last ten or so years as we have worked to build a circle of friends for our daughter, that issues of "daily living" are not as important as having people around you. When there are people around you who care about you, then those things that we call "acts of daily living" happen because people recognize that you might need to go to the bathroom or want a drink. It's just no big deal. When you don't have people around you or if the people around you see their responsibility as taking care of your "acts of daily living" then a very different picture emerges.

Many people who utilize PAS are very capable of directing people to do things and at the same time of meeting new people themselves. Hence, the primary concern is to have reliable people perform PAS functions. This makes perfect sense. However, the concept of PAS can be expanded to include the facilitation and connections to the community in addition to the traditional performance of assisting people with acts of daily living.

It is implied in the human service empire that the more skills you have the more freedom and opportunities you should have. Therefore, if you are a person who is seen as capable, but your body doesn't work very well then you would be seen as deserving of PAS. However, if your body doesn't work very well and you are not deemed to be a contributing individual then a cost\benefit analysis is quickly performed to determine whether it is worth spending money on someone who is not going to pay back the investment.

The other problem has to do with the concept of brokenness. People with disabilities are seen as broken and in need of overcoming this brokenness through learning skills of daily living. In fact, many people spend their entire lives trying to learn these "acts of daily living" so that they can become more active community members. We think this is a major mistake!

It is our belief that teaching Shawntell some of these "acts of daily living" is neither relevant nor useful, even if she could master them. Shawntell's friends and facilitator help
provide the day-to-day support that is needed, but it is done as a natural consequence of being around Shawntell. You have to think about helping Shawntell go to the bathroom, eat lunch, get into the car, etc., when you are going out.

Because Shawntell does not use language nor any other form of official communication (sign, pictures, etc.), the people closest to her must help others interpret what Shawntell is thinking, feeling, wanting, etc. Shawntell tells us what she likes and does not like by her gestures and body language, and those who know Shawntell will tell you that she communicates very well. Those who choose not to spend the time to get to know her would tell you that she is non-verbal and has no effective communication system. What Shawntell needs is people willing to be around her for a long time and get "inside of her" so they can make an informed guess about what Shawntell is thinking. This goes beyond the usual concept of personal assistance.

As implied in the comments above, we try hard never to count on the formal human service system for support. That does not mean we do not need some financial assistance—we do. However, the choice of who works with Shawntell and who that person answers to needs to be in Shawntell's hands. For example, only specific friends of Shawntell's are allowed to assist her with her more personal needs, such as bathing and toileting. Shawntell lets us know whom she wants to be around her.

But it would be an oversimplification to say that Shawntell should control her entire life without parental involvement. At the risk of sounding just a little defensive and a little too much like an overprotective parent, let me say that it is very naive and possibly dangerous to expect Shawntell to make all the decisions in her life. The people who help make the decisions in Shawntell's life are the people who know her best, who love her, who care about her and are her friends. Others have limited input. Many of these other people control resources or are agencies who have lots of control over people's lives. Moving that control from them to us has been and continues to be one of the most important issues at hand. At the same time, the degree of our involvement in decisions affecting Shawntell's life presents the very tricky challenge of separating out parental issues and desires from what Shawntell is thinking, feeling, and wanting.

Making systems change or extrapolating the experiences of one family to others may
not be appropriate or even useful. However, it is our experience that learning what is important in Shawntell's life and how to make it happen has been our first and foremost desire. We continue to learn by doing. We continue to think differently as we come to understand the universality of many issues.

Personal assistance is not a disability issue--it is the fundamental right of every person to obtain support with the frequency, intensity, and duration needed to live a decent life. It may mean temporary help while recovering from an injury or during pregnancy, long-term support to allow older persons to remain in their home, intensive 24-hour care, etc..

Shawntell's life can be a journey that is rich and exciting. In order for Shawntell to take this journey, she needs a little assistance in the "acts of daily living", but more importantly she needs people to be in her life because they care and love her. Without her friends, Shawntell will always be at risk of victimization, abuse, neglect, segregation, isolation, and human servicing. This is not the life that Shawntell wants and it is definitely not the life her parents envision. PAS can be a mechanism to help Shawntell proceed on her journey if she is allowed to control her destiny and if there is flexibility allowing her to use people to meet her more important needs--namely, her connectedness to friends and community.
How Personal Assistant Services Affected My Life and My Daughters' Lives

Leah Welch

I came down with polio in 1949 and was hospitalized and in a rehab facility until late December 1950. My daughter Donna was 2 years old and Jeri was 9 months old when the polio hit. They were 2 and 3 1/2 years old when I came home from the hospital. Prior to 1977, there were no programs that provided personal assistance services to people who needed them. People who did live at home usually looked to their families for assistance. Others were left to fend for themselves. I was one of those.

This was a very difficult time for me. I not only had to attempt to learn to adjust and cope with my disability, but to again live at home and try to restore a somewhat normal lifestyle for my husband Jim, my daughters Donna and Jeri, and myself. In addition, I had to find, hire, and manage my personal assistants. The struggle was horrendous and rocky. As I look back, I see I didn't really manage well; mostly, I just let things happen. My marital situation was also rocky, as I did not receive a lot of emotional support from my husband. I was having trouble coming to grips with my new way of life, and, as a result, had a lot of anger and no constructive outlet. I let the anger out but in negative ways--in the form of fights with my husband and being too hard on my children. Jim and I never talked about our feelings before the polio and neither of us was able to afterwards. Naturally, the children felt the animosity between us.

I never spoke to my children about my disability--what it meant, what my feelings were, how this would affect them, or how they felt about it; nor did anyone else. Nothing was ever said. I also doubt that much was said to them about it while I was in the hospital. In those days, sharing with children just wasn't done. Donna was old enough to remember what had happened and somehow she came away feeling that she had done something wrong to make me disappear so suddenly. This feeling could have been prevented if we had explained to her more of what was happening. I recognize it now as I look back on the

---

5 Leah Welch, a veteran of World War II and mother of two girls, became disabled as a result of polio in 1949, when government-funded assistance to the disabled was virtually non-existent. In 1970, with the help of personal counseling which increased her self-esteem and motivation, she became an advocate for the disabled. The Minnesota Personal Care Program, mandated by state statute in 1977, is at least in part a result of her efforts. Ms. Welch continues to provide advocacy for the disabled community. In 1976 she founded Independence Crossroads, a center for independent living of which she is Executive Director; and in 1988 she founded Independence Crossroads, PCA, and currently serves as chairperson of its Board of Directors.
situation and talk about it with Donna as an adult. She felt she had lost me once—she didn't want to lose me again. She was always there when I needed any help. If I choked, she would pound me on the chest, as she had been taught. If I was hurting because of wrinkles in my skirt, she would pull them out. Small things like those she would do willingly. When she was a little older, but still in grade school, she was taught to take charge of her sister Jeri in ways I could not, and she tried to take care of her in all ways. I put too much responsibility on her at too early of an age. If I had a PAS program to rely on, I could have avoided that.

When I first came home from the hospital, Minneapolis Family and Children's Service agreed to provide a "housekeeper" (as we called them then) for a temporary period of time. This lasted for about six weeks and then we were on our own. We placed an ad and found Sylvia, a farm girl who came to live-in five days a week, working from 6 a.m. to 8 p.m., and Jim did all the rest. She stayed with us for a little over a year and things went fairly well. Her wage was $20 a week, plus room and board.

Sylvia left, and shortly afterward Jim also left. He could not handle all the additional responsibility, my anger, his feelings that because I was now disabled I was asexual, and our inability to really communicate. This put another load of stress on the girls. They not only had a mother who was different, but no father on the premises. As many different housekeepers came and went, my daughters' feelings of insecurity were increased by their having to adjust to strangers coming into their home and lives.

I had frequent attacks of asthma and pneumonia, and had to be taken by ambulance to Sister Kenny [Hospital] where they had an iron lung for me. Donna and Jeri were never sure whether I would live or die. It was extremely traumatic for them, especially for Donna. With their dad gone, I was their only security; there was no one else whom they trusted and were comfortable with who could help. A good PAS program could have helped here also.

There was not much money for us to live on, much less with which to pay housekeepers, so the quality of applicants wasn't always the greatest. We had a couple of really long-term assistants, but in between was a day-to-day existence. While she was still in grade school, Donna would stay home or be late for school so she could get me up. This is too much for any child, and although she did it willingly, it should not have happened. Yet
My only alternative was to go to a nursing home and give up my girls, and that I would not do. The housekeepers had a big load also: they took care of the housekeeping duties, did the cooking under my supervision, helped with the girls, and provided me my personal care. This was a lot for girls who were in their late teens or early twenties.

My feelings about my loss of mobility caused me to give up control of my life to my husband, my sister, my housekeepers, and, to some extent, my children. My housekeepers assisted me with much of the discipline of Donna and Jeri, and consequently had too much control of them and me. My sister was supportive to a certain extent, but she had trouble handling my disability and my needs. She ended up telling me that if I wanted her help, the girls and I would have to move in with her and her family, which we did for a time.

In 1950, it was easier to recruit help than it is now. There were many farm girls who wanted to move close to the city and work. Working for us provided them with that opportunity. We lived in a suburb near Minneapolis, but it was still rural enough to attract them. It not only provided them with the opportunity to work, but with a place to live. If a person had the money, recruiting was not difficult. However, there were no financial programs at the time to help pay for personal assistants.

With the implementation of a personal assistant program in Minnesota, many problems were eliminated. Many people who require personal care can now remain in their homes and in control of their lives. Control is an important issue. As my need for personal assistance services has increased, I would, in the absence of the program, be forced to live in an institution. The finances allow me to have 24-hour care on a shift basis without a live-in situation, which not only gives me more control, but more privacy.

Recruiting the right person, however, still remains a problem because of the complex nature of my care. While the payment of $7.50 per hour is attractive, people seem to be less willing today than they were in 1950 to take on the challenge of providing care to a person with respiratory problems.

As I look back on my experience, I have some suggestions for others who are facing a similar situation:
1. Share with your family your feelings about disability.
2. Ask them to share with you what they are feeling.
3. Discuss how family life will be changed.
4. Convey to the children that they are not to blame for the disability or the problems it causes.
5. Convey to them that you will always be with them if you can, that you are not sick, only disabled, and that you will not die because of the disability.
6. Talk with your family and children about some of the myths of disability. For instance, that your brain was not affected and that you can still manage mentally (if this applies). If there is brain damage or memory loss, talk with your family and children about that also.
7. Interview prospective applicants with your children present. Let them feel that they are part of the entire process.
8. Maintain control of your personal assistants at all times. Your children can be negatively affected if you do not.
9. If you have a live-in assistant, make sure all the rules of the household are discussed, so there will be no surprises. At all times maintain an employer-employee relationship. This can be done in a friendly and pleasant manner.
10. Invite your children's friends and your own into the house, so having company is a part of your life.
11. Go to school, church, and community functions. Integrate yourself and your family as much as possible. Encourage your children to do this also.
12. Get personal and family counseling to help you through the rough spots. If you can, find someone who does not hold all the myths that society holds regarding disability.
The Influence of PAS on a Mother/Daughter Relationship
Donna Robb

When I was a child, my mother was dependent on me whenever we did not have a housekeeper (as we referred to them back then) for all her personal care, plus dinner preparation, cleaning, and taking care of my sister who was only 18 months my junior. There were many times when we were without a housekeeper. I was in constant conflict, because I didn't like the intrusion of different people coming into my life and then leaving, but I didn't like the responsibilities placed on me when the housekeeper wasn't there. I wanted to play with my sister, not discipline her. I wanted to play with my friends, not stay home and make dinner. I wanted to go to school and be like normal kids, not stay home and get my mother out of bed. I didn't like feeling like I had to be there for her; I felt guilty for wanting to play since she could not help needing me. I had my own needs, but the needs of my mother and sister were greater.

Consequently, I grew up putting the needs of others before my own. I grew up gaining self-esteem through the approval of others. I felt if I was caring enough, then maybe someone would care for me. I was always waiting for someone to love me. I didn't learn how to laugh, socialize, or accept responsibility for my own thoughts, ideas, or actions. I was too busy being responsible for others.

Overwhelmed with responsibility, I began getting into trouble at home because of my anger with my mother. That was a tough time for both mom and me. The years of growing up with all the personal care responsibilities created such a wall of anger between my mother and me that we didn't really start talking until she almost died in 1984.

When I was a teenager, I went to live with my father. He was my knight in shining armor. While I was at my dad's, I knew it wouldn't last--nothing good ever did. Mom wanted me home and we tried again without success, but I only got angrier and eventually went back to my dad's.

---

6 Donna Welch grew up as the elder of two children in a household with a disabled mother. In the absence of a personal assistance program, Donna took on the role of assistant at a very young age, and experienced first-hand the difficulties and challenges of life with disability. For twenty years she worked in the business world until, in 1988, she was hired to develop the new Independence Crossroads, PCA, program. She has been its Executive Director since 1990.
My years with my father are good memories. While there, I started to relax a little and to fit in with my peers. But when high school ended and I was supposed to go on with my life, I didn't have a clue about what to do. I felt I had no ideas of my own; I didn't know how to think for myself.

It's no wonder that I became pregnant at the age of 18 and didn't want marriage. Having a child meant I could take care of and be loved in return, whereas getting married meant more responsibility to care for another person. I was unknowingly getting tired of taking care of others and was learning socially acceptable ways of running from my mother and her disability. I say "unknowingly", because to admit it to myself would have caused too much guilt. I was already a walking time bomb from all the guilt and anger I was holding inside. I had lost my childhood at a very early age and I didn't know how to be an adult, and I blamed my mother because there was no one else to blame.

The provision of Personal Assistance Services reflects society's recognition that attending to a disabled person's needs should not fall exclusively on the family. The quality of care, the emotional wounds, and the dignity of the disabled person and the family are too important. Today, through the help of PAS and after many years of counseling, my mother and I are working together to make personal care available to many disabled adults and children. We have a mother-daughter relationship.

However, we did not get to our present relationship overnight. We had much to learn and unlearn. Mom had to learn how to be a mother to me and I had to learn to let go. I had grown up worrying about my mother--every time the ambulance came and took her away, I never knew if I would see her again--so as an adult I worried a lot. I always felt that I should be able to do more, to the point of exhaustion for us both. PAS has given me the freedom not to worry as much. We are able to go shopping together, take walks together, go to plays together without my having to do her cares. I still worry, but we are talking about it--which is new. I still become overwhelmed by all the care sometimes, because disability is a heavy load for anyone to carry. We all need laughter and joy in our lives, the disabled person as well as the care giver.

Today, at age 44, I still have a hard time sorting out all my feelings about disability and how it has affected my life. But I do know that without PAS I would still be running
from my mother and myself, jumping from job to job, relationship to relationship, location to location, and being emotionally miserable and depressed. It is also amazing to see how my behavior and feelings of being overwhelmed by disability were projected onto my daughter. She didn't grow up doing personal cares, but she grew up with the feelings about personal cares. Today we still have a lot of work to do both at home and for other people as well.
The service needs of people with mental retardation vary greatly, as much as individuals can vary from one another. Many people with mental retardation have multiple disabilities, including physical disabilities, necessitating their use of personal assistance services much the same as any other person with physical disabilities. Others, however, will have need for personal assistance services as a result of the limitations caused by their mental retardation.

In approaching the task of describing what personal assistance services can mean to people with mental retardation, I have chosen to illustrate the issues through a description of the needs of my brother Jud Ford, who would require personal assistance services as a direct result of his mental retardation and the limitations it places on him. This discussion will also touch on the impact of the availability, or lack thereof, of personal assistance services on the entire family.

Jud is now 35 years old, has profound mental retardation, and, from age 16 until October of 1991, lived in a state institution which only recently renovated his "cottage" to meet the standards for certification as an Intermediate Care Facility for the Mentally Retarded. For our parents and other family members to visit him required a three-hour round trip drive every weekend. While Jud lived in the institution for 18 years, it had been the hope of our parents, family, and friends that the appropriate support services would be available to allow him to return to his hometown to live near his family, friends, and favorite haunts. Jud expressed his desire on a more-than-daily basis to "go home". He has recently achieved that goal; however, it is on a "trial" basis and, as described below, is distinct in key ways from what would be available to him under a comprehensive personal assistance services system.

In the spirit of describing the potential role and importance of personal assistance in Jud's life, I first have to describe the impact the lack of a comprehensive personal assistance system has had on his life.

---

7 Martha Ford is currently Assistant Director, Governmental Affairs Office, The Arc (formerly the Association for Retarded Citizens of the United States) and a co-chair of the PAS Task for the Coalition of Citizens with Disabilities (CCD).
While we were growing up, our household consisted, at various times, of both parents, seven kids in the family (Jud is second from the youngest), our maternal grandmother, numerous exchange students and others who lived with us, and two housekeepers who spelled each other through the years in providing consistent help to the family. While we did not apply the term "personal assistance" to our activities, I realize now that Jud had quite an extensive cadre of informal personal assistants who helped him to function within the family unit and the community. (His needs for assistance will be discussed in more detail below.) Jud was regularly seen around town in the company of one of us, doing things that people typically do--going to the barbershop, post office, grocery store, or church; going to the drugstore for a coke; or, as teenagers, riding around and listening to rock and roll.

Prior to the 1975 federal establishment of the right to a free, appropriate public education, Jud was dismissed from a special education school because he was extremely difficult to serve. While Jud continued to participate in all family activities and vacations, the need for stimulation, challenge, and educational and support services from sources outside the family became more obvious as he grew older. As Jud's behaviors became more difficult and his size increased (eventually to 6'9"), our parents unsuccessfully searched for programs which could serve his educational and other needs. Simultaneously, the rest of us began in turn to go off to college or other pursuits. With no additional assistance or resources available and with their own increasing age, our parents were forced to consider and resort to institutionalization. It was an especially difficult decision since, throughout Jud's childhood, they believed in and practiced full family and community integration. Families today who have had the benefit of special education services and opportunities for community integration are similarly likely to resist, if not flatly reject, institutionalization as an unacceptable "alternative". Appropriate personal assistance services would help to ensure that people do not have to resort to such measures.

If personal assistance services (as envisioned by the disability community and discussed in the concept paper prepared by the Consortium for Citizens with Disabilities8) were available to Jud, he would be able to live in a home or apartment of his own, probably

---

8For information on the position paper, titled Recommended Federal Policy Directions on Personal Assistance Services for Americans with Disabilities, contact the Consortium for Citizens with Disabilities Task Force on PAS.
with a house-mate, in his hometown. To be successful, the services would have to cover a wide range of needs and be well coordinated. He needs assistance in showering, dressing, grooming, and personal hygiene. Some of that assistance could include actual help in performing the task, while some of the assistance could entail providing him with training, prompting, cueing, and/or supervision of his own performance of these necessary tasks. Jud needs significant assistance in maintaining good nutrition through meal planning, shopping, and preparation. He needs assistance in taking necessary medications and in monitoring his health status, particularly since he has had two cancers (including surgeries and chemotherapy) in the last three years. In order to maintain his home, he would need assistance in household tasks such as cleaning, laundry, repairs, and maintenance. He would also need the protection of the availability of emergency services, such as immediate replacements for personal assistants who are unable to work due to illness, or for additional assistance during a crisis. Jud also needs assistance in managing his personal income and resources, including the services of a representative payee to manage his Social Security benefits.

Since his speech is difficult to understand, Jud needs some assistance in communicating his needs and desires in social, work, and other situations. To get to and from work, the homes of family and friends, stores, church, and other places he chooses to go, Jud would need assistance in using public transportation, where available, and driving services. He would also need companion or roommate services to provide supervision and assistance in maintaining positive behaviors during those hours when he is not receiving such assistance through formal training programs. Jud would need work-related support services to assist him in acquiring the social, behavioral, and work skills necessary to be successful in a job. He would need advocacy services to help watch out for his own interests in numerous situations. He also needs support for participating in social, community, and other activities of interest to him, including an annual trip to the beach.

Jud would have continuing need for a strong system of service coordination and assistance in managing his assistants, including recruitment, screening, referral, performance evaluation, and quality assurance. As Jud gained more skills in community life and participation, it is likely that his needs for certain supports would diminish: changes in the mix of support services provided should come only with a thorough review of his needs and desires as well as a review of overall desired habilitation goals for him.
Without some outside direction and guidance, Jud's preference for spending his time would be to visit with our mother and drink Coca-Cola all day. While respecting the desire of many personal assistance users to choose and direct all personal assistance they receive, it is important to take into account and provide for people like Jud who need guidance in choice and decision making for their general well-being.

This past summer, our family had experience with what life could be like for Jud if he had the proper personal assistance. Upon the death of our father, Jud was able to join in a family gathering in our hometown with the personal assistance and support of ICF\MR staff who wanted very much for him to be able to participate. With staff assistance in toileting and personal hygiene, with maintenance of appropriate social behaviors, and with transportation to and from his hometown, Jud was able to participate fully as a family member in an important family gathering. (Such assistance is not typically available through an ICF\MR, and in this case was primarily due to the voluntary assistance of staff with a personal interest in Jud.) Heretofore, any such trip had included medications to help maintain behaviors, and family members providing the personal assistance in toileting, personal hygiene, and transportation. This time, he was able to participate more fully as an equal in the family circle. To have such assistance in all aspects of his life and to be able to participate fully in family and community life is Jud's dream and that of his family. A comprehensive system of personal assistance services, available to all people with disabilities and including a full spectrum of formal and informal support services, would make such a reality possible.

As stated above, Jud is currently back in his hometown on a "trial" basis in a community-based ICF\MR which serves six people. While the facility will meet most of his needs, such as monitoring of health status, supervision and guidance, and specialized habilitation services, the system of facility-based services has some basic flaws. In the ICF\MR Jud's life is still tied to the pattern of life in the facility and the federal regulations under which it operates. Those regulations virtually ensure, because of Medicaid reimbursement and eligibility issues, that Jud will not receive extensive vocational training to lead to competitive or supported employment. In addition, Jud and the entire family must be careful to avoid any financial actions which may jeopardize his Medicaid eligibility. Finally, while Jud is very happy to be back in his hometown near many of his family, his now frequently repeated wish to "stay in the new house" reveals the uncertainty of the "trial
placement". This situation contrasts markedly with the situation described above where personal assistance services would be provided on an individualized basis to support a person in his/her desired living circumstances. The ICF\MR setting leaves unanswered questions that concern Jud's family, such as: under what circumstances a "placement" would be determined "unsuccessful" and possibly result in a devastating return to the institution. A comprehensive system of personal assistance is seen by many as a way of ensuring that the person is supported and his/her needs are met without subjecting the individual and family to "fitting in" to a somewhat pre-programmed model.
As an 18-year-old woman with a disability living at home, I have largely relied on my parents or school personnel for personal assistance services; my mom actually gets paid by the state of California to be my In-Home Supportive Services provider. As a result of my disability, cerebral palsy, I am quadriplegic, with speech (articulation) and vision impairments. I need personal assistance for many of the routine tasks of daily living, like getting out of bed, getting dressed, going to the bathroom, menstrual care, grooming, bathing, and meal preparation.

One of the major problems of having family members as attendants is that even when we are really upset with each other, my mom or dad still has to take me to the bathroom! It also makes it much harder for all of us to see me as an independent adult when I must depend on them for all my PAS. There are a lot of issues that already come up between teenagers and their parents that become even more complicated by this kind of dependence.

On the positive side, my parents will really go that extra mile for me and do things on very short notice that might be difficult to get other attendants to do. They will do things without regard for the hours or the wages involved. Of course, the solution to this dilemma isn't that people with disabilities should have their parents for personal assistants, but that hours and wages should be adequate for our needs.

The overriding problem I have in terms of being independent in the community is the need for assistance in the bathroom. This simple fact of nature puts a huge constraint on everything I do. I don't need an attendant to hang around with me while I travel on public transportation, go to school, go to the library, go out to eat, etc., etc. But, every few hours I do need someone to take me to the bathroom. If I'm in Berkeley, I can use the
emergency personal assistance services through Vantastic (at seven bucks a pee!), but often I just have to hold it until I get home, or make some arrangement to meet one of my parents. (I might take paratransit or public transportation to meet my parents at work, or one of them might go to where I am.) At other times, I might persuade or pay a friend or acquaintance to help me; however, while I can bear some weight, it is difficult for people not familiar with my particular needs to understand exactly what needs to be done; it becomes a lot easier with a little experience. If I really am desperate (and feeling pretty bold) I might even ask a stranger to help me. This requires very good judgment, because I certainly don't want to get into any kind of unsafe situation. A couple of times when nature has called in a very insistent way during my visits to a local mall, I've asked women at the information desk to help me; it makes it a lot easier when two people can do it, anyway, and I don't think I could have gotten a much safer situation with strangers.

My dream for the future is that malls and other major points of interest will have some central place where people who need PAS can get help. It is stupid to have to hire a personal assistant for an hour or more when you just need one for five minutes in the bathroom! Independent Living Centers might be another good place for such drop-in services, especially if the centers are centrally located. I actually asked for bathroom assistance once at the Berkeley CIL during another desperate moment; while they agreed to help me that one time, I was politely warned not to try it again.

PAS was also an important consideration during my elementary and secondary years. Obviously, my parents attended to my needs at home, but I sometimes had trouble getting what I needed at school. In high school, the female para-professional who usually took me to the bathroom only worked until about two hours before school got out. If I wanted to stay after school for a club meeting, or maybe even just really needed to go to the bathroom again (disabled students were heavily discouraged from using the bathroom more than once a day), I just had to manage on my own. If the para was out sick, usually there was a para available form one other class, but sometimes I ended up having to recruit female teachers and even other female students.

Extracurricular activities, unfortunately, were the most problematic in terms of PAS. During the sixth grade, most of my class (this was my first year being fully "mainstreamed")
went on a three-day camping trip to a park about 60 miles from where I live in San Francisco. Since only two adults would be supervising an unruly pack of sixth-graders -- and one of those adults would only be there for a while -- I couldn't attend unless I brought a personal assistant with me. Naturally, that meant my parents ended up accompanying me. While they tried to leave me on my own as much as possible, it was kind of a drag to be the only kid whose parents had to be there. Not to mention that my parents were forced to take off work in order to make this possible for me.

All through my public school years we had to deal with the issue of extracurricular activities. When my classes would go on field trips, my mom would have to provide the transportation and the PAS or I couldn't go. (At that time, the public transportation in San Francisco was not as accessible as it is now, and I had not made it off the waiting list of the paratransit program.) I was in the choir in the seventh and eighth grades, and we went on frequent field trips to attend musical performances or to perform ourselves, and it involved a real commitment by my mom to make sure I could participate.

Also, for any non-school activities like camps, summer programs, and after school programs, PAS was always an issue and usually meant that I would only have the opportunity to attend segregated programs for disabled kids. (The kind of programs offered were rarely ones I was interested in.) A non-segregated social life was virtually impossible, because I wasn't allowed to be part of those kinds of programs. When I did manage to get together socially with non-disabled kids, personal assistance issues again presented limits--for example, if I spent the night at someone else's house, who would provide those services? Usually, kids would have to come over to my house, which meant I didn't get out of the house as much as I would have liked and my parents never got a break.

When I was a senior in high school, I actually ended up suing the school district over the inaccessibility of extracurricular activities and the lack of personal assistance services. In the fall of my senior year in high school, an advisory from the Legal Department of the California Department of Education had been sent to all school districts in the state, letting them know they were required by law to hold all school-related activities, including proms, field trips, etc., at accessible sites, with appropriate personal assistance services. If transportation was provided for any students, accessible transportation needed to be provided to disabled students at no extra cost. By this time, I had been to one prom held
at an inaccessible site, and to numerous other activities at which no PAS had ever been available (I would have to call my parents to come assist me if the need arose). During the spring semester, a two-day trip to Disneyland, sponsored by the senior class, was planned, along with a senior picnic. Naturally, none of the transportation was accessible, and there were no plans to provide personal assistance services. It was just assumed that my parent should fill in. This time, however, we were more familiar with the law, and decided to file suit through the Disability Rights Education and Defense Fund. The day after the suit was filed, the school district attorney called our attorney to say the district would comply with the law. Part of the agreement to drop the suit was that this policy will be made very clear to all principals, parents and students, so that no other kids would have to go through what my parents and I went through.

Last spring I was the grand prize winner in an annual essay contest sponsored by the English Speaking Union of San Francisco. The prize was a trip to Oxford, England, to attend a summer program at one of the colleges at Oxford University. Normally, the high school senior who wins the contest is given a plane ticket to England and stays in Oxford with an ESU family. Obviously, PAS and wheelchair access issues would mean that I would not be able to follow the usual pattern. To start with, the college that I would be attending was not accessible, and housing was not accessible. More critical even than that, though, was the issue of personal assistance. So the ESU granted me an alternative prize--a trip to England with my parents. We had a really wonderful time, and ended up going to Belgium, France, the Netherlands, Germany, Austria, and Italy, too. My poor parents even got me up to see the completely inaccessible "secret attic" of Anne Frank, and my dad carried my wheelchair up endless flights of stairs (in the Metro in Paris, for example), since there was virtually no accessible public transportation in the cities we visited, and accessible (cheap) lodging was also in short supply. I ended up seeing a lot more of what I wanted to see than If I had been with someone besides my parents, but in the future I want to have other options.

Next year, for financial reasons, I will be commuting to school at UC Berkeley, and my parents will still be providing most of my personal assistance. However, the following year I will live on campus, and participate in the Disabled Students' Resident Program. This will mean a huge change for my family, one that is a little scary but also very exciting. The program at Berkeley will provide me with the assistance and training I need to learn how
to function independently in the community and to hire and manage my own personal assistants. A lot of pressure will be taken off the relationship I have with my parents, but I'm sure it will be hard for all of us to let go, too. I'll also have to adjust to other people doing those intimate things that have largely been left to my family. Still, this transition is what becoming an adult is all about, and I'm looking forward to both the challenges and the new sense of freedom.
I am a forty-four year old lesbian with a neuro-muscular progressive disease which allows me only movement of my right thumb and some facial muscles. Because I have difficulty swallowing, all my foods must be pureed. I am partially respirator-dependent and suffer from constant muscle pain. I hold a Master's degree in Art Therapy from New York University. I am a practicing Registered Art Therapist working with both men and women survivors of physical and sexual abuse. In addition, I lecture nationwide on the subjects of disability, homophobia, sexism, and the ethics of genetic engineering. I am also a professional artist. Because my disability is beginning to limit my travel to conferences and speaking engagements, I have decided to write an autobiography which would serve to educate persons with and without disabling conditions. My lover of six years and I own a home together in Boston. I use daily full-time personal assistance services to enable me to live, eat, breathe, bathe, dress, use the toilet, run the household, write, paint, see my clients, serve on four boards of directors, and cook Italian gourmet meals. Although I write and draw on my Mac Plus computer, practically everything else I do depends on my personal assistants.

I have utilized various forms of personal assistance over the last seventeen years. While I was in graduate school, the Department of Vocational Rehabilitation provided funding for individuals that I hired and trained. After graduate school, when I lived in New York, I had to get my assistants through home health aide agencies like Upjohn. I had no choice about who the person providing my care would be. If I were married, the agency would tell that to the home health aide as part of her preparation for the job, just as they would tell her where I lived and what my limitations were. They never, however, told the aide that I was a lesbian. They refused to. I was told to keep it to myself, and that it was none of the aide's business. When I share my bed with a lover I live with, and the aide has to come in and turn me over or help me with a bedpan during the night, it becomes impossible to keep it to myself. Several times I have had home health aides "freak out" and leave because of my "sinful" lifestyle. I even had one woman's husband threaten to come over and shoot my lover and me for hiring his wife. When I

---

10See page for biographical note.
first came out, one of my heterosexual personal assistants said, "Well, I can understand that for you it's just easier to be with a woman if you are disabled and can't get a man."

In some ways it is easier in Boston, because I am under the personal care assistance program of the Boston Center for Independent Living. Now I can hire whom I like, but being a lesbian still presents particularly difficult problems when I have to hire new assistants. I never know whether or not they might be homophobic and not want to work for me. Sometimes I advertise in lesbian and gay papers, but the gay community is small, and it is difficult to hire a lesbian who doesn't already know someone (clients, friends, old lovers, etc.) that I know, and so confidentiality and anonymity become difficult. If I advertise in the Boston Globe, I am not permitted to use the word "lesbian" in the ad, even though I am only describing myself. When someone calls to apply for the job, I tell them on the phone I am lesbian, before I invite them to my home for an interview. That way, if they're going to have a weird reaction or threaten me, they won't know where I live.

One way of avoiding homophobia in my personal assistants is to hire lesbians. I often advertise in Gay Community News or Sojourners or Bay Windows for attendant care, but then I am fighting the ableism of a culture that seems to value rugged individualism, bodybuilding, and physical perfection, and recoils from those of us who must depend on others for our daily needs. Within this culture I have also found many who are more than willing to help me, as long as I am grateful and let them take over my care. It appears that the oppressed culture of lesbians still has a great deal to learn about ableism and disability.

Since many of my friends are lesbians with disabilities, and gay men with disabilities, we have shared in discussions of the problems outlined above. Many lesbians and gay men have found that hiring their lovers for personal assistance is a safer option which ensures their confidentiality. Often, however, this puts stress on their relationship, most often causing a decline in their sexual interactions. A combination of lovers, friends, and workers hired for personal assistance seems to work well for some people, while others prefer to have only hired personal assistants as workers.

The gay man or lesbian with a disability is caught between two cultures. I find it
imperative to educate my personal assistants on the oppression and positive aspects of both cultures. With the higher consciousness developing on HIV and AIDS, the gay person with a disability is often seen as having the qualities of HIV or AIDS, such as contagion or shortened life span. In the lesbian community there is a strong willingness to form life-support groups for women dying of cancer. The community is responsive to these women, yet women with disabilities which are life-long are often seen as too much of a burden, or seen as separate from the community. Gay men with disabilities have expressed similar feelings in their community where gay men are willing to provide assistance, often free of charge, to gay men dying of AIDS.

If funding were available for lesbians like myself to provide adequate screening, training, follow-up training, and support, as well as competitive wages with benefits, I would be able to hire and maintain a more appropriate professional staff. Persons with disabilities have the right to proper personal care assistants regardless of personal preference.
PAS Values and Issues Guiding Effective Services
For Multicultural Persons With Disabilities
Emeka Nwokeji

The focus of this paper is to continue the discussions from the October 1991 symposium in Oakland regarding personal assistance service values and issues in communities where extended family relationships act as barriers to self determination and living independently within the family structure. This position paper was written with a great degree of urgency and spontaneity, so it is neither conclusive nor exhaustive. Hopefully, it will initiate further dialogue.

There are several characteristics of extended families which need to be understood. First, the extended family system is a respected institution which is central to the culture and values of many people around the world. In the U.S., this same magnitude of respect for extended family relationships can also be found among African Americans, Native Americans, Americans of Latin origin and persons from South East Asia.

Secondly, the birth position of persons with disabilities in such cultures is constantly tested and challenged by others, both within and outside the family circle. Privileges, responsibilities and rights which accompany one's birth position must constantly be defended by the disabled individual and his/her family. If a person is unable to perform family duties satisfactorily, the individual and the family are stigmatized by the culture's assumption that this misfortune must be the result of something the disabled individual, his family or his forefathers did. Often disabled people in such situations choose to do everything they can to defend their birth position while neglecting to take care of their disability needs: it is easier to leave one's personal care and maintenance tasks to the family. The challenges and tests which evolve from one's position in the family distract people from knowing themselves and working toward independence. They also prevent persons with disabilities born into extended families from readily absorbing the philosophy of independent living and achieving disability awareness.

11 Emeka Nwokeji is a Nigerian wheelchair user of nine years who resides in Massachusetts with his nine- and eleven-year-old sons. He has held positions in the independent living movement as an IL Skills Specialist, Community Development Program Director, and Deputy Director of Northeast Independent Living Program in Lawrence. He is currently employed by the Massachusetts Rehabilitation Commission as Director of Advocacy and Consumer Involvement. He has been honored by the NCIL Minority Advisory Committee and by the Access Now Conference in Massachusetts.
Above all, economic disadvantage promotes the dependence of persons with disabilities within extended families in two ways. If a family with a disabled member cannot fulfill its economic obligations, that serves to perpetuate and sustain the negative cultural perceptions of the person with a disability and further emphasizes the assumption that the family's difficulties must stem from some sort of indiscretion. Secondly, the more affluent the extended family, the easier it will be for the disabled family member to live independently in a way s/he chooses. Affluence generally means that the family has in some way already interacted with the outside culture either through education or business transactions and may be more aware of other views of disability and available resources.

There are many ways these cultural differences impact the disabled individual's interaction with the disability movement and disability service providers. As a person of African origin who has a physical disability, I have encountered many of these cultural barriers. For example, access to community services is not available in the communities of ethnic minorities. People have a hard time finding out about resources. They are forced to step out of their cultural milieu to gain access. Yet their chances of knowing about resources in the larger community are remote.

When multicultural people with disabilities do venture out of their family environment, they encounter barriers to developing a trusting relationship with rehabilitation and independent living professionals. Often there are no professionals in the areas where extended family cultures are located. People depend upon the family for assistance. So even the idea of going to someone outside the family is foreign. Yet disabled people need to interact with people who are sophisticated in the development of resources which promote living independently.

Because of all the isolating factors discussed above there are very few role models of people with disabilities living independently within extended family cultures. This means that newly disabled people do not have readily available peer counseling or socialization within their immediate circle.

The extended family system can encourage and inhibit the person with a disability from living more independently. As noted earlier, families which already have contact with the wider society may know about resources, yet the family may continue to have
reservations and difficulty accepting their child's independence. Acculturation is accepted, but "letting go" of long held beliefs is not easily achieved. Family issues evolve.

In short, the ability of people with disabilities who are minorities to live independently and manage their own finances is dependent on:

1) His/her birth position in the family,
2) How sophisticated or affluent the family is,
3) How educated the person with a disability is, and
4) The sensitivity of the larger community within which the minority community exists.

These same issues apply to participating in PAS programs. Personal assistance services will only become acceptable within extended family cultures when community-based rehabilitation systems respect the extended family system.

Even though there are cultural barriers, bringing independent living values to multicultural disabled people is enormously valuable. The process of accepting independent living and developing the skills to achieve it is a process of empowerment. The self esteem that people gain helps them to look at other ways to be productive besides concentrating on only their cultural values. With these new skills people begin to expand their vision and their possibilities for success in life.

In summary, the ability and/or skills of multicultural persons with disabilities to exercise their rights are highly dependent on their culture of origin, the individual's ability to move out of that culture and accept a degree of acculturation, and the degree to which they seek to liberate themselves from their culture's perception of disability.
PAS and Specific Disabilities
PAS for People with Cognitive Disabilities
Beverly Evans\textsuperscript{12}, Connie Martinez\textsuperscript{13}, and Tom Hopkins\textsuperscript{14}

This article presents the first-person statements of developmental services consumers, assisted and facilitated by Barbara M. Blease, Advisor for Capitol People First. The consumers offered their observations in the format of taped statements and interviews, and approved the final manuscript version.

\textsuperscript{12}After attending segregated schools, Beverly Evans became the first wheelchair user in a "regular" junior high school. Her subsequent experience of living in nursing homes has made her a strong proponent of independent living, and she has been working for better personal assistance services. She has starred in a Disability Awareness video for the Hand-In-Hand education project in Sacramento and is a Board Member of Capitol People First.

\textsuperscript{13}Connie Martinez is a native of Sacramento with severe dyslexia and other developmental disabilities. She drew strength during her early years from the African-American civil rights movement and from her experiences as an adolescent farm worker. After some time in a segregated "adult school" for people with retardation, she rejected this setting in favor of independent living and activism. Currently an independent activist, she has served as a member on the California State Council on Developmental Disabilities and as president of Capitol People First.

\textsuperscript{14}Thomas Lester Hopkins, Chairperson of the Board of Capitol People First, was diagnosed as a child with cerebral palsy and mental retardation. After attending segregated classes at a variety of schools he graduated from high school in 1979. Denied access to history and philosophy courses at community colleges, he pursued these interests through public television programs. Tom describes his pro bono advocacy work and service on boards as "real and important jobs, helping other consumers learn about their rights."
Introduction by Barbara M. Blease

People with cognitive disabilities need comprehensive personal assistance services which go far beyond the traditional "attendant" duties of physical care. They share the same aspirations and support needs as people facing other types of challenges: access to friendships, community, travel, and the political process.

Many people with cognitive disabilities, of course, must also cope with physical disabilities of various sorts. Thus, Beverly Evans has used a wheelchair since the age of three, experiences other complications of spina bifida, and is legally blind; Connie Martinez must deal with developmental anomalies involving her bones and joints, as well as severe dyslexia; Tom Hopkins is ambulatory, but has problems with balance and mobility as a result of cerebral palsy.

A critical form of personal assistance for people with cognitive disabilities is facilitation: a very special kind of partnership with another person who helps in perceiving, explaining, and understanding the world while at the same time fostering informed choice and self-confidence. Facilitation may be most akin to mutual teaching; we would emphasize that this process is in fact essential to people of all abilities.

As our three spokespeople make clear, people with cognitive disabilities also need affective supports: people in their lives who can share feelings of self-worth, respect, mutual esteem, and interdependent autonomy. All too often, "independent living" can mean living in a bleak and isolated emotional landscape--being in the community, but not of it.

As a consequence, effective personal assistance means moving away from the "developmental curriculum" model which treats people with cognitive disabilities as children.

---

15Barbara M. Blease describes herself as "a lifelong activist in civil rights and civil liberties matters." As early as 1951 she was a teacher and counselor in the area of race relations. Her many years of work with students, including those with behavior problems, in public as well as alternative schools, gave her an appreciation for the variety of human abilities and the importance of community. From 1987 to 1992 she served as a board member of Training Toward Self Reliance, an independent living agency in the Sacramento area. In 1982 she participated with consumers in forming Capitol People First, Inc., and has continued to serve as its advisor.
who must "learn" certain "skills"—rather than as people who need to grow as others grow through valued experiences of friendship and contribution to community.

Of special interest, as one aspect of this growth process, is participation in the policy making process. Two of our spokespeople share their experiences and suggestions concerning facilitation for people with cognitive disabilities serving on public boards or other policy making bodies.

As Tom Hopkins summed up the nature of facilitation and affective supports: "The cognitive ramp—the person acting as a cognitive ramp to the information, and giving and taking information." This learning process is in fact basic to us all.

Connie Martinez

The time I started in the DD Council [California State Council on Developmental Disabilities], no one was in the picture. I realized I'd been asked to be involved in the DD Council...So I started going to the Council, and they give me this paper, and I take it home, ready to listen to a tape, because I tell them I cannot read, and really, I couldn't understand. I was so upset.

What to do? I mean, I'm ready to do my work, and I'm ready to give my energy, and I don't want to be the little puppet, just sit down to look good 'cause they have "a little retarded." I want to do work, and to show that a person who is handicapped, whatever the word, can function. We have so negative [images] about [the idea that] we couldn't function.

I was involved in independent living, I was involved in helping children make tamales, I was involved, already, seeing a lot of things I would like to see changed. I was involved in People First, so I was ready to change certain things—in my dreams and my hopes.

[When Connie shared a tape of the DD Council meetings with her facilitator, he couldn't understand it either—and let her know.]
Here's a person who's intelligent, and didn't understand it, so it really opened the door that it wasn't me. And I say, "I need somebody to help me." At the point where we started putting our heads together and saying, "Why not have somebody that knows me? I don't want anybody else that doesn't know me."

The first thing is, Bob has some knowledge because he was working at the Capitol, so he had some knowledge of the bills. What I had some knowledge of is how it affects consumers and my familia [i.e., the "family" of people with developmental disabilities], because I was the leader, and had been in the workshop, and had seen how they treat people at the workshop like a little child. So I had gotten knowledge, and Bob has a knowledge.

I think that a person that has the knowledge when another person does not--yes, work together, but also don't take completely over. If the person needs help, then, yes--but there's a different way to help the person. I'm talking about a person who cannot read or speak--to help, yes, the memory's really bad... "Perhaps we get together and talk about what you understand that person to mean, a certain thing that's going on, la familia"--then that person can decide.

Sometimes a person has a knowledge, and sometimes it's wise to listen to that knowledge, but if s/he believes it's wrong, you have a right to say you don't agree. You both might not agree on certain things, and that's your opinion, but if a person has some knowledge of a certain thing, and you haven't, I think you have to decide who's really...

The main thing is not to bend at each other, what's important is that the consumer and you...that person's working for you, and that person has knowledge. Yes, it's time to listen to him, but at the same time, you need to listen to yourself, and if you know some knowledge, then it's fine. And if you're not sure, then listen to what s/he knows, and if you listen and you believe it makes sense, then go with it. If you don't, then you decide that.

Well, there's so many things. This person did wonderful things for me. He helped me a lot. Without him, I couldn't do. What I need help with, OK, certain people that we need to have, we need to study certain things. I know my memory is bad, no question about it, I'm not denying it, but, we need to be able to look at it, so if I forget, I have somebody
to say, and sometimes he did that, and sometimes he's tired.

If a person is tired--Bob had been doing a lot, he did that, and I realized, OK, that he started to be tired, and that's why he took over. Bob did a lot of that, and that's why I think it happened.

A person who is deaf... They have two persons take over time. I would like to see a person have either two or three persons. When I see a person blind and deaf, they have three persons hired. One person gets tired, rests, and then they have another person. I think I would like to see that happen to a person who cannot read.

Tom Hopkins

What I would like to see, for instance, in personal assistance is somebody not only take care of the physical needs, you know, like "I need help in this, and I need help in that," but also help in finding out about social outlets like the YMCA or YWCA or the Sierra Club or something--find out about these things and help the person get in contact with these things.

See, that's one of the things that the DD system thinks is not that important. The whole thing is backwards, because that's one of the crucial, crucial, things--social. I mean, people think that's a soft service, like, well, "What you need is Independent Living things." And Independent Living Skills covers cooking and cleaning and taking care of your apartment, but it doesn't cover social skills.

Social skills is not really a priority to learning how to fix your bed, or learning how to keep your room clean. "Learning how to make friends, learning the give and take of relationships, is not that important because we can't document it, or can't make it fit in a little box marked X, Y, or Z."

And because they don't want to really take the time nor the trouble to do it, or the system's not set up for it, they don't have a program for it, the person suffers from it, the primary consumer suffers for it, because s/he doesn't get that essential of learning how to be a part of the community--to contribute. How can s/he contribute if s/he doesn't know
anybody's out there?

Part of decision making is critical thinking. If I choose this, what happens if I choose this? What happens if I do this? What's the cause and effect of what happens when I do this? Or what I think.

I think that's one of the essential parts: to go out there and explore. What are your values, what do you think is important? Your decisions do count. You count, and you make a difference.

But to do that, you have to have critical thinking. And that starts, you know, early. And so, even now, you have to--that's what the idea of a facilitator is, to help the person make some critical choices. And, this is not a six month thing like: "We'll do six months of critical thinking, class, I'll document it, and boom--and you're gone." Well, this is going to be a year-in, year-out problem, I mean.

* * *

For instance, having help on learning the background politics of boards. You see, when a person joins a board, s/he doesn't get the background information that everybody else has got, you know, because most of the other people on that board are either professionals, or they've been on them and know what goes on. And so when a new person joins a board, I guess, it kind of happens to a lot of people--they want to learn what goes on, and to learn this stuff, and find out what really goes on the board.

And it's hard to make those kind of things work when you don't have the heart because a lot of things happen on boards that nobody can plan for. I mean, people say things and do other things--you have to figure out whey do those things--politics, or pressure from some other side. And it takes a lot of explaining, you know, like: "This guy, well, how come he went this way, if he wants to go this way." You know, why this person made these decisions, and what was behind those things. Those things are hard to explain.

I think it's important, if you're going to do policy things, if possible, to find somebody that's not biased, like maybe someone whose experience is as a former board member--who
was a member of the board, but is not affiliated with the board at the time.

What do they believe, what are their values? That's part of the critical thinking thing. Finding out: what kind of advisor is s/he? What are her/his values?

Beverly Evans

Attendants are supposed to help with cooking, cleaning, personal care, lifting, transportation, helping read your mail, facilitation, all this other stuff--housekeeping, shopping, doctors' appointments, dentists, taking you if you have to go some place--they're supposed to be taking you places.

The problem that I ran into was many attendants didn't feel that it was their job to do many things. Some of them had drug problems, some had abusive problems; some--many--of them wanted to be the employer, instead of me being the employer. Most of the attendants wanted to take over, and so I had to learn, and I'm still learning, that they are not the employer. That I am the boss.

There are people out in the community who have personal assistance for independent living--attendants--who go through the same thing that I went through.

It was very unstable, because a lot of them didn't want to work because of the minimum wage. And there was no benefit, nothing. So I had to terminate a lot of the attendants--or, a lot of the attendants had to quit.

There's one attendant that I had--I don't remember if it was my second or third attendant--that was violent. She was an alcoholic, she was a drug addict, and she hit me, because I confronted her with her stealing money from me. So, I had to get my parents involved, and a friend of mine, another friend who used to work for me, involved, in trying to get this person out of my house, and out of my life.

The personal assistance network--the circle of support--they need to help me with a variety of different things--cooking, cleaning, personal care, attendant care; they need to help
me find resources such as entertainment, or church, or travel, transportation, that will accommodate me. I need help with my financial problems. I need help with everything. I need help with my animals, with facilitation.

I need someone to help me with facilitation, in other words, to help me catch up with all the things I missed in my younger years, you know, when I was a baby on up--help me find experiences, learn how to experience. For example, I want to ride on an air balloon.

I need ongoing help in finding people who would be my friends, who would teach how to have a relationship, some kind of relationship with people--kids, teenagers, and adults. I need help to communicate. I needed help to communicate, to deal with attendants--a variety of different things.

For example, I would like to have help in helping the homeless, helping the disabled community, I'd like to help people get off drugs, and off the streets. I would like to be around children, learning about children of all ages, even problem children, even children that have problems. I would like to be with disabled children, help them out. I want to communicate to the children that people with disabilities are just normal, just like everybody else, but have problems, have difficulties thinking, difficulties, physical disabilities, so on and so on. And I would like to do it through music also.

I would like personal assistance in trying to get together with people who have talent, music talents or acting talents, who are either not well known or known. I would like to help, to communicate to the world that the ADA should be starting in 1992, in January. I would like to stress that I'd like to have the personal assistance for independent living help me be forceful in that.

I would like to do my disability awareness through other groups, and to a lot of groups. I would like to start really catching up on everything from my childhood on up--all the things that I missed--for example, friends.

I wanted personal assistance in learning more about the world, how I can help make the world better. I wanted to learn how to contribute to the world through music, or going
out in the community, politics, I want to learn more about politics.

People need to realize that people with cognitive disabilities can also learn to live and love and live a normal life, just like everybody else—with the help of Personal Assistance for Independent Living. Also, PAIL needs to help the person with a cognitive or physical disability to go over crunches or those obstacles that normal people normally go through, or a person with a disability goes through.
Good morning Madame Chairman, my name is Sharon Gold. I serve as President of the National Federation of the Blind of California. My address is 5982 South Land Park Drive, Sacramento, California 95822; telephone, (916) 424-2226. Thank you for inviting me to participate in this hearing.

As I understand it, this proceeding is being held to examine various policy issues and considerations relating to the establishment of a national program of personal assistance services for persons with disabilities. I assume that some of the questions before you are whether, in fact, there should be such a program at all and, if there is such a program, how, and to what extent, should the federal government participate in making it possible. As one individual, I certainly do not presume to have all of the answers, but I will do my best to highlight some of the major concerns which policy makers, and perhaps ultimately the Congress, will need to address.

The first principle flows from the word "personal." If a program of personal assistance is desirable, it will only be so to the extent that each person served is treated as an individual. It follows from this that individuals with different disabilities must receive services that are appropriate to the limitations imposed by the particular disability in question. I am aware that some people oppose categorical approaches or programs because they think of disability as a generic condition. My experience in California, where we have a large general rehabilitation bureaucracy, is that generic programs tend to misclassify people with very particular disabilities. Of course, I am most familiar with services to the blind and with the poor results obtained for blind persons served by our general agency.

The single specious advantage about generic disability programs is that they seem to

---

16 Sharon Gold is President of the National Federation of the Blind of California, which is affiliated with the National Federation of the Blind. Blind from birth, she is a retired elementary school teacher of sighted children. She currently serves the blind as a consultant & advocate.
fit neatly on an organizational chart. It is claimed that generic programs may save money, but I do not believe that they actually do. I think that they waste money. Day after day I encounter blind people who are unable to secure responsive services from our state. Many of the problems these people face would be eliminated if the agency and its counselors were more specialized. For example, when counselors do not understand blindness, there is a great deal of lost motion and extra expense just to get a client's needs evaluated. This happens more often than you might think.

I am not saying that categorical programs are perfect, but client services from specialized programs have been found to be notably superior to those from general agencies. In the case of personal assistance services, I can see many disadvantages to service delivery through generic programs. The experience of California's blind students trying to obtain satisfactory reader service through disabled students offices would be enough to make my point. Such programs are rarely managed by blind people since they serve a much larger population. The reader services available from these offices are, in most instances, operated somewhere on a scale between wretched and punitive.

The rules governing service delivery are usually aimed at a much larger audience, with most of its members having substantially different needs. The persons who make the rules are usually sighted, even if they are disabled. They have no idea what elements should be present in a quality reader service arrangement for the blind. Corrections in the way the program should be run cannot really be made by advisory committees. I have served on my share of such committees, and, generally, they have very little effect. I am convinced that the best way to have a reader service program of high quality is to have a program which is specialized in providing reader service and to have blind people be in charge of the program.

My second principle is that a personal assistance program must not do for blind people what blind people can do for themselves. While blindness is appropriately classified as a severe disability, the significance of blindness can (with proper training and opportunity) be reduced to the level of a physical nuisance. One concern that I would have with a personal assistance program is that it might do too much. It may be a temptation for program officials to try to custodialize blind people into useless inactivity. In some colleges and universities some blind people are actually provided with notetakers. I have observed
this as one of the unfortunate results of the generic disability offices on campuses throughout our state.

It may be true that some people with disabilities have conditions which prevent them from taking notes effectively. Persons who know very little about blindness may think that it is such a condition. I can tell you categorically that it is not. In fact providing a notetaker for a blind person can do a great disservice. There are too many blind people who have received assistance in getting things done when they should have received training in doing things for themselves. Matriculation at college is intended to teach students how to manage their time and resources in such a way that the tasks of learning get done. One of those tasks is how to take and use notes. I imagine that there would be general agreement on this principle. I think it is particularly critical for blind people. Many of us have been robbed of our ability to function because a family member or other person assuming a caretaker role thought that he or she could do things better than we who are blind. The program to provide personal services should encourage blind people to work rather than encouraging laziness.

Our freedom depends upon doing things for ourselves. In the case of the notetaker example, there is absolutely no justification on the grounds of blindness for a blind person to have someone else take and keep his or her notes. I am not saying that every blind person has learned effective notetaking skills, but I am saying that notetaking services will discourage the learning of these skills.

My third principle is a corollary to the second. If a program of personal assistance is established, the scope of services for blind people should be limited to tasks for which few, if any, alternative techniques are fully satisfactory. Reader service is the only such form of assistance that comes to mind. It is my experience, based on my own life and my observation of thousands of other blind people, that we have managed to find suitable alternative methods for doing almost everything that we need and want to do. However, most information still comes in the form of print, which blind people obviously cannot read directly for themselves. Technology can help to some extent, but it is not a total solution.

In my experience, there is really no adequate substitute for personalized, high-quality reader service that is available more or less on demand. It seems obvious to me that blind
people, for the most part, do not have such a service available to them anywhere in the world today. However, many of us are able to come rather close to this ideal standard. Blind people are not without ingenuity. We all tend to develop our own systems for getting the things done that we need to do. Some people use volunteer readers extensively and quite successfully. Other people use paid readers or a combination. Spouses, other family members, and friends are used extensively to help with reading.

Apart from these personally developed arrangements, reader service programs designed to serve groups of blind people are largely limited to students at the post-secondary level. As I have already explained, employed blind adults are very much on their own in individually solving their needs for reader service. Employers may provide some help as a form of reasonable accommodation, but that only covers the work-related needs. Beyond this, we usually fill in the gaps with friends, family members, volunteers, or paid readers. I think this describes the general pattern.

This patchwork approach works well for many blind people much of the time. However, there are times when reader arrangements completely fall apart. Then, on rare occasions, demotions, or even job loss can result. In theory, rehabilitation can step in to provide post-employment services, but obtaining this assistance is not as easy as the law implies. A new program of personal assistance could be helpful in this type of situation. Alternatively, the vocational rehabilitation program could be required to provide reader service without delay whenever justified on grounds of immediate employment-related need.

Individual responsibility is my fourth principle. If a program of personal assistance services is developed in this country, we will do a great disservice to blind people if we remove responsibilities from the individual person who needs assistance and place the burden on society as a whole. I am not saying that there is no social responsibility to make personal assistance services available. I am saying that, to the extent that this is done, the responsibility of each blind person to arrange his or her particular blindness-related services must be preserved and respected.

One advantage of the present system is that if I fail to make arrangements for having the readers I need, when I need them, I will not have them. I will suffer the consequences. Although this is unfortunate, it is much more desirable than it would be the other way
around. If my reader service responsibilities are determined by somebody else, many of the other opportunities available to me are determined by somebody else. There is a practical reason for this attitude. I have found that a program can never meet my needs as well as I can meet them for myself—provided, that is, that I have the resources to do so. A program of personal assistance should provide the resources necessary to obtain the assistance. It should not diminish individual responsibility for determining the nature and kind of assistance required.

To use a frequent example, I will return to the situation in higher education. When a blind student does poorly in a course, it is sometimes said that the disabled students office failed to get the textbooks on time. I would call that line of thinking a "dependent mentality." The responsibility for knowing the material, attending classes, reading the textbooks, and taking the tests belongs to the student, whether the student is blind or sighted. Some of today's blind students, however, tend to think that they can forget about certain responsibilities such as getting taped or Brailled books because an entire office has been set up to take care of these matters.

This dependent mentality should concern all of us. It is not a healthy trend. The philosophy of the Americans with Disabilities Act espouses freedom and independence. I would not want to see a new program enacted that diminishes our ability to secure freedom and independence. There are many programs created by well-intentioned people that have gradually grown so big that they intrude on individual freedom. A personal assistance program must not do this—it must enhance freedom.

My fifth principle is that individuals should manage their own personal assistance services. Programmed services, offered on a "take it or leave it" basis, must be avoided. Again, let me return to the example of higher education. When I was an undergraduate student, the management of the reader service that I received was completely within my control. The Department of Rehabilitation and I agreed on the amount of money I would need each semester, and I was then authorized to have my readers submit bills for direct payment. I hired each reader and determined the rate of compensation. I determined the reading schedule and the specific items to be read. I dismissed unsatisfactory readers and replaced them with others. I approved payment vouchers and kept track of the money remaining for use. I was fully accountable.
Some would say that the students of today have it easier. There are programs that find, supervise, and pay their readers. All they really have to do is show up at the appropriate time for the reading sessions. Personal reader service tends to be viewed as a function of the institution. As an institutional program, it is operated for the convenience of the university not for the benefit of the student. Both the quantity and type of material to be read are determined by the program—not by the student. The selection and supervision of readers are done by the program.

By contrast, the reader service that I received was far less programmed and far more responsive to my needs. I managed that reader service entirely. I had only myself to blame when things did not go right. The assistance I received from the State of California was definitely a resource and not a form of control. I fear that blind students of today are far more controlled and regulated than they were in the past.

One fear that I have is that a new program of personal assistance services would be administered in such a way as to gain control over individual blind persons. Those who dispense services have the power to grant or withhold those services. I think that blind persons are already subjected to far too many controls because of their need for services.

Therefore, if a program of personal assistance services is established, it should be designed to compensate the individual for personally chosen and personally managed forms of assistance without control. While I am not opposed to a certain amount of regulation in appropriate circumstances, the personal use of a reader for a blind individual must be managed by the blind individual. Look at it this way: a blind person's reader actually functions as an auxiliary pair of eyes. Directing their use must be for the blind person's benefit and for no one else's.

My sixth principle is that persons who are eligible for personal assistance services should be able to receive those services without regard to economic need or ability to pay. In the case of blind people, eligibility should depend upon a statement of needs relating to the blind person's inability to obtain suitable and timely access to printed information. The eligibility criteria should focus on need for reader service—not on financial need.

I think we make a great mistake when service programs for persons with disabilities
screen out individuals who seem to have enough money to pay for assistance that is otherwise provided at taxpayer expense to persons who are less well off. For one thing, the administration of financial need standards is often filled with abuse. I know of situations where Social Security beneficiaries are being required to pay for the costs of their vocational rehabilitation. That is a disincentive, and it is wrong.

In my opinion, the very nature of the means test leads to this kind of abuse. Therefore, the provision of services under this program, if it is created, should be based on service needs—not on financial needs. It is a cruel joke when, for example, a person is found otherwise eligible for vocational rehabilitation, but is told that the services for which he or she is eligible will be provided only when the individual, not the agency, pays the bill. I should hasten to add that the means test is not a federal requirement in vocational rehabilitation, but it is discretionary with the states. I think it is time for policy makers to rethink this entire issue and to eliminate the means test altogether.

The means test also creates a two-class system. Those in one economic category receive one kind of service, and those in the other category receive a different service. Separate but equal is unworkable in services as much as it is in race relations. Therefore, there should be no means test.

This is my list of six principles. It may not be exhaustive, but certainly the major concerns are addressed. There is undoubtedly a need for personal assistance services. The need is probably more profound for persons with some types of disabilities than for persons with other conditions.

For example, a person who must have some form of attendant care during the day is certainly in a different situation from that of a blind person needing to get something read. I think that each type of situation must be looked at separately. Programs to provide reader service to blind persons are inadequate, and blind people often get left out. This is a disadvantage, but a program that ignores the principles outlined here would become a greater disadvantage.

I cannot speak to the situation of persons with disabilities other than blindness. Each type of situation and need for personal assistance should stand or fall on its own merits.
The practice of the National Federation of the Blind is to adopt positions on matters such as programs of personal assistance only after broad discussion and debate. At this point, we have not taken a formal position on the desirability of having a personal assistance services program. However, the principles that I have mentioned will undoubtedly weigh heavily in our evaluation of various proposals. They will be considered in the position that we take.

Madame Chairman, I thank you for the opportunity to take part in these proceedings. I appreciate the fact that this Council's recommendations are an important first step which could lead to an expanded effort to provide personal assistance services on a national basis. Therefore, I have tried to offer comments which could be helpful to you in accomplishing this task. Again, I thank you.
Personal assistance services for people who are deaf, hard of hearing, or have other hearing impairments, is different from PAS for people with other disabilities. For people who are deaf/hard of hearing, PAS is related to communication. However, such communication may also involve technology. Today, the choices of communication services and/or technology are numerous and accommodate the needs of a widely diverse group of deaf and hard of hearing individuals. For some, these services and technologies allow complete independence, and for others, independence to a degree. Technological advances and applications will continue to expand. Being a deaf person, Ed utilizes quite a variety of services and technologies as does Kate, who is hard of hearing. We will briefly try to give you an idea of the more common ones available today. They include:

1. INTERPRETER SERVICES: Sign language interpreters, who possess certification by either the Registry of Interpreters for the Deaf (RID) or the California Association of the Deaf (CAD), are highly skilled professionals who provide communication services for both deaf and hearing individuals who are trying to communicate with each other. Interpreter skills vary depending on their level of certification, but the best of them can interpret and transliterate at the highest levels of American Sign Language and English. They maintain a professional impartiality during the interpreting/transliterating process which allows the individuals communicating with one another to have complete control of the process. Additionally their skills allow them to convey the mood and intent of the message between the parties.

---

17Ed Rogers is the Program Manager for Services to Deaf & Hard of Hearing Consumers in the California Department of Rehabilitation. He has 16 years of experience in this field and was also an Interpreter Trainer at Mt. San Antonio Community College. Mr. Rogers is deaf and utilizes many of the personal assistance services mentioned. He has a special interest in technology and its applications to physical, sensory and communication disabilities.

18Katherine D. Seelman is the Research Specialist at the National Council on Disability. She has chaired and served on committees for the U.S. Congress Office of Technology Assessment and other government and private agencies. Dr. Seelman is widely published in communications accessibility and has conducted consumer trials and policy research on assistive listening devices, telephones and other products and programs important to people with sensory and physical functional limitations. She is a recipient of a number of awards including a Distinguished Switzer Fellowship in Disability Policy. Dr. Seelman earned her doctorate in Science, Technology and public policy at New York University. She is hard of hearing.
Another type of interpreter is an ORAL INTERPRETER. These interpreters are trained differently but are no less professional and perform the same function by verbally repeating without voice what is said by another person while using a normal rate of speed and natural, clear, lip movements. In addition, there are TACTILE INTERPRETERS, for people who are deaf and blind.

2. CART: Increasingly, late deafened adults are requesting Computer-Assisted Real Time (CART) services for meetings. CART involves the use of a stenotypist or a typist who types on a keyboard as people speak so what they say appears on a screen (CRT, VDT, projection, etc.) and people can read it. Some small businesses provide both interpreter services and CART.

3. TEXT TELEPHONES (TT): Also known as TDDs, TTYs, or TTs, these are probably one of the most ubiquitous communication tools among people who are deaf. A Text Telephone is like a visual typewriter which connects to the telephone by a direct connect jack or an acoustic modem. The conversation between the individuals (both must have TTs) appears on a moving LED screen above the keyboard. TTs come in a variety of sizes from small portable models to larger units, and have a variety of "bells and whistles" to pick from, such as ASCII compatibility (allows communication with a personal computer), paper copy, auto answer, memory, programmed messages, etc. Text Telephone Accessible Message Pagers have been developed as well. One has the option of purchasing their own TT or obtaining a free loaner through the various TTP distribution programs offered by Pacific Bell, General Telephone, and other telephone companies in California and other states.

4. DUAL PARTY RELAY SERVICES: Dual Party Relay Services (DPRS) enable Text Telephone users (including people with other communication disabilities) to communicate by telephone with non-Text Telephone users who communicate by voice, and vice versa. DPRS has taken off in California (as well as other states) resulting in incredible call volumes on the order of 300,000+ per month 24 hours per day. The system is constantly being evaluated and improved upon and now offers voice carryover (VCO) services as well. VCO allows people who are deaf with understandable speech to talk directly to the person they are calling and receive their response on the Text Telephone via the relay operator. Overall, DPRS is
exceptionally effective and allows deaf and hard of hearing pizza lovers to rest easy knowing Domino's is but a phone call away.

5. TELECAPTIONING: Telecaptioning, or closed captioning, is a process by which the audio portion of a television program is translated into captions which appear on the screen. A Decoder is required for this process. Captioning of programs is primarily done by the National Captioning Institute (NCI) and WGBH Caption Center, and you can identify captioned programs by checking your area TV program listings for shows marked "CC". Home videos are also captioned and are identified by the same "CC" mark or the NCI's registered service mark, "the box with the tail". Closed captioning opens up an incredible world to the deaf and hard of hearing consumer allowing access to a good majority of captioned videos and television programs, including public service announcements and commercials. The Decoder Circuitry Act will require all televisions with screens larger than 13 inches to have built-in decoder circuitry by 1993.

6. AMPLIFICATION DEVICES AND SYSTEMS: Hearing aids are miniature amplification systems. They come in a number of types such as: In-the-ear; Behind-the-ear; Eyeglass frame; Body type; etc. Digital programmable hearing aids have also been developed. A hearing aid does not correct poor hearing. It augments sound by making it louder in particular frequencies for the user. Thus people who understand these limitations, have been properly fitted for an aid, and who expend the necessary effort toward improving their "hearing" skills benefit greatly from hearing aids. A second group of assistive listening devices are designed for people who are hard of hearing for watching television and communicating in small group environments. There are also assistive listening systems which are installed in large public assembly areas. The types of assistive devices systems are infrared, FM, and induction loop systems. A third group is telephone amplification systems. People who are hard of hearing often require amplification to use the telephone system.

7. HEARING DOGS: Hearing dogs assist deaf and hard of hearing individuals in coping with some of the more practical difficulties of hearing impairment. They help sustain the skills necessary for independent living and enhance the emotional lives of their owners in many ways. These professionally trained dogs alert their owner
(by jumping, nudging or pawing) to a variety of household sounds such as a doorbell, a knock, alarm clock, telephone ring, smoke alarm, etc. They can also be trained to alert their owner to sounds outside of the household.

8. VISUAL ALERTING DEVICES: A number of visual devices allow people who are deaf to be alerted by fire alarms, door bells, ringing telephones, crying babies, etc.

For people who are deaf or hard of hearing, services and technologies are invaluable in assisting with communication. Technology is increasing the options, but some people will continue to need or prefer the assistance of an interpreter. Nevertheless, the options are many and technologies will likely be more fully explored and exploited.
My name is Gary Harmon. On July 14 of 1985 I was diagnosed with full-blown AIDS. My life has been a zigzag [existence] since, [as has been] the type of assistance that I've needed throughout those seven years. However, in the last three years I think it's kind of balanced off, and the types of assistance services and case management and especially in the nursing case management that I received [someone asks him to speak louder] --is that better? It's one of the problems that I have is expressing myself loud enough for people to hear me. I have a couple of friends who [...] the louder I get the more they hurt, so if I should taper off again, just tell me to speak up again.

Right now I have four forms of personal assistance service offered to me as a person with AIDS: In-Home Supportive Services, case management through public health, practical and emotional volunteer support. The IHSS assistant is basically a chore worker. The hours allocated to people with AIDS--it's a joke: I get 50.8 hours per month, and that's supposed to keep me and my home clean for the entire month; it doesn't work.

Through the social and nursing case management places that I go to I have a public health nurse that comes out to assess my needs. A part of that assessment is supposed to be to keep my hours of in-home supportive services to vacillate to meet my needs. It never works. Usually at the time that I'm going for re-evaluation, my disease will either have taken a further decline or an incline, and if it's an incline, then the hours stay the same. However, the case management component provides for me, through practical and emotional support volunteers that have been trained for a minimum of three months, different options in attendant and assistance care.

---

19 Gary Harmon is a 37-yr old African-American male and native of Oakland, diagnosed with AIDS July 1984. Finding himself homeless as a result of his diagnosis, he joined the ARC-AIDS Vigil campsite and became its commander and treasurer. While living at the campsite, he did outreach and education with a number of organizations serving people with AIDS in S.F.

Mr. Harmon obtained personal assistance services only after he moved into his own apartment, in 1988. He uses PAS, as well as an electric wheelchair, to help him remain active on many fronts: as Treasurer and Administrative Chair of the Alameda County AIDS Advisory board; as Secretary of the Board of Directors of the African-American AIDS Coalition, and as member of the National Association of Persons with AIDS. He is also involved with the Youth Environment Study (an organization for the prevention of AIDS and a model for the national condom and bleach distribution program) and is a member of the Alameda County Ryan White Consortium for the distribution of funds to agencies serving people with AIDS.
The practical support person picks up where the in-home supportive services person leaves off. And even with the practical and attendant care service I'm still finding myself with a lot of gaps in creating a conducive home environment for myself and facilitating my own personal needs. The emotional support volunteer—it's the person who comes by to make sure that all of my emotional and social needs are met and that I also have family support.

There's no coordinated effort on the parts of any of these people in their provision of services to me—I have to pretty much take charge of what's coming from what person, and what agency is paying for this, and how do I get that. It's very hard because two of the people are volunteers who are full-time employees and I can't demand any time from them, I can only get what they volunteer to me. It doesn't satisfy my needs. There's an awful lot of times that the isolation that comes into my life is filled by my attendant who will come by to do the laundry, to keep the place clean, and find my physical shape to the point where she just sits there and basically holds my hand and listens to me. The work doesn't get done, but she's paid for the hours. I have to come out of my own pocket each month to help pay for the actual amount of hours that my attendant provides me, because $4.35 an hour and 50.8 hours a month is just not enough.

It's made it very hard for me to have a good strong foundation of an incentive to continue on as a person with AIDS, but I am a survivor, I'm a battleground within myself. So I stay within the battle and try to access services for myself and for others—it's been very difficult.

I'm sure that the personal assistance services that the majority of the people in this room receive are quite different from what I'm receiving. I have some friends who are mobility-impaired people who have attendant care who look at me, and even though they get a little more attendant care, they're a little jealous, and it's like pitting disabilities against disabilities, because "you can get this, I can't get that", and I look at them and I say "well, you've got this kind of service, and I can't get that". I think there needs to be a universal type of system for attendant services for everyone, you know, that doesn't pit us against disabled persons, because that kind of jealousy, I find, at least in my life, adds to my own ill feelings. I have a tendency to hibernate, and lock up my apartment, turn off my phones and answering machine, and just turn away everyone in my life, because I don't feel
like I'm getting what I deserve, you know. Most of us either paid taxes or are paying our
taxes and I don't feel like I'm getting my fair share. This is echoed by many people with
AIDS, who, as a result of attendant services, practical volunteers, emotional volunteers, and
just their families--they isolate and they have a tendency to just ebb away, because there's
no real quality of life.

That's pretty much what it boils down to for me--my quality of life. Every day I'm
told I have a new disabling problem, and the system seems to make me feel I'm expendable;
I'm terminally ill and they don't have to invest as much money in services for me because,
somehow, they can go to bed at night and sleep. It's very difficult for me to watch other
people with AIDS such as myself not receive half of the services I'm receiving, and yet are
much more in need of those services, and these people generally give up--the quality is gone,
and then shortly after the quality the life is as well.
PAS for People With Psychiatric Disabilities
Lorelee Stewart

Personal Assistance Services should be available for every disabled person who needs them, regardless of their disability. This simple statement is understood and accepted by few disability advocates and even fewer members of the general public. This paper is an attempt to provide disability advocates and others with information which will be useful in understanding the need for and use of personal assistance by people with psychiatric disabilities.

As a person with a psychiatric disability who relies on PAS to live and work in the community, and as an active member of the disability rights movement, I understand the importance of personal assistance. In my paper I will outline the current system of services available to people with psychiatric disabilities, and how Personal Assistance Services could be utilized. Specifically, I will discuss possible ways a person with a psychiatric disability can use a personal assistant to function more independently. Also, I will discuss current barriers and solutions to receiving and utilizing Personal Assistance Services. Finally, I will provide personal examples with the hope that my experiences will serve to educate members of the disability community and the general public.

Overview of the Mental Health System

In the United States, the Mental Health System operates on a medical model. It strives to identify and eliminate an individual's "illness". The illness, rather than society, is determined to be the problem. The mentally "ill" person is "treated" by professionals who make their careers out of "diagnosing" and "curing mentally sick" people.

This model doesn't work. It is offensive, and is increasingly unacceptable to many persons with psychiatric disabilities. Such a medical model is inappropriate because the majority of psychiatric disabilities have no substantiated biological component. Thus, attempts by the mental health system to assist people in dealing with what are psychosocial

---

20 Lorelee Stewart is the Executive Director of the Independent Living Center of the North Shore in Lynn, Massachusetts; External Vice President of the National Council on Independent Living; and a member of the National Association of Psychiatric Survivors. She had Post-Traumatic Stress Disorder and uses Personal Assistance Services to live and work in the community.
problems are inadequate at best. Psychiatric survivors (survivors of the mental health system) across the country are fighting to change this archaic, haphazard, and often barbaric approach to their problems.

While there is growing recognition of the ability of people with psychiatric disabilities to live independently in the community, the system of services remains largely unchanged. The majority of service dollars are funneled into large state and private institutions where people receive little of what can be described as care or compassion. Remaining service dollars are utilized to fund a network of community based group homes and other professionalized residential and day treatment programs which simply mimics much of what is provided in institutions. The clients are forced to follow the service dollar when the dollar should follow the client. In Massachusetts, for example, less than $400,000 of a $438.6 million budget is spent on truly consumer-controlled programs and services. As a result there is little or no opportunity for consumer control over who, when, where, and how services are provided.

Independent Living and the Use of Personal Assistance Services

Individuals with psychiatric disabilities, like other people with disabilities, may experience difficulty in living in the community. However, "difficulty" is not an acceptable reason to keep people institutionalized when it could easily be eliminated with sufficient Personal Assistance Services. The availability of PAS would allow persons with psychiatric disabilities, including many of those with severe disabilities, to live independently. In much the same way that people with physical disabilities can accomplish daily tasks with assistance, people with psychiatric disabilities can also benefit.

Some of the ways in which people with psychiatric disabilities can utilize and benefit from Personal Assistance Services are:

Physical tasks--Persons with psychiatric disabilities may need assistance with a wide range of physical tasks, such as bathing, dressing, driving, cleaning, cooking, shopping, etc. This type of assistance may be necessary as things like depression, use of certain medications, and/or sleep disorders can reduce an individual's strength, energy, and endurance. In
addition, some people may not be able to do some physical tasks because they trigger an emotional response, such as panic.

Cognitive tasks--Assistance may be needed with cognitive tasks such as paying bills, making a shopping list, and learning travel routes on public transportation. Both the disability and use of certain medication or "treatments" may affect the individual's ability to process information effectively. For example, those who have been "treated" with Electro Shock Therapy (ECT) often experience memory loss and confusion.

Emotional tasks--Assistance may be needed with emotional tasks such as being alone, going outside, being in a large group of people, etc. For some people, assistance in managing emotions may be necessary. Such emotional support or assistance must be under the training and supervision of the Personal Assistance Services consumer. People with psychiatric disabilities should not be "assigned" a "caretaker" by professionals or family members. Personal assistance must not be used to perpetuate the control and paternalism of the mental health system on an individual basis.

Personal Experience

The following is an example from my own experience to illustrate these problems and possible uses of personal assistance. The other day, I had to ask one of my employees to come to my house to help me through a depression. She had to assist me with my morning routine, and drive me to work. The night before I had a very bad panic attack, triggered by intense flashbacks of sexual abuse I had experienced when I was four years old. I took my tranquilizing medication that evening, as I do every evening for my sleep disorder, and finally went to sleep, but when I awoke, I was devastated by depression and the lingering effects of the medication. I felt very physically weak, and had little emotional desire to shower and dress myself, which has become almost a daily experience. The only choices that awaited me that morning were to be taken to an inpatient psychiatric ward, lie in bed and pray that the depression would pass, or ask someone for assistance and try to go to work.

For me, working is therapeutic. It provides me with structure and helps me to put my problems aside, which is necessary to fight my intense depressive episodes. Almost
always, a severe depression will pass in several hours if I am able to get the assistance I need and get to work. Had I been taken to a psychiatric hospital I would have spent a minimum of two weeks (or until my insurance ran out) trying to prove to them that I was safe from harm and that I could be released. If I had stayed home and struggled on my own, the depression could have gotten worse and jeopardized my safety.

At present, I do not receive any funding for PAS under Massachusetts programs. I do receive some assistance from my employers for work-related activities, such as overnight travel. I have applied for PAS through a local Independent Living Center which acts as a vendor for these services for Medicaid. I expect to be denied these services because the eligibility criteria categorically exclude people who have psychiatric disabilities. If denied these services, I will appeal the decision to the highest level with the hope of changing the existing system.

Conclusion

It is inappropriate and demeaning for people with psychiatric disabilities to have to rely on an employee or even family or friends to assist them with daily activities. People with psychiatric disabilities deserve the privacy, dignity, and independence that comes from the use of a personal assistant. It is also important to note that it is absolutely unnecessary for this assistance to be provided by a professional just as it is unnecessary to have a nurse provide catheterizations.

People with psychiatric disabilities must be able to access PAS in order to truly live independent, dignified lives in the community. If given the choice, few psychiatric survivors would rely on the services provided by the Mental Health System. In fact, many persons end up in the mental health system precisely because of the lack of personal assistance and other community-based support services. Usually after a few weeks they are released back to the same inadequate situation. This is not unlike a quadriplegic who ends up in the hospital with a pressure sore from sitting too long in his wheelchair because he has no one to assist him in lying down. He enters the hospital, the sore is healed, and then he is sent back to the same situation of inadequate personal assistance to repeat the cycle.

A national Personal Assistance Services program MUST include principles from the
Independent Living Movement, such as consumer control and cross-disability service. All individuals who need assistance with activities of daily living, whether it be physical, cognitive, or emotional, must be afforded the opportunity to access Personal Assistance Services. This is consistent with eliminating costly and demeaning institutionalization of all persons with disabilities, and eliminating their needless dependence on medical and mental health professionals.

A national Personal Assistance Services program supports the opportunity for all people with disabilities to live, work, go to school, and be with friends and family in their own communities. Establishing a cross-disability PAS program is a necessary step in the effort to secure freedom, independence, and equal opportunities for all Americans with disabilities.
What does personal assistance mean to me? Perhaps the question should be what would it mean to me, because at this time people like me are not eligible for these services. I sustained a Traumatic Brain Injury (TBI) which has not limited me physically. Personal Assistance Services has mostly been available to people with physical disabilities. This needs to change to encompass a broader group of people with disabilities, which will only be done through education. This paper is intended to educate people as to how PAS could apply to me personally, someone who has sustained a traumatic brain injury. As President of the Survivor Council of the National Head Injury Foundation, I will bring out accessibility issues heard throughout the country, representing a large constituency of people with traumatic brain injuries.

I am in a position to address concerns of this population from the national as well as personal perspective. One of the most important qualities of a person is one's personality. A personality consists of a person's emotions. After sustaining my head injury, my emotions were out of control and very exaggerated. This gave my personality the appearance of changing even though I was the same person inside. Because of the exaggeration of emotions, when I was angry, I was really angry. Added to the exaggeration of emotions was the loss of control of my emotions which resulted in situations such as blowing up suddenly and five seconds later feeling sorry. Because of outbursts like this your personality appears to be different. It's not the personality. It's that people react to you differently than before because you are displaying emotions differently. People react to your over-reactions. This area would be the most difficult to train a personal assistant in but is an essential part. A training program must include teaching assistants how to maintain boundaries when dealing with the emotional aspects of a person's situation. For two years after my injury, my family acted as my assistant in the area of emotions. When going to

---

21 After sustaining a closed head injury eight years ago, Sherry Watson formed a local support group in Farmington, NM, and was instrumental in establishing a three-million-dollar rehabilitation center in the community. For this achievement she was honored as the Jaycees' "Outstanding Young Woman of the Year", an award presented by the Governor of New Mexico. Ms. Watson is co-founder of the New Mexico Head Injury Foundation, past President of the Survivors' Council of New Mexico, and President of the Survivors' Council of the National Head Injury Foundation. Most recently, she was awarded the position of Executive Director at the Disability Resource Center in Las Cruces, NM. She is very involved in the independent living movement speaking at regional and national conferences on accessing services for people with head injuries. Ms. Watson credits her husband with providing the support that has made her accomplishments possible; the greatest of these she considers to be her four children.
appointments, meetings, etc., they were there to help me assess the situation afterwards and role-play with me as to the emotions I displayed so I could see where I over-reacted or showed an inappropriate emotion for that situation.

An issue that must be discussed in the field of Personal Assistance Services and Traumatic Brain Injury is the newest trend of Case Management. The field of TBI is based on a medical mode while the scope of PAS is community-based. Case Management is usually provided by an RN who is the "middle man" working through an agency, so it is quite costly. As I look at the role of a Case Manager, I wonder why this cannot be seen as the role of an assistant at a much more cost-effective rate. One of the major areas of disability for a person with TBI is loss of memory. This loss of memory may also be a result of too many stimuli coming in at one time causing your entire system to shut down. For example, if I am writing a report, the phone rings and then someone comes in to ask a question, I forget what the report was about, which appears to make me unable to stay on task. As we look at this, it's not really a memory loss that made me forget what the report was about. It's too much stimuli at once and the brain has to shut down to gather thoughts again. Also it's not that I can't stay on task but that I need time to be reminded what I was doing. I need cues and then I can start again. I have had and still have a lot of assistance in cueing. In the beginning, I would be doing something, the phone would ring. I would get off the phone and my assistant would remind me what I was doing before the phone call. In my current working position, the Administrative Assistant cues me daily. For example, I am working on a grant on the computer, a staff person comes in and asks me a question and as I walk to the front office with my file folder in hand, I lay it down on the desk. Because of all the distractions, I sit down again to work on the grant and have forgotten where the folder is. The Administrative Assistant reminds me that the file folder for the grant is at the front desk which reminds me what I was working on before and I can continue where I left off.

Another responsibility of a Case Manager in the area of memory loss is to check in with the consumer daily according to the individual's needs to assist them in structuring their day. An assistant could assist in the same way. My insurance hired a homemaker the first year after my injury who served as an assistant at a more cost-effective rate than a case manager. She came to my house daily and helped structure my day. Without such assistance, many people are turned down by all agencies that offer assistance because the
person forgets to show up for scheduled appointments time after time and the case is closed. An important aspect of the daily structuring is teaching medication routines. Because many people with TBI have seizures, daily anti-seizure medication is required. An assistant needs to remind the individual regularly to take the medication.

Although physically a person with TBI may appear able-bodied, there are significant differences between them and their able-bodied friends. Because of the extended period of inactivity in the hospital, in addition to the motor impairments, some people with TBI require extensive fitness programs and assistance in these areas. An assistant may either provide the transportation for the individual to attend fitness programs or work with the individual at home with a fitness program. Driving is not allowed in many instances because of seizure activity, so an assistant will be needed in the area of transportation. Because people with TBI continue to show progress years later, it is difficult to let go of the person you were before. Many people have physical disabilities now, but continue to strive toward being who they were before. I played the piano and the saxophone before my injury but because of paralysis on my right side, I can no longer play the piano. Because I received occupational therapy for over a year and saw a gradual increase in the motor skills in my right hand, it was difficult to give up the dream of playing the piano again. My insurance would not last forever, so my homemaker/assistant helped me join a health spa to continue strengthening my right side. My assistant then had to drive me three times a week to this fitness program. The fitness area is also very important, as it increases your stamina enabling you to endure a full work day.

When returning to the work force, it is critical for a person with TBI to have an assistant to help with organizational tasks. By this I mean needing someone to sequence tasks or write an organized paragraph. An example of this would be that I am a good writer but I need someone to go through and organize the letter after it is written. My thoughts do not always flow in an organized manner. The thoughts are all there, it is just a matter of arranging them in an organized fashion.

An argument that I have heard as to why Personal Assistance Services would never work for people with TBI is the difficulty people with TBI have in decision-making. This is where the argument comes in that assistants are to be managed by the consumers and not manage the consumers. Having an assistant make decisions for the consumer would appear
like the assistant was managing the consumer's life. Let's look at that from another perspective. On a personal level, decision-making is an area that I need assistance with. It is not that I cannot make decisions—it is that I need someone to talk things through with me, to show me the options. Once that has been done, I can make the decision for myself. Even if the decision is as simple as deciding where to eat or what to present at an upcoming conference, a decision-making process needs to be implemented. Each individual has different accessibility needs in the decision-making process.

In summary, Personal Assistance Services is a needed option for people with Traumatic Brain Injuries. Areas that an assistant could be trained in would be:

- Emotions
- Memory
- Daily Structure
- Fitness/Physical needs
- Transportation
- Organization
- Decision-making

These are just some areas that an assistant could assist with. Because of the complexity of the brain and no two individuals being alike, the needs of each person are different. Personal Assistance Services is an option that gives people a right to live independently and to be in charge of their own lives. People with TBI deserve and demand options to achieve this lifestyle.
Living Without a Live-In: PAS in my Life as a Respirator User
Alana R. Theriault

Here I am. I use either a ventilator or a respirator 24-hours a day. I have very limited use of my hands and arms, need assistance with virtually all aspects of my personal care, and live an active, independent life, working and going to school without a live-in assistant. How do I do it? Aren't I afraid of something happening? Why don't I have a live-in?

Various people have expressed concerns about me sleeping at home without someone there to help if the power goes out or my respirator breaks down. Most people I know who are ventilator dependent are either institutionalized or have a live-in assistant or nurse. There are many reasons why I have chosen not to live with anyone other than housemates. The decision was easy to make; but explaining it is not so easy. It is more important to me to have the people who do my PAS not live with me, than it is to have somebody right there "just in case". To those who think that safety should always be the top priority, my choice may seem foolish. To me, my choice reflects many experiences which have taught me that having someone there does not necessarily guarantee that I am safe. This choice is also born out of deeply valuing my privacy and independence. Living alone safely involves a support system that respects my desire to do so, careful planning, and an acknowledgment of my own limitations.

Each morning I wake to my clock radio, which grants me a few moments before I must don the cap of employer. I try not to snap at the woman who taps on my door, walks in and asks me "How's it going?" I want to say, "What do you think? My eyes are not open, I actually have to pay you to jar me from sleep each day, and the whole ordeal is going to take at least two hours of my time." Instead, I grunt and rub my eyes. She opens the curtains and unplugs my wheelchair [from the battery charger.] Then, she moves the telephone and other bedside sundries, asks if I'm ready, awaits a sleepy nod, and snaps the power switch off on my respirator. From this point, there is no turning

22Alana Theriault is a 26 year old student at Mills College in Oakland, CA, studying English and Sociology. She will graduate in May of '93 and plans to teach high school English while continuing to be a disability advocate/activist. She has taught Independent Living Skills at CIL-Berkeley, written and performed with Wry Crips Disabled Women's Theater Group, been a disability educator for KIDS (Keys to Introducing Disability in Society) Project, is a writer and visual artist, and is an active member of the University Students' Cooperative Association (a 1250 member housing co-op) in Berkeley. She has Spinal Muscular Atrophy, uses a ventilator and motorized wheelchair by day, a respirator at night, and has 3-6 PAS providers.
Once awake, I am usually happy to see my assistant. We talk about work, friends, sex, politics, the weather, and the meaning of life while watching the clock and moving through the daily tasks of toileting, bathing and dressing, transferring me into my chair, turning on my portable ventilator, brushing my teeth, combing my hair, sorting papers, and making breakfast and lunch. We laugh, argue, listen to loud music, offer each other unwanted advice and get me off to work or school, mostly on time. The routine is usually the same. The conversation is what gives it all flair. Our relationship is like that of housemates. If we don't get along so well, it doesn't last very long (and we only talk about work and the weather). If we do get along, the working relationship can last a couple of years, while our friendship may even last a lifetime.

I have lived with assistants in the past, but found that living, working, and sometimes eating and socializing together was just too much of the same person in too many parts of my life. I use 7 hours per day of personal assistance services, paid for by California's In-Home Supportive Services (IHSS) program. In Alameda County it pays the minimum wage of $4.25/hr. and only offers Social Security and Worker's Compensation. I prefer to select, train and supervise my own employees, and so, use Independent Providers instead of going through a Home Care Agency. There are generally four to six people working for me, plus a housekeeper who comes in once a week. I have a list of friends, neighbors, and past employees whom I may call in a crisis. In addition, the City of Berkeley has an emergency services program that provides on call back-up 24 hours a day for personal assistance services, as well as wheelchair repair, transportation and interpreter services.

From age fourteen to sixteen I lived in a nursing home. There, I had no peers and was surrounded by a staff of thirty or more health care providers who each had a different idea about what I should or could do. I had little choice about who did my personal care, and while I went to public school and had an active social life, I had to contend with many more people than just my own mother when trying to get permission to see whom I wanted to see, when and as often as I wanted to see them.

Before that, I lived with my mother, sister and brother. Like many children
growing up with a disability, I had a single parent providing all of my personal assistance. This relationship was extremely stressful. It was complicated by my parents' divorce, alcoholism, and other circumstances unrelated to my disability. As a result, I experienced neglect and physical abuse surrounding most aspects of my personal care. It was not unusual for me to have a sprained ankle or a pulled tendon from being handled roughly while my mother dressed me, and it was difficult for me to ask for a drink of water or to go to the bathroom for fear of being yelled at and told that I was "a pain". I now greatly value having control over how much time I spend with each assistant, who they are, what they do, and how they do it. Having a few assistants, instead of one live-in, also preserves some level of privacy by limiting how much is revealed to any one person about my personal life. The first time I experienced this kind of freedom was when I left the nursing home and moved into an apartment with a disabled friend in Berkeley in 1982. I started using IHSS funds and finally had control over my own personal care and lifestyle choices.

Not having a live-in assistant proves to be difficult only in times of crisis. Through trial and error I have developed a plan for each potential situation. The most urgent one is when the power goes out or my respirator breaks down. I am able to breathe fairly well for about two hours before I need to have my respirator removed. It's a brace that is strapped over my chest and acts as a portable iron lung. When it is not turned on, its weight restricts my ability to breathe on my own. I have about two hours to find someone to help me out.

I always sleep with the phone beside me, and have all of my emergency phone numbers memorized. I have two neighbors and three apartment managers who all have keys to my apartment. I also have two assistants and a couple of friends who live nearby. All of these people are willing to be called in an emergency. I pay someone ten dollars for helping me out in a crisis, and try to call a different person each time. If the power is out, I have them put me on the battery-operated ventilator which I normally use during the day. If the respirator is broken, I have a back-up. When I can't find someone to come over, I phone Last Call, the city-funded emergency service program in Berkeley. During an earthquake, when it's not unlikely for the power and phone to go out, the apartment managers and my neighbors know to check on me. With this elaborate plan in place, I sleep easy and enjoy my privacy.
Some may still argue that it would be a good idea for me to have a live-in, despite the success and comfort I experience with my present back-up system. Their concern is usually based on problems that come with being on a respirator. For me, a live-in assistant would be useful in enabling me to do things like go to the bathroom or make a cup of tea at three in the morning. I would love to have the option of getting up to write down a poem that's floating around in my head, or to watch the sun rise on a clear morning. While these things would greatly improve the quality of my life, they are not as vital as breathing, eating and being clean. I hope that the policy-makers who allocate social service funds will soon see the importance of all aspects of daily living, not just those which relate to bodily functions. I'm not just a body.
**PUBLICATION EVALUATION**

Living Independently with Personal Assistance Services

*Thank you for taking the time to critique this publication. Your comments and opinions will be instrumental in revising these documents and developing new materials.*

1. Overall, how do you rate the quality of this publication?

<table>
<thead>
<tr>
<th>EXCELLENT</th>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
<th>VERY POOR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. The information is useful and appropriate for advocates

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

3. The information is useful and appropriate for policy makers

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

4. The information is appropriate and useful to PAS users

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

5. The information is appropriate and useful to state PAS program administrators and staff

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

6. The information is timely

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

7. The language is at the appropriate level

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

8. The publication's format is clear and easy to use

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

9. The publication is available in accessible media

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

10. The publication is the right length

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

11. The publication advanced my understanding of key matters

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>
12. What section(s) of this publication should be expanded/developed?
__________________________________________________________
__________________________________________________________

13. What section(s) of this publication should be reduced/cut?
__________________________________________________________
__________________________________________________________
__________________________________________________________

14. What other materials do you think would be useful?
__________________________________________________________
__________________________________________________________
__________________________________________________________

15. I am a (circle all that apply):
   ___ Disability advocate
   ___ Policy Maker
   ___ PAS User
   ___ State PAS Program Administrator
   ___ State PAS Program Staff Member
   ___ Academic
   ___ Other
__________________________________________________________

Send this evaluation, along with any other comments/suggestions, to:

The Research and Training Center on Public Policy in Independent Living
at The World Institute on Disability
510 16th Street
Oakland, CA 94612-1502
(510) 763-4100 (voice or TDD)
(510) 763-4109 (fax)