

Consumer Training Manual for Persons with Disabilities Receiving Attendant Care Services

Developed by Community Resources for Independence
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This manual is available on-line at www.crinet.org

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INTRODUCTION

This manual has been developed to assist people with disabilities to successfully use the Pennsylvania Attendant Care Program. In developing this manual we had many discussions with consumers, and three problem areas about access and participation with the program were most often identified.

1. Confusion about how the Attendant Care program works and the requirements of the program
2. Lack of knowledge, skills, or confidence to successfully manage personal assistants
3. Mis-communication or poor communication between consumers, personal assistants, and provider agency staff

We have addressed these problems by providing a manual that attempts to present a clear understanding of both the requirements, and the consumer rights and responsibilities in the Attendant Care Program. Through this manual, consumers can gain skills or improve existing skills of communicating more effectively and managing personal care assistants.

Working through the materials in the order they are presented will make the most sense. There is space to write in the manual and we suggest you “make it your own” by highlighting, underlining and completing the written exercises that are suggested.

This manual was developed by Community Resources for Independence, a Center for Independent Living in Northwestern PA, with the assistance of a statewide advisory group of service providers, personal assistants and individuals with disabilities, and the financial support of the Pennsylvania Developmental Disabilities Council.

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WHAT IS A PERSONAL ASSISTANT?

A personal assistant (PA) is hired to come to your home to help you do the things that you are not able to do , so you can continue to live independently in your own home. The personal assistant also can assist with activities that take an exceptionally long time to complete. The personal assistant finds out from you, the consumer, what you need and how you need the personal assistant to help you. Examples of activities you may direct the personal care assistant to do may include having the personal assistant cook a meal or help you with bathing or shopping. The personal assistant performs tasks directed by you the person with a disability.

PERSONAL ASSISTANT = PERSONAL ATTENDANT = PA

Personal assistants are also called personal attendants. Many people with disabilities prefer the term “personal assistant” to “personal attendant”. For that reason we will use the term “personal assistant” throughout this manual, even though the state of Pennsylvania uses the term “personal attendant”. We will also use the abbreviation “PA”.

INDEPENDENT LIVING

Independent Living Philosophy

Personal Assistance services throughout the world developed as a result of advocacy by individuals with disabilities. The philosophy of Independent Living is an integral part of the ideas and suggestions in this manual. Understanding the history and philosophy of the Independent Living Movement will help you utilize the Attendant Care Program. Independent living means that people with disabilities have the right to:

- Make decisions about their own lives
- Fully participate in their communities
- Live with dignity
- Have the appropriate support in their own homes
- Have the appropriate support to maintain employment

Independent Living History

The following information is adapted from “Working Together, A Consumer’s Guide to Attendant Management,” Access to Independence, Madison, Wisconsin.

The independent living movement began in the early 1970's and was founded by a group of students with disabilities in Berkeley, California. At that time, many people with disabilities lived in institutional settings, because there were no support services available in the community. The thinking at the time was that people with disabilities needed professional attention and management. This idea is known as the “medical model.”

Students at Berkeley envisioned a world in which they could live like anyone else, in the community, making decisions about their own lives. They began lobbying for services and more importantly, a change in attitude about people with disabilities.

The idea that people with disabilities have the right to self-determination, as well

as all of the rights typically enjoyed by people who don't have disabilities, was revolutionary back in the 70's. The idea that an individual with a disability should have the right to take risks and to make choices - regardless of whether these may appear right or wrong to others - is an idea many people still struggle with.

Part of achieving the goals of Independent Living is ensuring that people can get the assistance and services they need without institutions. The right to choose and receive personal assistance in their own residence is one important way that independent living can become a reality for people with disabilities.

Centers for Independent Living (CILs) around the world were created to advance the rights of people with disabilities, and to assist individuals to achieve the independent lifestyles they choose. Center for Independent Living staff can help you define and achieve your independent living goals. They provide many services including skills training in areas such as communication, assertiveness and management of personal assistants. No matter where you live, there is a CIL that provides services for your area.

See Appendix C for a list of Centers for Independent Living in Pennsylvania.
See Appendix G for resources on the Independent Living Movement.

PENNSYLVANIA ATTENDANT CARE PROGRAM

Eligibility

To be eligible for the program, a consumer must:

- be at least 18 years of age but less than 60 years of age
- have a physical disability that can be expected to last for at least twelve months or may result in death
- have a need for personal care
- be mentally alert and capable of selecting , supervising, and if needed, firing an attendant
- be capable of managing his/her own legal and financial affairs

Basic Services

The Pennsylvania Department of Public Welfare defines attendant care services in this way:

Those basic and ancillary services which enable an eligible individual to live in his or her home and community rather than in an institution and to carry out functions of daily living, self-care, and mobility.

Basic Services shall include, but not be limited to:

1. Assisting a person to get in and out of a bed, wheelchair and/or motor vehicle
2. Assisting a person to perform activities of daily living including, but not limited to the following:
 - Health maintenance activities
 - Bathing and personal hygiene
 - Dressing and grooming
 - Eating, including meal preparation and cleanup

Ancillary Services are extra services that may be provided if a consumer is eligible for any of the basic services outlined above. Ancillary services include the following:

1. Homemaker-type services including, but not limited to, shopping, laundry, cleaning and seasonal chores

2. Companion-type services including, but not limited to, assistance with transportation, letter writing, reading mail and escort
3. Assistance with cognitive tasks including, but not limited to, managing finances, planning activities and making decisions, in which the consumer maintains the ability to direct and control these services

The Process

Beginning in October of 2003, the application process for Attendant Care services will change. Prior to October 1, 2003, consumers should contact a provider agency. The process for determining eligibility may take up to twelve weeks. It includes an assessment by the agency provider and another assessment, called an Options Assessment, by a staff person from the Area Agency on Aging, and a form called an MA-51 to be filled out by your physician. The process also involves determining which funding source a person will use, Act 150 (Pennsylvania State Funds) or Medicaid Waiver funds (Federal and State Funds.) For a step by step explanation of this process, see the appendix A.

After October 1, 2003, consumers will contact the Community Resource Center (CRC) that serves their area. Appendix B has a list of Community Resource Centers and the regions they serve. CRCs will provide service coordination for the Attendant Care Program and a variety of other programs that provide in-home services. Other organizations will provide the actual attendant care services.

Models of Service

You have a range of choices in your management of personal assistants from agency management to complete management by you. The choices fall into one of the three categories outlined below. Your service coordinator can discuss these options with you in detail.

Please note that you can request assistance with *any* aspect of service regardless of the model of service you have chosen. You can also switch from one option to another. Your service coordinator can give you more details.

Characteristics of both models

- Consumers **MUST** direct own care
- Consumers **MUST** verify the accuracy of time sheets that personal assistants submits

I. Consumer Model of Management

- Consumer is the “employer of record.”
- Consumer chooses to interview, hire, train, direct, and fire attendants, usually without assistance from the agency.
- The PA is an employee of the consumer.
- Consumers who receive Medicaid Waiver funding, use the provider as a Fiscal Agent to take care of the payroll and taxing functions associated with employment.
- Consumers who receive Act 150 funding can use the provider as the Fiscal Agent, or can choose to receive the funds directly and take care of all tax filings and other payroll functions. DPW must approve this choice.

II. Agency Model

- Consumer allows the agency to coordinate the attendant care services. The agency hires and schedules the PA to provide services.
- PA is an employee of the agency

Consumers can combine model I and model II. For example, the individual can have his/her own PA at certain times of the day, and an agency PA at others.

Choice in the Attendant Care Program

As a consumer, you have the right and obligation to:

- make decisions about your attendant care services
- direct the provision of your attendant care services
- control your attendant care services

You can:

- make choices about the people you hire
- make choices about the times you have them in your home
- make choices about how much assistance you want from the Provider Agency

You cannot:

- ask personal assistants to do things which are outside of the realm of the Attendant Care Program, such as work on your roof, paint a room, or cook dinner for anyone other than you
- ask for your personal assistant to be paid for hours not worked
- hire immediate family members as personal assistants
- ask your personal assistant to engage in any illegal activities

Be aware that the State of Pennsylvania has a responsibility to promote services for the health and safety of the consumer. Therefore, the Provider Agency (and the CRC, after October 1, 2003) must step in if they feel a consumer is making a choice that may not be healthy or safe. The Provider Agency (CRC, after October 1, 2003) is legally responsible for ensuring the health and safety of all consumers utilizing the program.

The Provider Agency (CRC, after October 1, 2003) will intervene if they determine that:

- you are not directing your care
- you are not following program requirements
- you are putting yourself in an unsafe situation
- you are putting your personal assistant in an unsafe situation

If the Provider Agency (CRC, after October 1, 2003) intervenes they can:

- require certain training
- make a change to the service model or service plan
- stop services

You have the right to appeal any decision that the Provider Agency (CRC, after October 1, 2003) makes.

History

Highlights:

- The Attendant Care Program began in 1984 with a three-year demonstration program.
- Pennsylvania was one of the first states to begin providing personal assistance services.
- The program was designed to give participants the right to direct their own services, which was a major innovation at the time.

Major goals of the program:

- De-institutionalization
- Preventing institutionalization
- Assisting consumers to live in the least restrictive environment possible

The original program was made possible through Act 1986-150, and so has become known as ACT 150. ACT 150 had limited funds, and at times there were waiting lists to receive Attendant Care Services. To solve that problem, in 1995, the state of Pennsylvania began the Medicaid Waiver which uses Federal funds, to provide Attendant Care Services. This has made it possible for many more individuals to receive Attendant Care Services.

FINDING A PERSONAL ASSISTANT

This information is adapted from “Working Together, A Consumer’s Guide to Attendant Management,” Access for Independence, Madison, Wisconsin.)

This section gives a step-by-step method for recruiting personal assistants.

Finding and hiring a personal assistant can be a scary and rewarding adventure. You can ask your Service Coordinator to assist you with any or all of these tasks.

The steps in finding a PA are:

1. Defining what you need
2. Recruiting/Advertising
3. Pre-screening applicants
4. Interviewing applicants
5. Checking References
6. Criminal Background Check
7. Making a Selection/Hiring

Defining What You Need

The next few pages contain a Personal Assistance Needs Inventory and a Life Style Assessment. Completing these two assessments in as much detail as possible will:

- Give you a clear idea of the kind of assistance you need
- Help you think about the kind of person who might match your personality
- Help you clearly communicate your needs to your service coordinator and personal assistant
- Help you manage and direct your personal assistants, especially if you are new to directing others

The Service Coordinator from the Provider Agency will meet with you to complete a service plan. This plan assigns an hourly amount on each task you need help with. Even though an agency may have already completed your Service Plan, we recommend you complete this needs inventory. This will give you a better idea of ALL of your needs, even those not covered by the program.

Personal Assistance Needs Inventory

Completing this personal assistance needs inventory will help you define the range of specific needs you have for personal assistance. (Not all of those needs may be covered by the Pennsylvania Attendant Care Program.) Completing this inventory may also help you discover areas where you may need more knowledge before instructing the personal assistant you hire. For example, you may have trouble directing a PA with housekeeping if you know nothing about household cleaning products.

*If you are still in a rehabilitation facility, and are unsure of the assistance you may need, discuss the inventory with a rehabilitation professional. You can always change your assessment later.

Personal Assistance Needs

BATHING:

What type of bath (shower, bed bath, set-up) do I use?

Is there any equipment required for bathing (shower chair or bench)?

How often do I like to have a bath? How often do I wash my hair as well?

Do I shave in the bath or shower?

What time of day is preferred or am I flexible?

How long does bathing usually take?

What help do I need?

DRESSING:

Do I need complete or partial help? Specify the type of help needed.

How long does it usually take?

Do I need help with jewelry?

GROOMING:

What assistance do I need with this? Make sure to consider hair setting/styling, shaving, nail care, ears, applying deodorant, and toe nail care. (Your agency may not allow nail cutting by personal assistants.)

How long does it usually take?

ORAL HYGIENE:

What routine do I follow?

How much assistance do I need?

How often?

How long does it usually take?

BOWEL CARE:

Do I follow a structured program?

If yes, how often? What time(s) of day? How long does it usually take?

If no, do I need any assistance in this area? How long does it usually take?

Do I have any overnight needs in this area?

BLADDER CARE:

Do I follow a structured program?

If yes, how often? What time(s) of day? How long does it usually take?

If no, do I need any assistance in this area? How long does it usually take?

Do I have any overnight needs in this area?

TRANSFERRING:

*(*Personal assistants may not be permitted to lift you without equipment because they can injure themselves.)*

What type of transfer do I prefer?

When do I need transferring assistance?

Are there any special considerations about transferring that my attendant should know about?

EATING:

What kind of foods do I usually eat? (List likes and dislikes.)

Do I need to follow any special diet restrictions?

Do I eat at regular times or when I feel like it?

If I eat at regular times, what are they?

Do I require any special help when eating?

MEDICATION:

*(*Providers may limit the kind of assistance that personal assistants can provide.)*

What type(s) of medication do I currently take?

When do I have to take my medication?

Do I administer my own medication or do I need assistance?

If assistance is needed, list medications, times, and amounts.

EXERCISE/PHYSICAL THERAPY:

What type of exercise or therapy routine do I use?

How often do I go through the routine?

How long does it usually take?

What type of assistance do I need in this area?

Homemaking Needs

LAUNDRY:

How often do I need laundry done?

Where is my laundry done?

Special considerations?

HOUSEKEEPING:

*(*Agency guidelines may vary on what an assistant can help you with. For each room, list the applicable chores and how often you want each performed. Examples: sweeping/vacuuming, mopping, counters, sink, refrigerator, oven, microwave, tub, shower, toilet, changing sheets, dusting furniture, trash.)*

Kitchen

Bathroom

Bedroom

Living room

Dining room

Other rooms

What other specific housekeeping chores need to be done in addition to regular cleaning?

MEAL PREPARATION:

How many meals do I usually eat each day?

Do I have set times for each meal?

Do I plan/decide the daily/weekly menu or do I want help from my PA on this?

Do I need help with cooking?

How long does it take to cook the things I usually like to eat?

Do I need help with cleaning up?

How long does cleaning up after a meal usually take?

GROCERY SHOPPING:

How often do I like to have the grocery shopping done?

Where do I prefer to get my groceries?

What kind of help do I need from my attendant with grocery shopping?

Other Assistance Needs

JOB OR SCHOOL/TRAINING:

(Some of these needs may be provided by your school or Vocational Rehabilitation.)*

What is my current schedule of work or classes?

Do I need assistance traveling to and from these activities?
How long does this usually take?

Do I need assistance during these activities? How long
does this usually take?

SOCIAL/COMMUNITY ACTIVITIES:

*(*Hours from the Attendant Care program will be limited in this area.)*

What is my current schedule of social/community activities?

Do I need any assistance with these activities?

Do I need a personal assistant to accompany me to these activities?

If there is no set schedule, what days/evenings do I typically
like to get out socially?

Do I need assistance traveling to and from these activities?
How long does this usually take?

TRANSPORTATION ISSUES:

*(*Some agencies do not allow personal assistants to transport people.)*

Do I use public transportation?

Do I need someone to accompany me?

Do I have my own vehicle?

Do I need someone to drive my vehicle?

Do I need help transferring into a vehicle?

PERSONAL FINANCES:

What kind of help, if any, do I need with banking?

*(*Personal assistants can only help with the manual task of banking.)*

What kind of help, if any, do I need with writing checks and paying bills?

What kind of help, if any, do I need with correspondence?

What kind of help, if any, do I need creating a budget ?

COMMUNICATING WITH OTHERS:

Do I need help making phone calls?

Do I need my personal assistant to interpret my speech when I'm speaking to others?

Do I use any special equipment that needs to be maintained?

ATTENDING TO HEALTH:

Do I need help scheduling appointments with my doctor or dentist?

Do I need assistance when visiting the doctor or dentist?

VACATION & TRAVEL PLANS:

Do I regularly take trips out of town?

Do I need a personal assistant to accompany me on those trips?

How much assistance will I need on those trips?

Will I need more PA hours for the trip?

OTHER NEEDS:

List those not already covered.

Lifestyle Self -Assessment

(Please disregard those portions that are not relevant to your situation.)

This lifestyle self-assessment will help you explore:

- your personal habits
- you routines
- your skills
- your personality traits

Having a clear understanding of these things will make it easier for you to find a personal assistant who matches your habits and temperament.

When selecting a personal assistant, selecting for personality compatibility will help avoid problems later. For example, you may have a personal assistant who talks incessantly, but is an excellent assistant. This might be a trait you could live with for a few hours a day, but spending a large portion of your time with this person may be a different story!

This assessment is for you. Be honest.

Who Am I?

1. Do I consider myself an easy-going person? Why or why not?

2. How much am I affected by other people's moods or attitudes?

3. What are the things I really do not want to be asked to compromise on?

4. How well do I deal with uncertainty and change?
5. Do I usually like activities well planned, or do I like them to be spontaneous?
6. How do I react if I have to change my plans at the last minute?
7. How important is it for me to be able to confide in and trust an attendant?

**What Are My Personal Habits,
Routines And Preferences?**

1. Do I smoke? Do I mind other people smoking when they are with me?
2. Do I drink alcohol? Is this an important part of my life?
3. Am I at my best in the morning, afternoon or evening?
4. Do I like to sleep late in the morning or get up early?
5. What time do I usually go to bed at night?

6. What hobbies and interests do I have?

7. Would I like to get involved in a new activity or hobby?

8. What do I like to do for entertainment?

9. Do I regularly go out to visit friends and participate in other social activities?

10. Do I like to entertain friends and family in my apartment?

11. Do I like to listen to music? What kind? What volume?

12. Do I take vacations away from home?

13. At home, do I generally like a quiet and peaceful atmosphere?

14. Do I like to watch TV regularly?

15. Is there a spiritual aspect to my life which is important?

What Are My Preferences About Housekeeping?

1. How do I feel about giving instructions to my attendant on a daily basis?
2. How do I feel about giving specific instructions about cleaning, cooking, personal care?
3. Can I figure out all the things that need to be done around my house or do I need help with this?
4. Do I like things very neat or reasonably neat, or is neatness not a priority for me?
5. Would I like to decide day-by-day what my personal assistant does or would I prefer a definite schedule for cleaning, laundry, grocery shopping, etc.?

What Are My Preferences Around Cooking And Eating Arrangements?

1. Do I prefer to do my own cooking with or without assistance, or do I prefer to supervise my assistant while he/she does the cooking?
2. How do I feel about eating with my personal assistant?
3. Do I like to have friends or relatives over for lunch or dinner?

4. Do I have allergies to specific foods?

What Are My Preferences About My Personal Appearance?

1. What aspects of my personal appearance are most important to me?

2. Do I care about my appearance when I'm at home or just when I go out or have visitors?

3. Are the specific clothes I wear each day important to me?

Recruiting/Advertising

(The following information is adapted from "Pathways: A Self Manager's guide to Personnel Management", Independent Living Resource Centre, Winnipeg,,Canada.)

** The Service Coordinator can help with any part of this task, and the agency can pay for newspaper ads.*

According to Department of Public Welfare Requirements, personal assistants **MUST:**

- Be 18 years of age or older
- Have the required skills to perform attendant care service as specified in the consumer's service plan
- Possess basic math, reading, and writing skills
- Possess a valid social security number
- Be willing to submit to a criminal record check
- When required by a consumer, the attendant must be able to demonstrate the capability to perform health maintenance activities specified in the consumer's service plan or be willing to receive training to provide the health maintenance activities specified in the consumer's service plan
- Not be an immediate family member (spouse, parent, child, stepparent, step child, grandparent, grandchild, brother, sister, half-brother, or half-sister)

Where can you find personal assistants? Your Provider Agency or local Center for Independent Living may have a list of potential personal assistants. Make sure you tell family and friends that you are looking for a PA. They may know of someone they can recommend.

If you need to advertise for a PA, include the following information in your ad:

1. Specific work time frames (i.e., part-time, full-time, live-in, time of day, weekdays and/or weekends)
2. Your gender
3. Job duties (i.e., to assist with personal care, household management, cooking, etc.)

4. Wage and/or conditions of employment (i.e., \$8.00/hr., weekends required, evening shift, etc.)
5. Qualifications and requirements for the job (i.e., level of education/training, past work experience, specialized skills, personality traits)
6. How To Apply (Include phone or address for reply. You will need to decide if you will accept phone calls or inquires through the mail. You may need to decide which is easier for you and consider such things as your ability to answer the phone quickly or write while talking on the phone. It will take longer for you to hear from mailed-in applicants)

A Few Words Of Caution:

- Disclosing your phone number increases your risk of receiving unwanted or disturbing phone calls.
- Disclosing your address carries the risk of attracting unwanted visitors, vandals, or burglars.

For safety reasons, you could use a phone number of a friend, family member, or the provider agency, where messages can be left for you. You could also use a post office box. Most newspapers will assign a box number to you if you place an ad with them.

Where to Advertise

- city newspapers
- area newspapers
- newsletters
- schools, colleges and universities (financial aid offices)
- community bulletin boards
- employment agencies
- social service agencies
- computer mailbox

Advertisement formats will vary according to where the ad is being placed. Remember the size and length of an ad may determine the cost of placement.

Advertising Formats and Examples

1. **Newspaper**

- Your service provider can subsidize the cost of an ad.
- The best days to advertise are usually Saturday and Sunday.
- A bold, darker type heading catches attention.
- In addition to placing an ad, check the “Work Wanted” section for potential attendants.

Example of a newspaper ad:

Young male with physical disability needs part-time assistance for personal care and household management. Must have valid drivers license and be capable of heavy lifting. \$8 per hour. Leave message at 777-7777.

2. **Posted Ads**

- S You may need approval before posting an item on a community bulletin board.
- S Make the ad stand out by using colored paper or catchy phrases.
- S Post your notice centered and at eye level, if possible.
- S Size is important. If the bulletin board is small, a 3X5 index card might be preferable to a large flyer.
- S If you are mailing bulletin board ads they should be accompanied with a memo. (See memo example after ad examples.)

Example, 3 x 5" Index Card Ad:

***LOOKING FOR SOME EXTRA CASH?
PART-TIME JOB OPENING
PERSONAL CARE ATTENDANT***

Female student with a disability requires assistance with personal care, typing, and meal preparation.

***SATURDAY 8:00 a.m. - 1:00 p.m.
SUNDAY 2:00 p.m. - 10:00 p.m.***

LEAVE MESSAGE AT 777-7777

Posted Ads, continued

Example of a larger posted ad:

******HELP WANTED******

PERSONAL CARE ASSISTANT

*Young male who uses a wheelchair needs 4
hours of assistance daily with personal
care, meal preparation, and housekeeping.*

HOURS: 6:00 a.m. - 8:00 a.m.

8:00 p.m. - 10:00 p.m.

DAYS: Monday to Friday

SALARY: \$8.00/hr

*If interested please
leave message at 777-7777*

Posted Ads, continued

Example of a larger Posted Ad with more detailed information because no phone number is given:

Help Wanted **PERSONAL CARE ATTENDANT**

To assist a person who has a physical disability, with personal care and household management.

QUALIFICATIONS

- *Ability to maintain confidentiality with respect to employer's affairs*
- *Ability to take direction from employer and to accept responsibility in a flexible manner*
- *Ability to maintain good communication and cooperation with employer and co-workers*
- *Willing to perform personal care and household tasks*
- *Knowledge of and experience with personal care procedures and willingness to learn new procedures*
- *Dependable, reliable, and punctual*

A full job description is available on request.

Salary dependent upon experience.

RESUME TO: *Your Name*

Address

Posted Ads, continued

Example of a note to include when mailing notices to bulletin boards:

*TO: Student Aid Officer
 Student Aid Office
 Penn State University*

FROM: Your Name

RE: Job Announcement

DATE: June 1, 2003

Please post the enclosed on your bulletin board and, if possible, distribute it to interested people. Your assistance is sincerely appreciated. THANK YOU

Pre-Screening for Interviews

Use the telephone to pre-screen applicants. You will be able to eliminate people who don't meet your criteria, saving yourself time and energy.

Guidelines for telephone screening

1. Act Quickly.

Call people back as soon as possible. Good people find jobs quickly.

2. Be Pleasant.

This is common sense, but it bears repeating: Be friendly and pleasant on the phone.

3. Provide Some Basic Information about the Job.

- Write out the basics so that you are giving the same information to each person.
- Applicants can disqualify themselves if they are unable to fulfill your basic requirements.
- State the hours and days you need someone and a brief description of the job duties.
- State the hourly wage and start date.
- Tell people if you smoke or have pets, as this might eliminate some applicants.

4. Ask Questions of the Potential Personal Assistants.

The purpose of phone screening is to eliminate people who do not meet your criteria. With that in mind, some good phone screening questions are:

1. Why are you interested in this kind of work?
2. What experience or training do you have?

If the answers to both of the above questions are positive, ask a few more short questions designed to give you enough information to decide to invite the applicant for an interview. Other possible screening questions include:

- Do you smoke?
- Lifting and transferring are essential functions of this job (if they are).
Is there any reason you would not be able to do those tasks?

Use the Lifestyle Assessment, from the previous section to help you formulate the questions.

* Some questions are illegal. See the section on interviewing for a list of illegal and discriminatory questions and more information on interviewing.

5. Be organized.

Take notes. Write down the names and phone numbers of everyone you talk to. You can set up a personal interview for good candidates when you talk with them, OR you can call them back, after you have time to review all of your phone calls.

Set a day and time and give the person directions to your house. Be sure you have each other's phone number in case one of you needs to change the interview.

What if you don't want to interview someone?

You are not obligated to interview anyone. Just let each person know you are taking names and phone numbers and will call them back if you decide to interview them. You may find that you would like to interview someone later, even though your initial reaction was not to. Taking everyone's name and address will ensure you can get back in touch with people if you change your mind.

Interviewing Basics

The face-to-face interview gives you the opportunity to learn as much as you can about the person who is applying for the job. It also gives the applicant information about the job requirements so that both of you can make a good decision. This works best if you are prepared.

1. Be Safe

- Hold the interview in a location that is safe for you.
- Your local Center for Independent Living, apartment building, or community library may have rooms available for you to conduct interviews if you do not want to use your home.
- The service coordinator can be present for an interview, or you can invite a friend to sit in. In addition to safety concerns, having a second person is recommended since that person may notice things at the interview that you do not.

2. Setting the Tone of the Interview

- First impressions are important. Convey a sense that you are a capable individual able to direct your own care.
- If you have a friend or service coordinator present, make sure it is clear that you are the interviewer.
- Think about the location of the interview. A living room is a better choice than the bedroom, which conveys a somewhat dependent picture.
- Wear clothes that convey confidence. Don't wear sleepwear.
- Sit facing the applicant so that you can observe eye contact and body language.
- Eliminate distractions. Turn the TV and radio off. Make sure pets and children will not interrupt.

3. What if You are Nervous?

- Recognize that it is natural to feel nervous when interviewing.
- The prospective PA is also probably nervous.
- Breathing deeply is the quickest way to relieve anxiety.
- Being prepared for the interview will also lower your anxiety level.

4. Be Prepared. Before the Interview, Make Sure You Have:

- A blank application form (in the appendix)
- A job description (sample in the appendix)
- A checklist (if you are using one) of duties for the shift(s) you are hiring
- Information about your disability
- Information about special equipment you use
- A way to record your impressions (write them yourself, have a tape recorder, invite a friend to act as recorder etc.)
- A list of the interview questions you will ask (See below for suggested interview questions.)

5. Planning the Interview Questions

- Decide ahead of time what questions you will ask, and write them out.
- Frame your interview questions to give you the information you need. (At the very least you want someone who is trustworthy, reliable and responsible. Ask questions that will give you that information.)
- By using the same list of questions for each applicant, you will be able to compare their responses more easily.
- Don't ask illegal questions. See the chart on page 48.

The following are some questions that could be used:

Suggested Interview Questions	Information you are looking for
Do you have questions about anything on the job description?	Applicant's understanding of the job
Tell me about yourself and your experience, particularly with disabilities.	Experience, training, skills, attitude, opinions about disability
Why are you interested in this type of work?	Attitude, compatibility
What is your impression of people with disabilities?	Answers involving independence, choice, responsibility, right to live one's own life
What qualities do you feel you could offer in working for me?	Realistic appraisal of his/her qualities
Tell me how you have used that quality (named in the last question) in the past or give me an example of why you feel you have that skill.	Give you specific information about qualities and traits named. Allows you to evaluate how realistic his/her self-appraisal is.
How do you feel about taking direction from me?	Willingness to take direction
What kind of situations do you find stressful and how do you deal with stress?	Ability to handle stress
What is your understanding of confidentiality?	Understands your right to privacy
Situational Question: The food for the evening's dinner appears spoiled when you take it out of the refrigerator. What do you do?	Problem solving abilities, ability to recognize an unhealthy situation, importance of taking direction from consumer
Situational Question: On Sunday I get a flat tire on my wheelchair. Wheelchair service is not open on Sunday. What would you suggest to overcome this problem?	Problem solving abilities, importance of taking direction from consumer

Some interview questions are illegal. Sometimes consumers/employers unintentionally ask illegal questions when they are just trying to be friendly or make conversation.

Illegal Interview Topics	You CANNOT Ask:	You CAN Ask:
ethnic origin or background	Where are your parent's from?	-----
color/race	What is your racial background?	-----
nationality or national origin	Where are you from?	-----
religion	Do you go to church regularly?	This job involves work on Sunday mornings. Are you able to do that?
age	How old are you?	Are you over 18 ?
sex	What is your sexual orientation?	-----
disability	Do you have a disability? Do you have a pre-existing health condition?	Transferring me in an out of a wheelchair is an essential function of this job. Is there any reason you could not perform that task?
political belief	What political party do you belong to?	-----
family or marital status	Are you married? Do you have children? Do you have childcare?	This job involves weekend, evening, and holiday work. Is that something you are able to do?
source of income	Do you have any other income?	-----

Interview Outline

This information is adapted from "Pathways: A Self Manager's guide to Personnel Management", Independent Living Resource Centre, Winnipeg, Manitoba, Canada

1. Make the prospective attendant feel comfortable. You can ask, "Did you have any trouble finding the house?" A discussion about the weather is always safe and helps people relax.

2. Have the prospective attendant fill out the application. Then give him/her the job description to look over. This will give you time to review the application. (Some applicants may also have a resume for you to read.) Pay attention to:

Past experience

How does it look? Is it neat?

How specific is it ? (Does it give a reason for leaving the previous job?)

Are all the bases covered? (Does it include work experience and education?)

What are the patterns ? (Are there frequent job changes?)

Red flags on the application:

- Gaps (any time period of over one month -- ask for more details)

- Omissions (educational, former employers -- ask for details)

- Inconsistency (dates don't make sense -- ask for details)

If you have questions about any of the information on the application or resume, the interview is the place to ask them.

3. Explain your disability, as far as you feel comfortable.

- Give information that would be important for someone to understand if he/she were providing assistance.

- Review the duties on the job description ,Service Plan and checklist.

- Review the hours of work and the salary, even if you have already done so in the screening process.

4. Ask the Interview Questions.

- Have a method for recording responses. A sample interview recording sheet follows this section. You can check "good" or "poor" with each response, or assign a number value to each response.

- After you have completed your questions, ask applicants whether they have any questions. A lot can be learned about their grasp of your needs by their questions.

5. Avoid interviewing mistakes.

- Don't do too much talking. Let the interviewee talk.
- Don't fail to follow up with relevant questions. (For example, if the applicant tells you he/she had training at Lakeshore Rehab Center, you can ask for more details. How long was the training? What did you learn from that training that will help you with this job?)

Red Flags During the Interview Process

An applicant who:

- Has alcohol on the breath
- Has greasy hair and dirty fingernails
- Is rude
- Is late
- Discloses confidential information about previous employer
- Takes control of the interview
- Expresses sympathy, being overly considerate or hypersensitive
- Stares or makes prolonged eye contact, which could be a sign of aggression
- Makes little eye contact, which could be a sign of evasiveness. (Keep in mind it might also mean the person is shy or from a culture that finds too much eye contact disrespectful.)
- Begins the interview by telling you all the things he/she cannot do or all the times he/she cannot work
- Has no references (Even someone who just moved here should have friends or previous employers elsewhere.)
- Says he/she just really needs a job and will take anything for now
- Looks to the non-disabled person in the room for instructions and verification.

The next page has a sample interview recording form. You can copy it and use it during interviews. The first two questions are basic questions that will give you a lot of information. The other questions are blank so you can decide what else you need to ask.

Interview Reporting Form

Name of Applicant: _____

1. Tell me about yourself and your experience (particularly with disabilities).

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

2. Why are you interested in this type of work?

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

3.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

4.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

5.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

6.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

7.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

8.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

9.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

10.

Answer poor 1 3 4 5 6 7 8 9 10 good
Comments

Making Your Decision/Checking References

Review the answers to interview questions. If you had a friend sitting in on the interview, compare notes with him/her. Does the applicant meet your needs? Does the applicant seem reliable and trustworthy?

Checking References

We recommend that you always check references of someone you are planning to hire, even if you know the person well. You can either telephone or write for a reference. Most consumers find it easier to phone, although many employers require a written request with a signed release of information by the applicant. Even with a signed request, many employers will only tell you the dates that a person worked for them. Personal references, on the other hand, are often willing to talk to you on the phone, and will often provide detailed information. The form on the next page can be used for either a telephone or mail reference check.

If an applicant has asked you not to contact their employer, respect this, as the present employer may not know about the interview.

Once you have checked references for all of the applicants, you should compare this information to the information you received from the applicant. Look for any discrepancies in facts about employment. Also when talking to references, pay attention to how they respond to questions. If someone hesitates or seems uncomfortable with a question, he/she probably is. If a reference specifically states a reason why he/she thinks the applicant can or cannot do the job, you need to carefully consider that.

Reference Form

Name of Reference: _____

Address _____

Phone: _____

Circle one: Personal Reference Employment Reference

I, _____ (name of prospective PA), give permission for the above named person to provide reference information regarding my possible employment.

Signature of prospective PA

Date

_____ (name of prospective PA) has applied for a position with me as a personal assistant. This will entail assisting me with tasks of daily living and housekeeping chores.

1. Can you tell me when the applicant worked for you?
2. What was his/her job title and duties?
3. What can you tell me about his/her job performance?
4. Would you recommend him/her for a personal assistant job? Why or why not?

Being Flexible About Your Needs

Sometimes, the ideal person who wants to work the exact hours you need for the money you're able to pay will not appear. Think about the compromises you're willing to make. There are pros and cons about being flexible with your schedule in order to accommodate personal assistants. Often, if you can't find one person to act as your PA, you may have to consider employing a number of people to share the work. Although coordinating and managing a number of people is obviously more difficult than doing it with just one person, having a number of personal assistants also has its benefits. If you have many different people assisting you, you will have a better chance of getting back-up assistance if a scheduled PA is ill or needs time off for personal reasons. Remember this when considering applicants who can't do everything you require.

There are other ways you might consider being flexible to comply with the attendant's availability. Are you willing to get up a bit earlier or later in the morning? If you are looking for a weekday morning PA, would you settle for someone taking three days, while you continue looking for someone to do the other two days? If you can't find enough personal assistants to cover mornings, could you manage with a little less morning time by shifting some activities or duties to the evening? These are the kinds of hard questions you will need to ask yourself if you can't find a personal assistant who fits your needs as you've initially defined them.

But don't be too quick to change your lifestyle dramatically to suit personal assistants. Be patient with the advertising process if you can. No doubt you will know when its time to start compromising in order to make things work!

Hiring

Once you have made your decision, call and offer the job to the attendant(s). You will need to meet with the attendant to fill out the additional paperwork. The Attendant Care Service Coordinator should have provided all of the forms that a new employee will need to fill out. These forms will include:

- **a W-4 form**, Employee's Withholding Allowance Certificate, for Federal taxes
- **an I-9 form**, Employment Eligibility Verification, with copies of two forms of ID, to show US Citizenship or non-citizen authorized to be in the U.S.
- **Agreement between Consumer and Attendant** (see appendix)

The agreement is a contract that explains the job expectations for both consumers and attendants. DPW has a standard agreement that all consumers should use. This agreement does not cover the specific job duties (as your job description and checklists do), but instead emphasizes a general agreement of responsibility. The consumer and personal assistant should both read and sign the agreement.

- **Offer of hepatitis B vaccination**

The provider agency is required to offer Hepatitis B vaccinations to both consumer and agency Personal Assistants. The agency will provide you with a form for the new PA to either accept or decline the vaccination.

- **Criminal Record Check**

You can request a criminal record check on all new Personal Assistants. The provider agency will pay for this record check. Unless you are absolutely sure of the new Personal Assistant's background, you should have this completed. The Criminal Record check is not foolproof. If someone has lived outside of Pennsylvania, you may want to discuss with your provider agency having a Federal Criminal Record Check completed. You may also want to consider a Child Abuse Clearance Check, although at this time, you would need to pay for that expense.

MANAGEMENT OF PERSONAL ASSISTANTS

Orientation and Training of New Assistants

* *Your service provider can authorize additional hours for you to train a new personal assistant.* You may have had to hire someone quickly, but you don't need to skimp on training! This is an important step.

- Schedule a time to formally orient and train your new assistant.
- This gives you the opportunity to discuss your expectations and clearly explain job duties.
- Even if your new employee has experience, your situation is unique and different.
- Set a tone during orientation and training that you are the supervisor.

Training an employee might be completely new for you. Help is available!

- Your service coordinator can assist you in training a new personal assistant, regardless of the model of attendant care you have chosen.
- A skills trainer at your Center for Independent Living may also be available to help. (For locations of Centers for Independent Living in Pennsylvania, see the appendix.)
- Use your Service Plan and a checklist.

Orientation/Training Check List

Even though you may have discussed some of this information at the interview, orientation of a new employee should include:

1. Tour of the house showing where supplies and equipment are kept.
2. Information about your disability. Discuss your disability and any specific aspects about your disability that your attendant should know (i.e., Do you get more fatigued as the day goes on? Are you sensitive to cold? Do you have days on which you can do more for yourself than other days?).
3. Explanation/Demonstration of personal assistant duties. First give an overview of the job duties. Then, using a checklist, explain specific duties in the order they will be performed. An ideal way to train is to have your new personal assistant observe an experienced assistant completing all the tasks. If you have extensive attendant care needs, you may want to take more than one day to demonstrate duties.

Training instructions should be step by step and specific.

4. Safety and Security
 - A. Lifts and Transfers. Review safe procedures for completing lifts and transfers. Many provider agencies do not allow lifting by agency personal assistants without proper equipment, because of the high risk of injury. If you are requiring your personal assistants to lift you, be sure that proper lifting procedures are used.
 - B. Reinforce safety guidelines for any disability-related equipment the PA will be expected to use.
 - C. Reinforce safety guidelines for any household appliances or equipment the PA will be expected to use.
 - D. Discuss your emergency plan with your PA. (See the section on writing an emergency plan.)
 - E. How will your PA get in and out of your home? If you are not able to open the door, you will need to set up a procedure so that the PA can get in.
 - F. Universal Precautions. Reinforce the importance of washing hands thoroughly before preparing any food, and before and after any personal care duties. (See the section on Universal Precautions.)
5. Expectations - Review the following topics:
 - A. Jobs duties and Service Plan

- B. Confidentiality - What you say and do in your home is your business. Be specific. Some people think if they are not saying something bad about you it is not a violation of confidentiality. The attendant should be reminded that it is not only disrespectful, but that violating confidentiality can be grounds for termination.
- C. Importance of Being on Time
- D. Notice of time off - What are your expectations?
- E. Mutual Respect - Let your Personal Assistant know the kind of behavior you expect and the kind of behavior he/she can expect in return.
- F. Use of household items - Give some thought to your rules regarding use of the phone, the car, the washing machine, your computer/printer and eating your food. State these rules clearly at orientation. It is always easier to state the rules clearly during your first meeting, than to wait until later when bad habits have developed.

6. Review the rate of pay, schedule, and time sheet reporting requirements.

7. If possible, introduce your new personal assistant to other PAs .

Directing Daily Care and Tasks

Once you are on the program, day to day management of personal assistants has a lot to do with your interpersonal and communication skills. **Talk with and treat your personal assistants as you would like to be treated. Be clear about job responsibilities and be respectful when giving direction and feedback.**

Feedback about performance should be specific.

“You are a lousy personal assistant,” is unlikely to change anybody’s behavior. A more specific statement like, “I need you to follow the procedure you were shown at training when you are doing a transfer. Otherwise, I am afraid you will drop me,” gives the attendant information about how you want things done.

Positive feedback should also be specific.

A statement like, “You’re a great personal assistant,” might make your assistant feel good, but doesn’t give him/her any information about what part of the job performance you are pleased about. “I like the fact that you are always on time, and do a thorough job when following my directions,” gives a lot more information.

Because communication is so important to your success in managing personal assistants, an entire section has been devoted to learning about good communication skills.

Using Checklists for Ongoing Management

Checklists are a great tool for ongoing management of personal assistant tasks. Posting a checklist of the job duties you expect the personal assistant to perform is a good reminder for the assistant and you.

The service coordinator will complete a service plan with you that lists the amount of time each personal care task should take. The agency will also provide you with a job description for your personal assistant. The job description outlines general duties. While the service plan and job description are helpful in explaining what you need to a new personal assistant, many consumers find checklists to be most helpful.

A checklist:

- Provides a specific and detailed list of tasks in the order they are to be performed.
- Is much more specific than a job description, which just lists very general duties.
- Differs from the Service Plan because the checklist outlines when tasks are to be done and in what order. (Please note that nothing should be on a checklist that is not in the Service Plan.)
- Helps you think about the order in which you want tasks completed, and makes it easier for you to explain those tasks.
- Makes it much easier for a personal assistant, especially a new PA, to understand what you want done. (This is especially helpful if you have a different set of tasks on different days of the week.)
- Can be used for evaluating personal assistants and providing feedback.
- Will simplify things for back-up attendants or family members who may assist you occasionally.

You can write a checklist for a specific group of tasks that belong together (for

example, preparing breakfast **or** for an entire shift.)

Begin by writing down all of the smaller tasks associated with this task or shift. Then list the tasks in the order you want them done. This might be difficult if you are new to the program. If you have trouble deciding the order you want tasks done, you can ask your service coordinator to assist you.

Sample Personal Assistant Checklist: Daily Mornings

This is an example of a checklist so you can see the level of detail.

1. Assistance with Hoyer lift into bathroom: Begin bathroom toileting routine.
 - a. Set up bedroom with clean clothes: jeans, shirt, underwear, socks.
 - b. Set up urinary drainage equipment: leg bag, external condom catheter, plastic cup, lotion, and deodorant.
 - c. Wash hands.
 - d. Start coffee.

2. Finish bathroom routine. Then assist into bathtub with hoyer lift and begin bathing.
 - a. Complete bathing.
 - b. While consumer is soaking, set up q-tips, band-aids, scissors, and splint on back table.

3. Assist from bathtub into bedroom with Hoyer lift.
 - a. Begin drying and dressing as directed by consumer.

4. When finished dressing, bring wheelchair from kitchen.
 - a. Transfer consumer from bed by swinging legs to edge of bed.
 - b. Raise body from bed by lifting with arms.
 - c. Transfer consumer to chair by standing-pivot transfer method.

5. Wash hands. Put bread in toaster. Put splint on while waiting for toast.

6. While consumer is eating breakfast begin bathroom cleaning
 - a. Rinse Hoyer pad.
 - b. Wash bathtub with cleanser.
 - c. Wipe toilet and floor with cleanser (under kitchen sink).
 - d. Return Hoyer to bathroom, hang Hoyer pad to dry.
 - e. Hang towels and wash clothes to dry.

7. Bedroom:
 - a. Empty & clean overnight urinary drainage bag with bleach solution. (See the section on Universal Precautions.)

b. Make bed.

8. Wash hands and make sack lunch for work (as directed).

9. Wipe down kitchen counter, rinse & clean coffee pot.

10. Assist consumer with materials needed for day's work.

Record Keeping

All consumers need to sign time sheets and verify that their personal assistant(s) worked the hours reported on the time sheet. Some people use a clipboard that personal assistants sign in and out on, so that they can then verify the hours when signing the time sheet. Others use a calendar for tracking this information. You will need to find a system that works for you.

If you are using the consumer/employer model, you may have other paper work you need to keep track of. You should develop a system for keeping track of information about the program and information about your personal assistants. An office supply store will have a variety of file storage items. Items you should keep include correspondence from your provider agency, evaluations of personal assistants, and contact information for personal assistants. If you have trouble setting up a system that works for you, talk with your service coordinator or an independent living skills instructor from your Center for Independent Living.

Evaluations

You should give your personal assistants feedback about their job performance on a daily basis. A written evaluation completed on a regular basis is also a good idea. This is a more formal way to let your PA know what is going well, and what areas need some work.

A written evaluation can be a simple letter to your employees discussing their work performance, or you can use an evaluation form. (See the example on the next page.) The following points should be discussed:

1. Job Knowledge - understands the job description and duties of a personal assistant
2. Job Skills - has the skills to perform all aspects of the job
3. Time Management - is punctual, attendance is good, does not take unnecessary breaks or conduct personal business at work
4. Ethics and Integrity - demonstrates honesty, integrity and respects confidentiality
5. Communication - communicates clearly and follows instructions and guidelines
6. Initiative/Commitment - accepts responsibility, is willing to put in extra effort when needed
7. Flexibility/Learning Ability - willing and able to learn new ways of doing things

For each area you can simply comment on whether or not your employee(s) fulfills your expectations for the position. You can also set up a rating scale from one to five.

Use concrete examples of performance that support your rating of the employee in each area. This is what would justify any corrective action you may need to take with an employee.

Remember to have your employee sign a copy of the evaluation to confirm that he/she has seen it and retain this copy for your records.

EVALUATION FORM

Name _____

Evaluation Dates _____ to _____ Hire Date: _____

PERFORMANCE FACTORS:

	Excellent				Poor
JOB KNOWLEDGE	5	4	3	2	1
JOB SKILLS	5	4	3	2	1
TIME MANAGEMENT	5	4	3	2	1
ETHICS AND INTEGRITY	5	4	3	2	1
COMMUNICATION	5	4	3	2	1
INITIATIVE/COMMITMENT	5	4	3	2	1
FLEXIBILITY/LEARNING ABILITY	5	4	3	2	1

SUPERVISOR'S COMMENTS:

OVERALL PERFORMANCE:

EMPLOYEE'S COMMENTS:

SUPERVISOR'S SIGNATURE

DATE

EMPLOYEE'S SIGNATURE

DATE

Your signature indicates that you have read this review. It does not necessarily indicate your agreement with it.

Planning for Back-up

Consumers using the consumer-employer model are responsible for having back-up coverage in place. Even the best personal assistants get sick, have family emergencies, and sometimes quit and move on to another job. To pretend this won't happen and not plan for back up is short sighted and can leave you in a difficult situation.

Planning for back-up means that you ask people ahead of time if they can provide back-up, and you help familiarize them with your personal assistance needs. Back-up PAs can be people that you do not use as PAs on a regular basis, but who are willing to be available in this capacity. Do you have any friends or family members who could be available for occasional back-up? You may want to split your attendant care hours between two or more PAs so that if one is not available, the other may be.

If your back up plan fails, the agency will only provide for priority care. Priority care is defined as only those tasks which consumers need to ensure their health and safety. Ancillary services are not priority care. The agency will respond as quickly as possible, but you may have to wait longer than you would if you had your own back-up. Arranging for your own back-up also ensures that you know the people coming into your home.

Emergency Planning

Emergency Planning is a good idea for anyone. Have a plan for dealing with different types of emergencies: medical emergencies, hospitalizations, fires, power outages, blizzards, and other natural disasters. Planning should include:

- Identifying who needs to be contacted if you are hospitalized
- Identifying how you would contact family and personal assistants if there is a power outage or natural disaster
- Identifying medications or equipment that need to be taken if you must evacuate your home
- Organizing medical information, emergency contact information and living will information and placing it in an easy to access location
- Planning for extra food and water in the case of a snow emergency or other natural disaster
- Discussing your emergency plans with your PA

The form below will help you to organize the information.

Emergency Information Form

Your Name _____

Primary Care Physician _____

Physician's phone number _____

Hospital Preference _____

Insurance name and number _____

Disability _____

Other medical conditions _____

Allergies? _____

Where are medications kept? _____

List medications and dosage:

Emergency Contacts, to be contacted if I am hospitalized or not able to direct my own care.

Name	Phone	Relationship
------	-------	--------------

1.

2.

Termination of Employment

Nothing lasts forever. For many people, work as a personal assistant is a temporary vocation. This means you may be training new employees on a regular basis. If a personal assistant quits and gives notice, you should have time to find another assistant. Call your provider agency for help.

If the separation is initiated by you, you should do some advance planning, if at all possible. **Please note** that termination should be the last step in a process of giving feedback about performance, and specific ways to improve performance. If you have done those things, and the PA has not been able to improve, then proceed to termination.

You should anticipate any problems with termination before you discuss it with your personal assistant. If the personal assistant might get upset and quit immediately, you should plan for a back-up PA. If there is any chance that the personal assistant might become angry and you would be at risk, you should have the service coordinator or a friend sit in on the discussion.

In situations in which the personal assistant is just not working out (personality conflicts, scheduling difficulties), you may give a two week notice if you are fairly certain that will not put you in a risky or uncomfortable situation. This gives both you and the assistant time to plan.

You should terminate employment immediately if the personal assistant has:

- Stolen something from you
- Been abusive
- Severely violated your contract

Terminating employment with a personal assistant may be emotionally uncomfortable for you. The personal assistant may be a nice person who is just not meeting your needs. The Attendant Care Program exists so that you CAN have your needs met. You have a right to appropriate care. Your personal assistant may work out for someone else or in another type of employment. If there are parts of the job that he/she does well, you could offer to write a letter of reference highlighting those skills.

In situations in which a PA has been abusive, has stolen something from you, or has

severely violated your contract, services should be terminated immediately. Any actions that are against the law should also be reported to the police. Call the Attendant Care Service Coordinator if you need assistance.

At the time an assistant leaves your employment, you should get back all your keys: car, house, lock boxes, etc.

It is also your responsibility to let the Fiscal Agent know that the personal assistant is no longer employed by you. Notification in writing is preferable.

Keeping Good Personal Assistants

AN IMPORTANT TIP: Make sure that your personal assistants' time sheets are submitted on time. If you don't, he/she may not be paid on time. If you fail to meet this basic obligation, you can't expect the personal assistants to respect your schedule of needs.

The personal assistant job is often one of low pay, odd hours, and no benefits. Personal Assistants who stay with the job do so because they find it personally rewarding. You can help create an environment in which personal assistants want to work for you.

A Madison, Wisconsin survey of personal assistants provided some insight on the kinds of work environments personal assistants prefer, and those they don't. In order of importance, the characteristics that PAs looked for in their consumer-employers were:

1. Treating employees with kindness, fairness, and respect
2. Knowing their own care needs
3. Being able to offer both praise and criticism, when appropriate
4. Acting as independently as possible

The personal assistants said that their jobs were much more enjoyable when they had friendly relationships with their employers and there was mutual respect between employer and employee. The attendants preferred to solve job-related problems by talking them over with their employers.

PAs found the following situations difficult to work in:

1. Employers who are overly demanding and rarely, if ever, showed appreciation for a job well done.
2. Employers who are rigid about the way they want tasks done.
3. An employer who feels sorry for himself/herself. He/she will take frustrations out on the attendants.
4. Employers who try so hard to be nice to their attendants that the employer's needs are often not stated and therefore not met.

As already mentioned, good communication skills are vital to managing personal assistants, and keeping good personal assistants. For more information, see the

section on communication skills.

Your Role as an Employer Personal Boundaries and Staff Relationships

If you are using the *consumer/employer model* of Attendant Care, you are the employer and the personal assistant is your employee.

If you are using the *agency model*, you are not the employer, but you are still expected to direct the care in your home. This makes you a supervisor of your personal assistant.

The nature of attendant care work often blurs the lines between employer/supervisor and employee. The personal assistant will be involved with many of the private and sensitive aspects of your life. The personal assistant, in some instances, is more familiar with the intimacies of your life, than some of your closest friends.

The simple boss and employee relationship may not adequately describe the relationship you have with your PA. The longer an assistant works for you, the more likely it is that a friendship will develop. So, is it a friendship, an employer/employee relationship, or something else?

Since the Attendant Care Program defines your role as employer/supervisor, that part of the relationship **MUST** be maintained, even if you develop a friendship with your personal assistant.

There can be problems if you allow a strong friendship to interfere with your ability to make good decisions for yourself. If the personal assistant comes to work late, leaves early, or does not complete tasks the way you want them, will you have trouble correcting these behaviors if the personal assistant is a good friend? You will need to decide whether you can be a boss and a close friend to the same person.

Before the relationship starts, give some thought to balancing the relationship between employer and friend. Establishing a balanced relationship is a process that takes time. It is much easier to proceed from a business relationship to a friendship than it is to proceed from a friendship to a business relationship. For example, if you allow a new personal assistant to use your computer, it may be difficult to tell him/her later that you have changed your mind. On the other hand, if you begin the relationship by not allowing your personal assistant to use your personal items, you can always relax the rules later.

During the orientation period with any new PA, you could discuss the boundaries, rights and responsibilities for both you and the personal assistant. Some examples of this would include the following:

- Should your employee knock on your door before entering or just walk in when he/she arrives for work?
- How much notice should an employee give you if he/she cannot show up for work?
- What are your rules for use of your personal items (computer, phone, food etc.)?
- If you are making a personal phone call, do you want the attendant to leave the room?

Thinking about these kinds of boundary issues and planning in advance will head off future problems.

As an employer/supervisor you should also be aware of how your interactions with your personal assistant may be perceived. Any behavior that could be perceived as harassment or abuse could create legal problems for you.

This information was adapted from "Pathways: A Self Manager's guide to Personnel Management", Independent Living Resource Centre, Winnipeg, MB, Canada

Personal Assistant and Consumer Character Types

On the following two pages are character types adapted from the manual “Independent Living with Attendant Care, by the Institute for Rehabilitation and Research of Houston, Texas.” They illustrate specific character traits you might recognize in your consumers, friends, family, or even yourself. Traits are not exclusive to any one individual. The assertive personality, is of course, the one everyone should be aiming for.

If you see anyone you know, including yourself, in any of the negative character types, what steps can be taken to move toward the assertive personality?

PERSONAL ASSISTANT CHARACTER TYPES

1. **The MEDICAL EXPERT**
These are people who have developed their own medical techniques and refuse to do a task any other way. They direct the consumer’s care rather than the consumer assuming responsibility for his/her own care.
2. **The MOTHER**
The personal assistant feels his/her job is to take care of people and to nurture them. This is the type of person who hovers sweetly, pats people on the head or arm, and does things that are not needed.
3. **The BEST FRIEND/COMPANION**
The personal assistant allows no privacy for the consumer and refuses to allow him/her to have other social relationships. This PA would probably expect to be included in all social activities planned by the consumer and indeed, would be hurt if left out.
4. **The OVER PROTECTOR**
This personal assistant’s creed is, “I know what’s best for you.” The PA might try to prevent the person from taking even minor risks, thus encouraging a dependent relationship.
5. **The GOOD SAMARITAN**
The personal assistant is a “do-better” whose primary objective is to make himself/herself feel needed. This person’s creed might be, “You’ve suffered enough already, let me take care of you.” The GOOD SAMARITAN will do

more for the consumer than is necessary and may treat him/her like a child.

6. The DRUG ABUSER

These personal assistants may do a good job when they are not “spaced out.” They are usually unreliable and/or inconsistent in behavior.

7. The PREACHER

These personal assistants insist upon imposing their religious beliefs upon the consumers. They do not respect another person’s right to his own beliefs and values.

8. The GOSSIP

This personal assistant loves to come to work to find out the latest information on the consumer, the consumers family, other personal assistants and neighbors. This type of PA feels that his/her job is really one of “town crier” spreading lots of private information about other people’s lives.

9. The ASSERTIVE PERSONALITY

Like all assertive people, these personal assistants state their feelings and needs in a direct, yet non-threatening manner. They do not “put down” another person. They behave in a consistent manner and have a strong sense of self.

CONSUMER CHARACTER TYPES

1. **The AGGRESSOR**
These individuals are overly demanding and bossy. They show no appreciation to the personal assistant.
2. **The MARTYR**
This individual's favorite phrase is "Don't worry about me," followed by a big sigh. This attitude encourages feelings of pity and even guilt from the personal assistant and family members.
3. **The PACIFIST**
This person tries hard to avoid conflict of any kind. This often results in unmet needs because of a fear that the personal assistant might be angry if asked to perform a task.
4. **The GUILT-MAKER**
This person has difficulty accepting the disability and attempts to place blame on others. Their non-verbal message is "Oh poor me," or "The world owes something to me." People tend to avoid the Guilt-Maker because of the negative messages.
5. **The ROLLER COASTER**
These people experience extreme mood swings which cause their behavior to be inconsistent. One minute this person is happy, the next, sad. Not knowing what to expect can hinder effective communication.
6. **The DRUG ABUSER**
The consumer might behave in an inconsistent manner and/or be unable to assume responsibility for his/her own care. This puts the burden of care on someone else and is not conducive to the idea of self-direction in independent living.
7. **The PREACHER**
The consumer attempts to convert the personal assistant to accept his/her religious values. This person does not respect another person's rights to their own beliefs and values.

8. **The PERFECTIONIST**
These consumers are often described as “picky” by their personal assistants. Generally, the person insists that tasks be performed in very specific, detailed ways with no flexibility. Setting realistic priorities might be difficult for this individual.

9. **The ASSERTIVE PERSONALITY**
Assertive consumers are able to express their needs in a direct yet non-threatening manner. They do not manipulate other people. They know themselves and usually have an air of self-assurance.

COMMUNICATION SKILLS

A note about language

* *Some individuals with disabilities use their eyes to hear through an interpreter or their hands or communication boards to talk. The words “hear ,” “listen ,” or “talk, ” include all of those methods of communicating.*

The Basics of Good Communication

The basics of good communication can be summed up by the Golden Rule:

Do unto others as you would have others do unto you.

All of us would:

- like to be treated honestly
- like to be treated with respect
- prefer people to say what they mean and mean what they say

Taking the time to learn good communication skills will help you in all areas of your life.

Three Types of Communication

Most communication can be grouped into one of three categories: **assertive, aggressive, and passive.** The passive and aggressive methods are not effective.

Assertive communicators:

- treat themselves with respect
- clearly and honestly state their own ideas and needs
- are able to stand up for their own rights while not violating the rights of others
- are direct and honest
- are self-confident, even if others disagree

The goal of **assertive communication** is to convey clear messages and maintain good relationships.

Passive communicators:

- do not state their needs or opinions clearly, if at all

- may have low self esteem
- do not feel they have a right to their opinions
- often send mixed messages, saying yes when they mean no
- ignore their own feelings but may feel resentful later

The goal of **passive communication** is to avoid conflict, tension or unpleasant situations. It can be frustrating interacting with a passive communicator.

Aggressive communicators:

- do not respect the rights of others
- are confrontational, domineering, hostile and sarcastic
- use threats, swearing, yelling, calling names, blaming or accusing
- blame others or point out others "misdeeds" instead of clearly stating what they need
- try to humiliate or frighten others

The goal of **aggressive communicators** is to have their own needs met at the expense of others. This behavior is self-defeating because it alienates others. It can be scary and uncomfortable talking with an aggressive communicator.

The techniques below will help you improve your skills as an **assertive communicator**. If learned and practiced, they will help you with all areas of your life. These techniques are adapted from an on-line manual by Dennis Rivers, M.A. See the end of this section for more information.

Technique 1. Effective Listening

One of the most common listening mistakes is that people are busy thinking of a response rather than really listening.

When you listen:

- Give the other person your full attention.
- Pay attention to body language as well as spoken message.
- Maintain appropriate eye contact so the person knows you are interested.
(Appropriate eye contact does not mean staring, but does mean making eye contact in a non-threatening way.)
- Encourage the speaker by nodding your head, saying “go on,” “tell me more”, “uh-huh” or something similar. Verbal encouragement will be especially important if you are speaking with someone with a visual disability.

When the person is done speaking, **reflect back** to the person what he/she said to make sure you understood the content. This involves briefly summarizing what he/she said and capturing the emotional tone.

For example you can begin reflective listening sentences in this way:

Let me see if I understand what you are saying...

So you are saying...

You are angry because ...

You are excited because ...

I can see that you feel really...

If you notice that what the person is saying does not seem to match his/her body language, you should address this:

Although you are telling me you are happy, you appear to be very stressed and nervous.

You are telling me you don't mind working the extra hours but you sound angry.

When you take the time to reflect back what you think you are hearing, the other person has a chance to correct your thinking if you have misunderstood him/her. He/she can also give you additional information.

For example, the other person might respond:

Yes, I feel like you don't always give me enough time to change my schedule.

No, that is not what I am saying at all.

Yes I am angry. If you had called me earlier I could have joined my friends at the movie.

Yes, I am happy but also nervous about the new job.

If the emotion is unclear, make a tentative guess, as in, "So it sounds like maybe you were a little unhappy about all that..."

Pay attention to whether the person speaking accepts your summary by saying things such as "yeah!", "you got it," "that's right," and similar responses.

Reflective listening acknowledges the other person's *thoughts* and *feelings*. It does not mean you necessarily agree or approve of what he/she said. You still have the option of agreeing or disagreeing.

Often, if someone feels heard, she/he is more likely to work on a compromise or accept that he can't have his own way this time.

Some examples of acknowledging feelings but not agreeing:

I understand that you feel I am being unfair in the attendant care duties I have given you. Let me explain why I am making these decisions.

I hear that you would really like the weekend off because your sister will be visiting. I know you haven't seen her since last summer and you miss her. I wish there was something I could do, but I need you to work your regular hours this weekend. There was not enough time for me to make any other arrangements.

I understand that doing the laundry is your least favorite part of attendant care. I know it is difficult because I am on the second floor and the laundry is in the basement of the building. I still must insist that you do the laundry as part of your attendant care duties.

Can you think of any recent examples in which you could have applied this technique of reflective listening? (You might think of examples that involve your children or other family members.)

If using this manual in a group situation, you can divide up and practice the following scenarios using active listening:

1. An attendant wants more hours.
2. An attendant wants time off.
3. An attendant tells you she is uncomfortable doing part of your care because she does not feel competent.
4. An attendant tells you she is worried about her teenage daughter.
5. A friend tells you his disability is worsening.
6. A best friend tells you she is getting divorced.

Technique 2. Explain What You Want to Talk About

This step asks us to let the other person know what it is we want to discuss (our intent) and then ask if he/she wants to talk at this time. It will be helpful to use this technique when talking with both consumers and agency staff, especially about difficult situations.

Reasons for communicating number in the thousands. Here are a few that you probably use with consumers and service providers on a regular basis: give information, give directions, tell a story, share a feeling, share an experience, make a request, give an opinion, ask for information. The communication techniques described here can be used in any of these situations, even though some of them might be emotional or feel challenging.

Sometimes, however, the intent of communication is negative: to lie, deceive or mislead, threaten, hurt, blame, bully, intimidate, create fear, anxiety, anger, control or manipulate. Obviously, people will not usually announce that this is their conversational intent. If you find that this is your intent, re-think your reasons for pursuing this action. What is it you hope to accomplish?

Explaining intent allows our listeners to get ready for what is coming, especially if the topic is emotionally charged. Emotionally charged issues could include asking for time off or resigning.

Even if the subject matter is not emotionally difficult, some conversations require a lot more time, effort and involvement than others. Out of respect for the other person, we tell him/her what the conversation is going to be about, and ask if he/she wants to take part at this time.

Explaining intent also helps our listener's understand the "big picture."

Examples of explaining what you want to talk about:

"Maria, do you have a minute? I would like to talk to you about your job performance so far."

"Carl, I'd like to talk with you about the housekeeping chores. There are some things I would like done a little differently. Is this a good time to talk?"

Technique 3. Expressing Yourself Clearly by Using “I” Messages

This technique builds a common ground with the person you are speaking with. It can be used for pointing out problem areas or concerns. It allows the other person to see the problem from your point of view, which may lead to a more positive outcome.

“I messages” focus on you, the speaker. You share how you are experiencing a situation with the other person. “I messages” are more effective than “you messages” which focus on the other persons faults or mistakes. “You messages” can sound like you are attacking the other person.

Here are some examples:

TRY TO USE Positive “I messages”	AVOID USING Negative “You messages”
I feel frustrated when you interrupt me when I am talking.	You are disrespectful and rude.
I feel angry when I can’t get in touch with you to discuss my attendant care needs.	You are the worst service coordinator I’ve ever had.
I feel annoyed when I have to remind you to clean up the kitchen as outlined on the checklist.	You are a horrible housekeeper.

“I messages” can be made even more effective by combining them with the five ways of experiencing things. Communication researchers have identified five main ways of experience that helps the person you are speaking with understand what you are trying to say.

They are:

1. What you are seeing, hearing or otherwise sensing
2. What emotions are you feeling
3. What you think is causing those emotions
4. What you want to happen
5. What will be the positive result

FIVE DIMENSIONS OF EXPRESSION	EXAMPLE
1. What are you seeing, hearing or otherwise sensing? (Facts only)	When I hear you answering questions for me
2. What are you feeling?	I feel upset
3. Why are you feeling that way?	because it takes away my independence and causes others to see me as dependent.
4. What do you want to happen now?	I want you to respect my independence by not answering for me.
5. What will be the result? (No threats!)	Others will see me in the way I would like to be viewed.

MORE EXAMPLES

FIVE DIMENSIONS	EXAMPLE 1	EXAMPLE 2	EXAMPLE 3 your example here
1. What are you sensing?	To service coordinator: When I repeatedly get your voice mail instead of you	To attendant: When I heard that you were sharing my personal information	
2. What are you feeling?	I feel very angry and frustrated	I felt angry, violated and vulnerable.	
3. Why are you feeling that way?	Because when I call I usually have a critical issue that needs to be solved.	Because I have a right to privacy that was violated.	
4. What do you want to happen now?	I'd like you or someone from your office to call me back within 24 hours when I call,	I expect that what you see and hear in my apartment will stay in my apartment	

5.What will be the result?	So that my attendant care services run more smoothly.	So that we can regain the solid relationship we once had.	
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Technique 4. Use Requests Instead of Criticisms and Complaints

It seems to be human nature to complain and criticize when we are upset, rather than look for possible solutions. Often when others feel criticized they don't listen well. Their energy is taken up by trying to defend their position, planning a counter attack and saving face, so you are no closer to a solution.

This technique is basic to assertive communication. *When you have a complaint, think of how you can turn it into a request. This helps you meet your needs without hurting others.*

When you have a request:

- be specific
- make the request action oriented
- use positive language
- don't make comments about the person's character

Avoid "blanket" statements like:

You always...

You never...

Help your listener comply with requests by giving reasons for the request.

In the examples in the chart below, the complaints focus on character traits and do not give the person any ideas on how to improve behavior or performance. The requests focus on specific action steps and the reasons why you'd like things done a certain way.

Don't use the Complaints Below	Instead use Specific Requests with Explanation	
I wish you would be a better housekeeper	I would like you to wipe the counters down completely with anti bacterial soap after meal preparation.	This prevents germs from growing on the counter.
Can't you try to be a better cook?	I would like you to follow the directions in the cookbook I've picked out for this evening.	I think we'll have a great meal.
You are so slow with the chores. Can't you work any faster?	I'd like you to throw in loads of laundry as you are preparing dinner.	It will be more efficient to have the laundry being done while dinner is being prepared.
To Service provider: You always send me lousy attendants. What is wrong with you?	I would appreciate personal assistants who arrive on time and who have good hygiene.	I will then have time to finish all of my personal care and that I won't have to worry about infection.
your example here:		

Think about some recent complaints you have had with your attendants or service provider. Can you think of ways to frame the complaints as specific action oriented requests with an explanatory clause.

Technique 5. Asking Open Ended Questions

Asking open ended questions helps you find out more about what people are feeling and thinking. Yes/no questions will give you short and abrupt answers.

Open-ended questions allow the other person to give you a more in depth response. If you are trying to solve a problem or getting to know the people around you, open ended questions give you more information. We can learn to ask questions more creatively.

Examples:

How are you feeling about all of this? (This OPEN-ENDED question gives you the possibility for lots of information.)

Can you handle this change? (This is a YES/NO question. You will probably not get any additional information about the change.)

Do you have any ideas for keeping the kitchen cleaner? (This OPEN-ENDED question gives you the possibility for more information.)

Avoid questions such as:

Why did you do something so stupid?

Why are you always such a jerk?

Both of these examples are ineffective. They don't focus on solving the problem and instead focus on hurting the other person's feelings.

These examples are more effective:

What system can we put in place so this problem won't happen again?

How could we work together to solve this problem?

Learning better communication skills is a life-long process. It takes commitment and practice, but the rewards will extend far beyond the Attendant Care Program.

Much of this information was adapted from a wonderful manual on communication by Dennis Rivers, M.A. *Communicating More Cooperatively, The Seven Challenges*

Communication Skills Workbook and Reader. His workbook is available on line free of charge at www.coopcomm.org or can be ordered for \$10 from Dennis Rivers 133 East De La Guerra St., #PMB 420 Santa Barbara, CA 93101. We encourage you to check out this workbook.

PROBLEM SOLVING AND CONFLICT RESOLUTION

Problem solving is a process. The same steps can be used for problems involving a broken wheelchair as for interpersonal conflicts. The model below is a formal process that involves brainstorming about solutions and writing down ideas. You may not need to use the whole model to solve a problem, but it is helpful to be aware of the entire process.

1. Identify the Problem

This seems simple enough, but everyone might not agree that there is a problem. It may be a problem for you that the consumer's sister orders you around, but it may not be a problem for your consumer.

2. Define the Problem

Use the communication techniques outlined in the previous section. Define the problem without involving personalities, motives, blame and value judgements. Ask open-ended questions and use active listening to get a better understanding and definition of the problem.

Who owns the problem? By that we mean, whose problem is it to solve?

Examples:

- a. A broken wheelchair is your problem, but your personal assistant and family could help you solve the problem.
- b. A personal assistant who bothers you by talking too much is your problem, unless that behavior will lead to the personal assistant losing his/her job. Then the problem belongs to both of you.
- c. A personal assistant has lost her child care and can't make other arrangements for a week. The problem belongs to both of you.

Each person involved should have input, but whoever has ownership of the problem makes the ultimate decision.

3. Generate Solutions

Everyone involved should suggest solutions. Solutions should not focus on personalities. ("You shouldn't be so lazy." "You shouldn't be such a jerk.") Write down every solution, no matter how far-fetched it may seem without evaluating it or criticizing it at this point .

4. Discussion and Evaluation

Everyone involved should discuss the positives and negatives of each solution generated. Writing out a list of the pros and cons helps in the evaluation process.

5. Select a Solution

Decide on the solution that will best solve the problem.

6. Plan Actions

Everyone involved works out who will do what, where, when, and how to solve the problem. Set a future date to discuss whether the solution is working.

7. Evaluation of Solution

Set a date and time to discuss whether the solution is working and revise the plan as needed.

By facing and confronting problems as above, working relationships can be strengthened and improved. Working relationships that use problem solving keep both the employer and the employee working together and under less stress.

A Word About Difficult People

Suppose you have taken this manual to heart and are an assertive self manager. You use positive communication techniques and encourage your attendant to do the same. Will this guarantee that you won't have any difficult people in your life? NO! Communication involves more than one person. Even though your chances of success are better if you are using positive techniques, they are not guaranteed. Some people are just hard to get along with. You may meet difficult and challenging personal assistants and service coordinators. If you have tried your best to use positive communication techniques to no avail, it is time to just admit you are dealing with a difficult person and proceed to another level.

If the difficult person is a personal assistant, it may be time to think about termination of employment. If you have tried to give direction about the problem areas, and the person has not changed his/her behavior, it may be time to cut your losses and find a new PA. Problems should be documented as they come up. (See the section on termination of employment.)

If the difficult person is a service coordinator, and you have tried to talk with the service coordinator about his/her behavior, the next step is to talk with the supervisor. Again, problems should be documented and you should be specific about the behaviors that need to be addressed. The agency should also have an internal complaint/grievance procedure that you can utilize. If you do not get resolution with the supervisor, you have the right to call the Department of Public Welfare at 1-800-757-5042.

YOU AND THE ATTENDANT CARE PROVIDER

ONCE per year, the Provider (the CRC, after October 1, 2003) must conduct an in-home monitoring visit and a reassessment visit. The first in-home visit will take place six months after you are on the program.

During the annual reassessment, the service coordinator will reassess your level of care needs. It is possible that the number of hours you receive and/or your fee may change. After each reassessment you will receive the form, "Attendant Care Services Notification of Eligibility Determination, Form PW 1299." This form will outline any changes. If you disagree with any decisions, you always have the right to appeal that decision. If you wish to appeal a decision, you must fill out the reverse side of the form. It must be mailed and postmarked by the deadlines listed on the form.

Every three months, the service coordinator will also contact you by phone for monitoring telephone call. The monitoring calls and visits provide a good opportunity to ask questions, and discuss any problems or concerns.

Your service coordinator is available to assist you in understanding the requirements of the program and to provide training and support to you on any areas of attendant management including:

- Recruiting
- Interviewing
- Hiring and Firing
- Supervision
- Living Independently

The agency is required to provide training to your personal assistants on:

- Blood-borne pathogens
- Act 28, the Pennsylvania law on neglect of a care-dependent person.

The agency will also offer training in other areas of attendant care. Check with your service provider about when these training events will take place.

The provider agency (the CRC, after October 1, 2003) also has the right to intervene at anytime. If it appears that you are not managing your attendant or directing your own care in a way that is healthy and safe, the agency can require you and/or your personal assistant to take part in training on attendant care issues. You can appeal any decision made by the agency.

Your Rights As A Consumer

You have a right to:

Be treated with dignity and respect which includes the right to privacy and confidentiality

Participate in the development of a care plan

Have full access and understanding of all services and choices about those services

Have requests for information and assistance answered in a timely and professional manner

Be informed of the procedure for submitting complaints

Have concerns and complaints heard in a non-threatening manner

The following rights are spelled out in the Department of Public Welfare requirements:

Have an in-home eligibility interview within 15 working days after a request for attendant care services is made.

Have oral and written notification within ten days after the eligibility interview including the reason for the decision and description of appeal rights in accordance with the fair hearing process

Have oral and written notification of the disposition of an eligibility interview within ten working days after the interview. This notification may address the following : general eligibility, change in service hours, and medicaid waiver eligibility.

Have an alternative accessible format including the use of interpreters or of

taped copies of pertinent Attendant Care Program information , for those applicants and consumer who have vision or hearing impairment or who do not speak English.

Your Responsibilities As A Consumer

You have a responsibility to:

Provide prompt notice to service coordinator of problems or difficulties with services and/or personal assistants.

Express a concern or complaint by providing specific and accurate information about the circumstances in a non-threatening manner.

Maintain an adequate and safe environment for delivery of services.

Obtain information necessary to make informed choices.

Treat personal assistants and providers with dignity and respect.

Understand and follow legal regulations and requirements of the program and accept the consequences of non compliance.

Complete and submit time sheets so that personal assistants are paid on time, according to your pay schedule.

Don't ask personal assistants to do things beyond the scope of the program.

Give constructive feedback

Make emergency information available to personal assistants and service coordinator.

The following are responsibilities spelled out in Department of Public Welfare requirements:

Under penalty of law, to report within 14 days after a change occurs , a change in circumstances that might affect eligibility, including address, income, resources, medical assistance eligibility status and functional status.

Under penalty of law, to report within 14 days after a change occurs , a change in circumstances that might affect eligibility, including address

To provide documentation of eligibility related items when requested as a condition for receiving and continuing to remain eligible for attendant care service, including cooperation with Medicaid Waiver eligibility process.

Legal responsibility, under penalty of law for the truthfulness accuracy and completeness of information provided to determine or redetermine eligibility as attested to on Attendant Care program forms.

ABUSE & NEGLECT

KEEPING YOURSELF SAFE

Abuse can be physical, sexual, emotional or verbal. Abusive behavior is totally unacceptable and is also against the law.

Physical abuse is any action that causes physical pain including hitting, pushing, shoving, pinching.

Sexual abuse includes rape, any unwanted sexual contact, sexual harassment.

Emotional and verbal abuse include name calling, intimidation, yelling and swearing.

Neglectful behavior is the failure to provide the appropriate care, withholding of food, water, or medication.

If you are feeling afraid or intimidated by a personal assistant, you should talk with agency personnel immediately.

Don't minimize the situation or think that it will go away by itself.

Don't wait for the situation to get worse.

Act 28, part of Pennsylvania Law, forbids the neglect of a care dependent person. Criminal charges can be filed against caretakers who are neglectful or abusive.

DIVERSITY AND CULTURAL AWARENESS

General Guidelines

As a consumer, you may have the opportunity to work with people from many different backgrounds, with different values and beliefs. This may be a new experience for you. Tolerance regarding differences is the key to getting along with everyone.

You may observe all kinds of behaviors that are different from your own, including:

food choices

religion

attitudes about disability

attitudes about work

importance of family and including them in decisions

showing or not showing emotions

making or not making eye contact

importance of being on time

attitudes about children

levels of assertiveness

This is a short list. It would be impossible to list all the differences you might observe. **The best tool you can develop is an attitude of tolerance, acceptance and respect.** If it does not affect your attendant care services, then it should not be an issue.

Sometimes we may find other people's beliefs or practices odd or strange. It is human nature to think that the way our family or cultural group does things is the only correct way to do them, but that simply is not true.

Beware of stereotyping

If you know a person from a different culture, do not assume you know how everyone in that culture thinks or acts. That is stereotyping. Each person you meet

is a unique individual. You can interact with each person most successfully by getting to know him/her as an individual.

Appendix A

Understanding the Application Process

This is an outline of the application process prior to October 1, 2003. The process can take as long as 12 weeks. The steps in the process are outlined below.

1. Contact the provider to request service. Service Provider checks to see if you meet the following guidelines:

- at least 18 years of age but less than 60 years of age
- have a physical disability that can be expected to last for at least twelve months or may result in death
- have a need for personal care
- are mentally alert and capable of selecting , supervising, and if needed, firing an attendant
- capable of managing his/her own legal and financial affairs.

2. If you meet the basic guidelines, the Service Provider schedules a face to face appointment with you within 15 working days of your first contact.

3. First Meeting

-Service coordinator assesses your needs for attendant care and determines general eligibility, as well as the kind of assistance you need each day. Within ten calendar days, form 1299, "Attendant Care Services Notification of Eligibility Determination, will be mailed to you. The Service Coordinator will provide you with an MA-51 at this time. It must be completed by your physician and returned within 45 days to maintain eligibility.

4. If you are found to be eligible, the next steps determine which funding source will pay for your attendant care. There are **two funding sources** for the Attendant Care Program in Pennsylvania:

- Act 150 uses State funds. (Act 150 refers to the piece of legislation that created the program. You may have a weekly fee.)

-Medicaid Waiver uses a combination of state and federal funds. (Waiver refers to the fact that money is waived from nursing home funding to pay for in-home attendant care. You will not have any fee.)

-If you qualify for Medicaid Waiver funds, you must use those funds rather than ACT 150. (This step is mandated by the State of Pennsylvania.)

-If you don't qualify for Medicaid Waiver funds, but are eligible for attendant care, you will use Act 150 funds.

5. Medical Eligibility

-Service provider sends MA-51 to the Area Agency on Aging. The Area Agency on Aging has been mandated by the State to complete this next step for all applicants, regardless of their age.

-Someone from the Area Agency on Aging will call you to set up an appointment and then meet with you to complete an Options Assessment, which will determine your medical eligibility for the program.

-The Options Assessment may take 1-2 hours.

-Area Agencies on Aging have 30 days to complete and return the Options Assessment to the Service Provider.

-If you do not meet the medical eligibility for the MA Waiver, you may receive funding through Act 150

6. County Assistance Office

-The MA-51 and the Options Assessment are sent to the County Assistance Office, where the financial and medical eligibility are reviewed.

-The County Assistance Office will send a form called a PA 162 to the Service Provider to confirm or deny eligibility.

7. Start of Service

- Service Coordinator will send another form 1299 with the start date of services, and the hours of service you will receive.

Appendix B

Community Resource Centers

Northwest and Southwest Regions

Three Rivers Center for Independent Living (TRICL)
Mr. Bill Chrisner, President and CEO
900 Rebecca Avenue
Pittsburgh, PA 15221
(412) 371-7700

North Central Region

Lycoming-Clinton Joinder Board
Ms. Ellen DiDomenico, Human Services Director
200 East Street, Sharwell Building
Williamsport, PA 17701
(570)323-6467

Southeast Region

Jewish Employment and Vocational Service (JEVS)
Ms. Donna Boyer, Program Director
1845 Walnut Street
Philadelphia, PA 19103
(215) 854-1871

Northeast Region

Allied Services
Ms. Mary Lou Knabel, Director of In Home Services
100 Abington Executive Park
Clarks Summit, PA 18411
(570)348-2227

South Central

United Disabilities Services
Kathy Zumbrun, Director of Community Resource Center
1901 Olde Homestead Lane
Building B
Lancaster, PA 17605-0485
(717) 397-1841

Appendix C

Centers for Independent Living in Pennsylvania

All Centers provide four core services to people with disabilities and their families: Information and Referral, Peer Support, Independent Living Skills Training, and Advocacy. Most Centers also provide a variety of other services.

Allentown

Lehigh Valley CIL, 435 Allentown Drive, Allentown, Pa 18109, 610-770-9781,
TTY: 610-770-9789

Altoona

CIL Of South Central Pennsylvania, Station Mall - Suite 30, Ninth Avenue at 17th Street, Altoona, PA 16602, 814-949-1905, TTY: 814-949-1912

Camp Hill

CIL Of Central Pennsylvania, 207 House Ave, Suite 107, Camp Hill, PA 17011, 717-731-1900, TTY: 717-737-1335

Erie

Community Resources for Independence, 2222 Filmore Avenue , Erie, PA 16506, 814-838-7222, TTY: 814-838-8115

Erie

Voices for Independence, 3711 West 12th Street, Erie, PA 16505,
814-838-9890, TTY: 814-838-3702

Hazleton

Anthracite Region CIL, 44 West Broad Street, Hazleton, PA 18201-6418,
1-800-777-9906, TTY: 570-455-9800

Newtown Square

Freedom Valley Disability Enablement, INC., 3607 Chapel Road Newtown Square, PA19073, 610-353-6640, TTY: 610-353-8900

Philadelphia

Liberty Resources, Inc., 1341 North Delaware Avenue, Suite 105
Philadelphia, PA 19125, 215-634-2000, TTY: 215-634-6630

Pittsburgh

Three Rivers CIL, 900 Rebecca Ave, Pittsburgh, PA 15221, 412-371-7700, 1-800-633-4588, TTY: 412-371-6230

Reading

Abilities in Motion, 416 Blair Avenue Reading, PA 19601, 610-376-0010, TTY: 610-288-2301

Scranton

Northeastern PA CIL, 431 Wyoming Avenue, Lower Level, IBEW Bldg, Scranton, PA 18503-1228, 570-344-7211, TTY: 570-344-5275

St. Marys

Life and Independence for Today, 503 East Arch Street, St. Marys, PA 15857, 814-781-3050, TTY: 800-341-5438

Washington

Tri-County Patriots for Independent Living, 69 East Beau Street Washington, PA 15301, 724-223-5115, TTY: 724-228-4028

Williamsport,

CIL of North Central Pennsylvania, 210 Market Street, Suite A Williamsport, PA 17701, 570-237-9070, TTY: 570-327-5254

York

Center for Independent Living Opportunities, 3450 Industrial Drive York, PA 17402, 717-840-9653, TTY: 717-840-9653

Appendix D

UNIVERSAL PRECAUTIONS

All Personal Assistants must receive training from their employer (agency or consumer/employer) regarding universal precautions. If you use the consumer/employer model, it is your responsibility to make sure your attendants are trained in universal precautions. (You can ask the agency for assistance with this task.)

The idea of Universal Precautions is that ALL blood and body fluids should be treated as if they are potentially harmful. Universal precautions reduce the risk of AIDS, Hepatitis, B, and other blood-borne diseases. Anyone who could be exposed to blood or body fluids (including menstrual blood, semen, vaginal secretions, saliva when brushing teeth, open sores, stool or urine) should follow these procedures.

Following Universal Precautions will help ensure the health and safety of you and your personal assistants.

Universal Possible Exposure To Blood-Borne Disease

1. Immediately and thoroughly wash hands or other skin areas with soap & water or flush mucous membranes (eyes, nose, mouth) following contact with blood or other at risk body fluids and wash hands.
2. Remove and replace clothing that has become soiled by blood or other at risk body fluids and wash hands.
3. Report to your doctor and your employer any exposure where blood or other at risk body fluids could have entered the employee's body through the eye, nose, mouth, non-intact skin, bites, cuts or abrasions.
4. Upon reporting a possible exposure, request a medical evaluation and follow-up.

Universal Precautions Protective Equipment Procedure

1. Your employer should provide protective equipment such as latex gloves, plastic aprons and face shields.
2. Personal assistants should use protective equipment for any assistance that involves exposure to blood, semen, vaginal secretions, saliva from brushing, flossing, using a water-pic with teeth, open sores, body fluids with visible blood, or body fluids that may have blood such as stool or urine.
3. Gloves should always be used while providing the following assistance:
 - a. Assisting to bathe the rectal or groin area
 - b. Bowel care
 - c. Oral hygiene (employee brushes, flosses or uses a water-pic)
 - d. Using a safety razor for shaving
 - e. Toileting assistance including diapers/Depends
 - f. Bladder/catheter care when changing, cleaning urinary supplies, intermittent catheterizations
 - g. Feminine hygiene products - changing or disposal
 - h. Cleaning open skin areas or applying a dressing
 - i. Handling soiled clothes, bedding
 - j. Cleaning toilets, commodes or soiled equipment
 - k. When cleaning/disinfecting surfaces from blood, stool, urine or at risk body fluids
 - l. Any task that could cause hand contact with blood or other at risk body fluids
4. Tasks that should require the use of plastic aprons:
 - a. Those that involve splashing of body fluids
 - b. Handling soiled bedding, clothing
 - c. Tasks in which your clothing is at risk of becoming soiled by blood or body fluids
5. Use face shields for tasks that involve splashing, for example, when brushing, flossing or using a water pic.
6. Glove guidelines:

- a. Use the correct size.
 - b. Replace gloves when they become torn, punctured or contaminated.
 - c. Latex gloves are disposable - DO NOT REUSE OR WASH.
 - d. Remove gloves by peeling from the inside out without touching the skin or wrists/hands.
7. Used gloves & aprons should go directly into a lined trash receptacle.
 8. Face shields should be cleaned with a disinfectant and reused.
 9. Hand washing is required after the use and disposal of gloves or aprons and after cleaning face shields.

Universal Precautions Decontamination Procedure

1. Use latex gloves and/or apron as needed to protect skin and clothing.
2. Wipe up blood, soiled surface or equipment with a disposable towel or rag.
3. Apply a disinfectant or 1 to 10 chlorine bleach and water mixture to soiled surface and allow to air dry.
4. Throw all rags, towels, gloves, aprons into a plastic bag.
5. Be sure the outside of plastic bag is clean or re-bag into a clean bag and seal tightly.
6. Dispose of bag properly
7. Wash hands.

Universal Precautions

Laundry Procedure

1. Use latex gloves or plastic aprons if skin or clothes could have contact with blood or other at risk body fluids. Wash hands after removal.
2. Do not shake the soiled bed linen or clothes.
3. Keep soiled linen/clothes off other surfaces (i.e., furniture or floor).
4. Place directly in plastic bag at the site (i.e., bedside, bathroom).
5. Use gloves to put soiled linens/clothes into the washer.
6. Use hot water in wash cycle and high heat in dry cycle.
7. Wash clothes/bedding soiled by body fluids separately from regular wash.

Universal Precautions

Waste/Garbage Removal

1. All soiled gloves and aprons should be placed directly into a trash receptacle.
2. All soiled pads, paper towels, rags and hygiene products also go directly into a lined trash receptacle.
3. Be sure the outside of the plastic bag is clean and is not leaking, or put into another clean plastic bag for handling.
4. Seal tightly and set out for garbage removal.

Universal Precautions

Personal Hygiene Procedure

1. Do not eat, drink, smoke, apply cosmetics or lip balm, or handle contact lenses while performing tasks that involve body fluid exposure.
2. Hand washing is done with soap and running water for 10-15 seconds using a clean paper towel for drying.
3. Hand washing is a must:
 - a. before beginning direct care tasks;

- b. before touching, preparing, cooking, eating food;
 - c. before placing your hands by your eyes, nose, mouth;
 - d. after removal of gloves, aprons and cleaning face shields;
 - e. after direct care employees personally use the toilet;
 - f. after direct body fluids exposure (i.e. urine, stool, blood, etc.).
4. If a personal assistant has a dressing on their hand, a glove must be worn for all consumer contact.

Universal Precautions

Cleaning and Care of Urinary Equipment

Wear gloves whenever in contact with urine. Wear a plastic apron if you think you might splash your clothing while cleaning urinary equipment

Use ONE of the solutions below:

BLEACH SOLUTION is used to remove stains and odor from plastic (i.e. tubing, leg bags valves, connectors, etc.). Mix a one to ten (1 to 10) solution of chlorine bleach to water.

VINEGAR SOLUTION is used to remove mineral deposits (from the urine) that can plug tubing, connectors, valves, etc. Mix a one to ten (1 to 10) solution of household vinegar to water.

- A. Soak plastics 20-30 minutes in a large glass jar, plastic bucket or basin used only for this purpose.
- B. Immerse tubing and fill bags with this solution to insure all parts are exposed to the bleach solution. (A syringe is helpful for forcing the solution through the tubing)
- C. Pour this solution into the toilet after soaking, NEVER pour it in the bathroom or kitchen sinks.
- D. Refill the container with cold water and thoroughly rinse the equipment. Rinse the equipment at least twice, emptying the rinse water in the toilet after each rinse.
- E Hang to dry on the towel racks in the tub/shower area.

Appendix E

Meal Preparation and Food Safety

As a consumer, you may be directing a personal assistant with shopping, cooking, and storing food. It is important to be familiar with basic food safety techniques. Food poisoning can be a dangerous and potentially fatal illness. By following safe kitchen procedures, you will greatly reduce the risk.

TIPS ON STORING AND PREPARING FOODS SAFELY

1. Always wash hands before and after handling food.
2. Purchase only the amount you can use before it spoils.
3. For both shopping and storage, place meat and poultry in a plastic bag so meat juices will not contaminate other foods.
4. Discard any perishable food left out at room temperature for more than two hours.
5. Place the most recently purchased foods behind older items on the shelf so that the older items will be used first.
6. Store staples (sugar, flour, cereals) in airtight containers.
7. Keep the freezer temperature at zero degrees Fahrenheit (0°F) or colder and keep all items frozen in air-tight containers i.e. freezer bags or freezer wrap. Keep the refrigerator temperature at 40°F Fahrenheit or below and store all leftovers in air tight containers to prevent cross contamination and the transfer of odors and flavors.
8. Promptly remove and throw away all spoiled/moldy foods found in the refrigerator.
9. Allow enough space around items stored in the refrigerator for the air to circulate freely around them. This will prevent hot or cold spots in the refrigerator.
10. Store staples and canned items in clean, cool, dark, and dry cabinets away from water pipes, heat ducts, and off the floor.
11. Cutting boards and counters should be washed immediately after use with warm soapy water. Sanitize cutting boards by using a solution of one teaspoon of chlorine bleach in one quart of water.
12. Don't re-freeze thawed foods unless they have been cooked.

13. Don't use the same cutting board for meats and vegetables.
14. Don't store cleaning supplies with foods in a cabinet (i.e., bleach and potatoes under the kitchen sink).
15. Don't leave leftovers on the counter to "cool". Refrigerate them promptly.
16. Don't drain or soak ANY bladder equipment in the kitchen or bathroom sink.

From the USDA Website: Basics for Handling Food Safely

Appendix F

Social Role Valorization

What is it? Social Role Valorization, or SRV, is philosophy that seeks to improve the quality of life of people and groups that are not valued in society.

The Pennsylvania Developmental Disabilities Council, whose funding made this manual possible, believes that service providers and consumers should understand SRV philosophy. SRV gives some reasons why people with disabilities may have a difficult time getting the “good things” in life: a home, family, respect, acceptance, an education, opportunities for work, and a decent standard of living. More importantly, it gives us some ideas on how to improve this situation.

Some Basic Ideas:

SRV applies to all people and groups that are left out of the mainstream, not just people with disabilities.

People can occupy many different roles in society. Examples of roles include: parent, spouse, employee, friend, volunteer, artist, employer, hobbyist, pet owner, criminal, patient. Can you add to this list?

Roles have a value or status assigned to them, depending on time and place. For example, in some cultures, elders are respected, but not in others. Some people value stay-at-home mothers. Others do not. We all make assumptions about people because of their roles.

Think about the following roles and your opinions of each:

- artist
- personal assistant
- pilot
- mother
- waitress
- senator
- welfare recipient
- prisoner

The value we place on roles can change and can be influenced by other roles the person holds.

How do your opinions of those roles change if a person has more than one role?

A mother and a senator

A convicted criminal and a pilot

A welfare recipient and an artist

List some roles that usually have a high value:

List some roles that usually have a low value:

List some roles that you occupy:

If a person has a valued role in society, that person is more likely to receive the good things that society has to offer. If a person has a negative role, it is less likely that he/she will receive the good things society has to offer. A person with a negative role may also be rejected by community, society and even family, be kept at a social distance from others, have negative images attached to them, and may be the object of abuse.

Historically, people with disabilities have had a low or negative value in our society. The following negative roles have sometimes been assigned to people with disabilities:

child role

burden to society

object of pity

sinner

object of ridicule

menace

patient

subhuman

SRV suggests that the best way to have people become more socially valued is to encourage positive roles for historically devalued people and/or to improve the value of the roles that they do hold.

SRV suggests that we examine both language and image when trying to improve a social role.

Language

Words that convey images of victimization or pity create negative images. Use language that is empowering and creates positive images. Use language that puts people first, for example:

Person who has a disability

Person who has cerebral palsy

Person who has a spinal cord injury

Words that have negative connotations are:

Victim of

Invalid

Crippled

Wheel chair bound

Words with more positive connotations:

Person who uses a wheelchair

Person who has a disability

Image

We have often been told that one picture is worth a thousand words. Our minds quickly store images and we use them to form opinions about what is going on around us.

Negative images are very powerful. Sometimes people are trying to be helpful and yet the end result is the creation of a negative image. This negative image creates ongoing problems for the “recipients” of this help.

One of the best examples of this is the disability-related telethons. Most of the people involved want to be helpful, yet the images created on the telethons evoke pity. People watching the telethons form an opinion of individuals with disabilities that has long range damaging effects, even though the short term goal of raising money may have been achieved.

Because people with negative images attached to them are left out of the mainstream, they are unlikely to receive the “good things” society has to offer. Actions and situations can be evaluated with this in mind. We can always ask what kind of image is being created by our actions or the activities we support. For example, when you are accompanying a consumer in the community, does your behavior convey clearly that you are an employee working for the consumer? What image is created by your interactions?

Can you think of activities that you have been involved in that create positive or negative images?

Appendix G

Resource Materials

Independent Living Movement, History and Philosophy

BOOKS

The New Disability History: American Perspectives

Paul Longmore (editor) Lauri Umansky (editor). 2001. Cahners Business Information, Inc.

Beyond Ramps: Disability at the End of the Social Contract, Marta Russel. 1998. Common Courage Press.

Disability and Culture, Benedicte Ingstad (editor), Susan Reynolds Whyte (editor). 1995. University of California Press.

Nothing About Us Without Us: Disability Oppression and Empowerment James Charlton. 2000. University of California Press.

WEB SITES

<http://www.ncd.gov/> National Council on Disability

www.disabilityresources.org Disability Resources on the Internet Thousands of the best disability resources on the Internet, selected and annotated by the staff of *Disability Resources Monthly* and alphabetically arranged by subject for easy access.

www/ilru.org Independent Living Research Utilization

Living Well with a Disability

www.tell-us-your-story.com disability discussion forum, stories on awareness, rights and inspiration

Changing Lanes, Michael Creure, a guide for dealing with disability, aging, or illness

Supervising Personal Assistants

Avoiding Attendants from Hell, A Practical Guide to Finding, Hiring, and Keeping Personal Attendants, June Price.

Managing Personal Assistants: A Consumer Guide, from the Paralyzed Veterans Association, a manual available at

www.pva.org/NEWPVASITE/publications/pubs/PersAsst.htm or by calling (888) 860-7244

Hiring and Management of Personal Care Assistants for Individuals with Spinal Cord Injuries, a manual available at www.tbi-sci.org