



December 2003

Dear Consumer of Personal Assistance Services:

In an effort to reduce the barriers of employment for people with disabilities, I am writing to ask for your participation in completing a survey that will benefit consumers of personal assistance services, also known as attendant care, throughout Pennsylvania. The Pennsylvania Council on Independent Living (PCIL) is conducting a research study, on behalf of the PA Department of Public Welfare (DPW), to identify issues and potential solutions with regard to back up personal assistance services.

It has long been proven and known that the reliability of personal assistance services is critically important for those who utilize this service to pursue a job, to get to work, and to remain employed. When an attendant or personal assistant is not timely or does not arrive at all; the ability of a consumer to be employed or maintain a job is negatively impacted. The result is that many individuals wishing to work do not have the opportunity to do so or feel that they cannot try to work. In addition, many hardships are faced by those who are working; and in some cases they lose their employment.

To succeed in reducing these problems a reliable and timely back up personal assistance services system for consumers is necessary. Back up personal assistance services is thought of as a replacement personal assistant when a regular personal assistant does not show up or does not arrive as planned.

Kindly take some of your valuable time to complete and return the enclosed survey. It should take you about 15 – 20 minutes to complete the survey. Please be assured that your individual responses will be held in **strict confidence**.

If you have questions or need additional clarification, you may reach us at (866) 302-7245. The survey can be returned with the enclosed pre-addressed, postage-paid envelope; or filled out via telephone with our toll free phone service; or on our website [www.pcil.net](http://www.pcil.net). I ask that you return it to us within 2 weeks or as soon as possible.

Thank you in advance for your time and assistance in this project.

Cordially,

Michael A. Auer  
Executive Director

Anthracite Region Center  
for Independent Living  
Hazleton, PA

Center for Independent  
Living of Central PA  
Camp Hill, PA

Center for Independent  
Living of Southcentral PA  
Altoona, PA

Center for Independent  
Living of North Central PA  
Williamsport, Pa

Center for Independent  
Living Opportunities  
York, PA

Community Resources for  
Independence  
Erie, PA

Freedom Valley Disability  
Enablement  
Newton Square, PA

Lehigh Valley Center for  
Independent Living  
Allentown, PA

Liberty Resources, Inc.  
Philadelphia, PA

Life and Independence  
for Today  
St Marys, PA

Northeast PA Center for  
Independent Living  
Scranton, Pa

Three Rivers Center for  
Independent Living  
Pittsburgh, PA

Service Area Code:

**DEMOGRAPHIC INFORMATION**

1. What is your gender?  Male  Female      What is your age? \_\_\_\_\_

2. What type of area do you live in?  
 Rural                                       Urban                                       Suburban

3. What is your primary transportation?  
 I drive myself                       I rely on public transportation/transit                       I rely on others (family, friends, attendant/personal assistant, etc.) for transportation

4. How long have you been receiving attendant care/personal assistance services?  
 Less than one year                       4-6 years                                       More than 10 years  
 1-3 years                                       7-10 years

5. Which "model" do you use?  
 Consumer model                       Agency model                                       Combination model                                       Don't know/Not sure

6. Are you currently employed for a wage?  
 Yes (Go to a, b, c & d)  
 No (Go to e & f)

a. *If yes*, are you employed part-time or full-time?  Part-time  Full-time

b. *If yes*, are you self-employed?  Yes  No

c. *If yes*, are you enrolled in the Medical Assistance for Workers with Disabilities (MAWD)?  Yes  No

d. *If yes*, are you working as many hours as you would like to work?  
 Yes  No

*If no*, how many hours would you like to be working?  
 less than 20     20-29 hours     30-39 hours     40 or more hours

e. *If no*, have you done any of the following in the past year? (check all that apply)  
 Had a job interview                       Update my resume                                       Volunteered my time  
 Had skills training/internship                       Taken classes to learn a work skill                                       Reviewed area employment listings  
 Contacted/obtained OVR services                       Contacted/visited local Career Link



8. Are backup services available to you daily on a 24-hour basis?

Yes                       No                       Not sure

9. How would you rate backup coverage at the following times? (*circle answer*)

Early morning	<b>Very Poor</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>	<b>Excellent</b>
Evenings	<b>Very Poor</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>	<b>Excellent</b>
Weekends	<b>Very Poor</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>	<b>Excellent</b>

10. Have you ever offered a backup attendant/personal assistant extra "incentives" for being available and dependable?  Yes                       No

a. *If yes*, what types of incentives have you offered? \_\_\_\_\_

\_\_\_\_\_

11. Do you feel the backup attendants/personal assistants would be more available if family members could be paid?  Yes                       No

12. Are you aware of the differences between the "models" of service (i.e. agency, consumer, combination)?  Yes                       No

13. If your services are through the "consumer model," does the agency assist in paying for advertising for an attendant/personal assistant?

Yes                       No                       Not sure what is meant by "consumer model"

14. What would you say are the top two advantages and disadvantages of each "model" of service?  Not sure (*skip to next section*)

**Agency model:**

Advantages: \_\_\_\_\_

Disadvantages: \_\_\_\_\_

**Consumer model**

Advantages: \_\_\_\_\_

Disadvantages: \_\_\_\_\_

**Combination model:**

Advantages: \_\_\_\_\_

Disadvantages: \_\_\_\_\_

15. I would be in favor of a standardized “priority backup system” in which consumers are prioritized according to their needs and situation. (circle number)

Strongly Disagree	Disagree	Neither Disagree	Agree nor	Agree	Strongly Agree
1	2	3	4	5	

a. Rank the following in order of importance when prioritizing backup needs (1=highest priority; 5=lowest priority)

_____ Gainful employment	_____ Receiving training/attending college
_____ Consumer health & safety	_____ Going to medical or other important appointments
_____ Interviewing/applying for employment	<input type="checkbox"/> No priority should be given (skip to #16)

16. What is the most significant problem(s) with obtaining and using a backup attendant/personal assistant? \_\_\_\_\_

17. What have you found to be successful with obtaining and using a backup attendant/personal assistant? \_\_\_\_\_

**BACKUP ATTENDANTS/ASSISTANTS & EMPLOYMENT**

1. What would you say are the actions/behaviors (e.g. job interviewing) of someone who is “wishing to be employed?” \_\_\_\_\_

*The remaining questions in this section are only to be answered if you are currently employed or have ever been employed while using attendant care/personal assistant services. If not, please skip to the final section entitled “Concluding Thoughts.”*

2. How many times in the past year have you been late to work or missed work because of difficulties with obtaining a backup attendant/personal assistant?

<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 5-6 times	<input type="checkbox"/> 10-12 times	<input type="checkbox"/> No times
<input type="checkbox"/> 3-4 times	<input type="checkbox"/> 7-9 times	<input type="checkbox"/> > than 12 times	

3. Have you ever been terminated from a job because of difficulties with obtaining a backup attendant/personal assistant?  Yes  No
4. Have you ever had to change jobs because of difficulties with obtaining a backup attendant/personal assistant?  Yes  No
5. Do you receive personal assistance services/attendant care at work?  Yes  No
- a. *If yes*, have you ever required a backup personal assistant/attendant at work?  Yes  No
- b. *If yes to #5a*, please comment on what you do in those situations.
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6. *If you travel for your work*, are backups available to travel with you?

- Do not travel for work  Yes  No

7. How would you rate your employer's flexibility with being late to work/missing work due to difficulties with obtaining a backup attendant/personal assistant?

- Not at all flexible  Somewhat flexible  Extremely flexible

8. Are you given "priority" status for receiving a backup attendant/personal assistant over consumers who are not employed?

- Yes, given priority status  Not given priority, all consumers have equal status  Not sure if given priority status or not

## CONCLUDING THOUGHTS

1. What is the number one issue that makes it difficult to obtain consistent, reliable backup attendant care/personal assistance services? \_\_\_\_\_

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2. Do you have any suggestions on how to improve backup attendant care/personal assistance systems? *(If so, please share)* \_\_\_\_\_

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*Thank you for your time and input!*