

Consumer-Directed Home Care

April 9, 2013

2:00 - 3:30 PM Eastern Time

Participant Agenda

1. Welcome and Introduction

Sara Cirba, Advocacy and Development Associate, Consumer Voice

2. Summary and Overview of Consumer Directed Care

Peggy Powell, Director of Workforce and Curriculum Development, PHI

- What is consumer direction?
- What are the different models of consumer direction and what does it look like in various states?
- What do consumers say that they need in self-direction? (e.g., support, training for themselves and their workers, flexibility, technical assistance)
- Where can you go to learn about consumer direction in your state?

3. A Closer Look: Consumer Perspectives on Consumer Direction

Julie Sanchez, Consumer of Services

Nellie Ferrante, Consumer of Services

- How long have you been directing your own care?
- How did you find your workers?
- What interview questions did you ask?
- How many different workers do you have?
- How do you coordinate schedules with your worker?
- What you do when your worker can't come or doesn't show up?
- How is your worker paid?
- How do you determine how much you will pay your worker?
- What you like about directing your own care / what don't you like as much?

- Recommendations to others who are starting to direct their own or their loved one's care: tips for making it successful

4. Question and Answer

Facilitated by Sara Cirba

5. Wrap up/closing remarks

Sara Cirba

Overview of the Three Personal Assistance Options

If you are a consumer with a disability and you receive government aid to pay for your personal assistance services, you have the following three options for managing your PA services:

1. the agency-directed option,
2. the consumer-directed option, or
3. the blended option.

Case Manager

In all three options, your local government group or consumer support organization (CSO) assigns you a case manager. You work with the case manager to determine what services you need and how you can get them.

The best option for you depends on your particular needs and preferences and on how much you want to be involved in managing your services.

What Is the Agency-Directed Option?

With the agency-directed option, the agency is responsible for hiring, firing, training, and scheduling your personal assistants (PAs). The agency also handles administrative tasks such as payroll and benefits. Your case manager establishes the initial connection between you and the agency. You or a family member can give feedback to the agency about your satisfaction with your assigned PAs and any changes in your services.

What Is the Consumer-Directed Option?

In the consumer-directed option, you are responsible for some aspects of managing PA services. These responsibilities include hiring, training, supervising, and firing your PAs. You may also have to handle some administrative tasks such as approving timesheets for payment and obtaining PA medical clearances. You still work with a case manager.

What Is the Blended Option?

The blended option is a combination of both agency- and consumer-directed. You hire and supervise your own PAs to provide **some** of your services and supports, and contract with an agency to provide some of the other services. [And you still work with a case manager.](#)

Employer Responsibilities within Each Option

➔ Recruit and Hire Personal Assistants (PAs)

Responsibilities/Rights	Agency-Directed	Consumer-Directed	Blended
Advertise for PAs and cover costs	Agency	You	You, and a CSO, government group, or agency
Screen and interview candidates			
Check PA's work and other relevant references			
Hire PAs			
Ensure that paperwork for PAs is in order and submitted to government			

➔ Manage Assistance Services

Responsibilities/Rights	Agency-Directed	Consumer-Directed	Blended
Schedule PAs	Agency	You	You and a CSO, government group, or agency
Review and submit PA timesheets		You and a CSO	
Set up back-up and emergency plans when PAs are sick, on vacation, or unable to come to work		You	
Keep accurate PA records and report any changes			

Employer Responsibilities within Each Option

➔Oversee Administrative Matters

Responsibilities/Rights	Agency-Directed	Consumer-Directed	Blended
Calculate yearly salaries, weekly pay, and benefits	Agency	Government or a CSO, and you	A CSO or government group, and agency
Oversee PA taxes and benefits		Government or a CSO	
Cover work-related accidents and injuries following your state’s Worker’s Compensation Policy			
Ensure that PAs have annual physical exams and TB tests		You or a CSO	You and agency

➔Supervise PAs

Responsibilities/Rights	Agency-Directed	Consumer-Directed	Blended
Determine which duties PAs will and will not do	Agency	You and PA	You and a CSO, government group, or agency
Meet with PAs regularly to provide constructive feedback		You	
Determine training needs for PAs			
Fire PAs who are not meeting your personal assistance needs			

Advantages and Disadvantages: *Agency-Directed Option*

Recruitment, Availability, and Assignment of PAs

Advantages

- Agencies usually have PAs who need work.
- You can switch agencies, although agencies have similar rules.

Disadvantages

- The initial screening of PAs is based mostly on your medical and personal assistance needs rather than on your preferences.
- Availability determines a PA's assignment rather than matching the PA with you "as a person" who has unique needs and preferences.
- A PA's hours are less flexible since scheduling is usually around agency policies rather than your needs.

Training

Advantages

Agencies train PAs for you.

Disadvantages

Training usually focuses on clinical and personal care techniques for consumers who are aging or ill rather than on people with disabilities.

Meeting Personal Assistance Needs

Disadvantages

- PAs follow the agency's plan of care and may have limits on how much they can respond to your preferences.
- Agencies have policies for services that government covers, and create/ change care plans based on policies instead of your preferences or needs.

Supervision and Administration

Advantages

The agency is responsible for:

- completing paperwork—care plans, work agreements, timesheets
- approving payroll
- ensuring medical clearances and conducting background/reference checks

Disadvantages

PAs see the agency as their employer/supervisor and you as the "patient/ client" or "case."

Advantages and Disadvantages: *Consumer-Directed Option*

Recruitment, Availability, and Assignment of PAs

Advantages

You can choose your own PA and design your own schedule for your personal assistance services.

Disadvantages

You may have:

- limited knowledge and skills to advertise for and recruit PAs
- difficulties finding PAs to meet your specific scheduling needs

Training

Advantages

You can train PAs to provide services and support in your *own* way.

Disadvantages

You may have:

- physical, intellectual, or cognitive limitations that make training difficult
- discomfort when you train PAs and prefer to have someone else do it

Meeting Personal Assistance Needs

Advantages

You can:

- get the services and supports you want and need in ways you prefer
- have more flexibility in managing ADLs and changes in routine

Disadvantages

You may:

- have physical, intellectual, or developmental barriers to developing your own schedule and ensuring you get services in ways you request
- feel overwhelmed when you forget something or when changes occur
- hire PAs who are unwilling or unable to be flexible, resulting in no coverage at times
- have problems getting emergency or last-minute coverage

Advantages and Disadvantages: *Consumer-Directed Option*

Supervision and Administration

Advantages

You can:

- develop a sense of confidence from managing your services effectively
- learn communication and people management skills that can help you in all parts of your life

Disadvantages

You may:

- be inexperienced in supervising PAs or any staff
- have language and other communications barriers to understanding PAs

Advantages and Disadvantages: *Blended Option*

When you use a blended option to manage your personal assistance services, you can decide to:

- hire and supervise PA staff to provide **some** of the services and supports you need, and
- contract with an agency to provide **some** of the other services

Advantages

You can get the best of the consumer- and agency-directed options. For example, you can hire PAs to provide support in ways you want, but can also use an agency to provide PAs to fill scheduling gaps, such as in emergencies, on weekends, or during vacations.

You may be unable or unwilling to train a PA. So, you can hire a PA to provide services based on the skills and experience they already have **and** use an agency to provide a PA already trained in your required areas.

You may have to find the *right* PA quickly because your PA is not working out or has to leave without much notice. An agency can provide back-up service until you can recruit and hire the *right* PA.

Disadvantages

You have to manage the following **two** sets of relationships at the same time:

1. the relationship with the PA whom you hire and supervise directly, and
2. the relationship with the PA whom the agency hires and supervises.

You have to know and accept the responsibilities and limitations of receiving services from an agency while you advise and direct the agency's PA to meet your needs and preferences.

Furthermore, you and the agency will have different work policies that may conflict with each other. For example, you may need the PA to walk your dog as a support. However, agency policies prohibit their PA from providing a service that is not a direct personal assistance-related task covered by Medicaid or Medicare regulations. Or, you might need a PA to accommodate your social commitments during scheduled hours, but agency rules prohibit their PA from providing you with this kind of support.

Self-Direction Fact Sheet

- **What is self-direction?**
 - Self-direction is when a consumer is responsible for and in charge of their own services and supports. Self-direction gives the consumer control and flexibility as well as responsibility and duties.

- **What are different types of self-direction?**
 - If a consumer is eligible for Medicaid Waiver services, they can choose to be part of the self-directed waiver program. This waiver varies from state to state.
 - Under one type of self-direction the consumer is the employer and responsible for assuming both payroll and tax responsibilities. They are in charge of hiring, training, supervising and firing their attendants. In general, these workers can include friends or family members who are not considered to be “legally responsible” (for example, a spouse). Some states even permit the consumer to hire any family member, including someone who is legally responsible.
 - Another type of self-direction gives the consumer the authority to hire, fire, train and supervise their attendants, but responsibility for wages, payroll taxes, and worker’s compensation insurance is assigned to a state agency or a third-party fiscal intermediary with whom the state contracts. In a few states the fiscal intermediary is a “public authority” that takes on the responsibility for duties such as issuing paychecks and withholding taxes. The public authority may also run a registry that screens workers and then provides a list of the screened workers to consumers. Consumers can use the list to identify workers to interview and possibly hire. A consumer should ask their state Medicaid office if their state has a public authority.
 - Here are some points to think about when considering the option of self-direction¹:

¹*Help At Home*, published by the Ohio Department of Aging.

- The consumer can pick the worker who is most compatible with them and their situation.
 - The consumer has more flexibility in scheduling.
 - The consumer is responsible for hiring, training and scheduling workers and finding replacements to cover illness and other time off.
 - The consumer is responsible for paying workers (unless they use a fiscal intermediary or public authority).
- **How can I find out more information in my state?**
 - In most states, you can access services through Area Agencies on Aging (AAA) and, in some states, through Aging and Disability Resource Centers (ADRC).
 - **Area Agencies on Aging (AAA)**

An Area Agency on Aging is a non-profit organization that coordinates and often provides a range of services to assist older adults in a particular community or region. Many AAAs also serve younger persons with disabilities and may have some programs that are available to anyone age 18 or older. The AAA can connect you with the right information and available services for your particular situation. You can find the Area Agency closest to you by going to: [http://www.aoa.gov/AoAroot/AoA_Programs/OAA/How To Find/Agencies/find_agencies.aspx](http://www.aoa.gov/AoAroot/AoA_Programs/OAA/How_To_Find/Agencies/find_agencies.aspx) or calling the Eldercare Locator number (800) 677-1116.
 - **Aging and Disability Resource Centers (ADRC)**

These centers provide easy access to free information about the full range of long-term service and support options in a state or area to consumers and their families. To find the ADRC closest to you, go to: <http://www.adrc-tae.org/tiki-index.php?page=ADRCLocator> or call (800) 677-1116. Not all states have ADRCs statewide, and some states may only have them in a few areas.
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Self-Direction - Is it Right for You?
Adapted from “Mi Via: Is It Right For You,”
with permission from the New Mexico Aging & Long-Term Services Department

Pros and Cons

This worksheet can help you figure out if self-direction is right for you. In the column labeled “Pros,” write out all the reasons self-direction would be right for you. In the column labeled “Cons,” list all the reasons self-direction would not be right for you. After you have listed all the pros and cons, ask your family and friends what they think. They may have ideas that you didn’t think of. List their suggestions in the pros and cons columns too. After you have listed all the pros and cons, decide how important each is to you and rank it according to:

Not important = 1 It matters = 2 Very important = 3

When you are done, every pro and every con should be ranked with a 1, 2 or 3.

Pros	Rank	Cons	Rank

After reviewing all this information, self-direction is:

_____ Right for me

_____ Not right for me

_____ Still not sure

Job Description for My Personal Assistant

Make notes for each category. You will use this form as a guide when you interview PA candidates. If you do not complete this during the workshop session, complete it at home, before the next session.

My Expectations—I expect a PA to have these personal qualities:

My Preferences—These qualities would be great in a PA but are not required:

Job Responsibilities

Activities of Daily Living (ADLs)

Assistance with Medical Needs

Assistance with Work, School, or Appointments

Assistance with Leisure Activities

Other Kinds of Assistance

Ways to Find PA Candidates

Search in Your Community

- Ask your family, friends, peers, and current PAs if they know of anyone who might be interested or can help you spread the word.
- Check registries at Centers for Independent Living, Agencies on Aging, or advocacy organizations for lists of possible candidates.
- Post ads on bulletin boards in:
 - shopping centers, supermarkets, or food co-ops.
 - laundromats or laundry rooms in your apartment building.
 - coffee shops or cafés.
 - high schools or colleges.
 - gyms or community centers.
 - churches, synagogues, mosques, or temples.

Target Community and Local Colleges and Training Centers

- Place ads in career centers at colleges and other organizations that offer training in health-related programs.
- Call college departments offering a Home Health Care or Certified Nurse Aide/Assistant (CNA) program.

Advertise in Newspapers and Online

- Think locally by advertising in town or community newspapers.
- Post ads on sites that offer support for people with disabilities.

Contact Community Health Centers or Clinics, Day Cares, Nursing Homes, and Hospitals

- Post ads on bulletin boards to attract staff members looking for extra hours.
- Call to ask about students in work placements who might want extra work.

Other Ways to find PA Candidates
