

Chapter 8

PERSONAL CARE ASSISTANT/ATTENDANT (PCAs)

Some individuals with Spinal Cord Injuries and brain injuries may need assistance for their personal care and participation in community activities. The following are some definitions and tips for how to hire others to assist you.

WHAT TYPICAL SERVICES DO PERSONAL CARE ASSISTANTS PROVIDE?

A Personal Care Assistant (PCA) – variously known under alternate names such as **caregiver**, personal care attendant, patient care assistant, **personal support worker** and home care aide - is a **paid**, employed person who helps people who have disabilities or chronic illness or who have had surgery or need home hospice to be as independent as possible in their own home. Duties may include assistance with **activities of daily living** (ADLs – bathing, dressing, meal preparation, etc.), cognitive issues, health related need and/or assistance to get around in the community. While there is no single definition or professional title for PCA(s), in general they may be distinguished as people you hire, train and fire and you are the one directing your care.

CENTER FOR PERSONAL ASSISTANCE SERVICES

The Center provides research, training, dissemination and technical assistance on issues of personal assistance services (PAS) in the United States. Their research can be found under the project link above and prior trainings are in presentations, webcasts and on the PAS Users page. In 1999, the Supreme Court ruling in the Olmstead case found that institutionalization of individuals who are able and want to receive care at home and in the community constitutes discrimination under the Americans for Disabilities Act (ADA). Since then, consumers and advocacy groups have utilized the integration mandate of the Olmstead ruling to seek deinstitutionalization and increased Home and Community-Based Services (HCBS).

FINDING, INTERVIEWING AND HIRING A PCA(s)

“YOU ARE THE EMPLOYER

A Guide to Hiring and Managing Personal Assistant Service”

This guide was developed to provide you with the skills and resources you need to hire and manage your personal assistants. This module will provide you with some additional resources and organizations that can assist you with the various areas in hiring and managing personal assistants. As you learned throughout this guide, hiring and managing personal assistants can be complex. The more information and experience you gain the less complex the process becomes over time. It’s also helpful to talk with others who have similar experiences to hiring and managing their own personal assistants.

You will be surprised to know that many other employers have struggled with issues similar to yours; over time they were able to develop an approach that worked for them. Don’t feel like you need to know everything in this guide overnight. Determine what is important to your individual needs, and take one step at a time.

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Implemented by the Connecticut Department on Social Services and the University of Connecticut, A.J.Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service, 263 Farmington Avenue, MC 6222, Farmington, Connecticut, 06030. This guide can be made available in alternate formats upon request.

Address specific requests to the **University Center for Excellence in Developmental Disabilities** at 1-860-679-1500 (v) or 860-679-1502 (TTY)

HOW TO FIND A PCA(s)?

- The following sources can be utilized in your search:
 - College bulletin boards and placement boards
 - Friends who use attendants
 - Local and college newspapers
 - Employment offices
 - Public Health Department
 - Hospital bulletin boards
 - Local Personal Care Agency

After ads have been placed, people will call for information. Explain your general situation and arrange to meet the person. Do not hire a person sight unseen. The purpose of the interview is to inform the person exactly what the job involves. This includes wages, hours to work, problems that may arise and responsibilities.

You will probably need to employ more than one person, especially if you require an attendant for different times throughout the day. This also eliminates the problem of one person working seven days a week and needing coverage for vacation, illnesses, etc.

Call your county public health nurse to arrange for an assessment and learn more about PCA options available, including types of agencies that provide personal care assistance services and how to hire your own staff.

For more information, **contact your local county agency**. If you are enrolled in a prepaid health plan, contact your health plan for specific instructions.

FINDING LIVE-IN PCA(s)

You need to weed out details of the living arrangements. In essence you are hiring a roommate. Here, the initial weeding out can be done by factors such as where your apartment is located and what the nature of the job/living

arrangement is. This should be done in a more careful manner as you will be living with this person, and personality differences will (and should) play a much larger role in your decision. Honesty and your safety must also be considered. This approach however, can also help you afford a PCA and get assistance when you need it.

Connecticut ILC(s) <http://www.ct.gov/dss/site/default.asp>.

Connecticut currently has five independent living centers (ILC) that may be of assistance in locating and training attendants and providing other independent living services. You can also contact CT Disability Services, 800-537-2549 or Independent Living Services, toll free- CT, 25 Sigourney Street, Hartford, CT 06106-5033. The ILC(s) in Connecticut include:

Disability Resource Center of Fairfield County

203-378-6977
www.drcfc.org
Email: info@drcfc.org
80 Ferry Boulevard
Stratford, CT 06615

Center for Disability Rights

203-934-7077
www.centerfordisabilityrights.org
Email: cdr7077@aol.com
764A Campbell Avenue
West Haven, CT 06516

Independence Unlimited

<http://independenceunlimited.org/contact.html>
860-523-5021
Email: indunl@aol.com
151 New Park Avenue, Suite D
Hartford, CT 06106

Disabilities Network of Eastern Connecticut

860-823-1898
www.disability-dnec.org
Email: dnec@snet.net

Independence Northwest

1183 New Haven Road, Suite 200
Naugatuck, CT 06770
203-729-3299
<http://independencenorthwest.org/>
info@independencenorthwest.org

In addition many Case Management and Assessment Agencies, Companion and Homemaker Agencies and some Health Care Agencies can assist in locating Live-in Care, Home Health Aide Care and PCA(s).

INTERVIEWING: FINDING A GOOD ATTENDANT WHAT TO LOOK FOR & HOW TO KEEP YOUR PCA(s)

Don't hire a person if you foresee personality or employment conflicts. Often people looking for attendant work have no experience. Don't be afraid to explain to the person how you need the job done. You know your needs best. Pool your attendant information with other people with disabilities. The more contacts you have the better the chances of finding qualified attendants.

- Attendants should be paid for the entire time spent on the job. They should also be paid for time spent waiting for the employer
- Minimum wage (at least) should be paid for every hour worked.
- Time and a half after midnight plus transportation cost should be paid in compensation for the late hour and risk involved in travel unless you are providing room and board as part of the payment.
- Pay on time.
- Hire only people you feel are qualified to do the job.

HIRING PCA(s) – SOME THOUGHTS AND ATTITUDES

You want your PCA to have a happy and satisfied attitude toward their job. An attendant with good morale will do better work and will be more pleasant to have in your home. Having your physical needs taken care of with good grace will leave your mind free for more rewarding concerns. A person happy at work will be inclined to stay longer and do the job better.

How happy your attendant is will depend on how suited they are in

character and temperament to the duties required and the role in general. The attendant needs to accept your physical differences and the less aesthetic aspects of personal care. In addition this person must be able to accept the fact that although you are physically dependent, you are in charge of your own life and therefore you make all decisions regarding your care.

Ascertaining whether or not applicants have these qualities is difficult. It will help if you are accurate and complete in your description of the job so they can decide for themselves if they are suited to the job. Also, ask for and carefully check employment references. Beyond that, judging applicants is a matter of insight and intuition, both of which you will probably find improve with experience.

Individuals you hire need to know they are appreciated. Never take dependability, competence or consideration for granted. Showing them your regard may rebound to your benefit by building morale and stimulating the individual to continue the work. Compensation is also an expression of your appreciation. Your budget will probably impose strict limits on the actual amount you can pay your attendant but you can enhance its value in appreciation by paying it ungrudgingly and on time. Be absolutely fair and do not expect your attendant to put in extra work without adding commensurately to compensation. Your fairness will show that you value and respect them and the service they provide you.

One more requisite for feeling happy in one's work is the conviction that one is doing something worthwhile and important. This may be difficult for your attendant because some of the duties will be non-professional, repetitious and mundane. Treat your attendant as you would want and expect to be treated with honesty, fairness, kindness, patience and respect.

Sometimes it may happen that, despite your care in choosing and your efforts to maintain good rapport and good morale, the attendant you hire will prove irresponsible and uncaring. In that case, you will have to make your dissatisfaction plain and be firm in your right to expect better service. If lasting improvements are not quickly forthcoming, you should move quickly to find a more satisfactory replacement. Relying on someone who is unreliable is not healthy for either mind or body. You must regain control over how your own basic

needs are to be met in order to meet your goal of independent living.

INTERVIEWING AND SELECTING PCA(s)

If the person remains interested, then you can begin to elaborate upon the topics in the above, or ask them if they've had any experience in this kind of work or in other words strike up an informal but productive conversation. Find out if their schedule coincides with you and how flexible they can be. Ask them if they go to school and, if so, what their major is or ask a general question to get them engaged in a conversation with you, "Have you ever been in Trenton and wasn't it a terrible place?" This puts them at ease and might even make them like you. *(Request references before you interview them. They can bring these along with them.)*

Set up an interview, if possible in a public place or when someone else will be with you. A person that shows up on time for an interview shows that they are interested and reliable enough to come to the interview. It is desirable to check both work and personal references.

THE FORMAL INTERVIEW OF PROSPECTIVE PCA(s)

One of the main purposes of setting up a formal interview is simply to see if the person shows up. If they do not show up, inquire why.

These are the finalists, the people that aren't eliminated over the phone and do show up for the interview. These are the people with whom you should sit down and discuss in detail the routine, the exact hours and pay, and what expectations you have of each other.

The topic of commitment should be approached here by letting your prospective PCA(s) know how important they are. Once again check on how they will get to work, as occasionally a genuinely interested and caring person will agree to accept the job and its condition, but after a few weeks decide that the two hour bus ride is prohibitive or an unforeseen circumstance is affecting their position.

The most important thing to do during an interview is to evaluate the

person. Will the two of you be compatible? Remember the job is one-on-one. Does this person seem reliable and competent? Do they have a good attitude? You might want to test them on these things by asking them to empty your leg bag or put air in your tires or some such trivial act. Also, show them around their working environment.

Make decisions as soon as possible. A good idea is to hire more than you need. Have two people split up the weekday mornings rather than one person working all the hours. This leaves you with a failsafe and a choice. Review schedules and a time for the person to start working

HIRING

HOW DO I PAY FOR A PCA(s)?

Paying for PCA(s) may be difficult and require you to use several plans together. Some individuals are able to use personal funds. In some instances family members or friends are available to provide some of the assistance. Roommates or live-in/free room and board options could be considered. Reliability and compatibility will be essential. Get references from previous landlords as well as employers, personal references and school professors.

If you are covered by Workers Compensation you may be able to get financial assistance to pay for PCA(s). The Case Manager will have a lot of influence over this decision. The **Department of Rehabilitation Services** (formerly the Bureau of Rehabilitation Services) may be able to provide some assistance especially as it relates to work. If you are covered by Veteran's Benefits contact them to see if you can get assistance. For any of the options above you may need to educate them about the concept of Independent Living and Personal Care Assistants as an option over home care agencies and nursing registries.

You can also call your county public health nurse to arrange for an assessment and to learn more about PCA options available including types of agencies that provide personal care assistance services and how to hire your own staff.

Unfortunately most insurance companies are not yet ready to consider alternative options. Hopefully as insurance care managers become more educated the insurance companies may see this as a less expensive option than institutional care. (They of course limit their responsibility for home care or long term care. Restrictions are also imposed (as of this writing) as Medicare will only pay for in-home care or outpatient therapy but will not cover both options even if it is what individuals need. Many insurance companies follow Medicare guidelines.

Choices are for everyone: Connecticut's Community Integration Plan for the Elderly and People with Disabilities. This comprehensive 'plan in progress' identifies current home- and community-based services for elders and people with disabilities, including programs to transition people out of institutions and into community settings. The plan recommends additional community supports, as well as better education of the general public, service providers, and people with disabilities about available options for community living. The work is guided by the principles of the Americans with Disabilities Act and the U.S. Supreme Court decision in *Olmstead v. L.C.*

The American Elder Care Research Organization produces **PayingForSeniorCare.com** and the Eldercare Financial Resource Locator Tool. You can **also look at:** "Financial Aid & Care Resources for Long Term Senior Care." Use the **Eldercare Financial Resource Locator Tool** to find other public and private programs that can help pay for or reduce the costs of long term care for the elderly. **The American Elder Care programs** can help pay for or reduce the costs of long term care for the elderly.

Long-Term Care Services **www.ct.gov/longtermcare** - This website utilizes the United Way's 2-1-1 Infoline database and other sources to provide information under the following headings: What is long term care?, Determining needs, Finding care and support, Paying for your needs, Places to live, Rights and legal matters and Directory of providers. The Long-Term Care website also provides easy access to information on private and public long-term care services and supports in CT, including.

Others may look to State based financial assistance as described below. Some people choose to use assistance through Home Care agencies however this

option is much less flexible about who comes in, when they come in and whether they insist they know better than you. Some elder service programs may provide assistance even if you are still young. It may be possible to pay a PCA by offering room and board if you have an extra bedroom. Yet others choose to live in shared housing or supervised apartments and share PCA's.

Services to Adults and People with Disabilities – The Department of Social Services administers programs which promote social, physical and economic well-being while providing people with disabilities with opportunities to achieve their full potential for self-direction. The Department works closely with an advisory council comprised primarily of people with disabilities which makes recommendations to improve the planning, development and administration of programs.

Cash and counseling programs such as CT's PCA program are popular because family members can be paid to work as caregivers or Personal Care Attendants. In Connecticut, adult children can be paid to provide care, but spouses and legal guardians generally cannot.

- **Search for other Financial Options**
- **Get Medicaid Planning Assistance**
- **Find Affordable Home Care**
- **Look for Affordable Eldercare**
- **Learn More about this Option**

CONNECTICUT PERSONAL CARE ASSISTANCE PROGRAM

The State of Connecticut through the Department of Social Services (DSS) currently has a personal care assistance program for people with disabilities.

For information on the Personal Care Assistance program contact the Department of Social Services, 25 Sigourney Street, Hartford, CT 06106-5033, 860-424-4908, go to the **State of Connecticut webpage**, 1-800-445-5394 or go to Adult Support and Disability Services 860-424-5373. This includes how to apply and program availability. The program is available throughout Connecticut but it is not considered an entitlement program.

The PCA Program is designed for Connecticut residents that require assistance with their activities of daily living. Based on the national Cash and

Counseling project, this program allows for consumer or participant direction. This means participants are allocated the funds that the state would otherwise spend on personal care service providers. Participants then choose their own care providers and payments are made to them through a fiscal intermediary. At the time of this writing, Allied Community Services was serving in this capacity.

The Personal Care Assistance Waiver allows more flexibility since you can receive services when you need them, not at the convenience of an agency. Under the waiver you are the employer of the personal care assistant and you are responsible for hiring, training, supervising paying, and if necessary, firing your personal care assistants. Wages are negotiated between you and your PCA employee up to a maximum rate. The rate for a PCA is less than that charged by an agency, allowing you more hours of care for less or equal money. A fiscal agency will send out paychecks for your PCA. The applicant must be the essential participant in developing the PCA plan.

Persons who cannot afford their cost of care, but are over Medicaid's limits may still qualify in one of two ways: 1) Medically Needy—the state has a program which evaluates the individual's care costs and their income. If it is calculated they cannot meet their care costs, they can qualify for Medicaid provided they spend-down their excess income on their care. 2) Medicaid Planning—the second option to qualify when one is over the limit is to work with a Medicaid planner. These advisors help to re-organize a person's finances using trusts, annuities and asset conversion techniques that can preserve a family's assets and qualify the applicant for Medicaid.

FIND MEDICAID PLANNING ASSISTANCE

Employed Disabled – You may also meet the financial eligibility rules for the waiver if you qualify for Medicaid through the Medicaid for Employed Disabled coverage group. Under that program working individuals can have income up to \$75,000 per year, \$10,000 in assets and receive Medicaid subject to payment of a monthly premium. See DSS Publication 00-6 ***Medicaid for the Employed Disabled (A Tool for Self-Sufficiency)*** for more information. Participation in the waiver is limited. If all the available slots are filled, names will be placed on a waiting list.

Acquired Brain Injury (ABI) Waiver – If you had a brain injury as well as a spinal cord injury you may be eligible for the Acquired Brain Injury waiver.

Service Plan – If you meet the basic financial and programmatic eligibility requirements, a DSS social worker will work with you and your person-centered team to develop a Service Plan (see “Person-Centered Teams”). The Service Plan consists of those ABI covered services that will enable you to live in the community. If a proposed plan exceeds the funding limits established under the waiver, the Department will continue to work with you and your team to reduce plan costs to the available dollar amount. If this cannot be accomplished, your name will be placed on the Department’s ABI waiting list.

Person-Centered Teams – The ABI waiver is based on a person-centered model. This means that you developing a Service Plan that will fulfill your needs in the community. After completing an assessment of your needs, the DSS social worker will assemble a person-centered team to help you develop an appropriate Service Plan and to provide a continuing source of support to you after the plan has been implemented.

Quotas and Waiting Lists – The ABI program is not an entitlement program. This means that a limited number of individuals can be served. Individuals who apply after DSS has reached its quota will be assessed and, if they qualify for services, placed on a waiting list.

The Individual as the Employer – Under the ABI waiver, you are the employer of all your ABI service providers. As an employer, you are responsible for hiring/firing and paying your providers and, where appropriate, for paying FICA (Social Security), FUTA (federal unemployment), and other withholding amounts. The Department has selected Allied Community Resources, Inc. to be the waiver program’s fiscal intermediary. This means that they will act on your behalf to help you carry out all your payment and tax withholding functions as an employer.

ABI Covered Services – a total of 19 services are available under the ABI waiver. These include: Personal Care Assistance, Homemaker Services, Chore Services, Case-Management, Respite Care, Vehicle Modification Services, Pre-Vocational Services, Supported Employment, Environmental Accessibility,

Adaptations, Transportation, Specialized Medical Equipment and Supplies, Personal Emergency Response Systems, Companion Services, Transitional Living Services, Cognitive/Behavioral Programs, Home Delivered Meals, Community Living Support Systems, Independent Living Skill Training, Substance Abuse Programs and a Provider Registry.

KEY LEGISLATION THAT IMPACTS FUNDING

The Olmstead Act? What is it?

In *Olmstead v. L.C.*, 527 U.S. 581, 119 S.Ct. 2176 (1999) ("the Olmstead decision"), the Supreme Court construed Title II of the Americans with Disabilities Act (ADA) to require states to place qualified individuals with mental disabilities in community settings, rather than in institutions, whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the state can reasonably accommodate the placement, taking into account the resources available to the state and the needs of others with disabilities. The Department of Justice regulations implementing Title II of the ADA require public entities to administer their services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

In *Olmstead*, the Supreme Court stated that institutional placements of people with disabilities who can live in, and benefit from, community settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. The Supreme Court stated that "recognition and unjustified institutional isolation of person with disabilities is a form of discrimination reflect[ed] two evident judgments": 1) "Institutional placements of people with disabilities who can live in, and benefit from, community settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and 2) "confinement in an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Olmstead*, 119 S.Ct. 2176, 2179, 2187 [emphasis added]. This decision affects not only all persons in institutions and segregated settings, but also people with disabilities who are at risk of institutionalization, including people with disabilities on waiting lists to receive community based services and supports.

The Court indicated that one way states can show they are meeting their obligations under the ADA and the Olmstead decisions is to develop a "comprehensive, effectively working plan for placing qualified people with mental disabilities in less restrictive settings." Olmstead at 2179. Based on this, almost all states are in the process of developing, or have already developed such plans.

In support of these state efforts, President George W. Bush issued Executive Order 13217: Community-Based Alternatives for Individuals with Disabilities (the Olmstead Executive Order) on June 18, 2001, in which he extended application of the Supreme Courts Olmstead decision to all Americans with disabilities, and called upon selected Federal agencies, including U.S. Department of Labor, to help support governors in their implementation of the Olmstead decision. In support of these state efforts and in response to the direction set forth in Executive Order 13217, the ODEP is issuing this SGA for WorkFORCE Actions Grants."

Money Follows the Person

Home Care in Connecticut and the 'Money Follows the Person' Initiative

One of the most positive changes will be a major expansion in the "Money Follows the Person" program for seniors and adults with disabilities that wish to receive care in a home setting vs. institutional setting such as a Skilled Nursing Facility. What the program is designed to do is allow for some of the moneys' currently administered under the Medicaid program be spent on patient care services in home or community based settings.

Seemingly, this program is geared towards transitioning seniors living in Skilled Nursing Facilities back to home or community based settings. In fact, the governor identifies a goal of transitioning over 2,200 nursing home residents to the community by the end of fiscal year 2013, and expanding the initiative to 5,200 placements through 2016. It is hoped however that policymakers see that it is just as important – if not more important to consider the reverse in this cycle, which is to provide financial support to keep seniors and adults with disabilities at home with the proper support services and care to begin with.

How do I apply for MFP? – It is very easy to apply for **Money Follows the Person**- the consumer, a family member or even a friend can start the process. Simply call the MFP office at 1-888-99CTMFP (1-888-992-8637) and a staff member will be happy to fill out the simple one-page **application** over the telephone. Alternatively; You can request that an application be sent to you by mail, or you can **download a copy of the application by following this link** Simply print and fill out, and then mail the application back to us at the **Dept. of Social Services, Money Follows the Person**, 11th Floor, Attn: Tamara Lopez, 25 Sigourney Street, Hartford, CT 06106.

What information do I need to apply? – The only information we need to begin the process is the consumer's name, date of birth, social security number and the facility where they are currently living - we'll do the rest.

Connecticut has transition services to assist people based on their individual needs. Even if you don't qualify for the Money Follows the Person program, there are other services the Department may offer to assist you. Complete an application to access services as noted above.