



How to Work with Personal Care Assistants

When a young disabled person turns 18 years old, legally, they become an adult. He/she wants to be independent, but may need help with dressing, feeding, bathroom, exercising, and so on. That is where Personal Care Assistants (PCAs) or Personal Assistants come in. PCAs are hired and supervised by the person with disabilities.

This article offers tips about being a supervisor for PCAs as well as how to manage relationships with PCAs. Also, it covers information about personal managers, that is, a second supervisor who handles more responsibilities that a person with disabilities is unable to due to his/her limitations.

Rajiv's story:

A few years ago when I turned eighteen years old, I heard the term, "Personal Care Assistants" for the first time. I had no idea what that meant. I met with my Vocational Rehabilitation Counselor who introduced me to a woman in a wheelchair with a person helping her. Her name was Patti. I asked her about the person assisting her, and she said that it was her PCA. I watched how they communicated and acted professionally with each other. In addition, she gave me a manual on hiring and managing PCAs, and I learned a lot.

When I was accepted to attend the Youth Leadership Forum at the University of Connecticut the summer of 2005, I met my first PCA, Joel. It felt awkward this first time, especially when I had to spend four hours training him to do exactly what I wanted him to do. It was very overwhelming because of a communications barrier due to the fact that he had never handled a deaf person in a wheelchair, which was me! We shared a lot of things in common as well as learned from each other.

He told me his quote, "PCAs are there to fill in as my hands and feet," and it made me realize that PCAs are there to help me do whatever I want to do in life. A few days later I felt great that I had so much freedom for the first time!

Managing PCAs can be a tough job because PCAs all have different attitudes, skills, and learning styles. This can include family members and friends who act as PCAs. Think carefully about using family members as your PCAs even though you may care about and be very close to them. They can get burnt out easily from being a PCA *and* a family member at the same time. I went



through this, and it was not easy! My brothers were hired to work for me, and the relationship between us did not match well enough to maintain these two different relationships. That is why you as a supervisor should really consider hiring outside people. This may seem scary, because they will probably assist you with a lot of personal things which may include bills, medical information, and even your personal information. When you become a supervisor of a PCA for the first time I would strongly advise you to go to a local Center for Independent Living and have them train you how to manage a PCA.

Tips for Managing PCAs

Even if you have a significant disability that prevents you from taking care of yourself such as eating, using the bathroom, etc., you still want to run your own life. That is when you can hire and become a supervisor for a PCA, but sometimes being a supervisor is not an easy job. It is like running your own small business. Some states even require you to pay employer taxes (you'll need to research the rules in your state). When working with a PCA, you'll need to be self-directed. Being self-directed means telling PCAs what *you* want them to do and *how* you want the task to be done. They are there to help you to become successful in *your own way*, and they need to respect your needs and wishes.

Hiring a PCA can be very, very scary. You'll want to make sure you can trust the PCA. The first step when hiring a PCA is to interview potential PCAs to see if they are interested in working for you. After you have chosen the right PCAs for you and your needs, they will have to go through different steps depending on the agency or organization you are working through. They may go through background checks, have their references checked, and in some agencies, have health check-ups. Once a PCA gets approved by the fiscal agency (the group helping you pay the PCA), they will often give the PCA training on how to provide the type of assistance you need, and the PCA will fill out employment forms. If the agency doesn't offer training, then you may want to contact your local Center for Independent Living for help with training the PCA before they start working for you, as Rajiv mentioned above.

While PCAs are working for you, you are responsible for paying attention to their feelings as well as the way they do their duties. If you are too bossy to them,



they will not want to help you. They may quit if you keep being bossy or rude. Good phrases to use that are polite and not bossy are:

- “Please (then describe the task)”
- “I would like you to (then describe the task)”
- “Thank you.”
- “I really appreciate (describe the things that you thought they did well)”

Being polite will motivate them to want to work harder to help you to reach YOUR goals.

If you feel that a PCA is not doing a good job, have them sit down with you to discuss the issue and/or what bothers them. If this method does not work, or if you are not feeling comfortable with the PCA, you have the right to terminate (end) their employment. In addition, some agencies provide evaluations for supervisors to rate each PCA’s job performance. You will have to be honest and thoughtful about each PCA. If you have to give them a bad evaluation, they have the right to disagree, but you cannot let him/her yell at you. If you are concerned about solving issues without arguing or if you need assistance with communicating, ask someone like a friend, family members, or residential assistant (if you are in college) to help you and the PCA communicate and work things out.

Some Centers for Independent Living have a volunteer supervisor for the main supervisor (that is, you). They are responsible for certain duties that you might be unable to do such as: making calls to a PCA waiver specialist, finding new PCAs, interviewing/screening PCAs, and, in some circumstances, scheduling shifts. This volunteer supervisor knows about the different policies (rules) of the agency and can help you know how to follow the correct policies. Also, they can act as a neutral person if you and your PCA do not agree on things. They can act as a mediator (someone who helps both people feel heard and find a compromise to the issue).

Resources

The HEATH Resource Center of The George Washington University, Graduate School of Education and Human Development is an online clearinghouse on postsecondary education for individuals with disabilities. They have developed a guide for college students with disabilities on how to find and hire a PCA when attending college.



http://www.heath.gwu.edu/index.php?option=com_content&task=view&id=1057&Itemid=65

National Empowerment Center

Article: Personal Care Attendant (PCA) services available to people with psychiatric disabilities. By Patricia Deegan, Ph.D.

<http://www.power2u.org/articles/selfhelp/pca.html>

Statewide Independent Living Council Directory

<http://www.ilru.org/html/publications/directory/index.html>

For more information on what a Center for Independent Living is, see KASA's article: What Is A Center for Independent Living?

<http://www.fvkasa.org/resources/files/cil.html>