

The Bridge

PCAs: a bridge to community living

THE NEWSLETTER OF THE PERSONAL CARE ATTENDANT QUALITY HOME CARE WORKFORCE COUNCIL

Volume 1 Winter 2009

Welcome from Jean McGuire

*Assistant Secretary for Disability Policy and Programs
Executive Office of Health and Human Services*



As the Chair of the Personal Care Attendant (PCA) Quality Home Care Workforce Council, I want to welcome you to the first edition of *The Bridge*, the Council's newsletter.

The statute creating the Council states that our mission is to ensure the quality of long-term, in-home, personal care by recruiting, training, and stabilizing the work force of personal care attendants. To me, in practical terms, this means that the job of

the Council is to make sure that Massachusetts has a sufficient number of persons providing PCA services to meet the increasing demand from consumers like you.

In order to fulfill our mission, the Council has taken a number of concrete steps: We have negotiated a contract with 1199 SEIU, the union representing PCAs; this contract will significantly raise the wages PCAs receive as well as take other steps that will make PCA work more attractive. The Council has also signed a contract with Rewarding Work, a contractor who will operate a Web-based PCA directory that should make it easier for consumers to find and hire PCAs. More information about both of these developments is included in this issue.

We know that more needs to be done. All of the studies that I have seen show that the demand for PCA services will substantially increase over the next decade. One very important aspect of our work is listening to and communicating with the MassHealth consumer population. *The Bridge* is one method we have chosen for telling you what we are doing and for hearing your ideas. I hope you enjoy this issue and those in the future.

Sincerely,

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Para una versión en español, por favor llame a su Agencia de atención personal o al 617-210-5715.



About the Council

THE PCA QUALITY HOME CARE WORKFORCE COUNCIL is an innovative governmental body, similar to those in several other states, that uses citizen engagement as an instrument for strengthening the PCA program. The Council consists of nine members. Two members, the Secretary of Health and Human Services (or her designee) and the director of the Office of Workforce Development (or his designee), are members of the administration. The remaining seven members are appointed by one of the Commonwealth's constitutional officers in the following manner:

- The governor appoints one member from a slate of three consumers recommended by the governor's special advisory commission on disability policy.
- The auditor appoints
 - one member from a slate of three consumers recommended by the developmental disabilities council;
 - one member from a slate of three consumers recommended by the Massachusetts Office on Disability; and
 - one member from a slate of three consumers recommended by the statewide Independent Living Council.
- The attorney general appoints

- one member from a slate of three consumers or consumer surrogates recommended by the Massachusetts Home Care Association;
- one member from a slate of three consumers or consumer surrogates recommended by the Massachusetts Council on Aging; and
- one member chosen at her discretion.

At all times, a majority of Council members must be consumers of MassHealth PCA services. The Council is charged with ensuring the quality of long-term, in-home, personal care by recruiting, training, and stabilizing the work force of PCAs. More information on Council activities and projects is available at our Web site at mass.gov/pca.



Groundbreaking! Council & 1199 SEIU Sign First Labor Agreement

IN NOVEMBER 2008, representatives from the Workforce Council and 1199 SEIU, the union representing PCAs, initialed the first-ever labor agreement on behalf of the PCA workforce. After several months of bargaining, the parties were able to agree on a three-year contract that provides wage increases and puts in place structures that can begin the process of providing benefits for PCAs.

Effective July 2008, the wage for PCAs was raised from \$10.84 an hour to \$11.60. By the end of the three-year contract, which expires in June 2011, the hourly wage earned by a PCA will be \$12.48 (see accompanying information on wages). The contract also provides for a committee to study options for providing health-care benefits to PCAs. Once the study is completed, negotiations on the question of health benefits will begin again. The contract includes limited funds to pay for time off for some PCAs. The parties have yet to work out a formula on how to use these funds.

In addition to the higher wages, which should attract more people to work as PCAs, the contract upholds the original statute language of consumer control regarding hiring, training, and management of each consumer's PCAs. The contract also prohibits the filing of grievances against consumers by PCAs.

A labor-management committee is being formed to build the type of relationship that will both strengthen the PCA workforce and benefit consumers. As Liz Casey, a member of the Council bargaining team said, "Achieving a contract for PCAs is an historic and hard-won accomplishment for caregivers and consumers. By coming together, these two groups have shown their real strength."

Wage Increases Provided for in the New PCA Labor Agreement



Effective July 1, 2008, the PCA wage rate will be \$11.60 per hour.

Effective July 1, 2009, the PCA wage rate will be \$12.00 per hour.

Effective July 1, 2010, the PCA wage rate will be \$12.48 per hour.

Free CPR Training Available to PCAs

The PCA Quality Home Care Workforce Council is funding full scholarships to working PCAs interested in CPR training throughout the state. This can be a valuable resource to both PCAs and the consumers they work for.

You can check our Web site (www.mass.gov/pca) for details on the dates and locations of upcoming trainings.

Space is limited, so sign up now!

Consumers & PCAs Give Feedback to Council

Surveys Underway to Strengthen Program

IN 2008, the PCA Quality Home Care Workforce Council launched two important initiatives that will provide valuable information on both the needs of consumers in the PCA program and on the priorities of PCAs providing care to consumers.

Consumer needs and their overall satisfaction with the PCA program were assessed through a telephone survey of a statistically valid sample of the 15,000-plus consumers currently receiving PCA services through MassHealth. The survey, which is being supplemented by a series of focus groups with consumers in different regions of the state, was conducted by JSI Research & Training Institute, Inc., an internationally known public-health research and consulting firm.

“The PCA program is the critical piece of the system that allows consumers to live independently and work in their communities,” said James Maxwell, PhD, JSI’s Director of Health Care Policy and Management Research. “The more we learn about consumers’ actual experience, the more information will be available to strengthen this important program.”

The survey of PCAs, also being conducted by JSI, will ask questions about how PCAs were recruited, their perspectives on improving PCA retention, what types of training would be useful to them, and other aspects of their work. The PCA survey is being done in collaboration with 1199 Service Employees International Union (SEIU), the union representing MassHealth PCAs in Massachusetts. Union staff were involved in reviewing the questions that will be asked of PCAs in a phone survey. SEIU staff also helped organize a number of focus groups, which will provide more in-depth information on what PCAs like about their work, as well as what could be changed to improve their work conditions.

The consumer survey was completed in November and much of the data was included in the Council’s performance review report, which is required by statute and was filed with the governor and the legislature in December. Information from the PCA survey, due to be completed early in 2009, will provide data that will help the Council develop training and recruitment initiatives.

Help Is on the Way!

Rewarding Work to Develop Internet Directory to Find PCAs



THE PCA WORKFORCE COUNCIL has signed a contract with Rewarding Work Resources, Inc. (Rewarding Work) for that company to develop and operate a Web-based referral directory that will help consumers locate and hire PCAs. The directory, which will have a searchable database, will make the task of recruiting and hiring considerably easier for the 15,000-plus MassHealth members who can use the directory free of charge.

According to Dr. Jean McGuire, Asst. Secretary of Health and Human Services and Chair of the Council, “The mandate of the Council is to take a number of actions that will make it easier for consumers to find and retain PCAs. Establishing this directory is an important step in meeting our mandate.”

Rewarding Work, which is operating similar sites for Rhode Island and Vermont, as well as a paid site in Massachusetts, will also be responsible for recruitment and outreach activities to increase awareness of the Web site among consumers, PCAs, and potential PCAs.

Neither MassHealth consumers seeking PCAs nor persons seeking employment as PCAs will be charged to use this site. On the site, consumers will be able to screen for issues such as the PCA’s distance from their home, language, experience, and a range of other relevant factors. Consumers who do not have access to a computer will be able to telephone a call center collaborating with Rewarding Work. The approximately 30 personal care management agencies (PCMs) that assist consumers with evaluations and skills training will also have access to the Web site. Staff members at Rewarding Work are overseeing development of the site. The Web site should be up and operating by June 2009. Until then, consumers are still able to access Rewarding Work’s site for a small fee. Rewarding Work can be reached at www.rewardingwork.org.



PCA HEROES

When Hurricane Katrina struck New Orleans on August 29, 2005, hundreds of people with developmental disabilities were displaced. Roads were severely crowded or impassable. Cell phones didn’t work. Many didn’t know where their family members were. And yet direct-support professionals, people doing

the same work that PCAs do in Massachusetts, stayed with those they supported and made sure everyone evacuated to higher ground. For months, these dedicated women and men, working long hours for low pay, put others before themselves, providing care and support with improvised resources.

To see a video clip about these remarkable workers, paste the link below into the browser on your computer.

rtc.umn.edu/rtcmedia/higherground/

Interview with MassHealth Member Janice Ward

by Michelle Byrd

JANICE WARD WAS diagnosed with M.S. in 1980, one week before starting nursing school at UMass-Amherst. Her symptoms included double-vision, fatigue, and balance and coordination problems. After receiving this devastating diagnosis, Janice had to leave the nursing program. However, she was able to transfer to UMass-Boston to finish her education, studying psychology and sociology. At the time, Janice said she didn't know the extent to which her disease would place limits on her life or how difficult it would be to maintain her independence. Trying to live independently and find the care she required would soon become a major challenge.

Janice's first introduction to home-care assistance came in the form of homemaker services provided by an agency. This soon became problematic since it was always difficult for her to get help for as many hours as she needed, and many times the homemakers were unreliable and would not show up for work. When she complained about this to the agency, the response she received from an administrator was "some of my people don't have any help, so you're lucky."

Her next experience wasn't any better. Home health aides were available to assist her with personal-care issues; however, they were not able to help her with the instrumental activities of daily living (IADLs), such as laundry, meal preparation, and general housekeeping that

she required. When Janice experienced a major exacerbation of her disease, leaving her so weak that she was bedridden and sometimes unable to use the left or right side of her body, she found that she did not have access to the complete level of care she needed. A homemaker could not attend to the personal care needs that her disease flare-up caused, and a home health aid was not able to provide her with ongoing assistance with housekeeping chores.

INFORMATION ON MS

Multiple sclerosis (or MS) is a chronic, often-disabling disease that attacks the central nervous system. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. The progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another. Some people with MS experience clearly defined attacks of worsening neurological function. These attacks—which are called relapses, flare-ups, or exacerbations—are followed by partial or complete recovery periods or remissions.

When Janice became part of the PCA program back in 1985, all of this changed. A personal care attendant or PCA could attend to her personal care as well as assist her with daily living tasks. More importantly, the program allowed her to "have a say over how things in my house are done," which was important for a young woman creating her own independent life. Janice believes it is important that the PCA program remain consumer-run. This consumer model, which Massachusetts pioneered, does have its challenges. Janice reports that she has had difficulty hiring and retaining PCAs, due to low wages. While her current primary PCA has been with her for some time and everything is going well, she expresses concern regarding the low wages PCAs receive. "How do you maintain quality people when the pay is so low?" Janice asked. Janice expressed her anxiety about not having adequate PCA coverage, especially in the case of an emergency. In the past, friends have helped out when a PCA did not show up. However, she cannot always rely on their help. Janice has had some success in using student employment offices as well as Craig's List, but still finds it difficult to find working PCAs. She said that she looks forward to the Council developing a PCA referral directory. She would sleep better at night knowing there was another possible resource for consumers to secure help for the hours they are approved for, as well as to cover emergencies.

Janice said that being an employer in the PCA program has been a learning process: she has learned some good strategies for hiring PCAs; she always asks for references from potential workers, and checks them herself. She also supports background checks for PCAs.

Janice has lived independently since 1984 and has been a resident of the South End since 1988. She currently volunteers at the South End Technology Center, where she is also learning grant-writing. She hopes to become a grant writer for nonprofits. Janice provides peer counseling at a local hospital and is involved with a number of advocacy and activist issues concerning disability. She is a member of the Consumer Quality Care Council of Health Care for All and the Boston Center for Independent Living's action and advocacy group. When thinking about her future, she expressed her appreciation for the PCA program saying, "I don't want to live in a nursing home." She feels she is not alone in this. She shared a quote: "We are all temporarily able-bodied."

Consumer Rights under the New Labor Contract

NOW THAT PCAs have a union, a number of questions have arisen among consumers: Can I still fire a PCA that I am dissatisfied with? Can a PCA file a grievance against me? To clarify matters, below is language taken directly from the contract signed by the Council.

Article 2: Consumer Rights

Section 1: General Rights

As provided by M.G.L. c.118G, section 31(a), Consumers and/or their Surrogates shall retain the right to:

- 1. Hire PCAs of their choice;*
- 2. Supervise, manage and train PCAs in their employ;*
- 3. Determine the work schedules of PCAs in their employ;*
- 4. Terminate PCAs from their service at will; and*
- 5. Determine under any circumstances who may and may not enter their home or place of residence.*

Such authority and control on the part of the Consumers is not, and shall not be, diminished in any way whatsoever by this Agreement.

Article 14: Dispute Resolution

- 1) No matter arising from, or dispute pertaining to, the exercise by a Consumer and/or his or her Surrogate of any rights ... including, but not limited to, the right to select, hire, schedule, train, direct, supervise and/or terminate any PCA providing services to him or her, shall in any way be subject to the provisions of ... this Article.*

From time to time, consumers may receive union materials in the mail from fiscal intermediaries. Consumers should give these materials to their PCA. Remember: Consumers have a stake in a strong union, as the union promotes better wages and benefits for PCAs, thus increasing the number of people wanting to do PCA work and making it easier for consumers to recruit PCAs.

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Please share this publication with your PCA.