

Disability Issues

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Bill Filed Requiring Accessible Medical Equipment

By Laura Keohane

Kellyann Binari has never been weighed at her doctor's office. "There is no scale big enough to put a wheelchair on," Binari explains, and she cannot stand up to step onto a scale.

For Binari and others with physical disabilities, this gap in basic medical screening is a common problem. In fact, many medical exams and tests are often difficult or impossible to access because of the lack of appropriate equipment. "The equipment is usually too high or not adjusted for me or people are not trained to transfer me," says Binari, a resident of Somerville.

At one appointment with a specialist, Binari's hamstring was pulled while she was being manually lifted up onto the exam table by staff members. Binari did not go to her next follow-up appointment at that office. "I wasn't going back again because I didn't want to get hurt again," she says. Binari is faced with a choice between protecting her safety and accessing health care services. "I think every medical appointment is an important appointment to keep me healthy," she says.

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PCAs Receive Raises, Consumers Achieve Greater Voice

By Liz Casey



Towards the end of February 2009, personal care attendants (PCAs) who work for MassHealth received a \$.75 increase in their pay, bringing their hourly rate up to \$11.60 per hour. This is a significant victory and a good beginning, especially in these financially stressed times. The contract also stipulates that PCAs will receive additional raises to \$12 per hour on July 1, 2009, and to \$12.48 per hour on July 1, 2010.

All of us know that a better wage is the bottom line in attracting and keeping our good PCAs. Many of us have experienced losing quality people over the years, primarily because of the low wages and lack of benefits with this job. Our PCAs are so fundamental to helping our daily lives function smoothly. Without them we would be stuck in bed or at home.

So, when the state legislature voted unanimously in 2006 to create the **PCA Quality Homecare Workforce Council**, it was the beginning of a new consumer voice able to work within the state to make improvements to the PCA program. One of the roles of the Council has been to represent consumers as the employers of PCAs when it comes to collective bargaining with the PCA union. PCAs voted to join SEIU1199 (Service Employees International Union) back in November of 2007. Starting in January 2008, three members of the Workforce Council, as well as the Council's director, and labor negotiator, met together with SEIU 1199 and began collective bargaining. The issues of wages, health benefits, and paid time off were mutual goals, but challenges presented

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Concerned Citizen's Advocacy: A New Approach to Personal Care

By Kevin Wreghitt

The MassHealth personal care attendant (PCA) program has benefited many people with disabilities for over two decades. The program has undergone little change during that time. There have only been two major changes in its history. The first one came in the 1990s when the program had to incorporate a fiscal intermediary system to distribute employment checks and perform accounting work for tax purposes. The second change occurred more recently in 2006 when the Personal Care Attendant Quality Home Care Workforce Council Law was passed and allowed PCAs to unionize. Both of these events mostly have to do with funding and how it is spent.

In 2006, while the workforce council legislation was being passed by the legislature, I established a private advocacy and advisory board called Concerned Citizens for Personal Care (CCPC). The CCPC board is comprised of both people with disabilities and the able-bodied. Some board members are professionals, and some are not. PCAs are on the board as well.

Our goal is to advise the state government and other organizations on policy matters regarding personal care and associated disability issues. We also seek to engage in, support or otherwise inspire projects that will expand knowledge about and improve the delivery of personal care for people with disabilities and the elderly statewide.

I would be surprised if any PCA user reading this article has not had the experience of being left "high and dry" by a care provider. There have been attendants whom I really respected and thought were working out well who betrayed me in that way. For example, one woman, who had been doing everything right, did not show up for work one day, did not call and could not be reached. She contacted me about four days later, wanting her check. I insisted that she pick it up in person. When I confronted her she broke down, saying she had to move away and that she loved this job so much she could not find the courage to tell me. There were others who failed to show up without warning, and I am confident there are people who have more horrific tales than I do about the consequences of people not turning up for work.

Abuse is another risk that people face when employing PCAs. Although I consider myself lucky in this regard, I have been pushed and shoved by attendants. I also have been robbed. One friend of mine experienced credit card

fraud at the hands of one of her attendants. It took months to straighten it out, and she lost \$300. Several colleagues and I are working on an abuse project, which is going to educate people with disabilities on how to recognize, report and respond to mistreatment of any kind. There is anecdotal evidence that a number of people in this group do not trust their caretakers precisely because of past abuse.

Training is still another issue. Some attendants lack the prerequisite knowledge to be good PCAs. And no matter how hard one tries to train them, the results are not right. Some people with disabilities need specialized care, which is difficult to teach on the job. For example, people who have cerebral palsy need particular feeding techniques, and other individuals need to use ventilators. Such skills must be in the attendant's mind on day one, not on day five after a few training sessions.

CCPC has developed and is promoting a piece of legislation called the Home Care Accountability and Supplemental Act (HCASA) to try to rectify some of the problems cited. Among other matters, it covers such issues as having an ethics code for the PCA program, pre-screening/training for potential PCAs and disciplinary procedures to adjudicate complaints. The workforce council would administer most of this activity. Currently HCASA is in the House Ways & Means Committee, waiting for committee assignment. Rep. Barry Finegold, and Sen. Susan Tucker, Democrats from Andover, are sponsoring this bill.

A new day has dawned on the PCA program in Massachusetts, and CCPC is leading the way toward a new approach to personal care. We all have the opportunity to correct some longstanding problems, from the low wages PCAs are paid to the challenges of abuse and neglect. This state can be a model for the nation for in-home assistance. More work besides HCASA is going on at the CCPC board. So, if people would like to become involved, please contact us at **Concerned Citizens for Personal Care**, P.O. Box 1274, Andover, MA 01810-0022, e-mail ccpcboard@verizon.net, web site <http://tiny.url.com/4n6da8>.

Kevin Wreghitt is President of Concerned Citizens for Personal Care

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In this *Disability Issues*, despite the bleak economy, our fine writers manage to find some good news for people with disabilities. They report on a bill that would go a long way to eliminating the inequality in health care, a new approach to personal care services, advice on how to survive these difficult times, benefits to us in the recovery bill, and a better deal for PCAs.

I am very appreciative of their work, which they do on a voluntary basis. I am equally thankful to the members of my editorial board who also serve without compensation. Without the contributions of all these people *Disability Issues* could not exist.

If you would like to be involved in any way with *Disability Issues*, we would welcome your input. I am especially interested in recruiting new members for our editorial board. The requirements are quite simple: an interest in and knowledge of some aspect of disabilities, an ability to write, and a willingness to commit to meeting four times a year — usually in Cambridge. You can communicate your interest by contacting Michelle Nowers at Michelle.Nowers@umassmed.edu.

I look forward to meeting you.
Paul Kahn

The Impact of the Federal Stimulus Package on People with Disabilities

By Linda Long-Bellil

As a result of the American Reinvestment and Recovery Act, Massachusetts will soon receive \$6-9 billion in stimulus funds to help it through the current economic downturn. A central goal of the stimulus plan is to create jobs, but how many of those jobs will go to individuals with disabilities? This article will describe how some of the funds available through the stimulus package may increase access to employment for persons with disabilities.

The Massachusetts Rehabilitation Commission will receive additional funding of more than \$7 million. The stimulus package will also make \$64 million available through the Executive Office of Labor, Workforce and Development for employment, education, training and services. This funding will be used to strengthen a variety of programs, including the One-Stop Career Center System, which is open to all Massachusetts residents, including individuals with disabilities.

This funding will also include Workforce Investment Act (WIA) funds for young people across the country between the ages of 14 to 24, and this can include youth with disabilities. There are income limits on eligibility for the jobs provided with WIA funds, but many young people with disabilities may be likely to qualify because only their own income, not their family's income, is counted when determining eligibility. Much of the youth funding may be used, too, for summer jobs, but other youth employment services will receive funding as well.

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Summer Recreation Fair to Be Held in June

A **Summer Recreation Fair**, sponsored by the DCR Universal Access Program (UAP), will be held at **Artesani Park in Brighton on Saturday, June 6 from 10AM to 3PM**. UAP invites people with disabilities to kick off the summer with park festivities and explore possibilities for outdoor recreation. Activities at the fair will include trying out adaptive bikes and hiking equipment, getting your face painted, listening to a DJ and visiting with friends. You can also go on a treasure hunt for letterboxes and geocaches, sign up for a wide array of summer opportunities, such as kayaking, sailing and hiking in the Boston area and beyond and cool off in the spray pool. The Fair is free and open to the public. Refreshments will be provided. Pre-register by calling 617-626-1294.



Rewarding Work Wins Bid to Develop PCA Directory

The new PCA directory will be free for MassHealth eligible individuals, PCAs and for people seeking employment as PCAs. Using this site, individuals will be able to screen for issues such as the PCA's distance from their home, access to a car, hours of availability, experience and a range of other relevant factors. People who do not have access to a computer will be able to telephone a Call Center where they will get help accessing the database. The 30 Personal Care Management agencies that assist people with disabilities and elders with evaluations and skills training will also have access to the website.

The new PCA directory and website is expected to start by June 2009. Until that date, Massachusetts people with disabilities and elders can access the existing Rewarding Work site at www.rewardingwork.org/ma. Rewarding Work can be reached by e-mail at info@rewardingwork.org or by calling toll-free 1-866-211-WORK (9675) 24 hours a day.

Obama Opens up Stem Cell Work and Other Science

In March President Barack Obama urged researchers to follow science and not ideology as he abolished Bush-era restraints on stem cell research. "Our government has forced what I believe is a false choice between sound science and moral values," Obama declared as he signed documents changing U.S. science policy and removing what some researchers have said were shackles on their work. This change will also affect other scientific work, such as such is research into the physics of global warming,

The most immediate effect will allow federally funded researchers to use hundreds of new embryonic stem cell lines for promising, but still long-range research in hopes of creating better treatments, possibly even cures, for conditions ranging from diabetes to paralysis. Under the Bush administration, those researchers had to limit themselves to just 21 stem cell lines created before August 2001, when President George W. Bush limited funding because of "fundamental questions about the beginnings of life and the ends of science."

Adapted from an AP article

SSA Offers Jobs

The Social Security Administration recently received funding to hire a significant number of employees throughout the country. This hiring initiative offers a unique opportunity for individuals with disabilities who may want to get a job with SSA. These jobs will be at various skill levels including a number of entry-level positions.

SSA is recruiting employees to work in field offices and teleservice centers where they will assist the public by phone and in person with a wide variety of program related activities such as filing claims, applying for new or replacement Social Security cards and other types of inquiries. SSA also is recruiting employees to work in Program Service Centers where they will process claims and to work in hearings offices in legal and paralegal positions.

SSA will use a variety of avenues to recruit and hire people with disabilities. In particular, the Agency is reaching out to **Ticket to Work** ticket holders who are trying to return to work, veterans with disabilities through programs such as the **Wounded Warrior** transitional program, and students with disabilities. Many individuals with disabilities will qualify for consideration under a special placement authority

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called "Schedule A." A person is Schedule A eligible if he or she has documentation establishing both a disability and "job readiness."

Resumes and documentation for Schedule A eligibility should be sent to Selective.Placement.Applications@ssa.gov.

Social Security Disability Insurance Recipients to Get Extra \$250

Social Security Disability Insurance recipients can look forward to receiving a one-time \$250 bonus payment by early summer, according to Allsup, which represents tens of thousands of people in the Social Security Disability Insurance (SSDI) process each year. The American Recovery and Reinvestment Act of 2009, signed by President Obama, launches a \$787 billion national economic stimulus package that includes the one-time \$250 payments to those eligible for SSDI, Social Security retirement, Supplemental Security Income (SSI), railroad retirement benefits and U.S. veterans disability compensation or pension benefits.

The news is even better for couples who receive Social Security benefits, because each recipient will receive a one-time \$250 payment. "That means you'll have an additional \$500 in income available, which could be an important cushion," said Paul Gada, personal financial planning director at Allsup. "For example, this amount could be put toward an emergency fund." More details are provided in the "SSDI Overview" on Allsup.com.

Source: Justice for All

Google Lime Scholarship for Students with Disabilities

Google announced in April that they are partnering with Lime to offer scholarships to students with disabilities who are pursuing university degrees in the field of computer science in Canada or the United States. Scholarships will be awarded based on the strength of candidates' academic background and demonstrated passion. The amounts awarded will be \$10,000 (USD) for those studying in the US and \$5,000 (CAD) for those studying in Canada (based on average tuition costs).

Candidates must be:

- A student entering their junior or senior year of under-

graduate study or be enrolled in a graduate program in the 2009–2010 academic year at a university in the United States or Canada (in addition to US and Canada citizens, international students with disabilities studying at universities in the US or Canada are also encouraged to apply)

- Enrolled in a Computer Science or Computer Engineering program, or a closely related technical field as a full-time student for the 2009–2010 academic year
- A person with a disability (defined as someone who has, or considers themselves to have a long-term or recurring, issue that impacts one or more activities that others may consider a daily function); this definition also includes the perception among others that a disability exists

Lime is a not-for-profit organization that brings together global corporations and people with disabilities, bringing to light an untapped source of talent. Scholarships will be granted for the 2009–2010 academic year, and recipients will be invited to attend an all-expenses-paid retreat at the Googleplex in Mountain View in 2010. The deadline to apply for this year's **Lime Scholarship is June 1, 2009**. For complete details and to apply go to <http://www.limeconnect.com/google.html>

Source: Google, Lime and Justice for All

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Something as basic as routine weight measurement can be a key indicator of a person's health status and can factor into important medical decisions. Dr. Lisa Iezzoni, a professor of medicine at Harvard Medical School and the Associate Director for the Institute of Health Policy at Massachusetts General Hospital, researches barriers to health care services for individuals with disabilities. She points out that rates of obesity and being overweight are higher for individuals with disabilities, which underscores the importance of being weighed. Weight measurements are also important for patients seeking a variety of specific health care services, including heart failure treatment, chemotherapy, preoperative testing and obstetrical care.

Barriers to receiving tests like Pap smears and mammograms can carry significant risk for women with disabilities, including women with sensory disabilities. Dr. Iezzoni explains how equipment problems may contribute to lower mammogram screening rates for women who are deaf or have a hearing impairment. After a woman is positioned for a mammogram, the technician goes into a booth to be protected from radiation and gives audio instructions. A woman, who is deaf, explains Dr. Iezzoni, "could not communicate with the technician at this most important moment." "There is no accessible cue for when she should hold her breath while the image is being taken. If women cannot access breast and cervical cancer screening to catch potential problems early, they may be at risk of shorter life expectancy.

Medical equipment exists that would help to make health care services more accessible for individuals with disabilities. Adjustable height exam tables that can be lowered can be much easier to sit on for individuals who have difficulty stepping up onto tables and can accommodate independent transfers for many people who use wheelchairs. Some clinics have platform-type scales, where an individual in a wheelchair can be weighed by rolling onto the scale. Rather than relying on medical staff or security guards to manually lift patients, ceiling lifts or portable Hoyer lifts can provide safe transfers to exam tables or diagnostic equipment. Both audio and visual cues can be used for giving directions during tests and screenings, like mammograms.

Under the Americans with Disabilities Act, hospitals and doctors' offices are places of public accommodation that are required to provide equal access and equal benefit from serv-

ices to individuals with disabilities. Previous ADA lawsuits filed against hospitals in California and Washington, D.C. have argued that equipment barriers prevented individuals with disabilities from receiving the same level of care as patients without disabilities. Settlements in these cases have specifically addressed medical equipment by requiring the health care facilities to survey their clinics for availability of accessible equipment and purchase or modify equipment as necessary.

The lack of national technical standards about the accessibility of medical equipment contributes to the problem. The United States Access Board issues guidelines for some architectural components of medical facilities, like the minimum number of accessible inpatient rooms, but there are no regulations yet to establish similar guidelines for medical equipment. In 2007, Senator Tom Harkin introduced national legislation that would authorize the Access Board to draft such guidelines for accessible medical diagnostic equipment. In Massachusetts, the Boston Center for Independent Living and Greater Boston Legal Services are advocating for a similar bill on the state level that would require the Massachusetts Department of Public Health to create regulations on accessibility requirements for medical diagnostic equipment, including exam tables, scales and imaging equipment. The bill, "An Act Relative to Accessible Medical Equipment," is co-sponsored by Senator Patricia Jehlen and Representative Denise Provost.

Establishing such guidelines would be a major starting point for increasing the accessibility of medical tests and exams. "It's an essential step, but it's only a first step," says Dr. Iezzoni. To be used effectively, she explains, the accessible equipment must be combined with training for staff on how to use the equipment properly and outreach to the community to ensure that individuals with disabilities are aware of the availability of new, more accessible equipment.

For more information about "An Act Relative to Accessible Medical Equipment," please contact Evelyne Milorin or Bill Henning at BCIL (617-338-6665, TTD 617-338-6662) or Robyn Powell at GBLS (617-603-1665, TTD 617-371-1228).

Laura Keohane works as a paralegal at the Greater Boston Legal Services.

WIA funds for job training and employment for adults may also benefit individuals with disabilities. The stimulus funding for these programs includes competitive grants for worker training and placement in high growth and emerging industry sectors and funds for Employment Services to assist unemployed individuals to connect with employment and training, and other programs. Entrepreneurs with disabilities may also benefit from the stimulus package. The stimulus legislation includes disability-owned businesses among those that must receive particular consideration when agencies award contracts financed through stimulus funding.

Additional funds will be available for programs that, although not directly related to employment and job training for people with disabilities in the short term, may contribute to the community integration and employability of people with disabilities in the long run. For example, independent living center services nationwide will receive a substantial influx of funds. Special education funding under Part B of the Individuals with Disabilities in Education Act (IDEA) will also



receive a significant boost. Massachusetts alone will receive \$280 million dollars for school age children with special needs and \$10 million for preschool special education services. The federal government will also temporarily increase its share of Medicaid funding, which provides essential services and even job supports in some instances.

In addition, the stimulus package will provide some income to people with disabilities and others to encourage short-spending. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries will receive a one-time payment of \$250. It will also permit states to extend unemployment benefits by increasing them by \$25 per week. In addition, individuals who pay income tax and who earn up to \$75,000 will receive a \$400 tax credit, and married couples with incomes of up to \$150,000 will receive a tax credit of \$800.

People from all segments of society stand to benefit from the American Reinvestment and Recovery Act. For people with disabilities, the stimulus package means not only a temporary boost to their incomes, but also a much needed, though short-term, enhancement in essential employment services and job opportunities that could potentially lead to long term benefits.

Advocates Seek to Protect Disability Access on Stimulus Funded Projects

By Cathy A. Levin

As part of the national stimulus package to improve the US economy. Governor Patrick has identified 1,800 "shovel ready" construction projects in Massachusetts that could be funded by this money. Among Gov. Patrick's projects are more than 380 flagged by the Disability Policy Consortium (DPC), as potentially needing review by the Architectural Access Board (AAB), the state agency charged with protecting the rights of citizens with disabilities to access to public accommodations.

However, the Governor's task force on the stimulus package posted a document on the state's website, www.mass.gov, saying the Patrick Administration wants to speed through approval of shovel ready projects bypassing the AAB. The Administration's Department of Public Safety, which has jurisdiction over the AAB, asked the AAB for a Memorandum of Understanding (MOU) signing away its oversight powers in disputed cases and granting the administration "blanket time variances." Ordinarily, AAB review is triggered when over 30% of the total cost of the building is spent on property improvements within a 3-year period. Some stimulus funded projects, which would have triggered AAB review, will receive immunity from AAB oversight because of these blanket time variances. Disability rights activists have been concerned that the variances would not comply with state regulations, the Rehabilitation Act of 1973, the Americans with Disabilities Act, and the Massachusetts constitution.

The activists voiced their concerns at an AAB hearing in March, resulting verbal assurances from the Patrick administration that the governor was not going to abridge civil rights in any way. As this article goes to press, the AAB has written an MOU that offers to expedite reviews of stimulus funded projects, rather than granting blanket time variances. The final MOU will be posted on the DPC web site, www.dpcma.org.

themselves in the form of the state's financial limitations, the group's agreement on priorities and maintaining the privacy of the consumer/employer-PCA relationship.

The contract that was ratified in November 2008 covers three years, from July 1, 2008 to July 1, 2011. It addresses health benefit coverage by forming a Healthcare Study Committee. Representatives from State agencies, the union, the Workforce Council and other relevant entities are researching coverage for PCAs with the goal of presenting this information to the state for further action. Another highlight of the contract is the paid time off fund that the state has committed to. It will amount to a total of \$2.25 million by the end of the third year, and can be rolled over from year to year until it is determined how paid time off would be assessed and distributed.

These questions and others are being addressed by the Labor Management Committee, another joint effort uniting consumers with PCAs and their union. Aligning ourselves as

consumers/employers with the very people we are hiring and training makes us a stronger force in the campaign to improve the PCA program.

It is remarkable what we have accomplished over the past three years. In addition to the pay raises by this June, a PCA Referral Directory that is now online privately as www.rewardingwork.org will be accessible for free to any MassHealth consumer in the PCA program looking for a PCA. (See Information Briefs for more details.) The PCA Workforce Council has also been offering CPR training workshops for PCAs across the state and anticipates expanding to other similar trainings in the future. If you would like further information on the other endeavors of the Workforce Council, you can find us online at www.mass.gov/pca.

Liz Casey serves on the PCA Quality Homecare Workforce Council and is herself a PCA employer.

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