

Disability Issues

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PCA Program Bigger Than Ever, but Longstanding Challenges Remain

By Bill Henning

Amazing growth surrounds the Massachusetts Personal Care Attendant program — PCA consumers now number 15,000, an increase of approximately 300% since the year 2000. Propelling the growth are efforts to divert people to the program in lieu of institutional care and increasing numbers of children with disabilities and frail elders now using the program.

But as PCA consumer enrollment has grown, longstanding challenges to the program's viability remain. Perhaps the most serious concern facing the program today is the low pay of PCAs. Attendants last received a pay increase in January 2005, when the hourly rate was raised to \$10.84 an hour. This wage is barely competitive with fast food joints, but the work, while rewarding, is harder, plus there's no health insurance, sick time, or vacation time for PCAs.

"Assisting a person with a significant disability to get out of bed, go to the bathroom, get bathed and then dressed can take skill and a lot of

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Charles Carr

Interviewed by Paul Kahn,

Part One

Charles Carr was recently appointed Commissioner of the Massachusetts Rehabilitation Commission.



PAUL KAHN: *What does it feel like to be the new Commissioner of the Massachusetts Rehabilitation Commission?*

COMMISSIONER CARR: I started on August 13, so we are now in week four. And I feel pretty numb. But I'm beginning to find myself settling in and beginning to learn the operations of the agency and the operations of the state government. So now I'm feeling like I'm a little more grounded and able to be more effective. It's exciting! One of my philosophies is that you have to have fun. And I'm starting to have fun now.

KAHN: *How did Governor Patrick get to know you to think about appointing you?*

CARR: All I know is about a year ago I got really excited about his campaign. So I jumped right into it as a Precinct Captain in my home town and started organizing my neighborhood and the disability community. We worked with his campaign on helping them to define their disability issues paper, and we did work with Steve Rothstein from the Perkins School to have a community forum that was very well attended. And he was elected! I got a call asking me to come in for an interview, and I did. I have to be honest; I was not interested in MRC, really, because I had this picture in my mind of what MRC is and it just wasn't appealing to me. Assistant Secretary McGuire challenged me to redefine what I think it should be, and I didn't have any trouble doing that. One thing led to another, and now I sit here with you.

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I have the support of the Administration to try to put some of those changes into place.

KAHN: *Here we are in the proverbial corner office.*

CARR: The Wormwood corner office, which is pretty hollow-sounding because I've taken out a lot of the bookshelves and all of the artificial plants, and I'm slowly putting together a work station that's accessible. I don't feel as productive as I need to feel at the moment. But I think MRC has tremendous talent, tremendous potential, and I see myself as someone who has three to five years here to get a lot of things done.

KAHN: *How has your background prepared you for this new position?*

CARR: Well I think being an advocate for change in government, you have to be a quick study and you have to learn how government works. So, having had 30 years of that advocacy and community change work under my belt, I learned where you need to go to make change happen. Beyond that, I started to learn the personalities of the people in the programs who, in my mind, will benefit people with disabilities. A lot of my work in the independent living movement and the disability rights movement prepared me to come here.

KAHN: *You've been a pioneer in independent living. You were one of the first people I knew who got out on your own. What made that possible?*

CARR: I believe that most things people do are self-serving on some level. I just wanted to get out of Middlesex County Hospital, just like you. To me, the best way to do that was by establishing an independent living center. That meant working with people to get BCIL started. That meant advocating within government for personal care assistance, housing and many of the services that we have now. But I think most of my success has been because I'm very driven. I'm very focused. I have a strong base of friends and family who I can fall back on and take comfort from. So, all those pieces together made me want to push the envelope. When I was able to go up north and start the Northeast Independent Living Program, which was "my ILC" I just went bananas with it. I pushed, pushed, pushed and created what I thought was a model independent living center. It was very cross-disability and very grassroots-based and very advocacy-based. I loved it. I'm still grieving leaving there after 27 years.

KAHN: *Wow! Twenty-seven years!*

CARR: Now there's a new calling. So, I can take some of that knowledge and passion and chutzpah to this role and continue that agenda and broaden it into employ-

ment and other areas like long-term care. And I am really beginning to see a part of government that I didn't fully appreciate is status. I'm beginning to learn that a commissioner has status and standing. I will not allow myself to make the mistake of not using this office and my position as an agent for change. I don't have to demonstrate outside of somebody's office to get their attention. I can just make a phone call and actually speak with somebody. It's mind-boggling! So, I'm going to use that to the advantage of the people I'm here to represent – you and me and others.

KAHN: *You mentioned your early institutional experience. Can you talk about that?*

CARR: I was 14 in 1968. I had a diving accident at Revere Beach. I was whisked away at a time when institutions were the rule rather than the exception. I went from Mass. General to Chelsea Naval Hospital, then to the Mass. Hospital School. I graduated in 1971 as valedictorian of my class, which was bizarre! When I graduated, I applied to college. I had the grades to get into schools, but back then you'd go on an interview and they'd say, "Oh, you can't handle it." So, I moved to Middlesex County Hospital in Waltham where I met a very progressive physician named John Noble. He allowed us to move to Wellington Hall, which was a separate wing in that hospital that was almost like a dormitory. We were able to go to school and live there. While you and I were living there, we were able to plan and develop and implement BCIL. That was my ticket out. That was your ticket out. And then we wound up living in the same building in Medford.

KAHN: *I followed you there.*

CARR: That was 1975, I think. One thing I also have learned, Paul, is to not forget the people who helped. There's a woman who is an unsung hero, and her name is Adele Andrews. She was the registered nurse that made this all happen within that institutional setting. She's 93 years old and living down in Florida. I had lunch with her a few weeks ago. She is as sharp as a tack. She fully realizes the role that she played in sparking the independent living revolution in this state. It's phenomenal! We're all standing on somebody's shoulders. I am standing on Elmer Bartels' [previous MRC Commissioner for 30 years] shoulders. Elmer, in his time, did some incredibly important work. You and I wouldn't be here if Elmer hadn't fought some basic battles. For instance, the State House, the seat of power, was inaccessible. Elmer and Vivian Thompson and others had to fight to get the State House accessible.

End of Part One

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FROM THE EDITOR

In this issue we feature the first part of an interview I was privileged to have with Charles Carr, the new Commissioner of the Massachusetts Rehabilitation Commission. I've known Charlie for over 35 years, from the time we were both residents of an unorthodox transitional living program at Middlesex County Hospital in Waltham. The program had the atmosphere of a raunchy college dormitory, and you had to be resourceful and tough to survive in it. Charlie was both, and he became my mentor and a source of inspiration for what it might be possible to achieve in life with a disability. A few years later I gladly held onto his coattails and followed him into the brave new world of independent living. Over the years I have been continually impressed with what he has accomplished personally and professionally, and I salute his latest achievement.



But Charlie remains the exception, rather than the norm, when it comes to people with significant disabilities. This is largely because society and government make it so difficult to obtain the necessities for a reasonable life. Some of these problems are described in our other features. The PCA program, the very foundation of independent living, remains woefully underfunded and based on a medical model. What sense does it make, I would like to know, for one arm of the government to promote employment for people with disabilities, while another arm refuses to provide employment-related PCA hours and makes us compensate our PCAs so poorly that we have little continuity of care and our lives are continually being thrown into chaos, rendering us unable to behave like responsible, employable adults? Our feature on current federal legislation points to other systemic issues, like the eroding of the anti-discrimination provisions of the ADA and the continuing bias toward institutional care as opposed to community-based care.

Having a job, a family, one's own home and a little savings in the bank – the ordinary goals of most Americans – should not be made so difficult for people with disabilities to achieve, fraught with the dangers of losing critical supports such as healthcare coverage, reasonably priced housing and assistive technology. Charlie is without question a hero of mine. But I would rather live in a world in which heroics were not required to live a decent life.

Paul Kahn



**October is...
NATIONAL DISABILITY
EMPLOYMENT
AWARENESS MONTH**

Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs

Disability Coalition Urges Action by Wireless Industry

Consumers with disabilities are taking their concerns about lack of accessibility of cell phones to the Federal Communications Commission (FCC), with multiple complaints against numerous companies submitted by representatives of the Coalition of Organizations for Accessible Technology (COAT). The FCC is the federal agency that enforces Section 255, a law that requires phones to be accessible for people with disabilities. Complaints have been filed against both cell phone carriers and manufacturers.

The complaints from consumers with disabilities include:

- Cell phones not providing for audio output of information displayed on the screen for users with vision disabilities;
- Cell phones not built for compatibility with hearing aids;
- Visual displays difficult or impossible to navigate for persons with fine motor disabilities;
- No easily-found disability “point of contact” at the company as required by FCC regulations;
- Number and control keys hard to distinguish by touch; and
- Product manuals not available in alternate formats such as Braille or large print;
- No easy-to-find descriptions of accessibility features;
- Phone bills and customer contracts not available in Braille, large print, or other easily readable formats; and
- Customer service personnel ill-equipped to handle concerns of consumers with disabilities.

Source: *Coalition of Organizations for Accessible Technology*

Online Guidebook on Disclosing Your Disability Available

The Art of Disclosing Your Disability is an informative and concise guidebook from speaker/author Richard Pimentel. It covers the basic legal and practical considerations that people with disabilities need to consider as they determine how and when to disclose their disability to an employer. The guidebook has been produced by the Diversity World, Disability Network newsletter. To download it go to www.miltwright.com/articles/ArtOfDisclosingYourDisability.pdf

Plan to Celebrate the International Day of Disabled Persons

The annual observance of the **International Day of Disabled Persons** on December 3, aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. It also seeks to increase awareness of gains to be derived from the integration of persons with disabilities in every aspect of political, social, economic and cultural life. The theme of the Day is based on the goal of full and equal enjoyment of human rights and participation in society by persons with disabilities, established by the World Programme of Action concerning Disabled Persons, adopted by the General Assembly in 1982.

For more information, please contact:
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Two United Nations Plaza, 13th Floor
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<http://www.un.org/esa/socdev/enable/disiddp.htm>

Source: *United Nations*

Adaptive Environments Launches Institute for Human-Centered Design

Adaptive Environments has launched the Institute for Human-Centered Design. The web-site explains, “New design energy has been building around the world. It’s generating products and places that respond to a positive fact of the 21st century: people live longer and survive more than ever before. Call it design for social sustainability, universal or inclusive design - it’s about all of us designing a world that works for each of us. We’re bringing the global story to Boston with the first permanent and public hub in the US for exploration, exchange and inspiration.”

The elements of the Institute include:

- **International Exhibit & Showroom** – Manufacturers on the cutting edge of the field, some household names and some unfamiliar to American audiences, are exhibiting their actual

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products as well as demonstrating products via DVD. One area will be dedicated to making the business case for universal design. Other exhibits will showcase projects and competitions from the UK, Europe, Japan and anywhere in the world where good examples illuminate the vision of socially sustainable design.

- **Library** – the expanded library contains the largest collection in the US of publications and multi-media materials on accessibility and universal design.
- **Retail** – the new retail store addresses the need for well designed products that look as good as they work. There is no other “museum store” in the US that features the best international inclusively designed products. Focus will be on products that are not easily available elsewhere as well as on the best publications in the field. A parallel web-based retail showcase will expand the audience.

To learn more about the center, visit;
<http://www.adaptiveenvironments.org/index.php?option=Content&Itemid=406>

Source: *Global Universal Design Educator's Online News*

Guide to Eldercare Available

Stella Mora Henry, RN, with Ann Convery. *The Eldercare Handbook: Difficult Choices, Compassionate Solutions*. Harper Collins, 2006. 272 pages. (Also available in a Spanish-language edition.)

In *The Eldercare Handbook*, author Stella Mora Henry, RN, offers an instruction manual for those facing care decisions involving an elderly parent or loved one. Ms. Henry is well-qualified to write the book, having spent 26 years as a nursing home administrator witnessing firsthand the difficult choices families confront, as well as having struggled with the care of her own parents as they both endured Alzheimer's disease.

The book's first half identifies the warning signs that a parent may require long-term care and may no longer be safely cared for at home. Henry also discusses how to cope with the emotions (such as denial and anger) and shifting family roles that a parent's increasing disability typically

trigger. The second half of the book offers advice on selecting a long-term care facility and tips on accommodating to the new living arrangement, including when and how to visit, how to deal with “Take me home!” demands, and what to expect of the certified nurse's assistant (CAN), the person who has the closest contact with the nursing home resident. Henry also offers a brief roadmap to the medical, legal and insurance maze that inevitably accompanies the need for long-term care.

As Henry points out, the idea of a quick, peaceful death is a common myth. With life spans increasing, it is more likely that death will follow a period of protracted illness or disability. *The Eldercare Handbook* is a guide as that final stage of life unfolds.

Call for Contributors to Encyclopedia of Disability History

Facts On File and the advisors for the *Encyclopedia of American Disability History* are looking for contributors. This three-volume reference work will cover basic information on important events, issues, developments, laws, biographies, and related topics in American Disability History. Entries on significant historical themes and concepts – including civil rights, war, public policy, citizenship, media, institutions, education, and technology – will examine both practical and theoretical factors, as well as demonstrate the deeper meaning of the lived experience of disability. Each entry will illustrate the subject within an historical context, and show that, while disability has existed throughout American history, disability is neither a fixed nor static concept but one whose definition and understanding have changed markedly from era to era.

Because accessibility is a major issue in *Disability History*, the entries in this reference will accommodate a broad, diverse audience, from high school students to general readers, to individuals who assist people with disabilities. Clear language, accessible prose, and coherent, balanced, jargon-free interpretations are essential for every article.

The editors of this encyclopedia are currently seeking contributors for a wide range of entries. Authors interested in contributing to this important project should contact Dr. Susan Burch at susanburch1917@yahoo.com for further information and details regarding the full list of entries.

Book Review

A Million Reasons

Why I Fought for the Rights of the Disabled

By Alan Labonte with Brock Brower • Reviewed by Sandy Alissa Novack, LICSW, MBA

Alan Labonte was a high-earning administrator at a prestigious Boston law firm. He was about to get a raise for good performance after his first year of employment, when he learned he had multiple sclerosis.

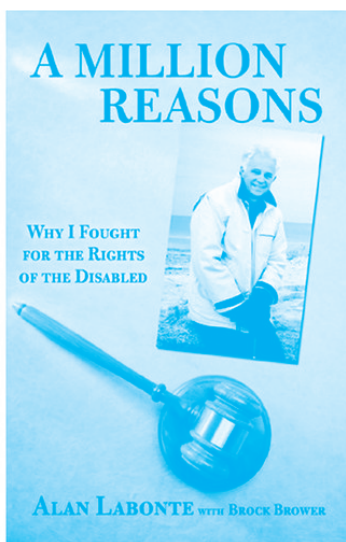
When he shared this news with others at the firm, he was shunned and soon terminated for poor performance. He had received the raise before the firm learned about his MS, so their argument that he was a poor performer did not hold water, as they had given him a raise before they knew of the MS. The shock and depression that ensued caused Labonte to doubt himself, for surely, he reasoned, a law firm of all places knew the law and wouldn't discriminate against him for having a disability...right?

This sounds like the set-up for a good novel, but it is actually a true story. The book, set in the 1990s and published in 2006 by Hot House Press of Cohasset, MA, is one I ordered at Barnes and Nobles recently for \$26.00 hardcover. That may sound like an expensive purchase to some, but I strongly recommend the book to anyone who has ever

felt discriminated against at work due to disability. It is also helpful to family and friends of the person facing such discrimination. You will often find yourself nodding your head or saying under your breath as you turn the pages "I can relate to that!" Packed into the book's 236 pages is information on everything from issues of disability disclosure, reasonable accommodations, and how job performance is related to accommodations...to the details of discrimination law. This book has it all.

The book centers upon the precedent-setting decision by the courts that Mr. Labonte had the right to sue for disability discrimination, even though he was receiving disability income, a view vehemently fought by the law firm that had terminated him. The employer's lawyer argued "...Courts all across the country have said you cannot speak out of both sides of your mouth. You cannot say—for the purpose of getting insurance benefits—

I'm disabled, and then turn around and say to a judge and jury, I could have performed the job." On the other side, Labonte's lawyer argued "There is no inconsistency whatsoever because there is nothing inconsistent if the employee, when he's asked, 'Can you do the job?' answers, 'No, I can't because no one's offering me accommodations.' The insurance company does not ask that question. Now maybe they should, but they don't ask that question. So when Mr. Labonte said to the insurance company, 'I am totally disabled, I can't be the executive director (of the law firm),' he meant 'without reasonable accommodation.'" For in-depth detail on Labonte's job and its demands on him, you can read the book in its entirety.



This case went on for many years in the legal system, and as the defendant law firm realized the jury could side with Mr. Labonte, they offered to settle with him for three million dollars. By this point, however, Labonte realized the firm was trying to buy his silence, because, if he agreed to the settlement, he would be required

to sign away his right to say anything ever again about the case. He did not settle; indeed he wrote this book. And it should make all who read it feel they are not alone in the fight for the rights of people with disabilities in the workplace.

As the case proceeded, Labonte entered a doctorate degree program, traveled abroad, and continued to own real estate. This can make Labonte's life experience seem too far outside the reality of many people with a disability. He had the knowledge and resources that very few can muster. Labonte himself writes that "barely 5% of handicapped plaintiffs prevail in the federal courts these days." Nonetheless, each inroad against injustice matters.

Sandy Alissa Novack is a geriatric social worker in Greater Boston and a member of the Disability Issues Editorial Board.

PCA Program - Continued from page 1

energy. It should be much better compensated," said PCA user Rob Park of Salem. "Because the pay is low, I, like thousands of others in the state, have a hard time finding attendants."

But as of the submission of this article, advocates' efforts hadn't borne any apparent fruit. Governor Patrick's administration was holding off on increasing PCA pay until collective bargaining commences, should a union of PCAs be formed. The right to collective bargaining, along with the cementing of consumer control in statute, occurred with the unanimous passage by the state legislature of the PCA Quality Workforce bill in July 2006. The service employees union, 1199SEIU, which is organizing PCAs, announced during the first week of September that an election is set for early October. It will be overseen by the American Arbitration Association, a neutral body.

Many advocates see joining 1199 as their best hope for securing benefits for PCAs as well as to make their compensation commensurate with the vital work they perform. The push by 1199 is expected to occur in late 2007 or early 2008. Becca Gutman, an organizer with 1199, said, "This will not only be the largest union election in Massachusetts history but is also a unique opportunity for consumers and PCAs to join together to create a more powerful voice for homecare in Massachusetts."

Paul Spooner, a user of PCAs since the late 1970s and director of the Metrowest Center for Independent Living, summarized the pay rate issue this way: "PCAs provide the ability to live in the community, the freedom to make daily choices and to have a quality of life in our society. PCA wages should reflect the value of this work, and the value of including all members of society in our community."

For more information on PCA advocacy initiatives, contact Bill Henning at BCIL at 617-338-6665.

Bill Henning is the Executive Director of the Boston Center for Independent Living and a member of the Disability Issues Editorial Board.

Congress Considers Disability Legislation

By Mary Margaret Moore

With the shift in Congress from the last election, there are many new bills being introduced that may positively impact the lives of citizens with disabilities. Three of these bills are identified below. Of particular concern to me is the amount of resistance building to these and other bills that would improve the long term care services and supports that are critical to independent living.

The first bill is the **ADA Restoration Act**, which addresses some of the Court decisions that limited the use of the ADA by many. Just three weeks after this bill was filed in the House and Senate the U.S. Chamber of Commerce, the world's largest business federation, in a letter addressed to the Members of the U.S. House of Representatives, went on record as opposing the ADA Restoration Act of 2007 (H.R. 3195) and urging Members not to co-sponsor or show support for the bill. The Chamber's letter mischaracterizes the ADA Restoration Act as an expansion of the ADA, when in fact, it is, as its name suggests, a restoration of the original intent of Congress when passing the ADA in 1990, which was to create a level playing field for everyone who wants a job to have an equal opportunity to work. Just like other civil rights laws prohibiting employers from basing decisions on characteristics like race or sex, Congress wanted the ADA to stop employers from making decisions based on disability.

However, that original, bipartisan, bicameral intent has since been distorted by the Courts through extremely narrow interpretations of the ADA. The employment rate of people with disabilities has not improved, and two-thirds of people with disabilities who do not have a job indicate they would work if they could only find employment. What's more, for those fortunate enough to find jobs, courts are deciding against people with disabilities who challenge disability discrimination 97% of the time, often before the person with a disability even has a chance to show that the employer treated them unfairly!

The ADA Restoration Act (H.R. 3195/S. 1881) ensures the right to be judged based on performance. It restores the original intent of Congress, harmonizing the ADA with other civil rights laws and requiring the courts to interpret the law fairly. The bill amends the definition of "disability" so that people who Congress originally intended to protect from discrimination are covered under the ADA.

The Community Choice Act of 2007 (S.799 & H.R. 1621) introduced by Senator Tom Harkin (D-IA) and Representative Danny Davis (D-IL-7th) addresses provisions that would provide a range of community-based supports, including activities of daily living such as eating, toileting, grooming, dressing, bathing and transferring; and also meal planning, shopping and preparation, financial manage-

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ment, and household chores. The legislation also addresses hands-on assistance, supervision and cueing. The Community Choice Act of 2007 will provide many people with disabilities the opportunity to choose where and how they receive personal assistance services in their homes and communities across the nation.

Community Living and Assistance Services and Supports Act of 2007, the CLASS Act, introduced by Senator Kennedy (D-MA) and Senator Harkin (D-Iowa) in the Senate and Representatives Dingell and Pallone in the House, would assist people with disabilities who need long term assistance or supports by providing a flexible cash insurance benefit that could be used creatively to purchase services, supports and technology. Beneficiaries

would choose how to best meet their own needs. The CLASS Act could help pay for long-term services and supports needed to maintain the independence of people with disabilities. Individuals would be automatically enrolled in the program and pay monthly premiums of at least \$30, but could opt-out. Cash benefits of \$50 or \$100 per day could give individuals the choice and control to acquire the supports that best meet their individual needs. The CLASS Act would provide an insurance program that is available nationwide and that is affordable and not tied to poverty and unemployment. This is a laudable goal and a much needed piece of the long term service puzzle.

Mary Margaret Moore is the Region 1 NCIL Representative and Executive Director of the Independent Living Center of the North Shore and Cape Ann.

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