

# Disability Issues

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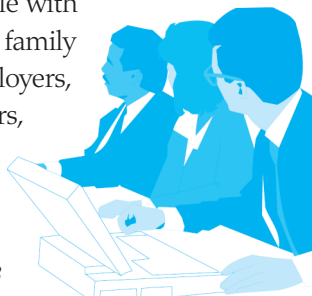
Winter 2009-2010

## An Opportunity for Dialogue: The Massachusetts Disability Employment Summit

By Jennie N. Fishman

On October 28th, 2009, the *Work Without Limits* initiative, a partnership between the University of Massachusetts and the Executive Office of Health and Human Services, sponsored the *Putting Our Abilities to Work!* Massachusetts Disability Employment Summit held in Boston. The event provided the opportunity for public and private entities to come together and begin a dialogue focused on improving employment outcomes for people with disabilities in Massachusetts.

The day was filled with inspiring speakers including Massachusetts Governor Deval Patrick; Commissioner Charles Carr of the Massachusetts Rehabilitation Commission; Jim Salzano, Executive Vice President of The Clarks Companies, N.A.; and Andy Imparato, President and CEO of the American Association of People with Disabilities (AAPD). Approximately 225 people attended the Summit, including people with disabilities and family members, employers, service providers, and state agencies.



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## Allegations of Fraud and Abuse in the PCA Program

By Ray Glazier

In October many readers of the *Boston Globe* were outraged by accounts of fraud and abuse in the MassHealth PCA Program, charges made in an alarmist article that drew selectively from an October 14th State Auditor's Report, claiming that: "A \$332 million state Medicaid program...is rife with fraud and employs personal care attendants who have committed felonies..." But many PCA Program consumers were especially distressed by the allegations, seeing in this a potential threat to the consumer-directed nature of the service system that enables them to go to work, to go to school, and otherwise to participate in their communities.

State Auditor DeNucci, in this Report's summation of the situation, wrote that: "Inadequate internal controls and procedures over MassHealth's Personal Care Attendant Program have resulted in a) repeated overpayments on potentially fraudulent claims; b) unregulated and unsupervised felons with multiple crimes of violence, theft, and drugs providing services to the elderly and disabled; and c) providers missing critical documentation relative to the PCA program..." The Audit Report's conclusions, based on detailed examination of the expenditures for and backgrounds of PCAs of 30 previously identified "problem consumers" were:

- That 90% of 30 consumers whose claims the Auditor reviewed had seemingly fraudulent payments to their PCAs while they were in the hospital or another inpatient facility.
- That 47% of the same set of 30 PCA Program consumers employed felons as PCAs, including persons convicted of assault and battery, other violent crimes, serious drug offenses, etc.; and 9% of the 82 PCAs had done prison time.
- That personal care management (PCM) agencies and fiscal intermediaries (FIs) were missing required records on 63% of the 30 PCA consumers the Auditor reviewed;
- That, of these 30 consumers, 17% (5) had their own history of serious crimes.

The *Globe* exposé recounted the more sensational contents of the report and made no mention of the MassHealth responses to these charges, rebuttals included verbatim in the Auditor's Report. The most telling of these criticisms

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# Olmstead Enters Double Digits

By Sandy Alissa Novack

This past summer was the tenth anniversary of the Olmstead decision by the United States Supreme Court. Over two hundred people rallied at the Massachusetts State House that day to show their interest in Olmstead and moving it forward. What follows is a brief overview of the history surrounding Olmstead, as well as an interview with Bill Henning, Executive Director of the Boston Center for Independent Living, in which he gives his perspective and reflections on Olmstead.

Tommy Olmstead was the Commissioner of the Department of Human Resources in the state of Georgia. The two plaintiffs were women with mental illness. Both were determined by mental health professionals to be able to be treated in a community-based setting, but the State of Georgia argued they should be housed and treated in an institution. The defendants claimed the plaintiffs had been denied community placements due to inadequate funding and not because of disability discrimination. Institutionalization, however, can lower the quality of life for people, curtailing their ability to participate in their community socially, job-wise, and every other way, hence isolating, constricting, and financially limiting the life and growth of people. The Supreme Court decided in favor of the plaintiffs because segregating them in an institution was a form of discrimination under Title II of the ADA.

## **NOVACK: What was the significance here?**

HENNING: The ADA provides for full integration of the highest degree possible. The Supreme Court agreed; you cannot segregate people in institutions. Advocates now had a tool to say to states: "You must provide community-based service and not hide people away." The state wasn't complying, (there were two further notable cases)—the Rolland case, and also the Hutchinson case involving people with brain injury.

## **NOVACK: What is happening now in Massachusetts?**

HENNING: Governor Deval Patrick came out with the Community First Olmstead Plan, because the state needs a road map to further comply with Olmstead.

## **NOVACK: Where are we now?**

HENNING: That's the ten million dollar question. Are we half-full or half-empty? We have an administration pledged to close institutions like Fernald, and I give credit for this. But, there are barriers to getting into programs. There are 30,000 people in nursing homes, but there could be more nursing home diversion. A shortage of housing keeps people in nursing homes, or keeps people in substandard situations in shelters. My point is, it's not just an issue of in

and out of institutions, but the highest quality of living. I applaud Patrick's support of health reform, but there can be limited pieces of the pie. If the economy improves, there will be more money to go around. Advocates must continue to push for nursing home diversion.

## **NOVACK: The spirit here...**

HENNING: The spirit of the ADA is independence and quality of life. It is not just having people out of institutions because, for example, no accessible transportation leaves people institutionalized at home.

The ADA is a prescription on what a program should be to be successful. It was a statement that people have a right to be productive and fully participate in the community. People with disabilities should not be considered second class citizens. People with disabilities should not just accept things. Good public education is needed.

## **NOVACK: Steve Gold and others have compared the black civil rights movement to the struggles of people with disabilities. Any comment?**

HENNING: There are similarities, but it is dangerous to analogize it. We cannot mirror another civil rights movement. Disability issues are different. And, we must sell NEW answers these days.

## **NOVACK: If a person with a disability is reading this now, what would you want to tell him?**

HENNING: We need people with disabilities to push relentlessly. The government will respond, but there are competing voices for government's attention, so people with disabilities must learn to be heard by speaking up, putting themselves on the public agenda. There are limited resources, and homelessness, women's rights, the move to end wars—they are all good issues—but we must have disability issues heard. Be engaged. If you have ten dollars, make a donation. Write letters, make calls to legislators.

A community is made up of activists, community organizations, but people with disabilities must speak up themselves, too. There's the Star Trek line: "Boldly go where no one has gone before." So say to yourself "I'm going to go on the bus in a wheelchair and people will see me." I went to a wedding where people with disabilities were dancing and being seen; they were demanding to be normal. You would not have seen this years ago, people would have been segregated. Again, Olmstead is about living in the community.

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

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## From the Editor: Discouraging Journalism

In this issue, Ray Glazier, frequent correspondent and *Disability Issues* Editorial Board member, responds to the *Boston Globe's* one-sided and misleading account of problems in the PCA program. We felt this was important to do in as many places as possible, because the PCA program is the backbone of independent living for so many of us.

Massachusetts has one of the oldest and best PCA programs in the country. I have been using it for over 30 years, and it has enabled me to live in the community, to work, to be married—in short, to be free and lead a full life that I could not conceive of as a child when nothing like it existed. The PCA program is one of the main reasons I continue to put up with our Massachusetts winters, even though my old bones increasingly long for warmer weather.

The program is not perfect by any means. Hours of care are determined on too much of a medical basis. Pay is not commensurate with the amount of responsibility PCAs carry. And the program is structured in a way that makes it very difficult to maintain reliable back-up PCAs. This means that my life is thrown into chaos when a PCA calls in sick or doesn't show up to work for other less innocent reasons. And sometimes it seems that the program attracts people who are lazy, social misfits or dishonest. (I should say that it also attracts some of the most dedicated, loyal people I have ever known.)

The *Boston Globe* article was irresponsible journalism by anyone's standards. But it is especially painful to see a vital support of ours attacked just for a bit of sensationalism. And it is discouraging to realize that we have to fight the same battles over and over—in this instance to prove that we are worth public investment. Nevertheless, that is what we must do. We should correct the media when it misrepresents us and the way we live. In a democracy it is the most insistent voices that win the battles for public opinion and policy change. Let us not lose vital services like the PCA program because we are too timid to speak out.

Paul Kahn

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was that the tiny sample of 30 consumers, from the PCA Program's 16,000 members, whose claims the Auditor reviewed, was not at all random or representative. Rather, these 30 individuals were a targeted sample of persons who had, in previous studies, been found to be the subject of fraudulent claims. Citing statistical percentages based on such a minute, purposefully skewed sample was misleading.

The Auditor's response to this MassHealth criticism was a disclaimer that the statistics were not said to be representative of the entire PCA Program. In this report and previous reports of 28 October 2008 and 10 June 2009, State Auditor DeNucci had taken a very constructive approach, making positive suggestions to remedy the problems the audits seemed to disclose.

Now, in addition to insisting on new MassHealth procedures to identify potentially fraudulent PCA claims, the

Auditor strongly recommended Criminal Offender Record Information (CORI) background checks on each PCA applicant. Requiring CORI checks on all PCA candidates would seem to be wasteful, time consuming, and very costly, expending many dollars needed for funding PCA services. Practically speaking as a consumer, just having to ask each PCA applicant to sign permission for a CORI check would turn many people off, most of whom have no criminal record, thus shrinking the already shallow pool of applicants. Certainly CORI checks should be an option (not a requirement), at no cost to the consumer.

On the "double dipping" during hospital stays, a few thoughts:

- 1) Although consumers are routinely cautioned to report hospitalizations to their PCA provider agency, it is not entirely unreasonable that a PCA would be doing shopping, cleaning, etc. during the consumer's absence, keeping up the home situation to which the consumer will return;

- 2) As I know from personal experience, it is difficult to retain good PCAs who get no paycheck during the consumer's hospitalization;
- 3) In recognition of this, the state-funded PA Attendant Care Program allowed PCAs to bill a minimal number of hours during the consumer's hospitalization;
- 4) If hospitals would only allow PCAs to come in and perform routine services for hospitalized consumers, it would reduce hospital care burden and costs, thus making severely disabled consumers more desirable as patients.

*Raymond E. Glazier, Ph.D., is a long-time consumer of the MassHealth PCA Program through the CommonHealth Medicaid Buy-In for working persons with disabilities, enabling him to be employed and function in his position as Director of the Abt Associates Center for the Advancement of Rehabilitation and Disability Services, Cambridge, MA.*

## Communities Gather to Develop Transportation Solutions

By Maura Mone

This past October nine regional teams from across the state converged for a three day intensive training and strategic planning institute around community transportation solutions for people with disabilities and other transportation disadvantaged populations. The event, entitled the **Massachusetts Institute for Transportation Coordination**, was sponsored by the *Work Without Limits* Initiative and brought national consultants "Community Transportation Association of America (CTAA)" to the state to facilitate and share their expertise.



*Amy Conrick from Community Transportation Association of America addresses attendees at the transportation summit.*

Teams were comprised of regional multi-stakeholder community representatives and brought together people from local transit and planning authorities, municipal and state government, disability advocacy groups and health and human services. Over the course of the three days, teams worked with facilitators to develop a ninety-day action plan and twelve month strategic plan to improve transportation coordination in their specific region. Projects included developing shuttle services in underserved communities, creating collaborative work groups, developing one-stop call centers and developing

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community resource web pages.

Community teams in attendance were: Berkshire County; Central MA region; South East region; Metro West region; the North Shore; Franklin County; town of Action; town of Sherborn; and the city of Cambridge.

Workshops moderated by national experts from organizations such as Easter Seals Project Action and United We Ride were also given to institute attendees. Sessions included information on coordination models that work, funding transportation improvements, utilizing technology and understanding mobility management.

Noted transportation experts also presented keynote addresses, including manager of transit planning John Englert from the Executive Office of Transportation and Mary Beth Mello, Deputy Director for Federal Transit Administration Region I. The closing session of the institute was highlighted by a keynote address from Lora Brugnaro who spoke about her personal experiences using transportation as a person with a disability. The speech left the team motivated to leave the event and to continue working toward transportation solutions.

The *Work Without Limits* initiative is a public/private partnership between the University of Massachusetts, the Executive Office of Health and Human Services and other key stakeholders to improve employment options for people with disabilities in the state. *Work Without Limits* plans to continue providing technical assistance to teams who attended the MA Institute for Transportation Coordination in 2010 to help them implement their plans.

## State Auditor and MassHealth PCA Program Resources

A link to the *Boston Globe* Metro Desk story by David Abel, posted at 1:45 PM on October 14th, the very day the Auditor's Report was released:  
[http://www.boston.com/news/local/breaking\\_news/2009/10/auditor\\_uncover.html](http://www.boston.com/news/local/breaking_news/2009/10/auditor_uncover.html)

(If the link is no longer active, check the *Boston Globe Archives* for October 2009.)

**For information on becoming a working person with a disability**, including health insurance concerns pertaining to PCA services for which you may be eligible, go to the new *Work Without Limits* website:  
<http://www.workwithoutlimits.org/>

**United Cerebral Palsy of MA**, a PCA Program Fiscal Intermediary has information on the Mass/health PCA Program:  
[http://www.masscp.org/pca/pca\\_frameset.htm](http://www.masscp.org/pca/pca_frameset.htm)

**The Boston Center for Independent Living**, like other agencies who are Personal Care Management contractors to MassHealth, also has PCA Program information:  
<http://bostoncil.org/pca-program/index.htm>

**The MA Executive Office of Health and Human Services** maintains an Online PCA Referral Directory that helps consumers and PCA candidates find each other:  
<http://www.findpca.org/State-Resources/Massachusetts.aspx/>

State Auditor DeNucci's Press Release, "**DeNucci Calls for Increased Safety Controls in Medicaid Personal Care Program**":  
<http://www.mass.gov/sao/Press%20Releases/2009/medicaidpcapr09.pdf>

**"MassHealth – Payment of Certain Claims for Personal Care Services,"** the Official Audit Report of 14 October 2009:  
<http://www.mass.gov/sao/Audit%20Reports/2010/200813743s2a.pdf>

**"Personal Care Attendant Program,"** the 150 pp. Official Audit Report of 10 June 2009, containing many suggestions for program expansion and improvement:  
<http://www.mass.gov/sao/Audit%20Reports/2009/200651243c.pdf>

**"MassHealth's Administration of Medicaid Payments for Personal Care Services,"** the Official Audit Report of 28 October 2008, in which the sample of 30 'problem consumers' was first identified:  
<http://www.mass.gov/sao/Audit%20Reports/2009/200813743s2.pdf>

**The MassHealth 'Personal Care Manual'** for providers details the State and Federal regulations that govern the PCA Program:  
[http://www.mass.gov/Eeohhs2/docs/masshealth/regs\\_provider/regs\\_personalcare.pdf](http://www.mass.gov/Eeohhs2/docs/masshealth/regs_provider/regs_personalcare.pdf)

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# INTERVIEW:

## Ayisha Knight-Shaw Deaf Artist, Poet and ASL Theater Consultant

*Interviewed by Ruth Celia Kahn*

**KAHN:** As a Deaf woman, how did you become interested in visual arts and theater?

**KNIGHT-SHAW:** I started to become interested in visual arts and theater when I was a child. I grew up with many ethnically diverse artists in my community, so I was exposed to various forms of art — going to museums, seeing dancers, poets, theater and printmaking.

**KAHN:** How would you describe your art?

**KNIGHT-SHAW:** I am a Deaf artist who blends ASL poetry, collage, photography, theater, and storytelling.

**KAHN:** What else do you do?

**KNIGHT-SHAW:** I am also an ASL theater consultant, Reiki Master Teacher (Japanese healing system), ASL teacher and ASL tutor. I'm on the advisory board at Wheelock Family Theater, Underground Railroad Theater, Museum of Fine Arts Boston, and Show of Hands Theater Company. I am also a Martial Artist taking karate at the Emerald Necklace Martial Arts in Allston.

**KAHN:** What is an ASL theater consultant?

**KNIGHT-SHAW:** An ASL theater consultant works with theaters to make sure that the play being produced is accessible to Deaf and hard of hearing audiences.

**KAHN:** What does an ASL theater consultant do?

**KNIGHT-SHAW:** An ASL theater consultant will work with the theater producer, director, actors, and ASL interpreters to ensure the play is accessible. I will get a script, hire interpreters who I feel will best fit the play, and rehearse with them to work on timing, style, ASL and create character name signs. When possible, I like to have a conversation with the actors



*Ayisha Knight-Shaw (left) and her spouse Stephanie*

and ASL interpreters, if I need clarification on what a speech or a specific line means, or the nuance of it, so that the Deaf audience can have the same experience as a hearing audience.

**KAHN:** Tell me about the rehearsal process.

**KNIGHT-SHAW:** The ideal rehearsal process is 3 months prior to a show. It gives me time to read the script, think about the interpreters I want, make sure they are available for the dates of the interpreted show, hopefully speak with the director and producer about their vision, where to place interpreters either on stage or in the best visual location. The interpreters work both independently and with me to make sure the ASL and English translations match as best as possible, also adding Deaf culture cues when needed. The interpreters and I will also see the show live and on DVD if possible to see the timing and rhythm of the show, and then get involved with the tech rehearsal, making sure the ASL interpreters have lights on them, where they will stand, what will they wear.

**KAHN:** Do you work with the staff at the theater?

**KNIGHT-SHAW:** Yes, I work with the staff, ticket takers, directors, producers, lighting tech and sometimes theater educators.

**KAHN:** If a theater wants to provide an ASL-interpreted performance, how should they start?

**KNIGHT-SHAW:** If a theater wants to provide an ASL interpreted performance, they should start by choosing a show that is as visual and active as possible. They should then hire an ASL consultant to work with.

**KAHN:** What kind of budget is needed for this?

**KNIGHT-SHAW:** Ideal budget is \$2000 to \$2500.

**KAHN:** Whom should they contact to get started?

**KNIGHT-SHAW:** To get started, theaters should contact ASL consultants in the area. I've worked with many theaters in Washington, DC, Maryland, Rhode Island, Boston, and surrounding areas.

**KAHN:** More about you. Did you receive any training to be an ASL theater consultant?

**KNIGHT-SHAW:** Yes, I was very lucky to be trained as an ASL theater consultant.

Several years ago there was a training with many Deaf people who were interested in becoming ASL theater consultants. It was thrilling to see how different our processes were, and I learned a lot.

**KAHN:** What was your first show as a theater consultant?

**KNIGHT-SHAW:** My first show was at the Huntington Theater, "Amen Corner".

**KAHN:** Do you have a favorite or most memorable show? What made it so special?

**KNIGHT-SHAW:** I loved working on the show "A Lesson Before Dying" at

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**Interview** - continued from page 6

the New Rep Theater. It was an amazing opportunity to work with a phenomenal cast and with director Lois Roach. The ASL interpreters were phenomenal, and the collaboration made the experience so rich.

**KAHN: Do you have any advice for anyone who wants to become an ASL theater consultant?**

**KNIGHT-SHAW:** I would advise anyone who is interested in becoming an ASL theater consultant to first have the passion for ASL and theater. Next, I would contact theaters they go to often and offer their services.

**KAHN: How do Deaf theatergoers find out about ASL interpreted shows?**

**KNIGHT-SHAW:** Deaf theatergoers can find out about ASL interpreted shows on the Mass Deaf-Terp list, by vlogs created and put out by ASL theater consultants, and emails from theaters themselves that advertise their ASL interpreted shows.

**KAHN: What's coming up for you this winter?**

**KNIGHT-SHAW:** This winter will be very busy and creative for me. I'll be teaching at Wheelock College, teaching ASL one on one with clients individually, offering workshops on Reiki levels 1, 2, 3 and Master, theater consulting, poetry and theater performances. I'm also working on a new book, and organizing an arts, education and social justice event for October 5-10, 2010. I've already got several artists and speakers lined up, including Adam McKinney and Dr. Daniel Banks, which is very exciting for me. I will be increasing my business Ayisha's Ki, launching a website, and hopefully showcase more photos in café's and galleries. People can see more of my work at [www.ayishaknight.com](http://www.ayishaknight.com).

*Ruth Celia Kahn is a freelance writer, theatrical open captioner and audio describer.*

# Information Briefs

## **Pamela Hyde Confirmed to Lead Substance Abuse and Mental Health Services Administration**

U.S. Department of Health and Human Services (HHS) Secretary Kathleen Sebelius recently announced that the United States Senate unanimously confirmed Pamela Hyde as Administrator for the Substance Abuse and Mental Health Services Administration (SAMHSA) within HHS.

Pamela Hyde has served as secretary of the New Mexico Human Services Department (HSD) since 2003. Hyde has 30 years of experience in management and consulting for public sector systems of health care and human services. She has held several key public sector management positions, including director of the Ohio Department of Mental Health, the Ohio Department of Human Services, and the Seattle Department of Housing and Human Services. She also previously served as a CEO of a private non-profit behavioral health care organization. Hyde is a member of or has served as a consultant to many national organizations, including the John D. and Catherine T. MacArthur Foundation, the American College of Mental Health Administration, and the President's New Freedom Commission on Mental Health. She has received awards from the American Medical Association, the National Governors Association, the Seattle Management Association, and a number of consumer and provider organizations for her leadership and commitment to the well-being of those who rely on publicly funded health and human services. She received a B.A. from Missouri State University and a J.D. from the University of Michigan.

*Source: AAPD*

## **MCDHH to No Longer Provide Emergency After Hours Interpreter Referral Service**

As a result of the severe economic crisis and budget cutbacks, the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) will no longer have funds to provide on-call interpreters for hospital emergencies during evening, weekend, and holiday hours. The MCDHH Emergency After Hours Referral Service closed on November 30, 2009. The closing of this service does not change an individual's right to qualified interpreters during hospital emergencies, and it continues to be the hospitals' responsibility to provide you with communication access during a medical emergency.

The Massachusetts Hospital Association (MHA) and member hospitals have informed MCDHH that they wish to establish their own plans for compliance with the legal obligation to locate and provide communication access for Deaf and Hard of Hearing persons. To assist hospitals in obtaining ASL interpreter requests during evening, weekend and holiday hours, MCDHH will provide a list of qualified ASL interpreters who agree to have their contact information given to hospitals. MCDHH will continue to provide regular Referral Services for daytime/scheduled ASL interpreter requests as well as daytime emergencies.

The right to communication access is protected by law, and it is important that all Deaf and Hard of Hearing consumers in Massachusetts be prepared to request qualified interpreters and other reasonable accommodations directly from hospitals. If additional information will be helpful, MCDHH is prepared to assist. Please contact Debra Lobsitz by email at [debra.lobnitz@massmail.state.ma.us](mailto:debra.lobnitz@massmail.state.ma.us), by VP at 866-970-7177 or by TTY at 617-740-1768.

*Source: Mass\_Deaf-Terp*

**Disability Issues**

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## Employment Summit - continued from page 1

Governor Patrick, who announced over the summer his goal of making the Executive Office of Massachusetts a model employer of people with disabilities, spoke of the “importance of leading by example” and called upon businesses in the private sector to also become model employers of people with disabilities.

Following Governor Patrick, Jim Salzano shared how The Clarks Companies has implemented a successful internship program called *First Step* that provides opportunities to “people with abilities” as an example of how businesses can develop programs within their own organizations. Mr. Salzano responded to Governor Patrick’s call for private sector businesses to become model employers and committed to lead a Business Advisory Council to educate, guide and support businesses in employing people with disabilities.

The event built upon the theme of employer engagement when Keynote Speaker, Andy Imparato commented on the need for society to develop a “baseline expectation that we expect people with disabilities to work.” Mr. Imparato highlighted research showing that companies who are committed to accessibility and that hire people with

disabilities improve productivity, employee retention, brand image, and enhance innovation.

Attendees also had the opportunity to hear panelists discuss their lived experience in navigating the path to competitive employment. The Panelist participants were Kevin McGuire of McGuire Associates, Inc.; Jennifer Lerner, Professor of Public Policy and Management, Harvard University; Laura Zirpolo Stout, from the Executive Office of Blue Cross Blue Shield of Massachusetts; and Oswald Mondejar, Vice President of Human Resources/Community Relations for Partners Continuing Care, Partners HealthCare.

Dr. Jay Himmelstein, Director of the *Work Without Limits* initiative and Professor of Family Medicine and Community Health at UMass Medical School, closed the day’s events by launching the *Work Without Limits* initiative and its website, [www.workwithoutlimits.org](http://www.workwithoutlimits.org), which provides information and resources for employers, people with disabilities and their families, and providers.

Dr. Himmelstein is the principal investigator on the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) funded by the Center for Medicare and Medicaid Services that provides the support for the *Work Without Limits* initiative.