***Disability Issues***

**Vol. 31, No. 4**

**Winter 2011**

Disability Issues is a joint publication of Work Without Limits and Spaulding Rehabilitation Hospital. Work Without Limits is an initiative of the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) located at the UMASS Medical School and funded by the Centers for Medicare and Medicaid Services (CFDA #93.768). It is managed through a partnership by UMASS Medical School Center for Health Policy and Research; UMASS Boston Institute for Community Inclusion; and the MA Executive Office of Health and Human Services. For more information visit [www.workwithoutlimits.org](http://www.workwithoutlimits.org).

Feel free to reprint articles. When doing so, please credit Disability Issues (Vol., No. and Date). For articles that appear under a byline or that will be altered in any way, please obtain permission from the editor. Any inclusion or exclusion of a particular entity, product or service in this newsletter does not constitute endorsement or opposition.

**Editor:** Marianne DiBlasi

**Editorial Board:**

Raymond E. Glazier

Bill Henning

Ruth Kahn

Linda Long-Bellil

Mary G. Mason

Oswald Mondejar

Susan Murray

Sandy Novack

J. Archer O'Reilly III

Elizabeth H. Pillsbury

Nancy Schock

Tanya Skypeck

Carolyn Thompson

**Contributors:**

Sandy Alissa Novack

Tanya Skypeck

Martina Robinson

Ross Elliott

Barry Schwartz

**In this issue:**

The Workplace: One of the Largest Minorities and the Workplace

Assistive Technology Summit: An Event to Change People’s Lives

The Advocacy Corner: Why Do I Occupy?

Money Follows the Person

The Opinion Corner: Being Open About Mental Health Disabilities

Information Briefs

**From the Editor:**

Dear Readers,

What an active fall we’ve had! Disability Employment Awareness Month brought a wide range of disability related topics to the forefront including; work, assistive technology, healthcare, affordable housing, education, transportation and advocacy. Christine Griffin, Assistant Secretary for Disability Policies & Programs in MA, gave the October keynote address at the Cambridge Public Library. In this issue, we bring you an article with highlights from her talk.

The movie premiere of “Lives Worth Living” a documentary about the disability rights movement aired on PBS in October. If you haven’t seen it, visit <http://www.pbs.org/independentlens/lives-worth-living/> for TV listings and lots of great articles with photos. The energy of activism is once again gaining national momentum with the emergence of Occupy movements throughout the world.

On November 9, I participated in the Occupy the Wang rally with more than two thousand seniors and disabled individuals to protest against proposed cuts to Social Security, Medicare and Medicaid. We marched from the Wang Center to Senator John Kerry’s office to bring him a large envelope stuffed with postcards supporting no cuts to these services. Senator Kerry is the only New England lawmaker on the 12-person bipartisan Deficit Reduction Committee, which is tasked with developing specific proposals to cut the federal deficit. On the march, I had the pleasure of meeting Martina Robinson, long time activist for disability rights. Martina enthusiastically contributed an article for *Disability Issues* sharing advocacy perspectives on participating in the Occupy movements.

We are thrilled to bring you a first time author, Elliott Ross, who shares his personal viewpoint of speaking up and speaking out about his mental illness. Whether your activism is on a larger scale or on a more personal scale, I encourage you to continue speaking up loudly and boldly. Your voice and presence matters!

Marianne DiBlasi, Editor

**The Workplace Corner**

**One of the Largest Minorities and the Workplace**

By Sandy Alissa Novack

Christine Griffin, Assistant Secretary for Disability Policies & Programs with the Massachusetts Executive Office of Health and Human Services, gave the October keynote address at the Cambridge Public Library to celebrate National Disability Employment Awareness Month. She set the tone for discussion on bridging gaps between people with disabilities and employers with the fact that, nationally, people with disabilities is one of the largest minorities, and people can join its ranks at any time.

One would think this fact would help sensitize the work world, and employers and co-workers would think of the Golden Rule and treat those with disabilities as they would want to be treated in the workplace if they were to develop a disability themselves. But, people with disabilities have a harder time finding a job, keeping it, and getting promoted. According to Griffin, this usually has to do with a department or institution having an attitudinal issue. “We got people out of institutions but they can’t live the American dream without a job…What’s the first thing people say when they meet you? ‘What do you do?’ If you’re not employed, this brings up self-esteem issues.”

Communication between an employer and a potential applicant is critical. It is a skill for a person to go in and ask for a job and discuss their abilities. Griffin believes “it depends” as to whether one should initially disclose that they have a disability. A deciding factor may be whether you need an accommodation right away. She believes if one has an invisible disability, one should consider not disclosing. “It would be nice if we lived in a world where we could just walk in and disclose what we need, but sometimes it isn’t safe, or welcoming, to disclose.” The state and federal government want people to disclose for many reasons such as their desire to hire, and for proof they hired people with disabilities. Yet, if you do not get a job you apply for, points out Griffin, it may be hard to prove it is because you disclosed.

It can be a big issue, states Griffin, if you are asking for an accommodation, such as a more accessible desk, time off for a medical treatment, or someone with diabetes needs a break to eat. On the latter matter, the employer may not want someone to take a break if no one else is taking one. “There is a legal requirement that there be an active dialogue, and preferably things put in writing,” says Griffin. “It is the lack of communication that prevents people from advancing in the workplace…A problem is frequently that the employer does not think the person needs an accommodation. The manager is protective of his budget because often the money comes out of the manager’s budget. Employers should have a centralized fund for accommodations.” Griffin continues to say, “If people without disabilities get bogged down in the bureaucracy of getting what they need to do their job, it can be even more challenging for people with disabilities. That is how people with disabilities burn out.”

Griffin says she is all for forced integration of people in the workplace so people with disabilities can start changing mindsets in the workplace and really extend opportunities for people. “To create change, we need a critical mass of people with disabilities in the workplace. Until we hire people with disabilities in a critical mass, and until we figure out how to communicate with employers, we can’t change anything. Awareness takes place in the workplace.” Until there is mass hiring, Griffin advises us to continue engaging employers in discussions on why they are not hiring more people with disabilities.

Many times, employers, because they do not know enough, start imagining all the things that could go wrong. Griffin once heard an employer comment that they were nervous about working with someone with a disability. They were afraid they would fall out of a wheelchair. Griffin’s response was, “Then we should not hire anyone, as anyone could have a heart attack at any time.”

*Sandy Alissa Novack is on the Editorial Board of Disability Issues and is a consumer advisor on the Beth Israel Deaconess Medical Center’s Universal Access Advisory Council*

**Assistive Technology Summit: An Event to Change People’s Lives**

By Tanya Skypeck

Even before registration and check-in officially began at 8am, the line for attendees of the Commonwealth’s assistive technology summit was already bustling. Throughout the day on September 23, consumers, providers, agency staff, and curious technology enthusiasts streamed through the Hynes Convention Center in downtown Boston to attend this event showcasing Massachusetts’ wealth of resources in assistive technology and accommodations for people with disabilities.

The summit, called “Products and Technologies that Change People’s Lives: Universal Design & Assistive Technology in Massachusetts,” was hosted by the Commonwealth of Massachusetts and convened by the Institute for Human Centered Design. In addition to the approximately 90 exhibitors whose booths filled the floor of the main exhibit hall, the event featured information/discussion sessions that ran throughout the day, covering the topics of assistive technology as applied to home, work, learning, and fitness and recreation.

These well-attended conference sessions featured architectural, engineering and design professionals familiar with creating and applying assistive technology, business professionals familiar with financing accommodations, and successful individuals whose lives have been transformed by having access to appropriate assistive technology.

In a special plenary session, Governor Deval Patrick, Lieutenant Governor Tim Murray, Secretary of Health and Human Services JudyAnn Bigby, and several other Massachusetts policymakers addressed the Commonwealth’s commitment to ongoing assistive technology innovation. To illustrate that point, down the hall, eager Massachusetts engineering students awaited the results of the assistive technology design competition they’d entered as part of the summit.

Back in the main exhibit hall, visitors scoped out adapted motor vehicles – including a wheelchair-accessible motorcycle – and a game of wheelchair tennis prompted some particular excitement in the hand-on demo area, all part of the effort to make living, working, learning, and having fun more universally accessible.

For Conference highlights and to view presentations in the focus areas of Work, Home, Learning and Fitness, visit <http://www.changepeopleslives.org/>

*Tanya Skypeck is a Research Coordinator in the Center for Health Policy and Research at the University of Massachusetts Medical School.*

**The Advocacy Corner**

**Why Do I Occupy?**

By Martina Robinson

1. I occupy because, if I have my way, no movement for justice is going to lack the presence of persons with disabilities (PWD). If I am the only person available and willing to fill that role in a moment of need so be it. But you can bet your last cent I'm going to spend some hours (or days) after that recruiting other PWD to fill that role, so I can have a life and know the work continues.
2. I occupy because I think it's unconscionable that PWD still have to struggle to achieve basic equality with home and community-based services. These things are seen as “too expensive” to fund, while multimillion dollar corporations and billionaires pay no taxes and banks who break the rules get bailouts.
3. I occupy because I think it's important for able-bodied people, especially activists, to see PWD standing or sitting on the front lines with them in what is wrongly classified as their struggles so that when we call upon them to come assist in what is also wrongly classified as our struggles they are more apt to do so.
4. I occupy because according to the Census Bureau’s latest finding 17.6 of PWD live in poverty compared to 10.6% of able-bodied Americans. Thanks to the Census Bureau I now have official proof for something I knew instinctively. Most PWD are part of the 99% and anyone who thinks differently is seriously misinformed.
5. I occupy because I know the one thing the 1% fears most is solidarity between different disenfranchised groups and I love to scare them.

To some, especially PWD and elders, the Occupy Movement may seem to belong to the young and physically able. It is vital to remember that if, for whatever reason, you can’t camp out, you can still be useful!

1. Gather supplies. Occupiers need hot prepared foods, water, long johns, sleeping bags and so on if they are going to camp out this winter. Occupy medics (the lovely people who keep occupiers healthy for free) need non-latex gloves, bandages, ointments, and over the counter medicines. Things many PWD have in abundance. Share a little in solidarity!

# Order a pizza. True one pie won’t feed a whole encampment, but let the powers that be worry about distribution. If you want to send a pizza to the original encampment in NYC, please call Liberatos Pizza at (212) 344-3464. Order the Occupie. Organizers request that orders be mostly vegetarian or vegan. Specify this! It will cost you about $25 with tax and tip.

# Share the wealth! Donate or fundraise for your local Occupy. Most of them have addresses that can be found online. Every penny matters.

# Use your social networks. Make sure everyone in your social circles, online or off, knows you support Occupy. Tell them why you think it’s important!

# Be a body if only for a few hours. Save your physical occupying for when it matters most!

# For information about Occupy Boston, including an actively updated blog, schedule of events and how to provide support, visit [www.occupyboston.org](http://www.occupyboston.org)

# *Martina Robinson is a woman living with Cerebral Palsy, Disability Rights Activist, Freelance Writer, Integrated Dance Instructor and Choreographer.*

**Money Follows the Person**

By Barry Schwartz

Massachusetts has recently launched a very exciting and positive new opportunity for people in long term care facilities to move into the community. The Money Follows the Person (MFP) Demonstration Grant was funded by the Centers for Medicare and Medicaid Services (CMS) and began operating in July. The grant is focused on “re-balancing” the state’s long term supports and services (LTSS) funding from medical facilities (e.g. nursing homes, rehabilitation facilities, etc.) to community based, person-centered services and supports. The grant will enable people with disabilities age 18 and older to make choices with respect to where they live, and with whom they live, and will provide case management and additional community based services in several ways. This community living alternative will support participants to find housing including apartments, family homes, or small group homes, and will include provision of a variety of support and services that enable participants to live as independently as possible.

For many years, Massachusetts has provided community-based services and supports to certain populations through Medicaid Home and Community-Based Services Waivers. These waivers allow the state to “waive” certain Medicaid requirements in order to provide expanded LTSS to individuals who would otherwise require care in a medical facility. The commonwealth currently operates waivers to serve people with intellectual disabilities, elders, traumatic brain injury, autism, and, most recently, acquired brain injury. This new MFP initiative furthers the Governor’s Community First initiative by making waiver programs available for additional people with disabilities and elders who are interested in moving to a community setting.

People must meet certain qualifications in order to enroll in the demonstration (must have resided in a long term care facility for at least 90 days, be MassHealth eligible, and have at least the last day in the facility paid by Medicaid). Once qualified, the person will work with a case manager or transition coordinator and will receive assistance to locate housing and prepare for community living.

MFP eligible people are now transitioning from facilities into community settings through the use of the existing waiver programs and Medicaid state plan services. Staff members are now working to create new waivers to serve other participants who will be eligible for the MFP demonstration and the commonwealth anticipates having these waivers available in mid-2012.

As a result of the MFP Demonstration grant, Massachusetts hopes to support over 2,000 people to move from long term care facilities to the community over the next 5 years. The bottom line is that more people will live in communities of their choice.

For further information about the MFP project and to see the schedule of “stakeholder” meetings that occur please visit [www.mass.gov/hhs/communityfirst](http://www.mass.gov/hhs/communityfirst) and select the tab for Money Follows the Person.

*Barry Schwartz is Project Director for the Money Follows the Person initiative at EHS/MassHealth*

**The Opinion Corner**

**Being Open About Mental Health Disabilities**

By Ross M. Elliott

This is my first time writing about my mental health disabilities. My name is Ross M. Elliott and I am 54 years old. I have OCD, ADHD, Bipolar, and Paranoid Schizophrenia. I take Prozac, Ritalin, and Risperidone. I am not ashamed or embarrassed to let people know about my disorders.

I have begun to do something new in my life. I let my friends and associates, who I frequently see, know about my mental health disabilities.

I get tired of people that I know ask me why I do things or act differently than they do. So I said to myself, “I will let them know why I do or act the way I do so they’ll understand who I really am and the challenges that I face on a daily basis.” I explain in simple brief terms about each of my disabilities. I do not bore my friends or associates with clinical explanations.

I have had no negative reactions from people that I have told this to. I only received comments saying I should have told them a long time ago about this. Other positive reactions were that they would help me in any way that they could. They were caring, helpful reactions. How liberating this has been for me to finally go ahead and do this.

You might say that my disabilities are no one’s business. I say that I want people to know so they’ll be comfortable with how I am and they won’t have to question or be puzzled by my behaviors. I found out who my real friends are when I started to do this, luckily for me all my friends and associates are still with me.

If for instance someone did say something negative about my disabilities or disassociate with me, I wouldn’t have any hard feelings toward the person. I am not judgmental about people. If that person wants to talk with me at a later date, it’s fine with me.

I don’t force my openness about my mental health disabilities onto my friends or associates, I just give them a chance to understand me better by talking to them about my issues.

This is what I wanted to do for a long time and I finally got the power inside me to do it.

You can also do this. You just have to trust yourself to do it. You’ll be amazed at how good you’ll feel about yourself and you just might find that other people that you know are dealing with issues also and you can both maybe help each other out in some ways.

Just try it and you’ll see, like me, that it is well worth the effort. I know you can do it!

*Ross M. Elliot is a MA resident and new subscriber of Disability Issues who asked if he could write an article about his experiences of living with OCD, ADHD, Bipolar, and Paranoid Schizophrenia.*

**INFORMATION BRIEFS**

**Inclusive Support Groups for People With and Without Disabilities**

The Multi-Cultural Independent Living Center of Boston (MILCB) is hosting two ongoing monthly support groups on a variety of topics. The first is a support group for Men without and without disabilities and the second support group is for Women with and without disabilities. The support groups will begin in January. For more information, please call 617-288-9431.

**Save the Date: “Focus” on Vision Impairment & Blindness Conference**

Meeting the Needs of Individuals with Intellectual Disability & Vision Loss on March 14, 2012, 8am – 3:30pm at the Four Points by Sheraton in Norwood MA.

**Keynote Speaker: Lotfi B. Merabet, OD, PhD., MPH,** Assistant Professor of Ophthalmology, Harvard Medical School and Director, The Laboratory for Visual Neuroplasticity, Massachusetts Eye and Ear Infirmary.

**“How the Brain Changes in Response to Blindness”**

Registration Brochure and Form, including CEU information, will be downloadable from "Training and Events" section of DDS website: [www.mass.gov/dds/visionloss](http://www.mass.gov/dds/visionloss)

and from the “Perkins Training Center Schedule” on the Perkins website: [www.perkins.org/professional/ptc](http://www.perkins.org/professional/ptc)

For additional information, including sponsorship, vendor or advertisement opportunities please contact: [Lisa.DiBonaventura@state.ma.us](mailto:Lisa.DiBonaventura@state.ma.us) or 508-384-5539.

**Brio Offers Community Theater Workshops for People of all Abilities**

Brio is a nonprofit organization located in Winchester MA. They offer integrated community theater workshops for people of all abilities who enjoy expressing themselves through the arts. These workshops are an opportunity for disabled and nondisabled people in the community to participate in physical theatre, a process that goes beyond verbal narrative, incorporating physical and verbal elements for expression. It is not just movement, but it includes elements of character, narrative, relationships and interaction between performers. Our workshop enhances individual creativity and allows the participants to be creators.

The workshops are integrated because they work with performers of all abilities and use music, visual art, drama, dance and theatre to express and understand thoughts and feelings. These workshops are inclusive and can accommodate most participants. Brio’s “mission is to create and perform integrated theatre through the collaboration of artists with and without disabilities. We believe that all individuals have the ability to create and that there are diverse perspectives and ways to express creativity.”

For more information and to see a calendar of upcoming monthly community theater workshops and other events, visit [www.briotheater.org](http://www.briotheater.org).

**Let's Go Skating!**

The Department of Conservation and Recreation (DCR) Universal Access Program (UAP) provides recreational accessibility to Massachusetts park facilities. For persons with disabilities, free use of accessible equipment and staff assistance are available. The UAP strives to increase participation in indoor and outdoor recreational activities in integrated settings.

Look for accessible ice skating options at rinks across the state, including the Fitzpatrick in Holyoke, the Cronin in Revere, and the Armstrong in Plymouth.

Seated ice skating sleds allow people with disabilities to skate during public skating. Use short hockey sticks with picks to propel yourself or a stroller bar handle allows another skater to push you.

For more information on accessible ice skating and other universal access winter sports activities, visit [www.mass.gov/dcr/universal\_access](http://www.mass.gov/dcr/universal_access) and also [www.everyoneoutdoors.blogspot.com](http://www.everyoneoutdoors.blogspot.com/).

**World Indoor Rowing Championship**

Members of the Athletes Without Limits/DC Strokes Rowing Team will participate in the World Rowing Championship (aka Crash B Sprints). This event will take place on Sunday February 19 at Boston University’s Agganis Arena, 925 Commonwealth Ave, Boston MA. This event happens every year in Boston and is one of the highlights of the indoor rowing year. Come down and cheer on the rowers!

Organized by Concept II (the company that makes the rowing machines) with adaptive categories for athletes with physical and intellectual disabilities. INAS Eligibility is not required but we’d love to hear from you if you are considering or plan to participate. Send an email to [info@athleteswithoutlimits.org](mailto:info@athleteswithoutlimits.org). Crash B’s are a great way to get ready for spring.

For more information, visit [www.crash-b.org](http://www.crash-b.org) or [www.athleteswithoutlimits.org](http://www.athleteswithoutlimits.org)

**“Disability Answers” Smartphone App Offers Help for People Seeking Disability Benefits**

The Advocator Group, an organization that helps Americans obtain disability benefits, has released a new smartphone app, “Disability Answers,” to help people with debilitating health conditions and their families assist people with navigating through Social Security Disability Insurance and Medicare eligibility. Available for both iPhone and Android devices, it offers clear answers to simple questions, such as “What is disability insurance?” as well as answers to more complex questions, such as “Tips for filing taxes for a lump sum retroactive award?” The “My Answers” menu walks users through a step-by-step survey to determine the likelihood of coverage. It’s good to know there’s an app that is designed to help with all that time-intensive paperwork.

**Subscribe to *Disability Issues***

Disability Issues is available without charge to anyone who finds it useful and interesting.

To request a print or e-mail subscription, please write to:

Center for Health Policy and Research University of Massachusetts Medical School

333 South Street

Shrewsbury, Massachusetts 01545

Call (508) 856-2710/voice or go to [www.workwithoutlimits.org/DisabilityIssues](http://www.workwithoutlimits.org/DisabilityIssues).

Disability Issues is also available on tape and in large print. To receive either

of these special formats, contact the Perkins Braille & Talking Book Library at 1-800-852-3133 or e-mail [library@perkins.org](mailto:library@perkins.org).

To view Disability Issues on-line go to [www.workwithoutlimits.org/DisabilityIssues](http://www.workwithoutlimits.org/DisabilityIssues).