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MetroWest Center for Independent Living, Inc.



March



March has been a busy month with several Duals forums, IL Education Day at the State House and more. All that with seemingly weekly snow storms! Hopefully we've seen the last of them.

from Paul W. Spooner,
Executive Director of MWCIL

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Doctors say offices not equipped for disabled

By Deborah Kotz

"More than one in six Boston doctors offices refused to schedule appointments for callers posing as disabled patients in wheelchairs, researchers at Baystate Medical Center reported Monday in a study of specialty practices that highlights obstacles to routine medical care. Legal specialists say the practice violates a federal law requiring that people with disabilities have access to appropriate care."

...

"The medical community hasn't understood the importance of equal access," said Bill Henning, executive director of the Boston Center for Independent Living. His organization three years ago persuaded Massachusetts General and Brigham and Women's hospitals to spend millions on architectural improvements, medical equipment upgrades, and staff training to better serve those with disabilities."

Read the entire article from the [Boston Globe](#).

About Us:
[MWCIL website](#)

Statewide Independent Living Education Day

Our 2013 event was a success! We had over 150 attendees, several excellent speakers, good food, and great company. The first thing I noticed this year was the better-than-normal spirit of camaraderie.

One focus of this year's event was to ask the legislature for \$1,100,000 to be added to the statewide independent living centers line item. If you haven't yet contacted your senator and representative, please download the two attachments and send them to your legislators! We could do much more for many more people with just a little money! Our favorite rallying quote was from Courtland Townes III: "A closed mouth doesn't get fed". [Fact Sheet](#) and [Advocacy Flyer](#).

We would like to thank all of the people who spoke: MRC Commissioner Charles Carr, State Representative Jeffrey Roy, State Senator Karen Spilka, State Representative Alan Silvia, Nick Kaltsas from SRC, and Courtland Townes III from BCIL. And thanks to IA Executive Director, Steve Higgins, for his great job as master of ceremonies!

The photos from the day have been posted at [MWCIL website](#).



State Senator Karen Spilka gave the MWCIL staff and consumers a tour of the Senate Chamber.

Violinist Uses Adaptive Technology

"At 28, Anantawan is one of the world's most accomplished young violinists. He has performed at the White House, at the Vancouver Winter Olympics, for Pope John Paul II, for Christopher Reeve and most recently for the Dalai Lama during an event at MIT. Anantawan played a piece by Bach, and when he finished, the Tibetan Buddhist leader approached him." Anantawan was born with "no right hand, only a stunted appendage with tiny stubs instead of fingers." He uses a spatula with this hand to help him hold the bow.



(past issues are available at our website)

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"In recent years, Anantawan has devoted his career to using adaptive technology -- from prosthetic devices like his own to sophisticated computer software -- to aid aspiring young musicians in overcoming a wide range of disabilities. By helping them make music, he believes this technology can help "reveal the inner humanity" of disabled children who struggle to express themselves through other means.

"Accessibility is not an act of charity," Adrian told an audience last summer during a TEDx talk in suburban Boston, where he is now an orchestra conductor at the Conservatory Lab Charter School. "It's one of lifting the ceiling of potential development so that all children can explore this world, but also possibly create new ones."

Click on this [link](#) and read the entire story by Brandon Griggs of CNN. The link also has a video and you can hear Anantawan's beautiful music.

Thanks to Peter, an MWCIL newsletter reader, for directing us to this story!

Money Follows The Person

Quarterly Stakeholder Meeting, March 28, 2013
(see MFP Overview below)

290 participants have been transitioned from nursing homes and other institutions. Of these, 112 moved into apartments, 57 into a home owned by a family member, 67 into a group home, and 52 into their own home and 2 into assisted living.



Efforts to Date:

- Online Tracking System
- Community Living Waiver for people who do not need 24 hour support
- Residential Supports Waiver for people who do need 24 hour support.

- \$5.4 million awarded to the Department of Housing and Community Development for additional Section 811 housing and rental assistance
- Housing Search Entities
- Administrative infrastructure including enrollment systems, training, report capability, and developed regulations

Current Challenges:

- Efforts must be improved to meet commitment to transition 1800 more people over the next 3 years.
- Develop better operational model instead of RCO (regional coordinating office) model
- Leverage existing community based organizations
- Expand relationships to more community partners with expertise in meeting the needs of MFP enrollees
- Significantly increase the number of transitions to the community
- Increase funding to agencies with experience in transitioning people to the community
- Establish a performance incentive for distribution of funding. Tie payment to results.
- Direct funding for transition coordination to ASAPs and ILC's

MFP Overview

from disabilityinfo.org:

The "Money Follows the Person" Rebalancing Demonstration Program (MFP) helps U.S. states rebalance their long-term care systems to transition people with Medicaid from institutions to the community.

MFP Program Goals:

- Increase the use of home and community-based services (HCBS) and reduce the use of institutionally-based services
- Eliminate barriers in State law, State Medicaid plans, and State budgets that restrict the use of Medicaid funds to let people get long-term care in the settings of their choice
- Strengthen the ability of Medicaid programs to provide HCBS; to people who choose to transition out of institutions
- Put procedures in place to provide quality assurance and improvement of HCBS

In February 2011, Massachusetts was awarded a five year MFP Demonstration Grant from the Federal Centers for Medicare and Medicaid Services. The Commonwealth of Massachusetts Executive Office of Health and Human Services (EOHHS) Office of Medicaid (MassHealth) is responsible for MFP administration and has collaborated closely with EOHHS state agency partners to develop and implement the program. This federal funding will support the transition of more than 2,200 Medicaid-eligible individuals who are currently residing in long term care facilities, including nursing facilities, chronic hospitals, and intermediate care facilities (ICF/MRs), into community-based care.

Beginning in July 2011, individuals ages 18+ who meet the following criteria may become qualified MFP participants:

1. Have lived in a hospital, skilled nursing facility or an intermediate care facility for at least three months AND
2. Meet the MassHealth program financial eligibility requirements AND
3. Have had the last day in the medical facility before the transition paid by Medicaid AND
4. Choose to move to a "qualified residence." A "qualified residence" is: a person's own home, a person's family's home, a person's own apartment or a group residence with four or fewer people

Starting in 2012, Massachusetts will offer a broader array of services and supports to a greater number of individuals who wish to return to community living. For example:

- Expanded and comprehensive transition services and support to MFP-qualified individuals seeking to move from a facility to the community
- Implementation of two new HCBS waivers for individuals not currently eligible for one of the commonwealth's existing waivers
- Promotion and support of housing development and access

SSI and SSDI in the News

What'cha Going To Do, When They Come for You?

by John Winske of the Disability Policy Consortium

Over the past few years, I have admonished people with disabilities for their participation in bashing individuals on welfare. On Facebook, I would cringe as friends (many on SSI and SSDI) applauded about the latest story about a state requiring drug testing of those who had the misfortune of begging for table scraps of financial support from their state governments. My admonishment was always the same, "What are you going to do when society calls for drug testing those on SSI or SSDI?" Usually I would be met with incredulity and a response of, "That would be stupid, SSI/DI is not a handout." But as always your view depends on the seat you are in.

National Public Radio's show, "This American Life" with Ira Glass, got the ball rolling with a story called "Trends with Benefits." The show can be found [here](#). That was quickly followed by a story in The Atlantic, "Disability Insurance: America's \$124 Billion Secret Welfare Program." It can be found [here](#). The significance is that these are not right wing screaming news outlets like Fox News. Both National Public Radio and The Atlantic are left leaning in nature.

Within days, right wing blogs and news outlets had picked up on the stories. So if you think these stories are going away, you are sadly mistaken. Disability advocates such as the Consortium for Citizens with Disabilities have responded with statements such as [this](#). But have no doubt, the stories have painted a big bulls eye on the SSI and SSDI programs.

As Washington D.C. begins to focus more intently over the next year or two on the federal budget and the deficit, Social Security is going to get a lot of focus. No politician will want to be seen as stealing money that elders paid into their whole working career. Thus disability insurance and SSI will be tempting targets.

For those who think society will never turn on people with disabilities, take few minutes and study what has happened in Great Britain over the last two years. What began as sensational news stories about slackers on disability has led to dramatic government cutbacks and a frightening increase in hate crimes against people with disabilities.

Buckle your seat belts, folks, this ride is about to get bumpy. So the next time you hear a politician speaking about drug testing folks on welfare, he may mean you.

Another SSI/SSDI Story

Another related story to the issue of increased numbers SSI/SSDI recipients was also told on WBUR/NPR. President Clinton successfully got many people off of welfare in 1998. One aspect of his program was to move some of the costs of welfare from the national government to the states, which gave the states incentives for reducing the rolls. The people being taken off of the rolls were getting jobs, according to the conventional wisdom. Instead, Mary Daly, a San Francisco economist, suspected that some people were switching to disability. She became completely convinced when in 2011, she met a man who told her what he "did for a living. Specifically, this man told Mary, states were hiring his

company to help them comb through their welfare rolls and identify people would could qualify for disability."

...

In fact, this man, Pat Coakley " works for a company called Public Consulting Group, PCG, that indeed helps states move people from welfare to disability. And Pat tells me business is going well. They have 17 contracts with states and counties all over the country." PCG is paid for each individual who is successfully transitioned from state-paid welfare to federally-funded SSDI/SSI Disability. Read the [full story](#) from WBUR.

Does this mean that many people on SSI and SSDI do not have disabilities, and do not need support? No. But it does mean that not everything is what it appears to be.

We suggest that with more accommodations and retraining programs, many more people would be able to work, with or without a disability. And that better incentives should be in place to transition people to work if they can. If there is fraud in the system, that doesn't mean the system is inherently wrong; the system may need tweaking, but many of us depend on SSI and SSDI legitimately.

Advocacy and Rally Day for people with lived experience of psychiatric labels, peer workers and allies

Pat, an IL Coordinator at MWCIL, attended Advocacy and Rally Day at the State House on March 26. The attendees had an extensive list of bills they supported for mental health rights and improving mental health services, as well as a list of bills they are concerned about. Download the [event flyer](#) for a list of some of these bills.

The event began with a rally outside of the State House where several people addressed the crowd. The group moved inside and gathered in the State House Hearing Room where State Representative Paul Heroux, and State Senator Patricia Jehlen spoke about the bills that they are sponsoring. The attendees then split up and visited their legislators for personal advocacy for the various bills.

For a partial list of the proposed bills, [click here](#). It's not too late to let your state senator and state representative know your opinion.

Advocacy and Rally Day was co-sponsored by the National Empowerment Center, MPOWER, Groundhogs and NAMI BG CAN.





Photos and story by Pat Elgert, Staff at MetroWest Center for Independent Living.

Medical Marijuana

Please read this letter posted recently in the [Taunton Gazette](#). You may have noticed the great reluctance for almost every community to allow dispensaries for medical marijuana, even though the people of Massachusetts approved it.



Dr. Eric Ruby is a practicing physician with admirable credentials. He is well aware of the opportunity for misuse of this drug. Dr. Ruby has many patients and a son who have found that marijuana has helped their painful symptoms that were unable to be resolved with traditional medications. With a few common sense guidelines and limitations, he recommends that Massachusetts is ready to implement the voters' will.

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