

MetroWest

Center for Independent Living, Inc.

December

It's been an interesting year, with many more changes coming soon. After years of providing Independent Living Core Services, MWCIL is embarking on some new endeavors - all consistent with the principles of Independent Living.

- One Care Independent Living Long Term Services Support
- TAP-Transition to Adulthood Program
- Money Follows the Person
- Housing Search
- Personal Care Attendant Management Program

We apologize for missing the past couple of months - we were flat out with the IL Conference and our annual Awards and Fundraiser event. Thanks to everyone who participated - both events were a success! You can see the photos on our [website](#).

If we don't see you at our [Holiday Open House](#) on Thursday, December 19, we wish you Happy Holidays!

from Paul W. Spooner,
Executive Director of MWCIL



Paul, Ed Carr, Rep. Chris Walsh, Senator Karen Spilka, Rep. Jeff Roy, Rep Tom Sannicandro, Bill Henning and Liz Casey at the Awards Fundraiser



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Calendar

Holiday Open
House
at MWCIL

Thursday, December 19

Legislator's Forum
at MWCIL

Friday, January 31, 2014

IL Education Day
at the State House
Thursday, March 20

Donations

If you appreciate MWCIL and the support it provides you, please consider a gift of any amount. By showing your appreciation and

The Ride Fare Settlement

Breaking News December 12: **MassDOT board unanimously approved the \$1 cut detailed below. The reduction will go into effect January 6, 2014.**

From John WInske and the DPC weekly newsletter:
November 26, 2013

Today the Massachusetts Senior Action Council, the Boston Center for Independent Living, Bay State Council of the Blind, the Public Transit Public Good Coalition, the Access Advisory Committee to the MBTA and the MBTA jointly state:

"The MBTA's decision to recommend that the MassDOT Board vote on December 11, 2013 to reduce RIDE ADA fares from \$4.00 to \$3.00 is a positive and significant step to mitigate the impact of the July 1, 2012 fare increase. The MBTA and the Massachusetts Senior Action Council, the Boston Center for Independent Living, the Bay State Council of the Blind, the Public Transit Public Good Coalition and the Access Advisory Committee to the MBTA agree to continue to work collaboratively towards long-term solutions that address the affordability and sustainability of the RIDE service, including examination of means-testing to create a tiered fare structure and examination of approaches to meet the transportation needs of RIDE customers at all income levels. Additionally, each of the parties commits to continuing to address the issues identified by the Governor's Executive Order 530 commission."

One Care Independent Living Long Term Services and Support Coordinator

What is One Care?

One Care combines MassHealth and Medicare benefits as a managed care plan for low-income adults in MA. Each consumer on One Care has a One Care team. One member of the team is the Independent Living Long Term Services and Support Coordinator. The program design team predicted that 19% of the consumers on One Care will use long-term services and supports coordinated by a Long Term Supports Coordinator. IL-LTSS covers a broad range of benefits such as wheelchairs, communication devices, and personal care attendant hours.

What does MWCIL do?

MWCIL has been approved to provide Independent Living Long Term Services and Support Coordinators as One Care team members. The role of the IL Long Term Services and Support Coordinator is to provide IL-LTSS advocacy and coordination on behalf of the member/consumer. For consumers in our service area, MWCIL staff will be working with Fallon Total Care (Southborough), and Commonwealth Care Alliance (all other towns) as the new One Care program rolls in Massachusetts.

Month Number One:

For the first month, the roll out has been slow. Participation is voluntary, and has been limited. The One Care organizations are struggling with start-up activities and their changing responsibilities.

The Independent Living Long Term Services and Support Coordinators (team member) are being underutilized or marginalized with very few referrals.

giving back, MWCIL can provide more services for the community. We thank you! Go to [MWCIL Webpage](#) or click on the Donate button.

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Email

Phone: 508-875-7853
280 Irving Street
Framingham, MA
01702

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Most referrals seem to be more sign-offs than providing actual services. We consider this marginalization to be a real issue, as the main providers follow the medical model, but the IL-LTSS Coordinator emphasizes the independent living model. A key component of One Care supports staying in the community, but without an educated advocate, this goal could be difficult for One Care providers and some consumers.

What Should Consumers Expect?

For consumers who need support services in the community, an IL-LTSS Coordinator must be a member of their One Care team. With MWCIL's extensive experience in independent living and knowledge of varied disabilities, we will take an active role in identifying and understanding how to implement services and benefits to ensure our consumers are as independent and healthy as possible. These two goals overlap significantly. Consumers should be aware of what their benefits are under One Care, and make sure both medical and support service needs for staying healthy are met. We all need some extra patience as the program develops and evolves!

Visit mass.gov for more information on One Care. And call MWCIL with your questions.

Housing Search Entity

MWCIL has been approved by Mass. Rehabilitation Commission as a Qualified Housing Search Entity. The Housing Search is a component of Money Follows the Person.

HSE responsibilities include:

- Determines specific housing preferences, conducts individualized searches and recommends options
- Submits and tracks housing applications
- Attends EOHHS housing training

MWCIL was deemed qualified because of our experience assisting individuals with disabilities to secure affordable and accessible housing. We also demonstrated a knowledge of local public and private housing resources, as well as state and federal housing programs. MRC has qualified 11 Housing Search Entities state wide.

Money Follows the Person

Essentially, the new Money Follows the Person demonstration brings targeted funding to get people out of nursing homes - the most basic function that Independent Living Centers accomplish. MFP is an official recognition of the fact that it typically is cheaper to live out of a nursing home, and that most people would prefer it. People with and without disabilities have a right to live in the community of their choice.

To qualify for MFP, and individual must

- have lived in a nursing home or long term care hospital for at least 90 consecutive days
- be 18 or older and have a disability or be at least 65
- receive MassHealth benefits
- move into an MFP qualified residence in the community

MWCIL will provide transition coordinators for MFP qualified individuals. In that role, using the MFP funding, we will assist with Household goods, supplies and furnishings, security and utility deposits, and more. MWCIL may help locate housing, as well as assist with other community services. MFP benefits are available for one year after moving.

Visit mass.gov for more information.

Transition to Adulthood Program - TAP

MWCIL has been approved, by MRC, to develop a Transition to Adulthood Program for 14-22 year old people with disabilities. TAP services help students with disabilities prepare for the transition from special education to adulthood. Students learn skills and self-confidence to prepare them for independence.

Happily, expectations for students with disabilities are evolving with broader opportunities for internships, job placement and advanced education and training.

This is a new arena for MWCIL and our program will be launched in early 2014.

Personal Care Attendant Management Agency

MWCIL is in the process of applying to be a PCA Management Agency. Bringing this program in-house will allow us to better serve our consumers.

Paul Spooner, the Executive Director at MWCIL, has been a member of the PCA Workforce Council for several years, and has used the PCA program since 1978. He understands why it's important, how it works and who needs it. (See article on Paul's reappointment to the PCA Workforce Council for a third term).

We are targeting (not promising!) July for a launch date, and will keep you posted.



2013 PCA Awardees

United Nations Treaty Defending the Rights of

People with Disabilities

The treaty still has not been ratified by the U.S. Congress. Defense Secretary Chuck Hagel is urging the Senate to pass the treaty. ([American Forces Press Service](#)) Let's hope it gets done before the holiday break!

Matthew Reeve, son of Christopher Reeve, recently wrote an opinion on the treaty for the [Los Angeles Times](#), encouraging the ratification. As he pointed out, 137 countries have already done the right thing.

PCA Workforce Council

Congratulations to Paul Spooner as he was sworn in for a third three year term on the Personal Care Attendant Quality Home Care Workforce Council (aka PCA Workforce Council). At the appointment ceremony by State Auditor Suzanne Bump, Paul also received recognition for his "outstanding commitment and loyalty to the elderly and disabled" from the House of Representatives.

Tony Williams, former Executive Director of Multi-Cultural Independent Living Center received recognition for his service.

Anne Johansen of Quincy and Cindy Purcell of Rutland were newly appointed to the PCA Workforce Council.



DCR Winter Schedule

The Department of Conservation and Recreation has posted their [Winter Schedule of Accessible Events](#). Events include: cross-country skiing, kicksledding, snowshoeing, snowmobile rides and ice skating.

The Autism Speaks Controversy

Autism Speaks:

[Autism Speaks](#) is the largest science and advocacy organization. The organization was founded in 2005 by Suzanne and Bob Wright. Autism Speaks focuses on funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders, advocating for the needs of individuals with autism and their families, and raising autism awareness.

ASAN:

[ASAN](#) - Autistic Self Advocacy Network - is run by and for Autistic people.

ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism. Activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research, and the development of Autistic cultural activities.

The Issues:

ASAN has come out strongly against Autism Speaks after Suzanne Wright's [Point of View](#) on the eve of the Washington summit. The ASAN [statement on the summit](#) addresses the message of pity and fear that Autism Speaks delivers, and accuses them of giving too small a percentage of their budget to supporting people with autism and their families. Autism Speaks does not have any people with autism in senior positions. This parent's blog also questions the attitudes at Autism Speaks: [No Misery: This is Autism. Suzanne Wright](#) by Shannon Des Roches Rosa.

And More:

After consulting with local colleagues who work in the autism community, we found that the issue isn't black and white. As an Independent Living Center, we agree that the message of fear and pity in the Washington Summit statement is contrary to our philosophy. But does that mean that Autism Speaks has no value? Autism Speaks has played a key role in getting insurance benefits for autism, provides a lot of good information and research, and applauds and improves lives with autism. Autism is one of the most visible disabilities today thanks to Autism Speaks.

As an IL Center, our values line up more with ASAN, but that doesn't lessen Autism Speaks contribution to improving lives with autism. They definitely deserve to be called out - the rhetoric of the Point of View at the summit, and the fact that no senior people at Autism Speaks are autistic - just aren't acceptable. The enormous spectrum of autism means blanket statements really aren't useful. Maybe ASAN has to get this dramatic in order for Autism Speaks to listen. Autism needs more services, research and solutions. We hope the two groups can resolve their differences, and continue to improve local services for people with autism.

Asperger Conference

Asperger Syndrome and Adult Life: Navigating the Massachusetts Public and Private Supports and Service Systems

This is a full-day conference for adults with AS/related conditions and parents of adults and older teens with AS/related conditions. Experts will explain the many public and private supports that may be appropriate for adults with Asperger Syndrome and related conditions living in Massachusetts.

When:

Sunday, January 11, 2014 8:30 p.m. - 5:30 p.m.

Where:

Laselle College
Winslow Academic Center
1844 Commonwealth Avenue
Newton

Contact Karen Doran:

karen.doran@aane.org
(617) 393-3824

[Click Here](#) for more information, including details about the Workshops and Sessions.

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