



MetroWest Center for Independent Living, Inc.

July

We did it! Independent Living advocates successfully convinced our legislators and governor to increase the IL Budget for FY '14 by \$1,100,000. We really appreciate the hard work it took to get this item passed, and we will use the money wisely, as always! Thank you to our legislators. Thank you to Governor Patrick. Thank you to our advocates.

Friday is the annual ADA Celebration in Gardner. We hope to see you there! As of this minute, the Friday weather forecast is for a sunny 83 degrees.

from Paul W. Spooner,
Executive Director of MWCIL



2012 ADA Celebration in Gardner



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Calendar

ADA Celebration - Friday,
August 3

IL Conference -
September 17-19

MWCIL Fundraiser Gala
and Awards - Friday,
November 3

Donations

If you appreciate MWCIL and the support it provides you, please consider a gift of any amount. By showing your appreciation and giving back, MWCIL can provide more services for the community. We thank you! Go to [MWCIL Webpage](#) or click on the Donate button.



All online gifts are tax deductible. *We couldn't carry out our important mission without you!*

Multiple Chemical Sensitivity

MetroWest Center for Independent Living is a scent-free environment. Staff recently attended a workshop on Multiple Chemical Sensitivity to learn more about this disability, and how we can ensure our environment is inclusive and accessible.

The staff learned about many commonly used products that chemically sensitive people could react to. The list of products is extensive, and goes well beyond the obvious scented soaps and perfumes. A few examples are vinyl, plastics, newsprint, car exhaust and almost all cleaning products.

[MACI](#) - MA Association for the Chemically Injured is a support network with lots of information.

Please remember, when you visit MWCIL, don't use any scented products. And if you have a friend, family member, neighbor or acquaintance with MCS, find out what products you can avoid to keep them symptom free. The disability is not well understood, and today's best treatment is avoidance of the trigger substances. Your acquaintance will almost certainly know what these substances are.

MBTA AAB Variance Request

Editorial: "Dr. Scott, The Decision is Yours"
by John Winske of the Disability Policy Consortium

Dr. Scott, we have not yet had the opportunity to meet. I have heard you speak and my friends who have met you think very highly of you. I write to you now because you have a decision to make. A decision which will define your tenure for people who require accessible transportation in the Boston area, specifically the commuter rail stations at Scituate and Waverly.

Last Monday, I was in attendance at the Architectural Access Board hearings where these stations were adjudicated. With all due respect, I have to tell you it was not a pretty sight. The MBTA looked horrible. Think Custer at Little Big Horn, Davey Crockett at the Alamo, Liston vs. Muhammad Ali or the Little League slaughter rule. Your staff and consultant were overmatched. They lacked a viable argument and it was painful to watch. I understand decisions were made before you arrived, but the mess is in your hands now.

By way of background, let me say I have seen the T from all sides over the last twenty five years. I worked as a consultant to the T for eight years. I served as the Chair of the Access Advisory for four years and I was one of the leaders of the first disability rights lawsuit against the T in 1988. I have seen General Managers come and go. Some were great with regards to accessibility, Tom Glynn and Daniel Grabauskus come to mind. Some were awful, no need to name names, just look at the history of the three lawsuits against the T and you will learn who they were.

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(past issues are available at our website)

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In the Scituate case, your staff argued that a busy intersection and bridge expansion joint gaps made conditions unsafe for people who need curb cuts to traverse the path of travel. With all due respect if people with disabilities did not travel in places with expansion gaps and at busy intersections, we would not trek very far. Indeed, in Boston, we would have to stay home and rely on The RIDE. You know the program the T doubled the fare for so we would not use it so often. And has your staff really never seen rubber or other materials that are widely used to mitigate expansion joints?

With regard to Waverly Station, your staff argued that a station with only 33 riders a day should not have to be accessible. It will cost too much and it is not technologically feasible or of substantial benefit to people with disabilities. There are several problems here. First the MBTA was warned that touching the platform would trigger the need for accessibility. Still they went ahead.

Dr. Scott, this station was modified using taxpayer money. It was done using American Recovery and Reinvestment Act (ARRA) monies. It was done using the money of all taxpayers. When I file my taxes, there is no little box that says here is your break because we used your money to discriminate against you. What was most embarrassing was that your staff tried to use a quick and dirty analysis of accessibility as proof of technological infeasibility.

Dr. Scott, the disability rights movement in Massachusetts is proud and resilient. We are well connected, we work remarkably well together, our technical knowledge is strong and our bench is very deep. We fight hard for our beliefs. I know you understand civil rights. As a woman and a person of color, I am positive you have battled during your lifetime. I heard you speak passionately about your physical limitations. We have seen your soul and we know you understand the pain of discrimination.

Now, the AAB has bounced this mess into your lap. You can go to court and fight the community and the AAB, or you can sit down and map out a road to full accessibility with the disability rights community. We are more than willing to meet and be a part of the solution. But the solution must have the goal of 100% accessibility. The decision is yours. We await your answer.

John Winske
dpcmaupdate@gmail.com

From the weekly Disability Policy Consortium Update on July 8, 2013. John received a response from Dr. Scott, the General Manager of the MBTA. They will meet in August.

ADAPT Protest in Washington, DC

Kate Ryan reported on the April demonstration in Washington, D.C. in [Disability Issues](#) - Vol. 33, No. 3, Summer 2013. Allegra Stout, Kevin Heaton and Ashley Schick of BCIL participated.

The group's first action, rushing a police line at the White House to protest "Obama's failure to follow through on promises to the disability community" resulted in 41 people being arrested and fined.

The next day's action was at the Department of Housing and Urban Development because of HUD's being too slow telling housing providers that they have to comply with Olmstead. "By the end of the day, they got a

promise that the guidance would come out within a month, and it did come out, in early June."

The final action was at the Department of Labor. ADAPT was protesting the fact that people with disabilities were left out of personal care attendant regulations. While this protest had no demonstrable results, they did bring attention to their cause.

"All three people said that they absolutely feel that they made a very real difference and would happily participate in further ADAPT events." We hope they continue to be active in these important issues!

United Nations treaty defending the rights of people with disabilities

You probably remember last December when the U.S. Senate vote (61-38) was five short of the needed 2/3 majority and the Senate failed to ratify the U.N. treaty defending the rights of people with disabilities.

"Senator Robert Menendez, a New Jersey Democrat and the chairman of the Senate Foreign Relations Committee, is now negotiating with the ranking committee Republican, Bob Corker of Tennessee, to arrange another vote."

Read the full piece from the [New York Times](#). There is no rational reason why the Senate should not ratify this treaty.

Boston ADA Celebration

Hundreds gathered in Government Center for Mayor Menino's annual ADA Celebration on July 25. Kristen McCosh, the Commissioner of Persons with Disabilities, organized the festivities. Mayor Menino spoke to the crowd. The Easter Seals of MA organized a Flash Mob of young people who gave a great demonstration of abilities and inclusion with their parachute. The smiles were amazing. I'm pretty sure some new friendships were started.



Our photos from the day are on the MetroWest Center for Independent Living [website](#).



The Ruling That Could Change Everything for Disabled People with Million-dollar Trusts

The Village Voice and Katia Savchuk reports on "A pissed-off judge, a \$3 million inheritance, and a neglected autistic man".

In 2007, a lawyer, Harvey Platt, entered Judge Kristen Booth Glen's court room to ask to become the guardian Mark Holman. Since Platt (and J. P. Morgan) had been responsible for Mark's trust fund worth \$3 million since his mother died in 2005, the request has typically been rubber stamped. When Judge Glen determined that no one responsible for Mark had ever even visited him, inquired about his needs or spent any money on him in the institution where he lived, she dug deeper. "Ideally, the guardian and trustee serve as checks on each other. But in Mark's case, they were one and the same."

Two months later, Robin Stavar, a professional care manager, was hired by JP Morgan, and visited Mark (now aged 20) at the Anderson Center for Autism where he lived. Stavar recommended some items for Mark, and she continued to assess him 4 times a year. Glen eventually appointed Platt as Mark's guardian, but he had to report back to court annually.

"New York's guardianship law for intellectually disabled people, known as Article 17-A, is one of the nation's few that doesn't require periodic judicial review. "If a guardian was appointed 15 years ago, we have no idea whether the kid's dead, alive, tied to a mattress in their own crap," Glen says.

Mark, Glen wrote in her opinion, could have remained completely isolated in an institution without his resources being spent to help him reach his potential. From now on, she decreed, all guardians appointed in Manhattan would have to report annually."

Mark showed significant improvements in his abilities over the next few years, but the trust continued to spend little money on him. In 2012, Judge Glen ordered a review of the trust fund.

"The trust was now worth \$3.6 million. In the five years after Marie's death, Platt earned more than \$26,000 in commissions, and JP Morgan received more than \$52,000. But through March 2010, they had only spent \$3,525 on Mark after Glen intervened.

In December, on her last day as a judge, Glen wrote her final chapter in Mark's case, which had implications that would reach far beyond him. She ruled for the first time that banks and other trustees have to figure out what disabled people need and spend money to improve their lives."

...

"The history reveals a severely disabled, vulnerable, institutionalized young man, wholly dependent on Medicaid, unvisited and virtually abandoned, despite a multi-million dollar trust left for his care by his deceased mother," she began.

According to Glen, in the four years since trustees hired Stavar and attended to Mark's needs, the intervention "has dramatically improved the beneficiary's quality of life and his functional capacity to enjoy what is now a near 'normal' existence in the community.

"It is not sufficient for the trustees to simply safeguard the Mark Trust's assets; instead, the trustees have a duty to Mark to inquire into his condition and to apply trust income to improving it."

[Click Here](#) to read the full story in the Village Voice - there is a lot more to it. Hopefully it *will* be a game changer!

Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act

"Thursday, July 18, 2013: [Press release](#) from U.S. Senate Committee on Health, Education, Labor and Pensions (HELP)

HELP Committee Report: Providing Services for People with Disabilities Outside of an Institution Is Most Cost-Effective Option, Yet More than 200,000 Americans with Disabilities Under Age 65 Remain Unfairly Segregated in Nursing Homes.

Harkin: Enforcement of Olmstead is a Civil Rights Prerogative

WASHINGTON, D.C.-A Senate Health, Education, Labor, and Pensions (HELP) Committee report unveiled today by Chairman Tom Harkin (D-IA) revealed that 14 years later, many states are failing to live up to the integration mandate of the Americans with Disabilities Act. The Supreme Court ruled in *Olmstead v. L.C.* in 1999 that the unnecessary segregation of individuals with disabilities in institutions is a violation of the Americans with Disabilities Act, thus directing states to enable community-based long-term care services for these Americans.

The report, titled "[Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act](#)," is the result of requests for information sent by Chairman Harkin to all 50 states on the progress made to transition individuals out of institutions. Harkin, who is the Senate author of the landmark Americans with Disabilities Act, has long sought to ensure that all Americans have a real choice to receive Medicaid-funded care in the community. Today's report is a comprehensive review of the types of community-based services states provide to individuals with disabilities compared to the institution-based services they must provide.

The report reveals that almost a quarter of a million working-age Americans remain unfairly segregated in nursing homes, and the number of working-age Americans with disabilities confined to nursing homes is actually growing. While progress has been made nationally, by 2010 only 12 states spent more than 50 percent of Medicaid funds on community-based care instead of institutional care.

"The Supreme Court's decision in *Olmstead* was a landmark moment for the disability community - holding that the ability to live in the community is a protected civil right under the Americans with Disabilities Act. Yet my report reveals that 14 years later, many states are still not making a commitment to provide all individuals with disabilities the choice to live in their own homes and communities. This is amazing given that study after study has shown that home and community-based care is not only what people want, but is more cost-effective," Harkin said. ... "States must set clear benchmarks to make the right to live in the community a real choice for all Americans with disabilities."

Read the Report! It has facts, conclusions and recommendations.

Self Advocacy and Employment: Finding the Right Job

When:

Tuesday, August 6, 2:00 - 4:00 PM

Where:

State Street Bank & Trust
John Adams Bldg., 1st Floor Conference Rm
1776 Heritage Drive
North Quincy

Five minute walk from the North Quincy Red Line MBTA Stop. Volunteers will be available to assist people from the T Stop to the State Street Bank and Trust Company. Parking is Free at the John Adams Building.

Are you a person with a disability or have a lived experience of a mental health diagnosis? Do you know or work with individuals who are looking for a job or are currently employed who would be interested in learning more about Self-Advocacy and Employment?

Individuals attending this interactive workshop will:

- Receive information on how/when to utilize your advocacy skills when looking for a job.
- Learn about resources available to assist you when seeking employment.
- Become familiarized with how to advocate for yourself in the workplace.

With support from State Street Bank & Trust Company, sponsoring partner of this workshop, Greater Boston Employment Collaborative brings together leading providers of competitive employment and rehabilitation services for individuals with disabilities to provide a comprehensive set of services.

To register for the workshop, please email cnppr@verizon.net or call Andrew Forman at 617-338-6665, ext. 217 or TTY: 617-338-6662. Please register by August 2nd. Reasonable accommodation requests must be received by August 1st.

Ed Roberts Biography from Our Stature Touch the Skies

The most recent posting to this Disabled Lives blog is a biography of Ed Roberts. [Excellent read!](#) I think i will have to redo our MWCIL biography...

"About this blog: Disability is part of the human condition. At any one time, perhaps 15% of the population have a disability: add illness and ageing and impairment comes to us all. In this blog, I want to share short biographies of famous and not-so-famous disabled people, and by doing so demonstrate the variety and the achievement of disabled lives."

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