



June 2012

Issue: 24

# MetroWest

Center for Independent Living, Inc.

## Supreme Court Rocks!

Greetings!

We're celebrating today's Supreme Court decision to uphold the Affordable Care Act!

By considering the individual mandate a tax, and therefore something that the federal government can impose on citizens, almost the entire act has been ruled constitutional!

Last night, the House and Senate Conference Committee has released its [Conference Committee Report](#). The Independent Living line item (4120-4000) received an extra \$50,000 for Assistive Technology, as well as approximately \$300,000 more than last year for the state's 11 Independent Living Centers. The next stop is the Governor's office where he has 10 days to approve, veto or change specific items. After that, the House can override any vetoes with a 2/3 vote, followed by the Senate. (The process is detailed on the [ma.gov](#) website.)

All of a sudden, it's *SUMMER*. After last year, with its tornadoes and hurricanes, we're feeling a little more cautious, and would like to remind everyone to review their Emergency Preparedness plans. MWCIL has an [Emergency Preparedness page](#) on our website with some online resources and advice.

Finally, we're looking forward to our annual ADA Celebration on Thursday, July 26 and hope you can join us.

from Paul W. Spooner,  
Executive Director of MWCIL



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### Summer Recreation

MNIP (MA Network of Information Providers) has compiled a long list of summer recreation opportunities. [Click Here](#) to download their newsletter.

### Disability Etiquette

Do you wish your family and friends were more sensitive, or maybe less sensitive to your disability? Share this publication: [Disability Etiquette](#) from the [National Spinal Cord Injury](#)



William Wells and Manel DesVallons from IA and **David Correia from MWCIL** at the NCIL rally held at National Hotel Association to protest the delay of ADA Regulations for Hotel Swimming Pools Washington, DC on Thursday, June 14, 2012

## Participate in Universal Design

Almost and Fully Accessibility Project for the November ABX Conference

The BSA (Boston Society of Architects) is planning to build a 600 sq. ft. 'almost accessible' and 'fully accessible' structure at its annual conference (ABX) this November. This structure will be a prominent element in the Exhibit Hall (on the main aisle). They will offer people (1,000's attend!) to move through this structure in a wheelchair, scooter, walker, etc. and experience some of the common issues on the 'almost accessible' part and the difference that 'fully accessible' elements can make. They hope to have the MIT Age Lab join this effort and provide its age simulation suits for people to use too. The idea is to help architects understand WHY the inches of minimum design standards matter, and why meeting/exceeding them is important for many people.

*They would like to have people with disabilities involved in designing and hosting this exhibit.*

We missed posting this before the second meeting on Wednesday, June 27. We're assuming there will be more opportunities - call Katherine if you are interested in participating.

Katherine McGuinness  
1121 Washington Street  
Newton, MA 02465  
617-641-2802  
617-641-2812

## MBTA News

The DPC Newsletter reported on what to expect starting next

## Association.

Here's a great video by the Stanford Push Project



S&\*t People Say to People With Disabilities

## 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.

**Donate**



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

## Got Computers?

Do you have computer parts sitting around unused? How about your

week:

"On July 1, fares on The Ride, the MBTA's paratransit service will double from \$2 to \$4, one way an increase of 100%. A trip on the bus for the same communities will rise from \$.40 to \$.75 and increase of 87%. A subway ride will increase from \$.60 to \$1.00 an increase of 66%. All these increases come as the T has worked diligently to hold general rider increases to about 23%.

In October the MBTA will also be implementing a new premium area. Trips outside of the ADA area or booked on the same day will cost \$5 one way. This change is going to be an unmitigated disaster. Understand the ADA area will change during depending on the time of day, as bus routes stop during the evening. The result is that a trip costing \$4 one way may be \$5 on the return trip."

The [Bay State Council of the Blind \(BSCB\)](#) has published specific guidelines for cutting MBTA costs and specific concerns about the rate hikes. They are asking everyone to let their legislator know that you are concerned about these hikes, especially for people with low incomes and/or disabilities.

May 21 Action:

Wheelchair users blocked traffic in front of the Statehouse on Monday, May 21, to protest the huge fair increase for The RIDE. The [Boston Herald](#), and [Boston Inno](#) reported on the action.

"Traffic was snarled for close to 45 minutes around noon time, as ralliers chanted "If we can't ride, you can't drive."

Boston police arrived on scene with a van and bolt cutters, unchaining protesters and threatening to arrest one man who refused to move out of the way of traffic." from the Boston Inno article.

MBTA gets Federal Transit Grant "New Freedom":

The MBTA plans to implement a pilot program with on-demand taxi service for people with disabilities. The program is expected to begin in fy 2014. "During the planning process, the T "will likely" request advice from customers about how to fully develop the program." The [Boston Globe](#) has more information on this grant.

employer or relative? Let MWCIL's Computer Recycling Program take them off your hands!

Donated computers are refurbished at MWCIL and given free to qualified consumers. All donated equipment ***must be three years old or newer, and in working condition***, providing a charitable tax donation to the donor. Refurbished computers are given to consumers who have passed the Center's basic computer course, enabling them to better access resources necessary for independent living.

MWCIL is a licensed Microsoft reseller of operating systems, so each donated computer's hard drive is completely erased according to industry standards. MWCIL installs a new Microsoft operating system. Worried about your old information? Don't be! Past donations have come from schools, law firms, and even the Internal Revenue Service, which were satisfied with MWCIL's security precautions. For more information, contact Michael Gentile, Computer Services/Systems Administrator. 508-875-7853.

## Tobin Calls For Wheelchair Consumers to Demand Access to Technology Critical to Independence

United Spinal Association's president and CEO Paul J. Tobin gave an impassioned [keynote speech](#) during the 2012 CELA Conference in Arlington, Virginia in April - a gathering of wheelchair consumers, suppliers, manufacturers and clinicians who advocate for people with disabilities to have access to proper mobility equipment.

Tobin's solution is the creation of a separate benefits category for complex rehab technology "This bill would carve out complex rehab from the durable medical equipment benefit, put standards in place to ensure the equipment is provided by qualified professionals, and

***About Us:***  
**MWCIL website**  
(past issues are available at our website)

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permanently exempt it from the punishing effects of competitive bidding. It would also remove a restriction that allows coverage for complex rehab only for use "in the home." You can read the [entire bill online](#).

Thanks to the National Spinal Cord Injury Association for this important news.

## Adapt Activists Ordered Back to DC

The recent ADAPT action, protesting cuts to Medicaid, in Washington resulted in many arrests, including actor Noah Wylie, and many people with disabilities. In a dramatic change from previous years, the courts are insisting that everyone arrested return to Washington to appear in court.

From [New Horizons ILC](#): "The requirement is leading to a mad scramble since several of those arrested live as far away as Colorado and Utah. Traveling back to Washington on short notice is costing some involved \$1,000 or more...." "This is the first time in more than 20 years that the court wouldn't allow an attorney to represent us and wouldn't entertain a motion to postpone," said Katz. "Are they doing this to dissuade us from exercising our first amendment rights?"

"Bruce Darling was one of the protesters. Here is what he had to say:

These protesters, including myself, were arrested doing what was right. We were drawing attention to policy decisions that could be devastating for millions of people. We spend months saving up for each trip because making our case is that important. Many of the people who are being called back to DC live on \$700 per month and have already paid enormous fines in the form of travel arrangements. I'm surprised and appalled that this is the price we must pay to protect Medicaid from being dismantled. In America we should not have to pay this price to exercise our right to address our government." From the AAPD Newsletter

## Building A Home Conference

### MA Families Organizing for Change

When: Saturday, September 29, 2012, 8 AM - 5 PM

Where: Hogan Campus Center at the College of the Holy Cross, Worcester

A full day of motivation, showing families how to BUILD A HOME and LIFE for their loved ones with disabilities giving them interdependent full lives in their community. This conference will give you an opportunity to network and meet individuals who are making it work.

Welcome: Susan Nadworny, MFOFC Chairperson

Remarks: Commissioner Elin Howe

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Keynote: Gail Fanjoy "Housing as part of an overall Good Life"  
Ms. Fanjoy is the Executive Director of KFI, a community-based provider agency in Millinocket, Maine

Partial list of Workshops:

- Person-Centered Planning
- You have to know what you want
- Family Panels: How they made it happen
- Housing Authority, Section 8's
- Creating a budget and a financial life plan
- Partnering with the Department of Developmental Services (DDS)
- Top 10 tips for parents to help their sons and daughters to live inspiring lives
- Staffing and roommates
- Autism housing survey results
- Accessing services; knowing where the doors are
- Housing 101- learn about a variety of creative living arrangements
- Maximizing the entitlement of school
- Benefits, Friendships and More

Also: RESOURCE FAIR and A LEGISLATIVE CALL TO ACTION!

Sponsored by Massachusetts Families Organizing for Change (MFOFC) in appreciation to the Niel M Wreidt 2003 Revocable Trust, Donald N. Freedman, Trustee.

Co-sponsored by the Massachusetts Developmental Disabilities Council (MDDC) in collaboration with: Arcmass, Arc of Greater Haverhill and Newburyport, EMARC, and the DDS Statewide Advisory Council (SAC).

## Judge Rotenberg Center

State Sen. Brian Joyce's has filed Budget Amendment #548 to require a full ban on shocks used at the Judge Rotenberg Center.

"No program, agency or facility funded, operated, licensed or approved by the commonwealth or any subdivision thereof shall administer to a person with a disability any procedure which causes obvious signs of physical pain, including, but not limited to, hitting, pinching or electric shock for the purposes of changing the behavior of such person. No such program shall employ any form of physical contact or punishment on a person with a disability that is otherwise prohibited by law or would be prohibited if used on a person who does not have a disability. No such program shall employ any procedure which denies a person with a disability adequate sleep, food, shelter, bedding or bathroom facilities."

We support this amendment! Contact your senator and ask them to support Amendment #548.

You can read more about the protests and objections to JRC in a [Boston Globe article](#) from June 3.



The controversy has also gained the attention of the United Nations. The UN's special rapporteur on *torture* has made a formal approach to the US government over the JRC. "The use of electricity on anyone's body raises the question of whether this is therapeutic or whether it inflicts pain and suffering tantamount to torture in violation of international law." (From the [Guardian](#)) Stay tuned!

## MassHealth Ombudsman

A new service from MassHealth provides an Ombudsman for people with disabilities. This office will provide personal assistance explaining the processes, understanding requirements and will give hands-on assistance filling out forms over the telephone.

Here is a list of what is available.

- Publications in Large Print
- Publications in Electronic Format
- TTY
- Personal Assistance via telephone/email
- Personal assistance in person
- Publications in Braille

MassHealth Disability Accommodation Ombudsman  
100 Hancock Street, 6th Floor  
Quincy, MA 02171  
masshealthhelp@ehs.state.ma.us  
617-847-3468  
TTY: 617-847-3788

Thanks to the Disability Policy Consortium for this news.

## Second Thoughts Challenges Ballot Measure Language

Disability Rights Group Challenges Language for Assisted Suicide Ballot Measure as "Misleading, Inaccurate, and Euphemistic"

(Boston, MA) - On Thursday, May 17, 2012, Massachusetts voters including members of the disability rights group Second Thoughts filed a challenge before the Supreme Judicial Court regarding the proposed ballot language for the measure that, if approved, would legalize assisted suicide in the state.

"The ballot language is clearly misleading," said Second Thoughts director John Kelly of Boston. "We want the voters of Massachusetts to know exactly what they are voting on this November," he said.

The petition asks the Supreme Judicial Court to remand the language to Massachusetts Attorney General Martha Coakley and Secretary of State William Galvin with the requirement that they

amend the language for clarity and accuracy.

"The ballot language repeats the problems of the bill itself," said Second Thoughts member Paul Spooner of Taunton. "The title is euphemistic, with the word 'medication' twisted beyond recognition. People will be led to believe that the measure is about palliative care, when it is about taking a lethal overdose -- in other words, poison. Why not just call the act by its common and legal name, 'physician-assisted suicide?'"

"The way 'terminally-ill' is used in the description is clearly misleading," said Kelly, "people will be encouraged to assume that being 'terminally ill' is a biological fact, rather than a human guess."

"People with disabilities are very familiar with so-called terminal diagnoses," said Second Thoughts member John Norton of Florence. "Everyone knows someone who has outlived their terminal diagnosis -- I was diagnosed with Lou Gehrig's Disease as a teenager; I'm alive and well fifty years later. The ballot language misleads by implying that a 'terminally-ill' diagnosis actually leads to death within six months. Instead, it should say 'diagnosed as terminal' or something similar in terms of accuracy."

"And what about choice?," asked Spooner. "There are no safeguards to protect patients from having the poison given to them by an heir or abusive caretaker. No witnesses are required under the law, so if someone else were to administer the drugs, who would know?"

The language submitted by the Attorney General Martha Coakley and Secretary of State is:

Title: Prescribing Medication to End Life [11-12] - Petition G

A YES VOTE would enact the proposed law allowing a physician licensed in Massachusetts to prescribe medication, at the request of a terminally-ill patient meeting certain conditions, to end that person's life.

## Olmstead Anniversary

This week marks the thirteenth anniversary of the Supreme Court's decision in *Olmstead v. L.C.*, where the Supreme Court recognized that the civil rights of people with disabilities under the Americans with Disabilities Act (ADA) are violated when they are unnecessarily segregated from the rest of society.

The promise of *Olmstead* is that people with disabilities will have the opportunity to live like people without disabilities - to have friends, work, be part of a family, and participate in community activities.

As the Department of Justice commemorates the anniversary of the *Olmstead* decision and reaffirms our commitment to its enforcement, we are pleased to present "Faces of *Olmstead*," a website profiling stories of some of the thousands of people whose lives have been impacted by the *Olmstead* decision and the Department's enforcement efforts.

Visit the [Justice Department's Webpage](#) for more about the

## ADA Celebration

### Celebration of the 22nd Anniversary of the Signing of the Americans with Disabilities Act

Join us for another fun day at Dunn Pond State Park.

When: Thursday, July 26, 11 a.m. - 3 p.m.

Where: Dunn Pond State Park, Gardner

Dunn State Park is among the state's most accessible recreational areas, with swimming, kayaking, and trails. We will enjoy a relaxing day with recreational opportunities, music, food, and great company!



## FYI - *Mean Spirited* Senate Blocks Food Stamp Money

"The Senate overwhelmingly rejected a bid to preserve some \$4.5 billion in food stamps funding, as part of the massive farm bill, on Tuesday." as reported in the [Huffington Post](#).

"The Congressional Budget Office estimated the decrease would amount to about \$90 a month for an affected family, representing a quarter of its food budget. Half of the food stamp beneficiaries are children, 17 percent are seniors, and unfortunately now 1.5 million households are veteran households that are receiving food stamps," Gillibrand said."

## Will the Reformers Come for Me, Too?

The New York Times published an [Op Ed piece](#) by Mike Ervin about Medicaid Reform, and what it could mean to him and his wife. They both work, but with both having a need for some services, they rely on Medicaid. Without it, they could be forced to



live in nursing homes - and as Mike points out - probably at a much higher cost.

Mike also writes an edgy blog entitled [Smart Ass Cripple](#). While we don't endorse all of his opinions, we completely understand where he's coming from.

## Netflix Lawsuit Moves Forward

The [LA Times](#) reported that a Federal judge denies motion to dismiss closed captioning lawsuit:

"A federal judge in Massachusetts has denied Netflix Inc.'s request to throw out a lawsuit brought by the National Assn. for the Deaf, which alleges that the service discriminates against the deaf and hard of hearing by failing to provide closed captioning on all of the movies and TV shows available through its Internet streaming service.

The case, filed last year by the civil rights group, alleges Netflix's popular "Watch Instantly" service failed to offer closed captioning on "the vast majority" of its ever-growing library of movies and TV shows that can be watched via the Internet on demand.

As a result, millions of people who are deaf or hard of hearing could not take advantage of the Internet subscription service, in violation of the Americans With Disabilities Act, the suit alleges.

...

The case is expected to go to mediation, according to a person with knowledge of the situation who requested anonymity because he was not authorized to speak publicly about the matter."

## MWRTA Wins Employer of the Year Award

"The MetroWest Regional Transit Authority has taken home the Massachusetts Commission for the Blind's 2012 "Employer of the Year" award.



Ed Carr at a 2010 event

The authority received the honor during the Annual Consumer Conference in Norwood on June 19, sponsored by the Massachusetts Rehabilitation

Commission, Massachusetts Commission for the Blind, Massachusetts Commission for the Deaf and Hard of Hearing and the Massachusetts Statewide Independent Living Council.

The commission recognized the MWRTA's outstanding leadership and best practices in providing training and employment opportunities for individuals who are blind.

The award was presented to MWRTA Administrator Ed Carr and his staff by Commissioner Janet LaBreck."

Ed Carr is also a member of the MWCIL Board of Directors.

Thanks to the [MetroWest Daily News](#) for reporting this story.

## Talking Prescriptions

The Law Offices of Lainey Feingold have shared information on a new accessible prescription pilot program for people with visual impairments.

"On June 8, Walmart announced that it is now providing the ScripTalk Talking Prescription Containers free of charge to persons with visual impairments as part of a pilot program. The ScripTalk Talking Prescription program is being offered to customers across the country through Walmart mail order, and also at three Walmart stores."

Read more at the [Lainey Feingold link](#).

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