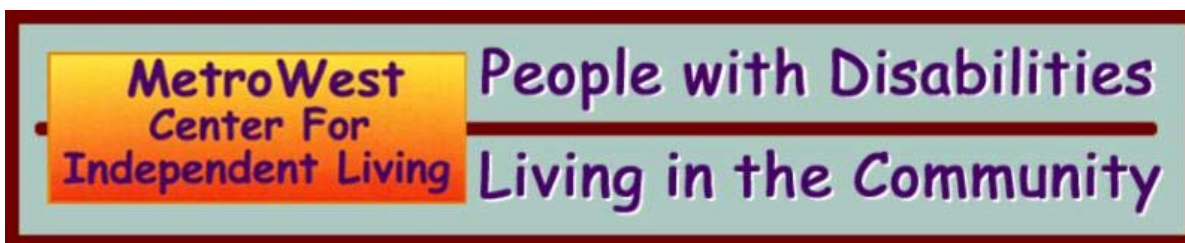


News from MWCIL - October 2017



While we dodged another bullet in the latest non-vote on repealing ObamaCare, Washington continues to put intense pressure on funding and civil rights for people with disabilities. Everything that happens in Washington will trickle down, even when you live in Massachusetts. Please read the articles below and learn more about some of the issues that we need to oppose this month.

Thank you,

Paul Spooner,
Executive Director

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Defining Independence

New Mobility Magazine nails it again with this article entitled "Independence: a Quad's Definition" by Ian Ruder. "Ian Ruder talks with six quads who use personal care attendants about how their definitions have evolved as they've learned to live with a disability."

As a quad himself, Ian begins the article *"If inspiration is the most overused "I" word when it comes to talking about spinal cord injury, independence comes in a close second. And just as what is inspiring for one person may be insipid for another, the dictionary definition of independence is open to interpretation."*

Read the entire article at www.newmobility.com.

ADAPT Actions Continue!

From SplinterNews: [ADAPT is Fighting for You, Whether You Know It or Not](#) by Kate McDonough.

We all have heard about the multiple efforts and opposition to dismantle ObamaCare. You may not know that ADAPT has been at the forefront of the opposition, with members from across the U.S. visiting Washington, many in wheelchairs. They spend long long hours setting up their actions, missing meals, and just being uncomfortable. Their message is clear, however. As Colleen Flanagan (from Boston) said ""You deal with it to be able to get the message out. Medicaid is important to everybody, but it's a lifeline for people with disabilities. Why am I not worth it?"

CHIP Reauthorization Update: Congressional Inaction Puts States in Limbo

From the [Massachusetts Medicaid Policy Institute](#): "Federal authorization for the Children's Health Insurance Program (CHIP) expired on September 30, 2017. Senators Orrin Hatch (R-UT) and Ron Wyden (D-OR) have filed a bill to extend CHIP for five years, but Congress did not act quickly enough to prevent the current authorization from expiring. Unspent federal CHIP funds may be carried over into the next fiscal year and Massachusetts's current allotment of federal CHIP funds should allow the state to continue to use CHIP funds for benefits until early 2018. However, we have now entered a policy limbo in which states are hopeful for reauthorization but must also

determine other coverage options for children if funds run out.

As follow up to the Foundation's June report (pdf), [The Importance of CHIP Reauthorization for Massachusetts](#), this brief provides an update on the status of federal reauthorization for CHIP and a summary of its potential impact on the program in Massachusetts."

Please - contact your senators and let them know how important these funds are.

Health care in Massachusetts

According to Commonwealthmagazine.org ([DeLeo, Rosenberg on Same Health Care Page](#) by Bruce Mohl), House Speaker DeLeo and Senate President Rosenberg are working together to pass state health care reform legislation.

"Rosenberg told the Health Policy Commission on Monday that spending on MassHealth was rising way too fast and crowding out other funding needs. DeLeo told the commission on Tuesday that the pace of MassHealth spending was "unsustainable.""

Both will work from proposals from the governor, as well as their own research. Neither was specific, and both agree that it will be a difficult path, especially when uncertainty in Washington is added to the mix. "Rosenberg said the Senate will vote on its health care bill before Thanksgiving and then send it to the House."

Stay tuned!

Upswing Farm Contribution to A Place To Turn

Upswing Farm in Ashland/Holliston donated over 500 pounds of delicious produce to [A Place to Turn](#) food pantry in Natick this summer. MWCIL delivered the produce from the farm to the food pantry in this successful endeavour. Thanks so much to [Upswing Farm](#)!



We found only one Farmer's Market open this winter - Natick will continue to hold a Farmer's Market on the Town Common on Saturdays from 9 a.m. - 1 p.m. Cash, WIC and SNAP are accepted. Please let us know if you hear of more weekly markets.

"DON'T TREAD ON MY ADA" - Oppose ADA Education & Reform Act of 2017 - H.R. 620!

Please sign this petition, as well as contact your Congressional Representatives in Washington, and oppose H.R. 620!

[Sign the Petition by Dara Baldwin](#)

Message to legislators:

As a person with a disability, an advocate for disability rights, an ally to disability rights and/or a social justice/equity advocates I sign this petition opposing the ADA Education and Reform Act of 2017!

H.R. 620 would **create significant obstacles for people with disabilities** to enforce their rights under Title III of the Americans with Disabilities Act (ADA) to access public accommodations, and would impede their ability to engage in daily activities and participate in the mainstream of society. Rather, the burden of protecting the right to access a public place is shifted to the person with the disability, who first has to be denied access; then must determine that violations of the law have occurred; then must provide the business with specific notice of which provisions of the law were violated and when; and finally, the aggrieved person with the disability must afford the business a lengthy period to correct the problem.

The bill's proponents purport to protect business owners from the burden of understanding and complying with rules designed to ensure that people with disabilities could access public accommodations, on the ground that this burden is too heavy for businesses. Yet people with disabilities are expected to shoulder this burden and to provide businesses with information about the specific legal obligations that they are violating-after those individuals have been denied the access rights that Congress gave them decades ago. We know of no other law that outlaws discrimination but permits entities to discriminate with impunity until victims experience that discrimination and educate the entities perpetrating it about their obligations not to discriminate. Such a regime is absurd, and **would make people with disabilities second-class citizens.**

Almost 27 years ago, the ADA was carefully crafted as a bipartisan compromise to take the needs of covered entities, including the types of businesses covered by Title III, into account. Among the compromises reflected in the ADA was the absence of any damage remedy in Title III; only injunctive relief and attorney's fees are available for violations of this part of the law. The fact that, almost 27 years after enactment, there are still organizations, businesses, and companies who violate the law and deny access to people with disabilities suggests that businesses should be better educated about their legal obligations under the ADA-just as they are expected to be about the other legal obligations that they undertake in running a business-**not that we should limit the rights of people with disabilities to participate in their communities.**

Section 2 of this bill states that the bill was written in consultation with ... and representatives of the disability rights community. But H.R. 620 was not written in consultation with representatives of the disability rights community and it would create barriers to the civil rights for persons with disabilities that do not exist in other civil rights laws.

As was mentioned earlier, the ADA has been law for almost 27 years. By this time, business owners have had ample notice of the ADA's requirements and opportunity to remove barriers. If, after 27 years, a

business has continued to not comply with the requirements of this legislation, **why should a person have to wait more time for enforcement of their civil rights? Should an individual who is not allowed to enter a restaurant because of their race, gender or religion, have to wait before seeking to enforce their civil rights?** Title III of the ADA already reflects a compromise that takes into account the concerns of businesses; it does not allow individuals to seek damages for violations of their civil rights. Now legislation like H.R. 620 seeks to further erode the civil rights of people with disabilities.

Oppose this bill and don't let it pass in the 115th Congress!

***Tell Congress, Vote NO on H.R. 620
by Christine Griffin***

I have been a wheelchair user for 37 years. I didn't become a disability rights activist until a year after the Americans with Disabilities Act (ADA) was passed in 1990 despite having had a disability for 10 years. This new law propelled me in my wheelchair into a career I never saw coming. I entered law school in 1990 with a different type of law practice in mind. I was an engineer and I had patent law in my sights. But it was a legal internship that gave me the opportunity to learn about the ADA. Tom O'Neill, Speaker Tip O'Neill's son, asked me to learn everything I could about this new law and tell him how it would impact his clients. I was lucky enough, with his help, to get into the EEOC/DOJ sponsored ADA Network training and that summer opened up a new world to me. I met the best advocates with disabilities from across the country and I fell in love with a law. I returned to law school knowing I would be part of a national effort that would help shape this new comprehensive civil rights law called the ADA.

While I have seen access to many places increase over the past 37 years, I become alarmed when I see any attempt to push disability rights backwards. Title III of the ADA currently requires businesses to remove architectural barriers, provide accessible parking if they provide parking for their patrons, etc. The ADA turned 27 years old on July 26th but the filing of HR 620 proves that the fight for our rights never ends no matter how old the law may be. Despite the "helpful" sounding title of this bill, the ADA Education and Reform Act of 2017, the only people it helps are business owners; not the people whose rights continue to be violated. These business owners have made a decision to refuse to comply with Title III of the ADA and when sued about their non-compliance, they convince their legislator to file a bill allowing them "more time" because 27 years isn't enough.

I will never forget the first time we saw a bill like this filed by Florida Congressman Foley, the ADA Notification Act of 2000. Foley received support

for his efforts from someone who wasn't even his constituent but applauded the ADA Notification bill Foley filed, Clint Eastwood. Yup, that's right, movie actor and director, Clint Eastwood. Eastwood at the time, owned a hotel/resort that had access problems. The suit filed against him was brought by a couple with disabilities under California Law and it was reported that Eastwood ended up spending more money opposing the complaint than it would have taken him to fix the access issues. A jury found him liable for non-compliance. This lawsuit pushed him into the national spotlight as a big supporter of the ADA Notification bill. Eastwood even showed up in DC for the Committee hearing on the bill and testified extra time was necessary for all small business owners who wanted to do the right thing but just weren't aware of their legal obligations. So like him, he argued, they shouldn't be punished by having complaints filed against them and the ADA should be changed. He even went on the Chris Matthews show that night and said that the reason the unemployment of people with disabilities was so high was because Hollywood celebrities like him aren't asked to do PSAs saying "Hire the Handicapped" anymore. I have a hard time watching anything he is in or makes to this day.

And while that first bill went no-where in 2000, others were filed and frankly we, as a community began to become complacent because the subsequent ADA Notification bills as they became known, went no-where too. It wasn't that long ago that I predicted the same for HR 620 and then it began gaining steam in Congress. I am now advocating for a change in our approach and it doesn't include blaming the attorneys who file large numbers of complaints in various states and cities. While we may disagree with their style and ultimate settlement deals, the facts are that they have clients with disabilities who have every right to file a complaint and the complaints themselves are dead on black and white ADA Title III complaints. The business owner either has compliant parking spaces or doesn't. The business owner either has an entrance that complies or doesn't. It is as simple as that. And you can drive around every city or town in this country without ever leaving your vehicle and document plenty of examples of businesses that are non-compliant with simple Title III requirements that most likely are readily achievable. In addition, there are plenty of free resources available to these businesses explaining the law and how they can comply with it. Besides the ADA Network Centers, every Better Business Bureau or other business association is well informed and able to help. In fact, when I was attending the ADA Network Training mentioned above, other disability rights activists, including Itzhak Perlman, were making Government funded training materials and videos for businesses to educate them about their obligations under the law. Free education for businesses has been available since the law became effective in 1992. The fact that a business waits for a complaint to drop before deciding what to do is just plain stupid and my rights should not be diminished because they want to wait for the lawsuit before complying. Would they wait for a health inspection before complying with health related rules? Would a business owner get lots more time to comply with non-compliance of food related laws while staying open and serving customers?

I don't think so. So why should these business owners get more time to comply with the ADA if HR 620 passes?

Supporters of HR 620 will tell you the bill only makes minor changes to the ADA. Not true. HR 620 removes any incentive that currently exists for a business to comply proactively. This bill will reward those who have waited for a complaint to be filed by requiring someone like me to give the business owner what could be unlimited time to provide access. If this law is passed, business owners won't face any penalty as long as a person with a disability goes through an elaborate notification process beginning with filing a very specific complaint with the business owner, wait 60 days for a response and another 120 days for removal of the barrier to access before going to court. After that, if the business owner claims he/she is making "substantial progress" toward access, whatever that means, the wait for access to that business may be a lot longer. Is this really what we have waited 27 years for? No it isn't.

A vote on the house floor on this bill is imminent. So, I am asking all of my fellow disability rights activists and your family and friends to start emailing, tweeting and calling your Congressmen and Congresswomen right now to tell them to vote no on HR 620 and to insist that they ensure that our rights to equal access to all businesses open to the public are maintained and protected.

Do it now!!! Call the Capitol at (202) 224-3121.

Your Message is: **Vote NO on HR 620, the "ADA Education and Reform Act,"**

Tweet your member of congress:

#Disability rights = civil rights!

Protect the #ADA,

Vote NO on #HR620!

Christine Griffin

Reprinted from the DPC weekly newsletter.

Electronic Visit Verification for PCAs

FYI: Over the summer, DPC met with MassHealth PCA program experts to review the changes to the PCA program as required under the 21st Century Cures Act. The DPC group has identified the issues below as needing more discussion.

Download the attached [EVV Talking Points \(doc\)](#) for more information.

Slow, thoughtful Implementation, listen to PCA users experience: Allow time and thoughtful examination of the day to day difficulties these proposals will create for Employers and PCAs. We recommend MassHealth take a slow, measured, approach with opt in consumer trials until statewide mandatory roll out in January 1, 2019

Expand opportunities for diverse consumer input: MassHealth should expand/open up the current MH EVV Stakeholder group and make process more transparent to individuals and communities.

Flexibility is key to effective PCA Management: Any changes to the system should ensure significant flexibility recognizing that individual circumstances may require variability in utilization of hours and overall PCA management.

Limits on scope and use of consumer and employee data: TPA/MH must not use any data collected for any other purpose than determining hours of service billed and should be destroyed once this purpose has been fulfilled.

Ease of use and sufficient training is essential: Sufficient optional training for consumer employers must be available, as well as for PCAs and surrogates.

Stay tuned for the dates of the MassHealth Listening Sessions!

Disability Backlog Tops 1 million; Thousands Die on Waitlist

In spite of decent laws for Social Security still on the books, there are ways for differing points of view to control delivery of needed services. The problems in Social Security predates the current administration, but we don't expect relief any time soon.

From CBS News on September 17, 2017:

[Disability Backlog Tops 1M; Thousands Die on Waitlist](#)

Emergency Preparedness for People with Disabilities

Thanks to the [One Care Ombudsman](#) for this information.

(MWCIL has a resource page for [Emergencies](#), and a resource page on [Emergency Preparedness](#).)

Ways you can prepare for an emergency:

1. **Put together a "go bag".** This will include medical documentation, flashlight with batteries, food for specific diets, information about your health and disability, cash, clothes, first-aid kit, cleaning supplies for equipment, and medication.
2. **Make an emergency plan.** Have a plan for safe transportation to places that are safe and accessible in the event of an evacuation,

- example, hospitals or shelters.
3. **Keep up to date necessary medical information.** Including current medication, equipment, blood work that requires regular checking, allergies, and health care provider contact information. Keep all this information in a waterproof portable container.
 4. **Food & Water.** Assemble enough water and food for 72 hours that do not need to be refrigerated.
 5. **Check the accessibility to a local shelter/hospital.** Is it accommodating to your disability? Check in with local shelters or hospitals to see which one is more accessible and make that your go-to location in the event of an emergency.
 6. **Backup for medical equipment.** For those who have oxygen, power enabled wheelchairs, and other medical equipment that requires power, make a plan to have a backup generator or extra battery supplies.
 7. **Make a plan for service and companion animals.** Will they be going with you or will they be transported to a local shelter for safety? Have an up to date record of immunizations, allergies, and other health-related conditions the animal may live with.

Storm Preparations

Thanks to the [Indoor Doctor - Environmental Testing Professionals](#) - for these practical preparations.

Inspect Property For Suspect Trees. Did you know your insurance may not cover damage to your home from a fallen tree if the tree is dead or dying.**Dust Off Your Insurance Policy.** Your insurance document is painfully hard to read (intentionally) but take the time to review with your agent. Focus in on water damage and mold. What are you included or excluded for (ice dams, basement water, pipe breaks) along with relocation**Document Your Stuff.** Photo tag all your valuables. Check the app store for easy to use programs to help you.

Service Backup Systems like your generator and wood stove. A faulty system can backfire causing severe damage and illness. The same goes for your water supply. Ensure extra gas cans are securely and safely stored to avoid unwanted fumes in the basement or garage.

PCA Pay Raise

PCAs employed by MassHealth consumers received a much-anticipated pay raise on July 1, when the hourly rate went from \$14.12 to **\$14.56**. This pay raise is part of a three-year contract between the PCA Workforce Council and the PCA workers' union, 1199SEIU United Healthcare Workers East. In July 2018, PCAs' hourly pay will reach

\$15 per hour.

From Rewarding Work

Architectural Access Board Bill S. 1379 and H.2498

Please continue to contact your state legislators and ask them to support the AAB bill. This bill is not a budget item, and will cost the state *no* money! Yet the bill will greatly increase the number of accessible housing units and accessible jobs. In our minds, it's a no-brainer. The bills were recently heard in committee, but we still need you to call your representatives and senators!

Download the [flyer](#) from IL Education Day.

Activist Resources and Directories

National Contact Information

[Directory of House of Representatives](#)

[Directory of Senators](#)

Senator Edward J. Markey

Address:

255 Dirksen Senate Office Building
Washington DC 20510

Phone:

(202) 224-2742

Contact:

www.markey.senate.gov/contact

Website:

<http://www.markey.senate.gov/>

Senator Elizabeth Warren

Address:

317 Hart Senate Office Building
Washington DC 20510

Phone:

(202) 224-4543

Contact:

www.warren.senate.gov/?p=email_senator

Website:

<http://www.warren.senate.gov/>

State Government Contact Information

[Directories of State Senators and Representatives](#)

[Contact Governor Baker](#)

[WhereDoIVoteMa.com](#) - Enter your address, and get a list of all of your elected officials.

National Resources

Indivisible - A practical guide for resisting the Trump agenda - Former congressional staffers reveal best practices for making Congress listen. [Download the pdf](#) or [Visit the website](#).

Save My Care - a movement to bring together families, advocates and health care providers to protect the health and financial security of all Americans. [Visit the website](#).

National Council on Independent Living has Action Alerts for issues on the table in Washington. [Visit the Advocacy Monitor webpage](#).

Join REV UP - Make the disability vote count!

For more information, visit www.revupma.org.



Disability Pride Toolkit

[NCIL](#) (National Council on Independent Living) has compiled a [Disability](#)

[Pride Toolkit and Resource Guide.](#)

This guide delves into what Disability Pride is, and why it is so important. The difference between the Medical Model and the Independent Living paradigm offer a framework of the disparities between how society works and how it should work.

The guide also offers many resources and ideas on how to advance the discussion and how to educate others. *We highly recommend this toolkit and resource guide for anyone who wants to be active in the fight for disability rights!*





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