

**MetroWest
Center For
Independent Living**

**People with Disabilities
Living in the Community**



Senator Spilka at IL Education Day at the State House

IL Education Day at the State House had the familiar themes of affordable, accessible housing and getting the AAB regulations in alignment with federal regulations. In Massachusetts, we have made progress but we still have room for improvement. Overall, advocates are appreciative of our MA legislators and Governor Baker's positions on health care and other services for people with disabilities.

One recent very favorable ruling was a case for IDEA - Individuals with Disabilities Education Act - where the Supreme Court sided with the student.

We would like to thank the Senate for increasing two of our favorite line items, IL Funding and the Alternative Housing Voucher Program, in their newly released budget. (See more below)

Meanwhile, the latest TrumpCare legislation passed by the House of Representatives is a disaster. Complete disaster.

Thank you,

Paul Spooner,
Executive Director

In This Issue

Articles:

- Senate Ways and Means Budget

- ADAPT Action
- IL Education Day at the State House
- The Affordable Health Care Act and Pre-existing Conditions
- DDS Commissioner Elin Howe Retiring
- Axing Smiling Becky and Delaying Community Services; We Cost Too Much by John Winske
- Job Opening at MWCIL
- 2017 IL Conference - Call for Workshops

Information for Activists:

- Washington Contact Info
- National Resources
- State Contact Info
- REV UP

Senate Ways and Means Budget

We would like to extend a *huge thank you to the Senate Ways and Means Committee* for increasing our IL line item (4120-0200) by \$500,000 to \$6,630,018, and for increasing the Alternative Housing Voucher Program (7004-9030) by \$900,000 to \$5.5 million. These increases will help us advance our mission of allowing more people with disabilities to live independently in the community.

Senator Jamie Eldridge has filed an amendment restoring AHVP (7004-9030) to \$7.5 million to expand housing opportunities for low-income adults with disabilities. Of course, this number is even better!

The Senate Ways and Means Budget is not final, and still needs House support and the Governor's support.

Contact your Senators and ask them to support Senator Eldridge's amendment, and thank them for supporting the current AVHP and Independent Living Line Item increases. Then, call your Representative and ask him or her to support the increases. (See contact information below.)

Download the Senate Ways and Means FY 2018 Appropriations Recommendations: [FY18 SWM Appropriations.pdf](#)

ADAPT Action in Washington D.C.

ADAPT is petitioning President Trump for disability rights on Monday, May 15. Visit their web site at adapt.org and [Facebook page](#) for updates.

How can the Trump Administration demonstrate support for the Liberty of disabled Americans?

Liberty through Independent Living!

There is only one national network run by people with disabilities that promotes community integration of people with disabilities - the Centers for Independent Living. The Title VII independent living programs (Centers for Independent Living, Statewide Independent Living Councils and programs that provide technical assistance to both) are currently funded at \$101.1 million.

These programs are woefully underfunded. To demonstrate support for the Liberty of disabled Americans the Trump Administration should increase funding of the Independent Living programs by at least \$125 million, targeting additional IL funding to support Centers for Independent Living (CILs) to engage in and expand community integration activities. Additionally, the Administration should set aside between 5 to 10 percent of these funds for SILC coordination/data reporting, peer to peer technical assistance and other projects of national significance, as well as enable ILA to distribute disaster relief funding from HHS and FEMA to CILs in disaster areas like the Administration on Aging now has the authority to do.

Reform Medicaid to Promote Community Integration!

For disabled Americans, Medicaid is the funding stream that provides for life and liberty. For decades, ADAPT and others in the Disability Community have tried to engage elected officials and various administrations in discussions about real Medicaid reform that would help contain costs while ensuring disabled Americans and seniors are able to receive the services and supports they need to live in freedom. Such reforms include increasing opportunities for consumer direction, streamlining systems, and promoting community integration over costly institutionalization.

Instead of capping and cutting Medicaid, the Trump administration should ensure that Medicaid programs like Money Follows the Person, Community First Choice Option and Balancing Incentives Payments continue under any legislation enacted regarding Medicaid, while working with ADAPT and the Disability Community to explore other legislative and regulatory ways to reduce the institutional bias such as incrementally increasing the FMAP so that states are incentivized to ensure that disabled Americans are no longer denied the fundamental liberties that most other Americans take for granted.

2017 Independent Living Education Day at the State House

We had an excellent line up of speakers:

- Senator Karen Spilka
- Senator Barbara L'Italien
- Senator James Timilty
- Austin Carr - youth from Easter Seals
- Karen Langley - REquipment
- Anne Johansen - housing
- Charlie Carr and Dennis Heaphy

- Steve Higgins from IA

We were reminded once again of how Massachusetts is one of the best places for people with disabilities to live, with effective support in government. Housing and accessibility continue to need more resources and enforcement, and many people are still stuck in institutions. Anne Johansen, Charlie Carr and Dennis Heaphy gave compelling testimony on why people need the option to leave nursing homes. Thanks to Sadie Simone, MASILC Coordinator, for a great event. You can see all of our photos at www.mwcil.org/gal.



Attendees



Bill Henning of BCIL and Senator Karen Spilka



Austin Carr, youth speaker
from Easter Seals MA



Karen Langley speaks for REquipment



Charlie Carr, Dennis Heaphy and Steve Higgins



Kayla and Alex with staff for Senator Eldridge

Affordable Health Care Act

The latest version of the Affordable Health Care Act (Trump Care) passed by the House of Representatives is a disaster for people with disabilities. From the major cuts to Medicaid to the elimination of protections for pre-existing conditions, this act will result in higher health care costs, less coverage and a greater risk of institutionalization.

(from the Advocacy Monitor: www.advocacymonitor.com)

Rooted in Rights in partnership with the National Council on Independent Living created the video below. The video is of people with disabilities sharing their stories about what this bill would mean to them.

(www.rootedinrights.org).

Take action - call your Senator! Even though Senator Warren and Senator Markey are strong advocates, your call will help.



I am a Pre-Existing Condition

DDS Commissioner Elin Howe is Retiring

Elin Howe, the Commissioner of the Department of Developmental Services will be retiring on July 14 after 10 years under Democratic and Republican governors.

The following is reprinted from Gary Blumenthal and the Association of Developmental Disabilities Providers news on May 12:

"Commissioner Howe has been viewed by members of the advocacy, self advocacy, family, provider and legislative community as an extraordinarily talented manager bringing together diverse elements of the community in the pursuit of best outcomes, supports and lives for the people impacted by the department's services and programs. Howe's reputation for leadership, innovation and determination made her a respected national leader in the disability field. She was often cited as the best DDS Commissioner in the nation.



Legislators, advocates, family members and providers respected her for her devotion to people with disabilities, transparency and excellent leadership. Her door was always open to those who agreed with her policies and priorities and those who had differing opinions.

...

The departure of Commissioner Howe is coming at a particularly difficult time when programs, such as DDS are threatened by the efforts of the Trump Administration to cut over \$880 Billion from Medicaid (the source of 50% of DDS funding); and during a time when authority in EOHHS appears to shifting away from program specific departments and towards centralized and less program specific control at Mass Health and its

contracted third party agents."

***Axing Smiling Becky and Delaying Community Services;
We Cost Too Much***
by John Winske at the Disability Policy Consortium

"A story on Public Radio International, last month, noted that Mattel had discontinued Barbie's friend Smiling Becky. Becky used a wheelchair, but could never fit into Barbie's house or its elevator. At one point, Mattel indicated they were looking at redesigning Barbie's house so Becky could visit. In the end, access was too difficult and too expensive so Mattel just axed the Crip. Problem solved.

I was thinking of Becky this week when the Centers for Medicare & Medicaid Services (CMS) was giving States three extra years to come into compliance with Home and Community-Based Settings Criteria. States will not have to comply with the rules developed in 2014 until March 17, 2022. Now, implementation plans will not be due until 2019, originally those plans were due this year.

The new rules set standards of care for disability services in the States. Among the changes were increased consumer rights to privacy, limits on the number of people living in group facilities to no more than seven and required the phasing out of sheltered workshops in favor of integrated, competitive employment.

Medicaid administrators and private companies had lobbied against the 2019 deadline to achieve compliance. Among the concerns expressed were a lack of resources and the need to develop complex plans. One must wonder how States will ever come into compliance if the House of Representatives succeed in their plans to cut \$880 billion from Medicaid.

In the end, we are just like Smiling Becky, very cute to look at, but too damn expensive to accommodate. I just hope no one decides to discontinue us because of the high cost of compliance."

For more information on the CMS delay, visit Kaiser Health news at khn.org. View the CMS announcement of the extension at www.medicaid.gov.

Job Opportunity at MWCIL

MetroWest Center for Independent Living is currently seeking a **TAP Coordinator** to oversee an exciting program, the Transition to Adulthood Program (TAP) for youth with disabilities, which provides support for the youth as he/she prepares for adult life, independent decision making, and responsibilities.

For all of the details, visit our Jobs Page at www.mwcil.org.

2017 IL Conference - Call for Workshops

The Massachusetts Statewide Independent Living Council (SILC) is seeking proposals for workshops for the 2017 Independent Living Conference of Massachusetts. The conference will be held on September 27th and 28th at the Best Western Hotel and Conference Center Marlborough. The proposal deadline is June 15.

[Click Here](#) for more information, and to fill out an online proposal.

The following topics are of interest:

- Independent Living
- Youth and Transitions
- Advocacy - Systems Advocacy- Advocacy through Social Media - Legal advocacy and rights
- Emotional and Behavioral Health
- Housing -Housing Search
- Employment
- One Care
- Budget Allocating
- Strategic Planning
- Americans with Disability Act
- Health and Disability
- Assistive technology
- Immigration
- Outreach to hard to reach populations

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.





MetroWest Center for Independent Living

Website: www.mwcil.org

Email: info@mwcil.org

Phone: (508)875-7853

Address: 280 Irving Street, Framingham, MA 01702

Facebook: 

Sign up for our Newsletters and Action Alerts.

[Subscribe](#)

MetroWest Center for Independent Living | (508)875-7853 |
info@mwcil.org | www.mwcil.org | [FaceBook](#)

MetroWest Center for Independent Living, 280 Irving Street, Framingham, MA 01702

SafeUnsubscribe™_srorke@mwcil.org

[Forward this email](#) | [Update Profile](#) | [About our service provider](#)

Sent by srorke@mwcil.org in collaboration with

Constant Contact 

Try it free today