News from MWCIL - March 2018

Another year, another budget!

In the FY 2019 budget released by the governor on January 24, IL Funding is set to the same level as FY 2018 projected spending... which is $104,000 less than FY 2017! Unfortunately our expenses have increased, so we will again be advocating for an increase in line item 4120-0200 at Independent Living Education Day at the State House on Tuesday, March 20.

We had a productive Legislative Breakfast on February 2. We are lucky to have such supportive legislators in MetroWest and Massachusetts.

MassHealth has moved people to Accountable Care Organizations this week. Don't miss the informative article below from the DPC Newsletter by Dennis Heaphy and Bill Henning. We need to understand the new system and help make it work for everyone.

Paul Spooner,
Executive Director

In This Issue

Articles:
• 2018 Legislative Breakfast
• MassHealth Moves to ACO’s this Week!
• Participants needed for National Survey on Health Reform & Disability

• How to Make Your Social Justice Events Accessible to the Disability Community: A Checklist
• 2018 Paralympics in PyeongChang
• HR 620
• Massachusetts Annual Independent Living Education Day at the State House
• Architectural Access Board Bill - S. 1379 and H.2498
• Vocational Rehabilitation at MRC

**Information for Activists:**

• Washington Contact Info
• National Resources
• State Contact Info
• REV UP
• Disability Pride Toolkit

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**2018 Legislative Breakfast**

We hosted our annual Legislative Breakfast with the Easter Seals Massachusetts on Friday, February 3. Our MetroWest legislators are all committed to ensuring that Independent Living Centers continue to be funded, and that the programs we rely on continue to be funded.

We discussed the need for additional funding for the following:

• Independent Living Line Item 4120-0200
• Transition to Adulthood Program
• Housing Vouchers
• REQuipment - the DMR Reuse Program
• Assistive Technology

Bottom row l-r: Paul Spooner and Joe Bellil

MWCIL Staff
MassHealth Moves to ACO's this Week!


On Thursday, March 1, Massachusetts will be following the lead of other states by enrolling people on MassHealth into new Accountable Care Organizations (ACOs) and other new managed care entities. The change will impact up to 1.2 million MassHealth members. A significant percentage of this population are people with complex medical, behavioral, cognitive health care needs and other chronic conditions, including 80,000 people with disabilities.

Disability Advocates Advancing our Health Care Rights (DAAHR), a joint effort of the DPC and BCIL, is supportive of the state's efforts to build a more integrated and cost-efficient healthcare delivery system for MassHealth members. The system currently is a challenge for many; we ask MassHealth members to embrace new opportunities that may be available to them. At the same time, it is important that we point out some concerns, particularly as they pertain to the start of this new initiative.

The new system is complex and may be confusing for providers and consumers alike. There are 17 ACOs and some will offer access to the full array of MassHealth providers and others will have narrower networks. Primary care providers are permitted to contract with a single plan. Some specialists, acting as primary care providers, may not be recognized as a primary care provider by a plan.
For MassHealth members with stable health conditions or limited behavioral health or medical needs, these changes may be frustrating, but not lead to medical harm. But for consumers with thin margins of health and complex needs, who have knitted together very fragile networks of care, disruptions to these networks could be a big problem. A personalized network may be unraveled as you discover that your new plan's hospital or the specialist you rely on is not in the plan's network.

Do you stay with those few specialists with expertise in treating your particular condition or do you choose your primary care provider who has been successfully acting in partnership with these specialists to keep you healthy?

Do you forfeit a specialist who no longer has admitting privileges at a hospital in order to continue receiving care at the hospital?

MassHealth is aware of these concerns and at a February 23 meeting with advocates, EOHHS Secretary Marylou Sudders said, "Our top priority are our members," while MassHealth Director Dan Tsai said, "We really want seamless transitions for our members."

Program elements that should reduce problems include a minimum 30-day continuity of care requirements that enables members to see and receive care from their current providers through March 30. This requirement will protect most prior authorizations for home care, durable medical equipment, and other services, including prescriptions. Coupled with this are requirements that plans actively assist members during the transition. This includes actively doing outreach to MassHealth members with more complex needs and working with these members to establish single case agreements with out-of-network specialists to support continuity of care.

Additionally, MassHealth has also put in place what they are calling an "escalation protocol." The protocol is for members who may have trouble understanding the changes or facing new or urgent medical situations to get more hands-on support. There's also unwritten understanding that many plans will go beyond the 30 days during the initial months of this initiative.

One thing people will want to pay attention to is the so-called 90-day lock-in. This is a requirement that will prevent people from changing from one plan to another after three months, though there are exceptions. If it's getting close to June 1 and a plan is not working for you, you may want to switch.

One concern we have comes from the experience with One Care, the plan for those on both MassHealth and Medicare. When it started in 2013, many people with the most complex needs, those who are homeless, have a mental health diagnosis, or a combination of needs, were not able to be
reached in the first 90 days of enrollment. It will be important that those in similar situations with ACOs in 2018 have flexibility to switch plans if necessary to ensure quality services and care.

While there are real concerns about keeping your medical team, and new rules, terms and names to learn, we do wish to emphasize why ACOs can be a big plus. Not everyone has been able to create coordinated networks of care, and a key part of ACOs are coordinated care teams that are supposed to emphasize community-based services. This can really help people, if it's all clicking, to live healthier, independent lives.

Healthcare innovation is a marathon, it's no sprint. A key to making this work will be MassHealth members with disabilities speaking to their health care plans, to MassHealth, to advocates, to DAAHR.

Your voice is absolutely the most important one!

Dennis Heaphy, DPC and DAAHR co-chair
Bill Henning, BCIL and DAAHR co-chair

Download the ACO Informational flyer (docx) from BCIL, DPC and DAAHR.

Participants needed for National Survey on Health Reform and Disability

The NIDILRR-funded Collaborative on Health Reform and Independent Living (CHRIL) is looking for adults with disabilities to complete an online survey about getting and using health insurance and health care services. Whether you have private insurance, insurance from an employer, Medicaid, Medicare or no insurance please complete the survey. We want to know how the Affordable Care Act (ACA) may be affecting your life.

Adults ages 18 to 62 with any type of disability are encouraged to participate.

The survey should take about 20 minutes to complete and your responses are anonymous.

To go to the survey click here: National Survey on Health Reform and Disability (or copy & paste into your browser: https://kusurvey.ca1.qualtrics.com/jfe/form/SV_cRVi7OagAy883vn)

Whether or not you complete the survey, you can choose to enter a drawing to win one of five $100 gift cards.
If you prefer to take the survey over the phone or have any questions about participating, please call toll-free 1-855-556-6328 (Voice/TTY) or email healthsurvey@ku.edu.

NIDILRR is the National Institute on Disability, Independent Living, and Rehabilitation Research under the Administration for Community Living.

**How to Make Your Social Justice Events Accessible to the Disability Community: A Checklist**

With our civil rights (HR 620) under attack as well as our funding, the disability community needs to stay active. In the heat of planning an event, even people who know better may take shortcuts or just "forget". Rooted in Rights has compiled an excellent checklist to share with other activists to encourage them to keep their events inclusive. [www.rootedinrights.org](http://www.rootedinrights.org)

**2018 Paralympics in PyeongChang**

The Paralympics are scheduled for March 9 - 18 in South Korea. The International Paralympic Committee (IPC) has announced that all sporting action from the PyeongChang 2018 Paralympic Winter Games held 9-18 March will be streamed live on Paralympic.org using an Olympic Channel player.

Videos on demand will also be available on the IPC website, as well as the IPC's YouTube Channel. There will be some live streaming on the IPC's Facebook page.


**HR 620**

Activist organizations such as ADAPT have been in the front lines in Washington saving health care, and now trying to save the Americans with Disabilities Act. The House recently passed the ADA Education and Reform Act - HR 620 which guts the ADA. NCIL will be sending a letter from over 500 organizations to the Senate. If the Senate schedules a vote on this horrible act, we will need all hands on deck!

To learn more about this act, read "Myths and Truths about the ADA Education and Reform Act" from the ACLU.
Massachusetts Annual Independent Living Education Day at the State House

Please join us for this annual event on Tuesday, March 20, 2018 at 10:30 a.m. for Speakers, Lunch and Legislator visits.

2018 Priorities:

- Align MA AAB regulations with the ADA
- Support Independent Living Centers
- Services and supports for Youth
- Increase funding for AHVP Vouchers
- Access to Health Care

Download the pdf flyer or visit www.masilc.org for more information.

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.
Vocational Rehabilitation at MRC

We have heard that some consumers have recently experienced issues with the Vocational Rehabilitation program run by the Mass. Rehabilitation Commission. Please let us know and we will try to help out.

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.


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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