

**MetroWest  
Center For  
Independent Living**

**People with Disabilities  
Living in the Community**

## Join Us for Healthcare Worker Advocacy Day!

Personal Care Attendants are a key component of Independent Living. *In fact, over 35,000 people in Massachusetts rely on 50,000 PCAs!* Please join us at the State House next Wednesday, May 15 at 1:30 to tell Governor Baker to invest in, and protect the PCA program. PCA's deserve to earn a living wage. Please see the article below.

Paul Spooner,  
Executive Director



PCA Rally from 2011

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### ***In This Issue***

#### **Articles:**

- [Healthcare Worker Advocacy](#)
- [Evv](#)
- [2020 Census](#)
- [Human Centered Design at Stanford](#)
- [Forced to Divorce](#)

- [Mental Health Awareness Month](#)
- [Obamas Netflix project](#)
- [IL Education Day](#)
- [AAB Bill](#)
- [2019-2020 Housing Application](#)
- [Newsline](#)

**Information for Activists:**

- [National Contact Info](#)
- [State Contact Info](#)
- [National Resources](#)
- [REV UP Massachusetts](#)
- [Disability Pride Toolkit](#)

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## ***Healthcare Worker Advocacy***

**When:**

Wednesday, May 15, 1:30 p.m.

**Where:**

MA State House  
3rd Floor  
24 Beacon Street, Boston

Download the [Healthcare Advocacy Day pdf flyer](#)

Letter from Rebecca Gutman, 1199SEIU:

"I am writing because 1199SEIU PCAs are bargaining our 6<sup>th</sup> contract with the PCA Workforce Council. 1199SEIU represents 50,000 Personal Care Attendants across Massachusetts who support people with disabilities and elders in their homes through the consumer directed PCA program. This includes consumers through the Fee for Service MassHealth PCA program, OneCare and SCO.

PCAs work every day supporting people with disabilities and elders so they can live with dignity and respect, contribute to their communities, work, volunteer, raise families, and live their lives fully. Meanwhile, this important workforce faces many challenges. Comprised primarily of women of color, immigrants, and people with very limited financial resources, they struggle to stay in these important jobs. Our country and Commonwealth are facing a rising challenge of a shortage of these workers and we - together - need to ensure these are good jobs moving forward.

Our goals at the bargaining table are to protect our union in the face of attacks from the Trump administration, win higher wages and improve benefits. PCAs deserve to earn a living wage with benefits for the important work they do. But so far, the response we have gotten from the Commonwealth is not enough. 1199SEIU will be gathering at the State House on May 15 at 1:30 on the 3<sup>rd</sup> Floor to demand what PCAs deserve: a union that can continue to fight and win, raises and a flexible paid time off benefit. We need your support."

Independent Living has a history of supporting PCAs - please join us at the

State House!



PCA Rally in 2015

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## ***2020 Census***

From Marlene Sallo, Executive Director of Disability Law Center

"On April 1, 2019 elected officials, nonprofit workers, and the public gathered at Nevins Hall in Framingham to kick off the state's 2020 census. This event marked the one-year countdown to the National Census Day (April 1, 2020).

The census is mandated by our Constitution and aims to include every person living in the United States. Census data provides the basis for distributing more than \$675 billion in federal funds every year to support states, counties and community programs, such as housing, education, transportation, employment, and health care.

During the #2020Census, households will be able to self-respond in three ways: Internet, Telephone or Paper Questionnaire. The Census Bureau has indicated that the online questionnaire and telephone contact centers will all be fully accessible to people with disabilities and that the paper questionnaire will be available to download in both braille and large print. Completing the #2020Census form ensures that neighborhood schools, health centers, and other vital parts of our communities are adequately funded.

Please make sure to participate in the upcoming census. Find out more at [www.censuscounts.org](http://www.censuscounts.org)."

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***EVV - Electronic Visit Verification***

MassHealth has been working on this requirement of Medicaid-funded personal care and home health services by January 1, 2020. Some of the disability community are opposed to EVV. As chair of the National Council of Independent Living EVV Task Force, Charlie Carr is an opponent of EVV.

He recently wrote a letter, asking that MassHealth look into the model followed by California with a goal of ensuring that "EVV protects our privacy rights while at the same time provides MassHealth with the means to comply with the 21st Century Cures Act".

"California DHS has the support of the broad disability community and SEIU 2015 as well as the United Domestic Workers of their EVV Electronic Time Sheet (ETS) due to their extensive stakeholder involvement over the past year." California's extensive stakeholder involvement in the design was key.

California's system is documented at their state website:

<http://www.cdss.ca.gov/inforesources/IHSS-Providers/Resources/Timesheet-Information>. It appears that the GPS component, that many find objectionable, is not included in the CA implementation.

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## ***Human Centered Design project at Stanford***

**Mar. 22, 2019 by Durell Coleman and Marie Trudelle  
The Stanford Social Innovation Review**

Stanford has created a new program based on fully addressing inclusivity in design. Their inspiration comes from seeing how attitudes shape expectations and access.

**Design the Future** was created to "address the gaps in the everyday quality of life of those with disabilities and ensure they can fully participate in our society.

The week long program at Stanford University shows high school students how to design products for and in partnership with individuals with physical disabilities. It was created by the social impact design firm [DC Design](#) and developed in collaboration with the d.school, the [Hasso Plattner Institute of Design at Stanford University](#). It involves student teams...producing functional products that improve the quality of life of their project partners."

The program is based on a three tiered approach: 1. Meet Compliance Standards, 2. Go Beyond Compliance Standards and 3. Additional Resources Required - to ensure every facet of the program was fully inclusive. The article provides details and insights, and could be a roadmap for making your own programs fully inclusive.

Read the article at [ssir.org](http://ssir.org).

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## ***Forced to Divorce: Americans With Disabilities Must Pick Marriage or Health Care***

**April 29, 2019 by Luke Sharrett Ozy**

Thanks to the DPC Newsletter for this encompassing discussion of marriage, Medicaid and Supplemental Security Income (SSI).

Because eligibility is based on personal income if single, and joint income if married, many couples reliant on the services and supports *only supplied by Medicaid* are unable to afford marriage. For those whose disability may come after marriage, divorce may be the only way they can survive. The income limits are quite low, but the loss of services can be very high.

This article discusses how the system evolved, and the ramifications for couples. And while there are some legislative improvements that are proposed, they appear to be unlikely to pass anytime soon.

Read the whole story at [www.ozy.com](http://www.ozy.com).

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## ***May is Mental Health Awareness Month***

The Shine Initiative in Leominster, MA, developed a toolkit to eliminate the stigma of mental illness among young adults and adolescents. The toolkit provides information about the underlying causes of mental illness, the stigma around it, and the signs of mental illness.

While listing some of the causes, it also provides information on resources where a person can seek assistance. Most of the resources listed are with organizations in the Framingham area. Additionally, the toolkit has pictures of famous people that have dealt with mental illness such as musicians Demi Lovato and Billy Joel, actress Jennifer Lawrence and author J.K Rowling. The toolkit can be found at [www.shineinitiative.org](http://www.shineinitiative.org).

Thanks to the City of Framingham Community Development Department for this information.

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## ***Obamas Bringing Disability Rights Film to Netflix***

**May 3, 2019 by Shaun Heasley**  
The [DisabilityScoop](#)

The evolution of the disability rights movement is at the heart of a documentary that former President Barack Obama and first lady Michelle Obama are bringing to Netflix.

The couple's production company Higher Ground said this week that it will bring the film "Crip Camp" to the streaming service.

The feature-length documentary tells the story of a summer camp for teenagers with disabilities in the 1970s near Woodstock, N.Y. that helped springboard the disability rights movement.

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The content is set to be released in the coming years.

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## ***IL Education Day at the State House***

We had another productive day at the State House on Thursday, March 14. IL **Priorities** continue to be:

- Align MA AAB regulations with the ADA
- Support Independent Living Centers
- Services and supports for Youth
- Access to Housing for People with Disabilities
  - *UPDATE: The Senate Ways and Means has fully funded the Alternate Housing Voucher Program at \$8 million!*
- Access to Assistive Technology and Durable Medical Equipment
- Access to Health Care

We heard personal stories from advocates and promises of support from legislators. Visit [mwcil.org/photo-galleries](http://mwcil.org/photo-galleries) for all of our photos, and [masilc.org](http://masilc.org) for more information on our priorities.



MWCIL Staff and Consumers



Senate President Karen Spilka



Speaking to legislator's staff

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## ***Architectural Access Board Bill H.2029 / S.1441***

Please help us make 2019 the year that Massachusetts Architectural Access finally aligns with the Americans with Disability Act. This bill costs the state nothing, and will greatly improve housing and employment options for people with disabilities.

Download the [AAB/ADA.docx](#) document and share the information with your legislators! Help us dispel inaccuracies and promote all the benefits of this important legislation!

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## ***2019-2020 Housing Application***

The state has announced a new public housing application to streamline the process to apply for public housing.

- Applicants can apply using the CHAMP application for state-aided public housing only [online](#), or they can find their existing applications, which have been transferred into CHAMP.
  - Only the applicant can log on to CHAMP and file, find or update an application.
  - Applicants need an email address to create an account in CHAMP. Creating an account allows the applicant to review applications at any time and to keep the application current with updated information, such as address and household size.
  - If an applicant does not have an email address, s/he can easily sign up for one for free using, as an example, gmail or yahoo.
  - The email address used must be the applicant's email. An agency or advocate email cannot be used as the applicant's email because it must be unique to that applicant.
  - Download a CHAMP paper application from DHCD's [website](#) or request an application from a local housing authority (LHA).
- Information provided by an applicant in the CHAMP application form is accepted by the LHA as provided. No supporting documentation is needed at the time of application, but verification must be provided when requested at a later time.

Please note that applicants should only apply to housing authorities in communities where they want to live. If they decline two housing units, applicants lose priority status at all PHA's for 3 years.

Thanks to the City of Framingham Community Development Department for this information.

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## ***Newsline for MetroWest***

Joe Weisse from Natick is working on adding the MetroWest Daily News to Newsline. He is fundraising \$10,000 for this project by getting pledges from local organizations. *Please let us know if you know of an organization who might contribute.* This is a wonderful opportunity for Newsline and Talking Book Library participants.

The \$10,000 is a one-time startup cost to Gateway news. Ongoing, the



Perkins Library will fund annual costs of \$5000.

We have about 227 Newsline readers in our 26 town service area and approximately 1000 subscribers to the Braille and Talking Book Library. We are hoping that adding local news will increase Newsline subscriptions.

### **Who is eligible for the Talking Book Library at Perkins?**

A person who is blind or visually impaired, who is unable to read regular print or unable to turn pages as a result of temporary or permanent visual or physical disabilities. They receive talking books and newsline among other library services. *This service is free.*

### **What is Newsline?**

Newsline is a free national service provided by the National Federation of the Blind in conjunction with the Braille & Talking Book Library at Perkins school for the Blind in Watertown. The service enables the user to listen to more than 300 newspapers, numerous magazines, access state-specific information, tv listings, job postings along with grocery and shopping advertisements. This can be accessed in English and Spanish over the phone, online, downloaded to a portable device, an app on your phone and by email. You can take a favorites list based on the newspapers and magazines you want to receive to be read or downloaded.

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## **Activist Resources and Directories**

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### ***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](http://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:

<https://www.warren.senate.gov/contact/shareyouropinion>  
Website:  
<http://www.warren.senate.gov/>

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## ***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.

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## ***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](#).

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Join REV UP - Make the disability vote count!

For more information, visit [www.revupma.org](http://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!*



2018 Staff


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