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DisABILITYissues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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Photo courtesy of https://www.mass.gov/topics/accessible-recreation

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From the Editor...

Dear Readers,

July is Disability Pride Month—a time to celebrate the history, experiences, contributions, and resilience of people with disabilities. It is also a time to recognize that disability is a natural part of human diversity and that true inclusion means creating communities where everyone can participate, belong, and experience joy.

This summer, I had the pleasure of experiencing what inclusion can look like when accessibility is thoughtfully designed. I visited the Salisbury Beach Carousel, where a wheelchair lift made it possible for me to ride the carousel without using my crutches. Once on the carousel, there is a designated wheelchair space, allowing people who use wheelchairs to enjoy the ride alongside family and friends. It was a simple experience—a carousel ride—but it represented something much bigger: the freedom to participate in an activity that many people take for granted.

Accessibility is not just about meeting requirements or adding accommodations after the fact. It is about imagining a world where people with disabilities are expected, welcomed, and included from the beginning. When spaces are designed with accessibility in mind, they open opportunities for connection, independence, and shared experiences.

As we celebrate Disability Pride Month, I hope we continue to recognize both the progress that has been made and the work that remains. Every accessible trail, building, program, and attraction sends a message: people with disabilities belong.

I hope this issue of *Disability Issues* inspires you to celebrate disability pride, share your stories, and continue advocating for a more accessible and inclusive world.

With Pride,
Marianne, Editor

Marianne DiBlasi has been the editor of Disability Issues *since 2011. She was born with Spina Bifida and uses a combination of crutches and wheelchair to assist with mobility. Her background is in sales and marketing, program management, and disability inclusion training.*

Birdability

By Jerry Berrier

I have been totally blind all my life, and I began birding by ear in 1972, thanks to a wonderful biology professor at Indiana University of Pennsylvania, where I was a student.

People have often asked why a person who is totally blind would choose birding as a lifelong passion. At first, I wondered the same thing. After all, it used to be called "bird watching," which sounds like a very visual activity. In reality, however, the best birders learn to identify birds by sound as well as by sight.

Birding has enriched my life in countless ways. It has increased my awareness of how human activities affect the environment that both we and the birds share. It has made me more conscious of the changing seasons, the rhythms of sunrise and sunset, and the habitats that surround me wherever I go.

Whenever I travel, the moment I step out of a car, my ears are tuned to the possibility of hearing a new bird. I also enjoy learning the sounds of frogs, toads, and just about any other living creature I encounter.

I learn bird sounds through recordings, websites, and other resources, but a species is never truly "locked in" for me until I hear it in the wild. Spring is my favorite season, and each year I am filled with joy when I hear my first Baltimore Oriole singing.

One of the biggest challenges I have faced as a birder has been finding sighted companions to bird with. For many years, my interaction with other birders was limited. That began to change several years ago when I learned about an organization called Birdability. Birdability is a 501(c)(3) nonprofit organization whose vision is that "birding truly is for everybody and everybody, regardless of disability or other health concerns."

Birdability was founded by Virginia Rose, a birder from Austin, Texas, who uses a power wheelchair. She discovered that birding not only brought her enjoyment but also fostered independence, confidence, community, and a deep connection with nature. She wanted others with disabilities to have those same opportunities.

I serve as a "captain" for Birdability, taking on leadership roles when I can. I promote Birdability and participate in its activities when the opportunity arises.

In 2024, I was honored to represent Birdability at "The Biggest Week in American Birding" in Ohio, and in May of 2025 I spent a week in Colorado as a mentor for National Park Service interns with disabilities through a program called "Let's Go Birding." I have also participated in numerous bird walks and birding by ear workshops.

The Birdability website offers a wealth of resources for birders with disabilities, including:

- A crowd-sourced map of accessible birding locations, highlighting features of interest to people with various disabilities.
- A newsletter that reaches hundreds of subscribers.
- Educational resources and accessibility information.
- Annual birding programs and events.
- And much more.

Last year, myself and two other blind birders organized a Bird-a-Thon for blind birders across the United States. Our goal was simple: to introduce blind people to birding and to build community among both blind and sighted birders. With tremendous support from Birdability, the event was such a success that we held it again this year and expanded participation worldwide. Hundreds of blind birders from ten countries took part. We could not have done it without Birdability.

I am deeply grateful that Birdability has connected me with a vast network of people who share a passion for birds, nature, and inclusion.

I hope you will visit Birdability's website to learn more about this remarkable organization and the opportunities it provides for birders of all abilities.

I also have a website of my own at https://www.birdblind.org. I initially thought of it as a place where I could share bird sounds I recorded, but it has evolved into much more than that. My passion for birding also spawned my interest in audio editing. My love of birding has enriched my life in many ways.

Photo by Freya McGrego

After 18 years in Human Resources with Verizon, Jerry Berrier spent more than 20 years in assistive technology, most recently serving for nine years at the Perkins School for the Blind before retiring in June 2021. He has consulted on numerous accessibility projects with Mass Audubon Society, including more than fifteen all-persons trail initiatives, and has a passion for audio production, accessible web design, and birding by ear.

Accessing the Vote

by Brianna Zimmerman

Many Americans agree that voting is a key part of good citizenship. Despite having an equal interest in voting, people with disabilities are less likely to vote than our nondisabled counterparts.

This turnout gap has been decreasing in recent years, partly due to increasing voter registration efforts by groups such as REV UP; and the expansion of vote by mail, absentee voting, and voter registration options during the COVID-19 pandemic.

However, there is still more work to be done.

Barriers to the vote include inaccessible polling places; and a lack of access to clear, reliable information about voting: including key voting rights and accessible voting options. These obstacles are especially pronounced for voters in facilities, who are often inaccurately told that they cannot vote, or lack access to information about voting.

What You Need to Know:
Key Voting Rights for Voters with Disabilities
All parts of the voting process should be accessible, including registering to vote, our polling places, and voting. Massachusetts voters have the right to vote privately, independently, accessibly, and with help if we choose. The only people who cannot help you vote is an employer or representative of your labor union.

If you are 18 years old; a Massachusetts resident; U.S. citizen; and you are not currently incarcerated for a felony conviction; you have the right to vote in Massachusetts.

Most people with legal guardians can also vote in Massachusetts, as long as their guardianship decree (a legal document signed by a judge) does not explicitly take away their right to vote. It is very rare for a guardianship in Massachusetts to limit someone's right to vote. Check out the Secretary of State's website and this resource from the Massachusetts Office on Disability for more information about the rights of voters with disabilities.

Voting In-Person on Early Voting or Election Day
You can vote at your polling place on Election Day (from 7 AM - 8 PM in state and federal elections) or during your town's early voting period. Polling places are required by state and federal law to be accessible to voters with disabilities.

However, in our 2024 survey of nearly 140 polling places across Massachusetts, the Disability Law Center (DLC) found that 69% of polling places across the Commonwealth had at least one accessibility issue: ranging from uneven pavement, inadequate signage, to improperly set up accessible voting equipment.

Many barriers could be quickly fixed with inexpensive solutions; including placing temporary signage for accessible entrances and parking spaces; installing temporary curb ramps; or propping open heavy doors.

Below are steps to take if you experience voting barriers.

Voting By Mail or Absentee Ballot
Massachusetts voters can vote by mail in **most** elections. In state and federal elections, vote by mail is available with no excuse required. This option was made widely available following the COVID-19 pandemic. However, you need to apply every year to vote by mail.

In some special circumstances, voters need to have an excuse to vote by mail and should apply for an absentee ballot. Absentee voting works the same way as voting by mail; the only difference is that an excuse is required to vote by absentee ballot.

For example, some towns and cities opted out of vote by mail for local elections. However, if you have a disability that prevents you from getting to your polling place on Election Day or will be out of town on Election Day, you can still always request an absentee ballot.

If you are admitted to a healthcare facility within seven days of an election, you may also request an emergency absentee ballot before the close of the polls on election day.

If you are a voter with a permanent disability, you may ask your local election official about getting a permanent absentee ballot so that you do not need to apply yearly.

Accessible Vote by Mail (Electronic Ballot)
If you have a disability that makes it difficult for you to vote independently with a paper ballot, you may apply for Accessible Vote by Mail (AVBM).

The AVBM system allows you to request an electronic ballot, which is secure and screen reader accessible. You do need a working email to access the electronic ballot.

AVBM is a great option for voters who have trouble reading or writing independently (for example, people who are blind, low-vision, or who have dexterity issues may benefit). Massachusetts is one of only a few states that allow voters with disabilities to vote and return their ballot electronically.

You need to apply yearly to vote by accessible electronic ballot or request a permanent accessible ballot from your local election office. To learn more about accessible vote by mail, visit the Secretary of State's website.

What to Do If You Encounter a Barrier to Voting
For the quickest response, if you experience or notice a barrier at your polling place, ask to speak with the warden or head of your polling place. This person may be able to quickly address the issue.

If the head of your polling place is not available or unable to solve the issue; or if you are experiencing issues with voting by mail, absentee, or electronic voting, you can contact your local election office.

The Secretary of State's office may also be able to respond to issues quickly and should be made aware of accessibility issues that voters are experiencing. Contact the Elections Division by calling 1-800-462-VOTE, using TTY at 1-800-720-3480, or emailing elections@sec.state.ma.us.

The Disability Law Center also wants to know about any accessibility issues you experience. Although we may not be immediately available on Election Day, we can help people with disabilities advocate for their voting rights. Contact us by calling 617-723-8455, or ask for help online.

Get Involved

If you are interested in surveying polling places for accessibility issues, helping people with disabilities register to vote, or advocating for accessible voting processes, consider getting involved in the REV UP MA coalition.

For more information, email info@revupma.org or visit our website.

MA Primary Date is Tuesday, September 1st for Senate and House Elections

How to Get Ready to Vote:

- Check your voter registration status
- Know your polling place
- Bring required ID (if applicable)
- Explore early voting or mail-in options

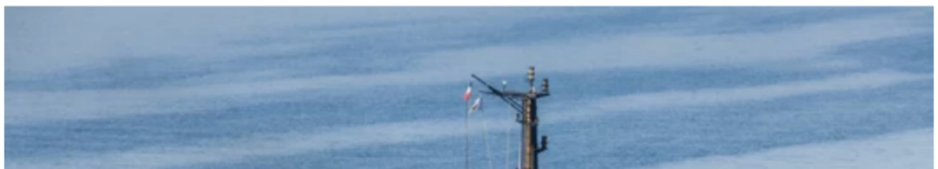
Brianna Zimmerman (she/her/hers) is the Voting Rights Advocate at the Disability Law Center (DLC). DLC is a statewide nonprofit legal services organization and the Protection and Advocacy (P & A) agency for Massachusetts. Under the Protection and Advocacy for Voting Access (PAVA) program, Brianna conducts voter registration drives, voting rights trainings, and ensures that voting is accessible to disabilities. She also helps coordinate the REV UP MA coalition, a group of organizations and self-

advocates that are passionate about civic engagement and voting access.

By Ms. Love

At a recent Disability Policy Consortium (DPC) meeting of consumers who are participating in the DPC Disability History Project, we read a *NY Times* article about older adults living in a 600-person complex who were asked what dreams and wishes they would like to see fulfilled. Some people in the article responded that they didn't need anything or have a bucket list of things they wanted to do or see. Even with staff outreach, only 30 people came forward with their dreams and wishes. Here are some of the wishes that were submitted and how they were fulfilled:

One person had watched tugboats from her waterfront window for 40 years and wished could take a ride on one. The staff at the complex found a tugboat operator willing to make her wish come true. She spent two hours aboard the boat, enjoying a close-up view of the water and learning how the crew operates the tugboat.



Another person wanted to attend an opera, and they did!

A third person wanted to have hamburgers and fries, which isn't part of their current diet. After a nutritionist signed off on it, they enjoyed a special meal with food they usually can’t eat for health reasons.

Inspired by the article, the disability history project leader asked the participants to imagine that, instead of older adults, the article focused on people with disabilities of all ages who could be granted a wish. What would they wish for? What dreams did they have? What would they like to be able to do, see, or have?

After a short pause, one participant hesitantly shared that she would love to host a favorite singer, along with her mother, for an evening. She knew it might not be possible because the singer lives in England, but the group asked if the singer ever tours in the United States. The wishful participant said she did, but they didn’t have a date scheduled in New England. Both participants expressed a willingness to reach out to their celebrity singer, but weren't sure what response to expect, if they received any response at all.

That’s when the group began brainstorming creative possibilities. Perhaps a Zoom conversation with their favorite singers would be a way to make their dreams come true. Then the leader suggested another idea: if the participants wanted to be sung to, perhaps the group could learn their favorite songs and heartily perform them? That idea had us rolling over in laughter, which felt good in its own right! Some days in life can be hard and there isn’t much to laugh about so laughing amongst ourselves was a wish fulfilled in itself.

Why not pursue our own dreams and wishes in different ways when life doesn't grant us exactly what we hoped for? As The Rolling Stones sang, "You can't always get what you want, but if you try sometimes, you just might find, you get what you need." People with disabilities may not have the health they wanted, the housing they dreamed of, or the career they desired, but why settle for only what we need? Why can't we have more of what we want? Like everyone else, we can dream, set goals, and pursue the things that bring meaning, joy, and fulfillment to our lives.

When I proposed the topic of publishing an article in *Disability Issues* about fulfilling dreams and wishes at our recent editorial board meeting, a wise person commented that when dreams go unfulfilled for an extended amount of time, it may be easier to stop dreaming so you're not disappointed. Later, someone said the societal and physical barriers people with disabilities face, can make it harder for dreams to come true.

The disability history project group leader threw down a gauntlet at their meeting; she wants us to dream more and dream big. She gave participants two weeks to start showing progress on connecting with the two singers that two group members want to connect with. We don't know if the singers will agree to meet in person, speak with them on Zoom or grant them tickets for a performance, but until we give it our all, we don't know if these dreams can come true. The worst that could happen is, we all end up learning the tunes and songs to sing together, which would also be special. That's the thing about dreaming big, sometimes you might get what you want – and what you need – but you surely won't get it if you don't go after it.

Dream big, dear readers, dream big.

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions, and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com. Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy and may be edited.

What is DISCO?

By Kim Charlson

Disabled Stories Collective Inc. or DISCO Inc. is a newly formed non-profit organization headquartered in Melrose, Massachusetts. DISCO began as a project through MassCreative's Arts Advocacy and Organizing Fellowship.

The impetus for Disabled Stories Collective was an event hosted in Melrose as a collaboration between the Melrose Commission on Disability and Follow Your Art Community Art Studios. The first storytelling event, consisting of eight storytellers, was a great success and enjoyed by many. As has been the standard for all DISCO events, they are a diverse tapestry in terms of disability and human experience.

In August 2024, Garin Boyd and Erin Ryan Heyneman submitted an application to MassCreative as the first ever partnership for their Arts Advocacy and Organizing Fellowship. Garin and Erin were selected and began working on the project that would become DISCO.

Disabled Stories Collective is a storytelling project that creates space for disabled people to share their **lived experiences** through **story, poetry, music,** and **performance.** Events bring together community members, artists, advocates, and listeners for evenings of honest, funny, moving, and powerful storytelling. **Disability is part of human diversity.** When disabled people tell their own stories, the result is connection, understanding, and a stronger community for everyone. DISCO applied for 501(c)(3) status in February of 2026 and received confirmation in March.

DISCO storytelling nights are open to all — disabled and non-disabled alike. Able-bodied people are encouraged to come listen, learn, and be part of the conversation. DISCO has now hosted five storytelling events, featuring over twenty different storytellers with very diverse life experiences and backgrounds.

DISCO, Inc. events highlight accessibility and accessible space. The events are live close captioned through CART (Communication Access Realtime Translation) services. All DISCO events are free and funded by generous donations.

To increase inclusivity and accessibility, DISCO hosted two events in 2025 at the Cambridge Foundry. The July event, "All Dressed Up: Stories of Disability and Fashion," premiered one day after the 35th anniversary of the signing of the Americans with Disabilities Act (ADA) on July 27th, 2025. This event was followed by "Hire Diversity: Tales of Disability at Work," both held at the Cambridge Foundry. The Advocacy and Organizing Fellowship was completed in December 2025. Garin decided to continue hosting storytelling events, and next on the agenda was "Whether Permitting: Stories of Barriers to Access" held at the North Hampton Center for the Arts in Northampton, MA. In May 2026, DISCO partnered with the Perkins Braille & Talking Book Library to host a full online event, "Virtually Able: Tales of Disabled Tech Life."

The next Disabled Stories Collective event
will happen on
July 25th, 6:00 pm to 9:00 pm,
and is a celebration of Disability Pride Month.
It will take place at Follow Your Art Community Studios at
647 Main Street in Melrose, MA.
You can find out more about DISCO at
disabledstoriescollective.org and on Facebook and Instagram.

Kim Charlson is Executive Director of the Perkins Library, a division of international NGO Perkins School for the Blind. She was the first female president of the American Council of the Blind (2013-2019) and was selected by the Board of Trustees and leadership for the American Foundation for the Blind (AFB) to receive the 2024 Migel Medal. Charlson was also awarded the Anna Eliot Ticknor award in 2025 from the Massachusetts Board of Library Commissioners' (MBLC).

Manic Depressive Disorder

by Sarah Hesterlee

That's what they call it,
all of this nonsense —
what we've been going through
and now can name.
And I thank you for the love
you've shown through it all,
and ask that you continue to
come and find me.

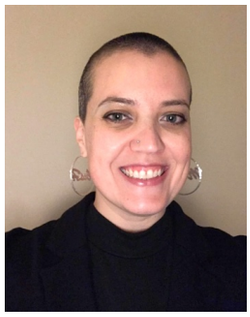
When I am in my bed,
come and find me.
When I am in my head,
come and find me.
Whether I am in a low
or 'on the go,'
or I'm in a place
you just don't know,
and I'm stumbling,
and stuttering,
or mumbling real slow…
Please, come and find me.

For you are my happy place,
and your faces are reminders
of my reason why
I should come back to the surface
and bask in the sunshine.
For you are mine,
and this could never take that away.

So, please don't give up
and leave me alone in the dark.
Don't come down here
or join in the despair,
but remind me that we're
not beyond repair.

Have hope.
And in doing so,
help me have hope —
that together we can beat this,
and apart we can beat this,
and forever we can beat this,
and from wherever, we can beat this,
and whenever I am lost,
you'll come find me…

And we will beat this.



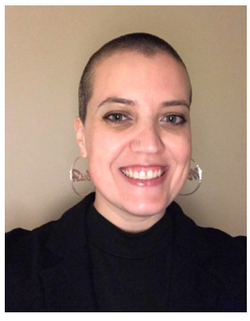
Sarah Hesterlee is a middle-aged mom of two who didn't have a clue that she sufferers from several mental illness, including OCD, PTSD, and the one written of above. Here, she writes to her family, who she credits with helping her through tough times; they are the three loves of her life – Mark, Lily, and Tyler.

Simple Sarah
by Sarah Hesterlee

If I were to stop speaking
and simply wrote poetry,
what would the world
say about me?
Would I seem lonely,
like Emily D?
Or would they realize that
this is just me?

I hope for the latter,
as nothing's the matter;
I'm merely returning to
my earliest nature.
I take time to think;
it's always a need
to revise and reflect:
Is this worthy of a read?

Reviews may be mixed,
but aren't they already?
So, say what you want;
I'll reply when I'm ready.



Sarah Hesterlee has always found it easiest to express herself through poetry. She started speaking at age five, but by age six she discovered that she preferred writing and rhyming to using spoken words. To this day, she speaks selectively and is starting to see that it's okay.

Running To You
By Sandy Alissa Novack

It is a very cold, winter day but that is
Not the reason my pace picks up.
I am thinking of you,
Missing you, and
I start crying on the sidewalk.
The world blurs as my glasses fog up.
My gait stretches wider and I am covering ground
At quite a clip for someone who walks with a rollator walker.
The more I think of you
The faster I pass the apartment buildings and stores.
I hear you calling me in my head, and

I envision your outstretched arms reaching for me
To come hold your hands and
Tell you I am here.
You are not alone, and
I am here.

The tears are falling and
I don't care who sees this
Nor do I slow down to wipe the tears away.
Faster and faster the wheels on the walker turn, and
Louder and louder the metal of the walker clunks on the broken,
And in some places uprooted by nearby trees, sidewalk.

I am coming, Tuvye, I am coming.
The urgency I feel is propelling me faster and faster.
I weave in and out of pedestrians,
parents with their strollers,
and even bicyclists,
As if I am a football player
Running with the football across the field
With the opposing team chasing me
To intercept my walker before I can get to you.

No, No, NO
No one and nothing are going to intercept this time.
I won't stop until I can grasp
Your hands in mine
And hold you tight,
Never to let go, again.
Never to let you go to the assisted living facility,
The hospitals,
The nursing homes,
The hospice,
And heaven.

No, no, NO, NOOOOOOOO.

It is as if I have no braces on my legs as
I am flying down the street.
I am coming, Tuvye.
I am coming.

Cars at the intersection have the right of way and
I barely register the hard stop I make
To allow them their roadway.
Faster,
I am off again as soon as the last car passes in front of me.
I have lost time with these cars,
Just as I lost time with you
On the days the pandemic separated us.
No, No, NO and
My chest pushes out in front of me
As if to get some part of me over a finishing line to you
Before you are out of reach of my embrace.
Hurry, hurry, hurry
I think to myself.
Tuvye is reaching for you
HURRY.
I am breathing hard and harder,
But it is as if I am at the racetrack
As a horse,
Giving its all,
But that is never enough.
It is me who was not good enough for you.
I cry harder.
Tears are pouring down my face over my pandemic face mask,
Over my winter coat.
I am breathing heavily.
I don't care.

I only care that
I was not enough to protect you, and so
You died.

Come back to me, Tuvye,
Come back to me.
I am running to you, Tuvye
Running as fast as I can push my walker.
Which isn't very fast
Which is very slow
Which isn't good enough
And in my mind your arms lower
No longer reaching for me
No longer thinking I am here for you.

I stop in the middle of a block,
And find myself surrounded by noisy traffic,
People walking by smoking
Or drinking coffee
Or laughing.
I am bewildered.
I lost you in the crowd.
You went away
Because I wasn't enough to save you.
What city block am I even on?

I stand here crying
And the dozens of people move around me
As if I am not even there.

If I am not there
And you are not here with me
Where are we?
Post-funeral grief,
It is all so hard to wrap my head around this.

Tuvye,
I feel very alone.
I am reaching out to you.
Please come back,
Kiss my hand as only you can do.
Hold me close.
Never let go.

Sandy Alissa Novack is the Vice President of the Board of Directors of the Disability Policy Consortium (DPC) and is spearheading DPC's Disability History Project. She is active also with the Boston Center for Independent Living and Dignity Alliance Massachusetts.

Reasons Not to Live in a Nursing Home

By Penelope Ann Shaw

As a person with a disability who has been living in a nursing home for 24 years, I have had both good and bad experiences there.

We have a new owner who treated some of our best staff disrespectfully, so they resigned. Now there are plans to eliminate per diem staff who know my care, so the quality will be reduced.

The owners said my unit would never be converted to a neurobehavioral one. That wasn't true. Now residents in my unit listen to behavioral residents screaming and swearing. Also, my previously open unit was changed to a locked unit, requiring staff to let me out every time I want to go someplace.

Because there are several bariatric residents on my unit, there isn't sufficient staff to care for them. Once – when there should have been two aides for me – I had only one aide to dress and position me for a transfer to my wheelchair.

My aide attached me to a lift and I was ready to be transferred. Just then, another aide came into my room telling my aide that she needed her assistance because a bariatric resident required 4 aides to be washed. Therefore, I had to wait in bed – attached to the lift – for a long time. Luckily, it didn't fall over and injure me.

Unbelievably, staff who are providing care for other residents, sometimes come into my room and take supplies that are mine.

One day on the 3pm-11pm shift, there was no aide assigned to my unit who knew how to safely transfer me to bed or how to move and charge my electric wheelchair. A nurse who knows my care did both with assistance from an aide.

The Massachusetts Noise Law forbids individuals from bothering neighbors with noise from 11pm-7am. This law also applies to nursing homes. Our owner does not enforce this law, so I am often awakened in the middle of the night.

Some aides do not treat me respectfully and complain about the length of time my care requires. One aide told me that asking her to adjust my pillow while I was in bed – something I cannot do myself because my shoulders do not work – was abuse. Another aide asked if she could avoid repositioning me flat in bed, even though this is necessary to prevent pain throughout the night; I said no. On another occasion, an aide repositioned me onto my side instead of my back, causing injury to my right hip and knee.

An aide criticized me for buying a blanket for a resident who has no family support. I purchased the blanket after she told me she was cold, so she would have something warm to cover herself with while sitting in her wheelchair.

A resident ordered something to be delivered. He was not allowed to show his ID to the delivery guy to prove he was delivering it to the right person. Turns out there is a new facility policy that does not allow residents to identify themselves. The resident was rightfully angry

when he did not receive what he ordered.

In addition to providing care, our owner expects aides to manage resident behaviors and take them outside to smoke. Neither of these responsibilities were in their job description when they were hired. Without receiving a salary increase, this added work appears to violate MA labor laws.

Our new payroll person doesn't like residents passing by his office and stopping to ask the scheduler and staff in the business office questions. Now we now must ask the receptionist to call the person we want to talk to and ask them to come to us, which can mean a long wait.

When two elevators were not working, our owner chose the company with the lowest bid and decided to repair only one elevator. Now everyone has long wait times to use the elevator.

Our administrator criticized me for sending him an email on a Sunday, which was when I had time to write. Did he really think I expected a reply on a day when he wasn't working?

Physicians I've had in the past have been good, but my current physician has been problematic. He questioned my ability to drive my wheelchair outdoors, even though federal regulations say all residents are free to come and go from the facility as they please unless there is a documented medical reason, such as dementia, that limits their decision-making ability. To assess my mental status, he asked me to recite the months of the year backward, starting with December!

Once, the physician came to the door of my room when I was in the middle of being lift-transferred from bed to my wheelchair. I was up in the air when he said he had a quick question! I responded that I was being transferred, ignoring him, since it was unsafe to stop in the middle of a transfer.

Another time, the physician wanted me to get an x-ray of some swelling in my left chest. I said “no” because I knew what had happened. My chest had been briefly caught in a sling. The swelling went down in two days.

The way laundry is done caused me to lose 3-4 pieces of clothing weekly. My clothes are now washed separately because it became so expensive for the owner to replace them.

I have problems getting the right food from the kitchen. For breakfast, I eat Cream of Wheat cereal, which needs to be thick – like meatloaf – so it will stay on a spoon and not slide off, spilling all over me. This problem can be solved easily by making it with less water.

I like some of the fruit that is available – bananas, strawberries and grapes. I don’t like watermelon because when I bite into the large pieces, the juice drips all over me. Because my shoulders don’t work, I cannot reach up to tilt taller bottles of water, so I need short bottles. I don't always get the food, or water bottles I'm supposed to.

Weather permitting, if breakfast is wrong, I go to a supermarket and buy finger foods like raspberries. When dinner is wrong, I eat snacks that I have purchased. I get reimbursed for both, but I don't like that I have to go to the supermarket because it wastes my time.

These are just a few examples of the challenges I face regularly.

Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes.

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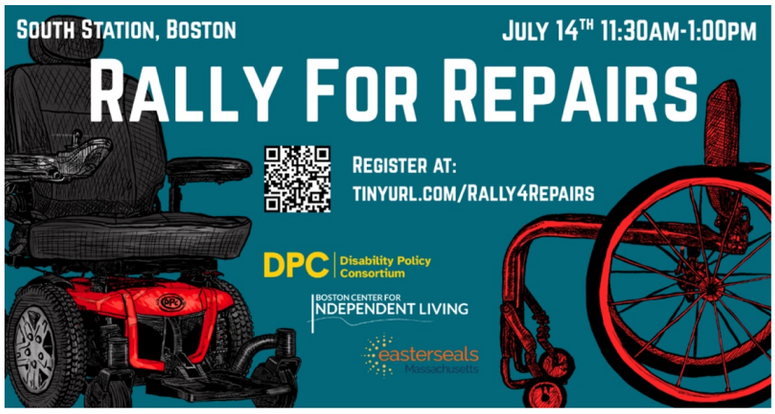

Wheelchair Repair Rally
Tuesday July 14

Together, Boston Center for Independent Living, Disability Policy Consortium and Easterseals are bringing wheelchair users, families, advocates, and allies together to raise awareness about ongoing wheelchair repair delays and the impact they have on our daily lives.

When: Tuesday, July 14, 11:30 to 1:00 pm
Where: outside South Station in Boston

REquipment will be at the rally with 5 manual wheelchairs. These will be available at the end of the event for permanent adoption to anyone attending who needs a wheelchair.

If you are interested in attending, it would help if you could fill out our optional RSVP form and survey: **tinyurl.com/Rally4Repairs**.

Let's come together in numbers to make our presence felt and our voices heard. Please save the date and share as widely as possible. This moment cannot wait.

Disability Pride and ADA Celebration Events

Several Disability Pride Month events are scheduled across Massachusetts for July and August. Highlights include museum celebrations, community fairs, and inclusive beach days marking the anniversary of the Americans with Disabilities Act.

Boston ADA Day (July 15, 2026): Taking place from Noon – 2 PM at the newly renovated Copley Square Park (a new location). This two-hour lunchtime event includes a brief speaking program, disability resource fair, food, and fun! The event is for people of all ages to come together to celebrate disability community, access, inclusion, and rights. Learn more at Boston ADA Day 2026.

Museum of Science Disability Pride Celebration (July 25, 2026): Join the museum in Boston from 10:00 AM to 4:00 PM for live presentations, community partner activities, and programs centered on the disability community. It is included with standard Exhibit Halls admission. Check the Museum of Science for more details.

Methuen Disability Pride Fair (July 25, 2026): Taking place at 10 Hampshire Street, Methuen, from 11:00 AM to 3:00 PM. The free, family-friendly event features food trucks, vendors, adaptive chair yoga demonstrations, and resources. Visit SPED Child and Teen for more information.

Dunn State Park ADA Celebration (July 31, 2026): Hosted in Gardner from 11:00 AM to 3:00 PM by the Massachusetts Statewide Independent Living Council. Celebrate the anniversary of the ADA with accessible hiking, kayaking, swimming, and live music. Learn more at Massachusetts Statewide Independent Living Council.

Fairhaven Disability Pride Beach Day (August 7, 2026): The Fairhaven Commission on Disability is hosting its second annual inclusive beach day at West Island. The event is fully accessible, open to all abilities, and a great opportunity for families. (Rain date: August 21). Find updates on the Fairhaven Commission on Disability Facebook Event.

Berklee College of Music

The Berklee Institute for Accessible Arts Education

The **Berklee Institute for Acccessible Arts Education** (BIAAE) is dedicated to increasing opportunities for individuals with disabilities in all aspects of performing and visual arts education. A wide variety of programs are offered in the following areas:

- **Arts Education Programs**: Highly trained instructors tailor their teaching to meet each individual participant where they are in a safe and welcoming environment. We offer an array of programs for individuals of all ages and abilities.
- **Academic Programs**: Berklee's team of educators are leaders in the field of music education for students with disabilities. For 10 years, we have offered arts education programs for people with disabilities, ages 3–93. Through teaching in these programs, graduate students gain valuable hands-on experience.
- **Professional Development:** Provides resources, workshops, a conference, consultations, and other support for professionals in the field, including educators, arts educators, special educators, administrators, program leaders, and visiting artists.

Editorial Board (L-R): Sandy Alissa Novack, Raymond E. Glazier, Joan Burrows, Marianne DiBlasi, the late Mary Grimley Mason. Missing: Marybeth Barker, Kim Charlson

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The ***Disability Issues*** newsletter is a free and independent publication and is available without charge to anyone who finds it beneficial. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

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