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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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TABLE OF CONTENTS

From the Editor... | Marianne DiBlasi

Getting Involved in Social Movements | Abbie Goldberg

Love & Intimacy Corner: Revolutionary Love | Ms. Love

The PCA Corner: The Training Process | Raymond E. Glazier

How I Thrive with a Significant Disability | Penelope Ann Shaw

Movie Reel: *Justine* | Mary Grimley-Mason

Information Briefs:

• #WearAMask Challenge!

From the Editor....

Dear Readers,

It's been a challenging and stressful summer. Along with being hot and humid, we are also experiencing multiple simultaneous pandemics – COVID-19, healthcare, economic, and racial justice. Systems are revealing injustices that were always there, but less visible because they weren't under strain. This is certainly a time to get (or stay) engaged in social movements and be part of creating a more equitable and compassionate world that honors all life. In this issue, we continue to share stories about creative ways to focus on what we *can* do to participate in reform movements for healthcare and long-term care facilities, racial justice, PCA training to ensure safety and well-being, and how acts of revolutionary love can heal a hurting world.

I recently came across a poem, [*Songs for the People*](#) by Francis Ellen Watkins Harper, who was a 19th-century abolitionist, suffragist, educator, organizer, advocate black woman. I was particularly drawn to the last two stanzas, which offers a way to sustain oneself for the long-haul of advocacy work and living life:

*Our world, so worn and weary,
Needs music, pure and strong,
To hush the jangle and discords
Of sorrow, pain, and wrong.*

*Music to soothe all its sorrow,
Till war and crime shall cease;
And the hearts of [people] grown tender
Girdle the world with peace.*

In her poem, Watkins Harper talks about how music plays an

active part in healing pain. How it helps us not to succumb to despair, or the lack of progress, or the painful past. She says music, art and beauty make our hearts grow tender, and with that tenderness, we can create peace. During these challenging times, I encourage you to double-down on art, beauty, music or whatever nourishes you and soothes your pain.

This summer, I have doubled-down on spending time on my patio surrounded by the beauty of flowers, quietly watching bees and an occasional hummingbird drink nectar from blossoms. I have doubled-down on shopping at the Farmers Market for locally grown food. I delight in biting into a juicy peach or an ear of buttered corn. These forms of nourishment may seem small and insignificant, and they are in the grander scheme of things. But I discovered, when I savor the small moments and engage wholeheartedly, the ordinary is transformed into something beautiful, something that soothes my sorrow. May you discover and wholeheartedly embrace what nourishes and comforts you.

Marianne DiBlasi, 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 & marketing and disability inclusion training. In May 2020, she earned a Master of Divinity degree from Meadville-Lombard Theological School.

Getting Involved in Social Movements

By Abbie Goldberg



On March 13th, Louisville police officers Jonathan Mattingly, Brett Hankison, and Myles Cosgrove shot and killed Breonna Taylor, a 26-year-old Black woman. On May 25th, George Floyd, a 46-year-old Black man was murdered by the Minneapolis police. These deaths, in addition to countless other murders and acts of violence towards Black people by police, white supremacists, and the anti-Blackness built into many systems in the United States have sparked a powerful upswing in Black Lives Matter actions. I was especially inspired by a Black Lives Matter march in my hometown in rural Maine where in a population of just over 2,000, several hundred people took to the streets with signs proclaiming, "Racism is a pandemic" and "Say their Names." I have never heard of such a thing happening in my little town! It's clear there is a lot of energy right now around stopping anti-Black racism and the only way we will achieve meaningful, long-lasting change is if *we keep going!*

That said, it's not always easy to know where we fit in social movements. I struggle with anxiety and depression and sometimes I feel like I'm not doing enough because I can't always go out into the streets and protest. The truth is we need *everyone*. Social movements work when there are lots of people approaching an issue in lots of different ways, each offering their own unique strengths and skills. Here are some creative ideas for ways to be involved in the movement for Black Lives.

Make Art for a Protest or an Action

Even though I don't usually attend protests, I still enjoy supporting them by making banners, signs, and even one time a puppet for people to use at the action. Having powerful visuals can help get a

message across clearly and even help an event get better news coverage. Oftentimes an event will have a hashtag and/or a list of slogans they plan on using. Since not everyone will have time to make a sign, it can help to make some extras to send along. Make sure to stick to the same messaging/visual points the organizers are using and you can support an action by helping to make it more beautiful!

Attend a Protest / Be an Accessibility Point Person

One of the most visible ways to be involved is to go to a protest. Certainly, many protests and actions *are* organized by disabled people and their allies, but unfortunately, disability is sometimes treated as an afterthought and protests are not accessible. Sometimes you can find the contact info for an accessibility point person in the "about" section of a Facebook event or on an event flyer. If so, this may be someone who can help answer your questions and help meet your needs around access.

If you know people who are involved in organizing a protest and you have the capacity, you can also volunteer to be an accessibility point person. Some things to consider if you take on that role are making available information about march route length and conditions, what public transportation will be nearby the starting and stopping points, that there will be water and chairs available in locations the group will be stopping in, and locations of restrooms. Black Lives Matter protests have been met with a disproportionately violent response from police. Sometimes this has included pepper spray, tear gas and physical violence all of which can be especially harmful (even lethal!) to people with disabilities. There should be a clear and easily accessible plan for what to do in the event of such a response.

Put Your Money in the Movement

If you are able to, there are lots of ways to support social movements financially. For the racial justice movement, you can donate to bail funds, mutual aid funds, and other organizations. Some examples of Massachusetts organizations involved in racial justice work are Ujima which strives to develop alternative economic models, Alternatives for

Community and Environment which takes an intersectional approach to environmental justice, and City Life/Vida Urbana which does housing justice work.

The way to have the most impact is to commit to a monthly donation to a program in your community. That way instead of getting an overwhelming one-time influx of money, an organization can plan more long term. You can also buy from Black-owned restaurants, businesses, and artists or even donate directly to Black organizers and knowledge producers through Venmo, PayPal, Cash App, and Patreon.

Have Conversations About Race

Especially if you're white, it's important to talk about race with your friends, family, coworkers and community. When people talk about privilege and oppression it becomes clear how unjust the system is towards Black people. It can be helpful to write out a script for how to confront racism in yourself and others with specific responses to specific points.

Offer Resources to People Protesting

Heating food kills coronavirus (and studies indicate it is rare to impossible to get coronavirus from food) so you can always cook or offer meals to people you know who are out in the streets or are otherwise involved. You can also offer masks and PPE or childcare. Helping people stay fed and safe has been a crucial, and often overlooked, aspect of every social movement from the suffragettes to civil rights, to today. If a protest is happening near where you live you can also open your house to people in the event of police violence (being mindful to take precautions against coronavirus).

Get Involved in Politics

When calling or emailing your senator or congressperson, it is far more effective to communicate a unique message than to use a form. Duplicate messages often get deleted or quickly scanned through so talking about your personal connection to the issues, even if the

message is short, it is more likely to be read.

Also, look into local politics. Your selectman, mayor, school boards, and people in municipal level positions are likely making the decisions most affecting your community and will be most willing to invest in you as a constituent. Form relationships with the people representing you!

Keep Learning!

There are tons of resources on the internet and at your local library for learning more about the racist history of the United States, and the powerful resistance of Black people from its founding till today! Follow Black bloggers, and thinkers, and don't forget to consume joyful Black media too (like Black written fiction, TV shows and movies!) Listen to Black people and amplify their voices.

Whatever your role is, *it is valid!* The fight for racial justice will not be over quickly. It's important to think about what things we can do to stay in this movement for the long haul. Our role may change over time and that's ok too. When everyone contributes what they are able to and we use a diverse array of tactics, that is how we win.



Abbie Goldberg is a Boston based community organizer and artist. She has been previously published by Autostraddle, Dame Magazine, and Sinister Wisdom.





Revolutionary Love

By Ms. Love

Have you known revolutionary love? Have you ever had a relationship with someone whose love of life and people will forever change the way you see the world? I have.

I have a much-beloved friend who, sometimes with his seeming innocence, has amazed me. Tuvye has trusted organizations, leaders in the community, and more; some of whom have seriously short-changed him, stomped on him, and ignored him. I can relate, probably like many of you, my dear readers, can too. Rather than become cynical, however, he continues his behavior of dealing with others with love.



Tuvye is very giving. Many a time, I have walked down a street with him, and he will stop at every down-and-out person we see; reaching deep into his pocket to give what he can to support another. Now mind you, he has little himself, very little. While he scrimps on himself, he gives money to those who seek to borrow from him because they can't get a loan from a bank. Those who don't pay him back, not even a penny, after saying they would, leave him with less for himself. Yet, he is not so much mad as saddened that others did not keep

their promise to pay back his loan. He wonders how he will manage himself and how he will continue giving to others in need since he now has less money.

People from miles around have called or come to visit my friend. They want to share their troubles with someone who listens at a deeper level, without adding in his own troubles to detract from theirs. Or they seek advice on work, relationships, and more. No matter what he is doing at the time, no matter how tired he might be, he never says he is too busy to talk, and he manages to never be disinterested in what these people have to say. Each is treated as they are the most important person at that moment.

Yes, he has been taken advantage of, more than once, for his kindness and compassion.

Yet, the longer I know Tuvye, the more I am in awe of him. He practices what I call "revolutionary love." He is there for anyone in need, in any way, to make a difference in their circumstances or to validate their experiences and feelings without judgment. Yes, there have been users and con-men, power-seekers, and abusers. But that never sways my friend from his resolve to trust, love, and see the best in people.

To so believe in people, to so extending himself to others, to be so present for others, that is revolutionary love.

May you experience such love yourself and may you offer this type of love in your own part of the world. Certainly, the world could begin to heal if we could each, individually and collectively, engage in acts of revolutionary love.

Thank you, Tuvye, for being willing to stand up for human frailty, injustice everywhere, and trying to always do the right thing. What a

model of endless love you have been for me. When I see how people have hurt you by taking from you and abusing your kindness, I see something strong and more approachable in a man who shows his vulnerability. By knowing you, it encourages the best to come out of most of us.

My visionary, loving friend; my role model; my rock; my world: You exemplify revolutionary love, and it is contagious to all who are open to its ways.

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.



The Training Process

By Raymond E. Glazier

The hallmark of the MassHealth Program, as originally designed by consumer advocates in conjunction with state legislators, was and is consumer control in hiring/firing, training, and supervision of personal care workers. We don't always think of the training aspect as an ongoing two-way process, continual teaching and learning as external

circumstances and both consumer and worker abilities and resources evolve or devolve. It is especially vital that surrogates not think of training as a once-and-done-proposition. Or as a one-way process.

First of all, training is not simply a matter of academic style instruction; it must involve shadowing in an on-the-job setting as the initial step after completion of the mandatory PCA training module for all new hires. Usually, a seasoned PCA can demonstrate most effectively, although this can be awkward or downright impossible if that PCA is being discharged or otherwise leaving on bad terms. Most new PCAs prefer to be shown rather than told how to do things. In my personal experience, this is particularly important for new hirees with limited English proficiency or different cultural norms around topics like sanitation, personal hygiene, infection control, privacy, food habits, etc. or lacking what we consider common knowledge of human anatomy, bodily processes, and the basic laws of science.

As time goes by, any PCA develops his or her own different or modified technique for performing everyday tasks. If the consumer has any discomfort or misgiving about such alteration, it is best to nip things in the bud by addressing the situation before it becomes an ingrained part of the PCA's routine. For surrogates, this highlights the importance of regular, private, frank consultation with the consumer about any problematic PCA behaviors or issues, in addition to unannounced observational check-ins. Of course, the surrogate should also have a parallel discussion with each PCA along the same lines to assure that things run smoothly.

Maintaining an optimally functioning work environment requires that all parties be on the same page at all times. And the key to this state of affairs is that everyone involved realizes that training and learning are ongoing processes that never end; life itself operates that way. Without the learning process, life would be bland.

But I can eat. I can feed myself. I can speak. I can think. I can read, write and use both a desktop computer and an iPad. I can drive a power chair. I can be a full member of my local community.

I can use my prior life experiences and skills from having been an academic. I can advocate on behalf of older adults and persons with disabilities by writing, publishing and speaking, and by being a member of state and national advocacy organizations and work groups.

Neither my legs nor my feet work. So, I use a power chair for mobility. Both my hands are contracted, not fully opening. All my fingers on both hands overlap. My shoulders only work a little so I basically cannot raise my arms. To reach up, I either use a traditional wooden cane to assist myself or, if I only need to elevate my right arm a little, I use my left elbow to place my left hand under my right arm and lift it. The use I have of my upper extremities, although limited, has been my salvation.

With experimentation, I learned to accommodate my impairments and am able to have a rich life. Here a few of my adaptations:

I write with Pentel gel pens because regular ballpoints require downward pressure, which I cannot produce with shoulders that don't work. I type with a single finger on my right hand. I grasp writing and eating utensils with the crevice between my thumb and first finger of my right hand. On my iPad, I use a stylus, as without it and having non-working shoulders it is difficult to position my finger where I want it.

I use a flip phone because it is narrower and fits into my contracted hands. iPhones are a challenge because of their width and slipperiness. I grasp things differently and I drop things easily, so I added hooks to the backs of my flip phone and iPad. I threaded a parachute cord through the hooks, giving me loops to put my arm

through for safety.

Without fine motor skills, I cannot tear things, so I carry scissors with me at all times - to open envelopes and individually wrapped hard candy or to cut my nails, for example. I use a very small matte knife to cut articles out of journals for my work.

Since my right shoulder doesn't work and I cannot press down to cut food with a knife, I stab food with a fork and take bites off of it. I use a knife to cut into the end of a banana, allowing me to pull the skin back. I use a fork to open milk cartons and small ice cream containers since my fingers cannot hold onto something that small. I use only metal silverware because it requires less pushing down than plastic. I eat some foods that are not ordinarily considered finger foods with my fingers, such as cold cereal and baked potatoes. Since I cannot use a spoon for thin liquids, I drink soup from small juice glasses. To drink, since neither hand opens completely, I use both hands together to grasp a drink.

As for clothing, since my hands don't flatten out, I need bigger gloves or mittens to cover my hands and keep them warm when it's cold. Putting on and closing a jacket that has snaps is preferable because I cannot grasp the end of a zipper or push buttons through a buttonhole.

Once I am in my power chair, I am mostly independent, only needing assistance when I drop things or can't reach something that is not at wheelchair height. Like others in the disability community, even if we do things differently, we can – and do – thrive.

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.



Justine:

a film written and directed by Stephanie Turner

By Mary Grimley-Mason



This film, available on Netflix, chronicles the turbulent time of grief and despair of Lisa Wade, a wife and mother of two young girls, whose happiness is tragically disrupted when her military husband is killed. Consumed with mourning, she is unable to relate to her devastated father-in-law, who has taken her in and is caring for his grandchildren while she seeks employment. Somewhat reluctantly, Lisa takes a position as a nanny, a kind of work she has not done before. Happily, she and her charge, Justine, a bright, feisty eight-year-old who was born with Spina Bifida, develop a mutually caring and healing relationship. Lisa is able to begin a return to herself and her family, while bringing new life to the child, whose family have overprotected her by keeping her out of school at home with a tutor,

unwittingly depriving her of friendships and normalcy.

Justine discovers the outside world when Lisa takes her to the local playground where she meets other children. She finds that at first, some children tease her because of her disability, but she learns to stand up for herself and earn respect and friendship. Lisa rediscovers the warmth and feeling of caring for someone; she is able to enjoy and relate to her two young daughters again.

There is a subtheme in this rather short film (106 minutes), perhaps overburdening the main story a little. Lisa's husband, a marine, was African American, and we understand he and Lisa grew up together in a mixed-race neighborhood; they were close as children and went to the same school. This racial theme is developed showing Justine's parents, particularly her father, as racists. However, by the end of the film, through the natural friendship of Lisa's daughters and Justine, the two families find a mutual relationship.

Above all, the film shows a clear and moving picture of the importance to any child, isolated by a disability, of having the chance to be part of the mainstream of life: to go to school and have friends and to be as adventuresome and involved as this child became.



Mary Grimley-Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; "Life Prints: A Memoir of Healing and Discovery, Working Against Odds: Stories of Disabled Women's Work Lives", and "Taking Care: Lessons from Mothers with Disabilities."



#WearAMask Challenge!

The World Health Organization (WHO) has launched a new #WearAMask challenge!

By wearing a mask, you are sending a message of solidarity and protecting people, especially those most vulnerable, from COVID-19. Take a photo or a video of yourself wearing a mask, share it and nominate friends to do the same.

To watch a short video about the challenge, visit

<https://www.youtube.com/watch?v=8wvv4sV6qxM>



2020 Voting in Massachusetts

There are now more ways to cast a ballot in Massachusetts than ever before. Thanks to a new voting law spurred by the coronavirus pandemic, voting by mail is available to all voters for all elections in 2020.

VOTE EARLY

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Voting by Mail:

1. **Complete** a [Vote by Mail Application](#);
2. **Deliver** your application to your [local election office](#);
3. **Vote** when your ballot arrives;
4. **Return** your ballot.

Applications must reach your local election office by **August 26** for the State Primary. Applications must reach your local election office by **October 28** for the State Election.

State Primary ballots need to be back at your local election office by 8 p.m. on **September 1**.

State Election ballots need to be postmarked no later than November 3 and must be back at your local election office no later **than November 6**.

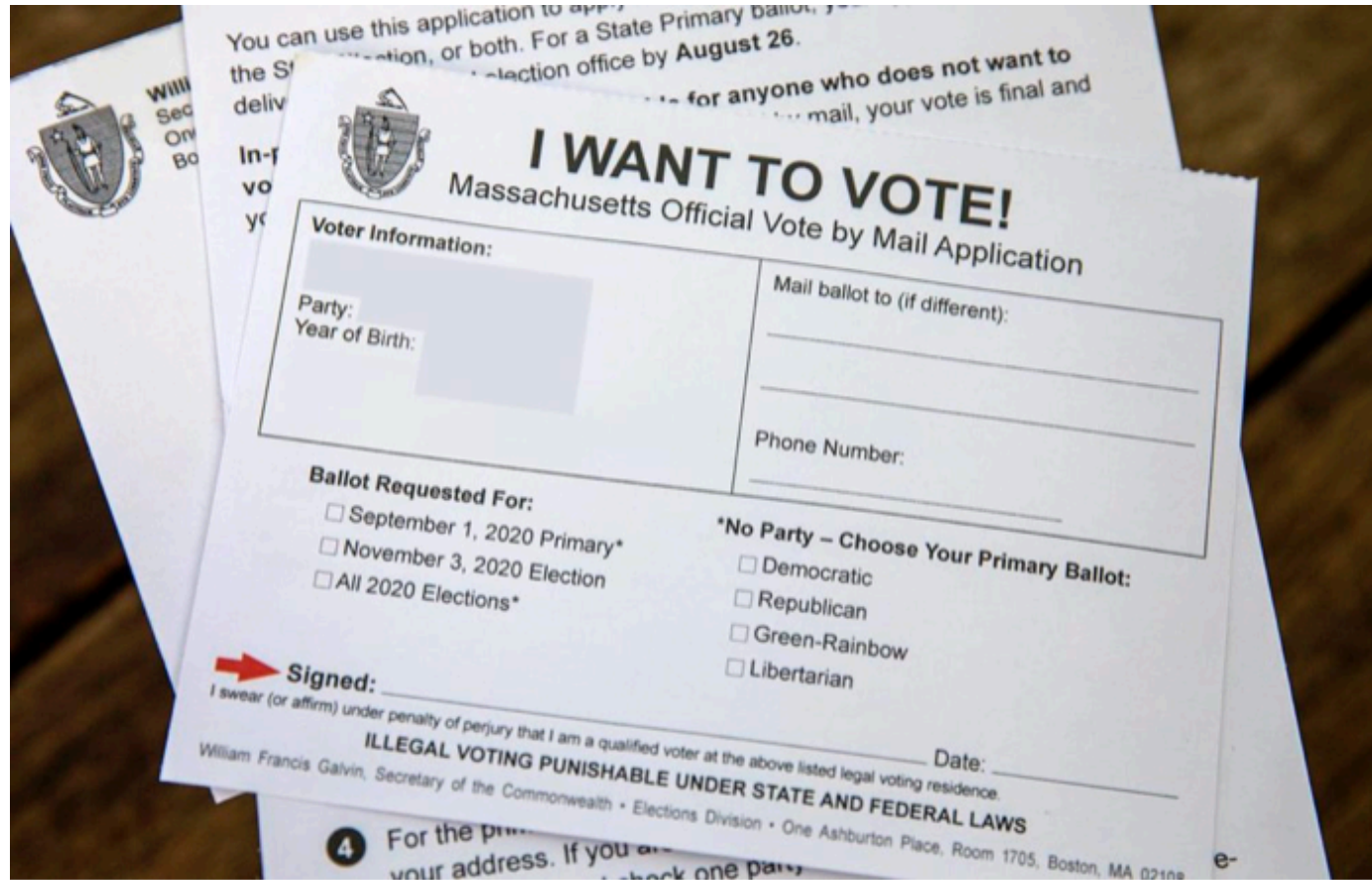
Voting in Person – either early or on election day – is still an option for those who prefer to cast their vote at a local polling station. Whichever way you choose to vote, the important thing is to vote – either by mail or in-person – and make your voice heard.

To learn how to register to vote, find your polling place and more, visit <https://www.mass.gov/topics/voting>

For answers to Frequently Asked Questions on voting by mail, visit <https://www.sec.state.ma.us/ele/elev/early-voting-faq.htm>

For a summary of voting options, visit <https://www.wbur.org/news/2020/07/24/2020-covid-mail-early->

For information on election dates and deadlines in MA, visit <https://www.rockthevote.org/how-to-vote/election-dates-deadlines/massachusetts/>



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Spaulding Rehabilitation Network is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. The Spaulding Rehabilitation Network is a member of Partners HealthCare and includes Spaulding Rehabilitation Hospital. Spaulding Rehabilitation Network, a member of Partners HealthCare, includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts.

Spaulding has been awarded a Model Systems designation in three specialty areas - Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital

in New England continually ranked since 1995 by U.S. News and World Report in its Best Hospitals survey with a #2 ranking in 2018-2019. Spaulding was recognized in 2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit www.spauldingrehab.org

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