***Disability Issues***

**Vol. 43, No. 3**

**Summer 2023**

*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

**Mass General Brigham** is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. Mass General Brigham is an integrated academic healthcare system, uniting great minds in medicine to make life-changing impact for patients in our communities and people around the world. Mass General Brigham connects a full continuum of care across a system of academic medical centers, community and specialty hospitals, a health insurance plan, physician networks, community health centers, home care, and long-term care services. Mass General Brigham is a non-profit organization that is committed to patient care, research, teaching, and service to the community. In addition, Mass General Brigham is one of the nation’s leading biomedical research organizations and a principal teaching affiliate of Harvard Medical School. For more information, please visit [www.massgeneralbrigham.org](http://www.massgeneralbrigham.org).

Feel free to reprint articles. When doing so, please credit Disability Issues (Vol., No. and Date). For articles that appear under a byline or that will be altered in any way, please obtain permission from the editor. Any inclusion or exclusion of a particular entity, product or service in this newsletter does not constitute endorsement or opposition.

**Editor:** Marianne DiBlasi

**Editorial Board:**

Marybeth Barker

Joan Burrows

Raymond E. Glazier

Mary Grimley Mason

Sandy Alissa Novack

**Advisory Members:**

Bill Henning

Ruth Kahn

Oswald Mondejar

J. Archer O’Reilly III

**Table of Contents:**

**From the Editor** | Marianne DiBlasi
**Ready & Able: Coordinating Government Advocacy for Community with Disabilities**| Tim Sullivan
**Building Financial Security with Accessible and Affordable Housing**| Sandy Alissa Novack
**The PCA Corner: PCA Wage Increase Campaign and Programmatic Changes**| Ray Glazier
**Disability Ingenuity** | Penelope Ann Shaw
**The Poetry Corner: Reflections**| Sandy Alissa Novack
**Love & Intimacy: Are Relationships Possible If I Have a Disability?**| Ms. Love
**Information Briefs:**
• GBH Presents: August Press Play Saturdays
• PBS Disability Pride Month Documentaries

**Graphic Design:**

Louise Martling, Eleventh Hour Design

<https://11th-hour-design.com>

**Mass. General Brigham Liaison:**

Colleen Moran

**From the Editor:**

Dear Readers,

In this issue we have multiple articles that speak to advocacy, reimagining what could be, ingenuity, reflections, and generosity of sharing insights and expertise that happens on a daily basis to improve the well-being of people with disabilities.

I’m deeply moved by the time, commitment and energy expended by members of the disability community and their allies to enhance the lives of those with disabilities. I’m also feeling the weight of exhaustion that comes with the chronic need to continually be a self-advocate and advocate for others in order to live with autonomy and dignity. I’m frustrated by the emotional and physical toll this chronic advocacy takes and how it saps our energy that could be used for more pleasurable, fulfilling pursuits.

This summer there were multiple incidents that heightened my awareness of the emotional and physical energy it takes to determine how really accessible a place is. I’ll share one example with you, which I’m sure you can relate to, and add to, based on your own experiences. An able-bodied member of my local community sent me an email saying she wanted to write an article about how accessible our town was. She asked if I was willing to tell her how I determine how really accessible a place is. I was willing, and my response surprised me. I started writing one thing, then another, then another until I had quickly listed 9 ways that I determine accessibility.

Here’s my list:

1. Call the establishment, place, or home and ask about accessibility that meets my needs. If it’s a home, sometimes I ask people to take photos and send them to me.

2. If it’s local, I often drive by the location to check out the accessibility situation e.g., parking, ramps, how many stairs, is there’s a railing. If it’s outside, I check out the terrain e.g., is it asphalt, grass, gravel etc. and what is the slope.

3. Enter the address into google to see a photo of the street view to check out the accessibility situation.

4. If the establishment or place has a website, search for information on accessibility.

5. If it’s local, sometimes I don’t do any research.  I go knowing in advance that if it’s not accessible, I will turn around and leave.

6. Sometimes I decide to stay home because I don’t want to go through the effort of asking about or researching accessibility to someplace new.

7. It’s especially vexing when, after doing all the research and feeling excited about going someplace that I’m confident is accessible, only to discover that it really isn’t. Almost accessible is *not* accessible.

8. It’s rare, but greatly appreciated, when information about accessibility is proactively included in invitations to events at homes or other locations.

9. If I’m traveling someplace new e.g., on vacation, I google to learn about accessibility in the area. The google results are often huge and their usefulness is very mixed.  If I can find a personal blog written by someone with a disability, that’s often the best resource.

Writing this list revealed to me the variety of ways I determine how really accessible places are — I usually just do it and don’t often think about it.  It reinforced what I already know; that the onus of responsibility is typically on the person with the disability to take the initiative of determining accessibility. Writing and seeing this list in black and white, stirred up a lot of emotions – frustrated, angry, exhausted – about the contortions that I and others with disabilities go through to participate in community life. These contortions sap our precious emotional and physical energy, which could be, and should be, used in more life-enhancing ways.

On the positive side, an able-bodied member of the local community was taking the initiative to write about the accessibility of our town. I am grateful for her allyship and willingness to ask and be educated about the real-life experience of living with a physical disability. I ended my email to her by saying, “This is an important topic to raise awareness about determining accessibility. I’m grateful to you for writing about it, asking for input, and using what I share.  I also appreciate that you didn’t ask me to write the piece (as often happens), but you are willing to learn and share what you learn.”

I am grateful to the authors who submit articles to *Disability Issues* and expend their precious physical and emotional energy to write about their personal experiences and share wisdom from others in the disability community. Likewise, I am grateful to the readers of *Disability Issues* who take the time to read and benefit from their time, commitment, and energy. Without authors and readers, this newsletter wouldn’t exist. Thank 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 and marketing, program management, and disability inclusion training.*

**READY & ABLE**

**Coordinating Government Advocacy for Community with Disabilities**

**By Tim Sullivan, in collaboration with**

**Mass General Brigham’s Disability Resource Group**

The power of legislation to provide meaningful change to society and increase access and opportunities for the community with disabilities is well documented. Perhaps none more so than the 33rd anniversary of the enactment of the American with Disabilities Act (ADA). The world today for members of the disability community is vastly improved in terms of access and equality due to this transformative piece of legislation. The passage of the ADA was the result of the unrelenting dedication of so many trailblazers and leaders from diverse and intersectional communities. From ensuring physical access to buildings and city streets, to highlighting the significance of ASL interpreters, to creating pathways to employment and more, the ADA made the bold statement that all citizens have inherent value and the ability to contribute.

And yet, there is still so much work to be done. The pandemic exposed critical issues impacting persons with disabilities, some of which were mitigated by the pivot to remote and hybrid engagement and opportunities. As we move out of the pandemic, it is paramount that those advances are not lost and that we continue to make strides in accessibility, equity, and inclusion. At Mass General Brigham, with community partners and government leaders, the goal is to continue to advocate for robust access to care, the reduction of healthcare disparities, and the elimination of barriers to employment and independence.

In the past year in coordination with many groups from across the legislative and community spectrum, leaders from Mass General Brigham including members of the community with disabilities have been hard at work coordinating stakeholders to advocate for key issues. Among the areas this past year that leaders went to the Massachusetts State House to offer testimony on bills related to wheelchair repair, expanding availability of accessible housing, and a success of increased digital access.

These coordinated efforts recently helped support a major advancement for people living in Massachusetts. Governor Maura Healey, joined by Secretary Jason Snyder and representatives of the disability community, [signed Executive Order #614](https://www.mass.gov/executive-orders/no-614-establishing-the-digital-accessibility-and-equity-governance-board), creating the Digital Accessibility and Equity Governance Board to strengthen and advance digital accessibility and equity within the Commonwealth. The Board will be chaired by the newly established position of Chief Information Technology Accessibility Officer within the Executive Office of Technology Services and Security and will work with Secretary Snyder to lead the active engagement in driving all digital applications to be fully functional and accessible for everyone.  Through ongoing monitoring, support for testing, and internal reporting, the Digital Accessibility and Equity Program will ensure that digital accessibility and equity standards are aligned across the executive department.

“In Massachusetts, we strive to be a model for equity, inclusion, and accessibility. Through the leadership of Secretary Snyder and the Executive Office of Technology Services and Security, we’ve made significant progress on people-centric improvements to government digital services,” said **Governor Healey in the official news release.** “The establishment of the Digital Accessibility and Equity Governance Board represents our commitment to supporting individuals with disabilities and making government more accessible and equitable for all.”

While the signing of this important bill is progress, it is also vital for the community with disabilities to continue to share its important voice with leaders and stakeholders. Mass General Brigham is committed to coordinating ongoing advocacy for equality and access as a fundamental core to its mission. With the combined voice of healthcare leaders, researchers, advocates and community members we all can continue to build on the legacy and promise of the ADA. To learn more about Mass General Brigham’s work on diversity, equity, inclusion and access programs [visit the website](https://www.massgeneralbrigham.org/en/about/diversity-equity-and-inclusion).

*Tim Sullivan is Director of Communications at The Spaulding Rehabilitation Network.*

**Building Financial Security with Accessible and Affordable Housing**

**By Sandy Alissa Novack**

Over the past few years, there have been many articles written about people who owned a house or condominium and saw the value of their property increase considerably. The articles made the point that owning property is a major way to build wealth over the decades. Some people in the disability community have been able to own property, and perhaps build a nest egg for themselves and their family, but this isn't the experience for the majority of people with disabilities.

Most homes on the market are not accessible to people who use mobility equipment or have other disability related needs. Some of our disabled peers are fortunate to own their own accessible home, which was made possible by using their own sweat and ingenuity to renovate an existing home. Two examples are:

**Tina Pederson**, former Ms. Wheelchair Rhode Island, who renovated an old house in Rhode Island to make it accessible with the help of Habitat for Humanity and its community of volunteers. Her story was featured in [*Disability Issues*, summer 2021](http://disabilityvisibility.com/blog/wp-content/uploads/2021/07/DI-2021-Summer-PDF-Vol.41-No.3.pdf).

**Ray Glazier**, fellow *Disability Issues* editorial board member, was able to buy and renovate a home by using the small cash settlement he received from his injury lawsuit. His father, friends and PCAs did a significant amount of the renovations. His story was featured in [*Disability Issues*, fall 2018](http://disabilityvisibility.com/blog/wp-content/uploads/2014/06/DI-2018-Fall-PDF-Vol-38-No-4.pdf).

What if, now stay with me here, what if more people who identify as needing accessible housing had the opportunity to buy a condo or house and building equity to achieve some degree of wealth? What if *you* could do what folks who do not need accessible housing can do: go to open houses and choose which neighborhood you wanted to live in? Isn't that part of the American dream to own a home of your own? Why can't more people who need accessible homes share in that dream?

This past June, the Real Estate Section of the Boston Globe featured a 3-bedroom, 3-bath, 3-fireplace, 2-garage ranch-style house in Hopedale, MA. The house was originally built decades ago but was recently gutted and rebuilt so one could “age in place,” the article said. The asking price was $854,900. My first thought was “ouch” because of the price. My second thought was, who needs three fireplaces? But my third thought was my favorite. As I continued staring at the outside of the house, I noticed the house was on a significant piece of land, but there was zero landscaping. I thought about that land being like a blank canvass where an artist could create what their imaginations could envision.

So here is my vision. Instead of gutting an old house and re-building it to be accessible, I would put multiple smaller one-story ranch houses on the lot, each one fully accessible. A smaller house would have a smaller asking price. Owners of smaller houses built on one piece of land could share the cost of snow shoveling walkways and driveways, mowing the lawn, raking leaves, plumbers and other needed handymen for maintenance and repairs. This would be especially beneficial if disabilities limit the occupants' abilities to do these things themselves. Just as important, it would be nice to have neighbors with various disabilities for friendship and support, an instant community right outside their doors. We need more contractors building accessible apartments, houses, and condos. We need these homes to be reasonable in price and size.

At a recent Massachusetts State House hearing, I heard a state representative say that only 5% of housing nationally is accessible. At that hearing, I gave testimony on the need for accessible and affordable apartments. All communities need this type of housing, but why do we only focus on apartments or nursing homes for people with disabilities? Shouldn’t more of our peers have the same opportunity as others do for building wealth by owning a home? Some may have relatives who can contribute to down payments, others may have a job with high enough earnings that they can afford to buy their own home.

Many non-disabled people buying homes for the first-time avail themselves of housing counseling. Why can't the disability community offer housing counseling with the twist of addressing disability concerns and support to find subsidies for ramps and other home needs?

Let's push for more, many more, options for accessible housing at various levels of affordability for the thousands of Massachusetts citizens with disabilities who need it. Envision the possibilities and share your ideas with your local Center for Independent Living. Let's see what our communities can build. When people are running for election, tell them you will consider voting for them if they support building apartments, condos and houses that are accessible and affordable-at-all-price points. If your legislators are already in office, scrutinize what, if anything, they have done in the state to help you have secure, accessible, affordable-to-you homes. Tell them your housing story and what you need and want. Engage them to make your vision of a true home become a reality.

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**THE PCA CORNER**

**PCA Wage Increase Campaign and Programmatic Changes**

**By Charlie Carr, as told to Ray Glazier**

For this column I turned to disability activist and consultant Charlie Carr for commentary on three very significant changes in the MassHealth PCA Program that is so important to us. Readers will remember Charlie as the former Commissioner of the Mass. Rehab. Commission and currently a legislative liaison for the Disability Policy Consortium. But I remember Charlie best as a fellow patient on the White Nine rehab unit at Mass. General Hospital eons ago.

Charlie, I want to focus on efforts you are advancing with the Boston Center for Independent Living, the Disability Policy Consortium, and others to get PCAs $25.00/hour. I want to hear all that you have to say about that and what readers of *Disability Issues* can do to help, given that Bureau of Labor Statistics data show that animal caretakers have a median hourly wage that is 6.5 percent greater than that of personal care providers. During our conversation, I’d also like to get your take on two other PCA Program developments.

**Ray Glazier (RG):** Please outline the PCA wage increase campaign. What will its success require? How do we get there? What can readers of *Disability Issues* can do to help?

**Charlie Carr (CC):** Many members of the disability community have worked with SEIU, the PCA union, pushing for a base rate of $25. This isn't just a number pulled from thin air. A wage of $25 per hour is competitive with giants like Amazon, Walmart, and McDonald's, who are now drawing in PCAs because of the poor pay. If you are a PCA consumer employer or surrogate and are wondering why it's so hard these days to find PCAs, this is the reason. PCAs and potential PCAs are simply following the money, and no one can blame them because they have families to feed and bills to pay.

The negotiations for the PCA pay rate are still ongoing, and we have the opportunity to weigh in. Please call the Governor's office at 617 -725-4005 today and tell your story and demand $25 per hour just to survive in the community. Governor Healey made a campaign promise to support the PCA program and now is the time for her to make good on that promise.

**RG:** As a PCA Program consumer who is quadriplegic and requires nighttime care, do you have concerns about the consolidation of day hours and night hours? What are your thoughts on this?

**CC:** MassHealth has decided to eliminate the category of Night Time Attendant (NTA) hours and just use all regular hours throughout the day. For many this seems like a good idea. But not for people with complex disabilities who require nighttime assistance for brief interventions like taking medications, repositioning, hydrating and other tasks that may take less than an hour but still remain critical to a quality of life.

What this change does, by eliminating NTA hours, is remove the provision that a PCA can come in often during the middle of the night and provide the services that are generally short term and still get reimbursed for a full two hours. That pay provision makes it reasonable for a PCA to travel to the consumer’s home for a brief service period.

This has been the practice for decades and now that's about to change. This is deeply concerning and makes it nearly impossible to find PCAs who will come in at that hour, provide this service and only be paid one hour or less. I feel this must change back to the previous practice of paying for a full two hours, regardless of how much time was actually spent with the consumer employer.

**RG:** You led efforts to head off implementation of Electronic Visit Verification (EVV) in MA. MassHealth recently unveiled its schedule for gradual introduction of EVV. Did the Resistance campaign, ultimately unsuccessful, secure any concessions from MassHealth and, if so, what were they?

**CC:** EVV is rolling out as this newsletter goes to press. Many of us have spent years fighting the implementation of EVV but have been unsuccessful. But what we did accomplish in Massachusetts was to have the least invasive EVV system with the ability to travel in the community outside of the home and not be tracked. When we look at other states, the systems in place are very punitive and restrictive. Every moment of every day is followed by GPS or other forms of biometrics like facial recognition etc.

We are seeing serious consequences: People who have been living in the community with PCAs for decades are forced to go into nursing homes because they can't comply with restrictive requirements and can't get PCAs who are willing to be tracked. I fully expect we'll see problems here in Massachusetts as the rollout reveals difficulties navigating this system.

Furthermore, we are going to request that MassHealth share how much in funds they've spent to date on the EVV system and what has been collected in fraudulent billing, given that this is the stated objective of EVV. It is widely anticipated that the cost of EVV far surpasses any money that a state has recouped due to fraud or abuse. We've seen this in Texas, where the implementation costs of EVV are astounding. Basically, the end doesn't justify the means.

*Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA consumer who has studied PCA issues for decades. He is currently founder and Principal of disAbility Research Associates in Belmont, MA. Contact Ray at* *RaymondGlazier@gmail.com* *with questions, comments, or suggestions for future columns.*

**Disability Ingenuity**

**By Penelope Ann Shaw**

In December 2021, I was eligible for MassHealth to pay for a new electric wheelchair. I provided the specs from the 2016 chair I was using to the company who was building the new one. The new chair was delivered in October 2022. There were several problems with it: the controller was too far down on the armrest and difficult to reach; the joystick was loose and needed reprogramming; the back was very painful; and the overall height of the chair was a few inches higher up, making for a steep unnerving angle when going down inclines.

There was one extremely dangerous problem that I was most concerned about: the bars on both sides of the chair connecting the seat to the footbox were lower than on my previous two chairs. When I tilted the chair back to slide down to reposition myself both knees bent and slid right and left over the bars. Then, when I sat back up – little by little – both my feet slid off the footbox, which was a safety issue.

Technicians from the company came and fixed the easier problems – controller location and joystick reprogramming. Sometime later the company notified me that they had mistakenly put the wrong back on my chair, so they came and put the right one on, eliminating the pain. Regarding the height of the bars, the technicians told me the chair was built according to the specs I gave them, the ones that were used for my 2016 chair, which did not have this problem. They wanted to use a knee adapter for my right knee to keep my knees from bending. This wouldn't have worked because I need something on both bars to give them greater height. The technicians told me they did not have any parts like I was requesting.

I sought legal advice. A lawyer who represents people with disabilities took my case and told me she needed a physical therapist assessment. I had an assessment via Zoom with a PT who saw the problem. Later, the lawyer told me she also needed an in-person PT assessment to know what changes she should ask the company to make. I couldn't find a PT who could come to me. Nor could I take my new chair in a van to the office of a PT because my legs would very likely slide off the footbox, which was a safety risk. My lawyer continued to work diligently trying to help me. She had in-person meetings with technicians from the company and consulting with our local Independent Living Center.

By March 2023, I'd had several police and pedestrian assists. Some of these individuals actually put my feet back on the footbox and even accompanied me all the way home to make sure I was okay.  After these incidents I felt too frightened to take my chair outside, so I stayed in. Restless and frustrated from being cooped up, I reached out to colleagues in the disability community for advice. A friend and colleague who also uses an electric wheelchair came to see me in person to understand the problem. She returned several times, sometimes bringing a friend to help her. Step-by-step, she worked through her ideas and succeeded in designing and building leg supports for both bars of my chair. With these supports are now attached to the bars. My knees are unable to bend, so my legs no longer slide off the footbox.

My friend liberated me. No one from the company, but rather a friend in the disability community freed me.

I can once again go outside. I can travel on the sidewalk, feel the sun and wind on my face, look at cloud formations. I enjoy people's gardens with beautiful flowers, stone walls, and sculptured bushes. I look at the architecture of churches with Greek columns and tall steeples. I ponder the history of our now-city, especially the historic birthplace of Sylvanus Thayer, the first Commandant of West Point, which was built in 1720.

Driving fast I have the feeling of real movement again. On my way to my destinations, I pass by people on the sidewalks who often greet me. I am once again part of our community. I go back to my local public library where I can use a computer that works properly and buy books to read from the book sale area. I can once again go shopping and have my toenails done at Nails and Spa.

People who know me ask me why they haven't seen me in a long time, and I explain to them what happened and that my friend gave me outdoor mobility, reentry into community life, a larger life space and I am no longer restricted. There are no longer barriers to the outdoors, except in bad weather.  Overall, being outside again has felt somewhat surreal, almost a culture shock. I experience seeing places I haven't seen in a long time as if I am seeing them for the first time, instead of just revisiting them.

Personally, I have been vindicated. From the beginning, I said that increasing the height of the bars on both sides of my chair would solve the problem. I feel my story exemplifies what we in the disability community know: those of us with disabilities are often the experts of our needs and how to get them met.

The parts my friend used to build the leg supports were “ingenious”, a word a mutual colleague used to describe her solution to my problem. Here are the materials she creatively used:

* 5.5” wide 1/4” wood
* Air Conditioner foam
* Pipe insulation
* Yoga pants
* Hot Glue Sticks
* Zipties
* Fray Check

Here is what my friend said about the process she used.

"Short version: I cut the wood to length and angled the corners near her armrests to transition it better. Hot glued it all together. Then zip-tied the supports to the frame of her chair so that no manufacturer warranty would be impacted. :) "

*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.*

**THE POETRY CORNER**

**Reflections**

**By Sandy Alissa Novack**

Passing by the hallway mirror

I see I am

Wearing double pandemic face masks --

The three-ply all cotton Klimt's The Kiss art reproduction mask

Holding closer to my face

The standard medical mask which is way too big on me, and which

Could

Make me incognito

Even to myself.

No wonder I am not ready to shed even one of the masks

Like so many in my community

Shed as soon as the public health emergency ended.

I passed through the world these past three years

Invisible to others.

This includes the bank that put up

Barriers

To narrow the line to the tellers,

Which prevented me from passing through

With my rollator walker.

On my way out, I complained to an employee who

Shrugged.

My walker wears no face mask

Yet so many avert their eyes from it

And me.

The chain grocery store

Said elders and people who are immune-compromised

Could

Be prioritized

In line to enter the store

When they were counting

How many people

Would be allowed to enter at a time.

The customer service man

Could

Only see my walker

And told me it isn't allowed in the store;

My “walker isn't sanitary.”

My walker is a big part of me.

I clean my walker

Every time I return from leaving home and

Often while still out and

About.

My walker is more sanitary than the feet of many of your

Other customers.

I will long remember

That your store referred to

Me

As unsanitary.

I

Do not want to shop your store.

For years and years I shopped a big-name pharmacy

But come the pandemic and shortages

Of products I needed and you sold me pre-pandemic,

You would not put aside some of your

Limited supply of what I continued to

Need.

“It is first come, first serve,” you said.

I remove my face masks when I come home and

Stare at the person in the mirror.

There are my eyes, my nose, my mouth.

I see my hair, my hair barrette, my glasses.

It is

I.

I remain myself when the face masks are removed.

That means

You do, too.

How can you forget

I am a human being

Who happens to have physical disabilities

When I don the face masks?

Oh. Now I understand better.

When I don the face masks I see

You.

I am protecting me from the covid that still circulates and sickens.

That you don't care about protecting me from when you unmasked

Prematurely for me and people like me.

I

Recognize you with and without your own face masks.

Too bad, too bad.

I recognize you

As you have been and are.

Ableist.

*Sandy Alissa Novack, MBA, MSW is a member of* [*Dignity Alliance Massachusetts*](https://dignityalliancema.org/)*, which has been trying to systemically support people with disabilities and elders who feel vulnerable now that a large part of society has stopped wearing their face masks with the end of the covid public health emergency.*

**Commentary from the poet:**

There remain many vulnerable people in our communities who still need to wear face masks to protect themselves since Covid continues to circulate. If you are one of them, know that you are not alone. You have the right to ask your medical team to put on masks when you go in for medical appointments. You can also try asking for reasonable accommodations to be safe as you go about your business in the community. Please stay current with getting the Covid vaccine and other vaccinations you are eligible for. And always, take care of your yourself.

**LOVE & INTIMACY CORNER**

**Are Relationships Possible If I Have a Disability?**

**By Ms. Love**

There are no simple questions or comments sent from readers to your Ms. Love, such as the question I received today, “How are relationships even possible if I have a disability?” In reflecting on her question, I thought about a YouTube video I listened to last year, “[Women Living Paralysis and Dating](https://www.youtube.com/watch?v=5InuhhSuFa8),” presented by the Christopher and Dana Reeve Foundation. The video is an open, honest panel discussion with four women who provide practical insights and advice to start or continue dating more confidently.

One woman in the video said she prefers meeting people in person and outside because she feels many people think people with disabilities do not go out. She also does online dating and describes her experience. “I take a picture of myself with my wheelchair showing. The people whose first question is, ‘Can you have sex?,' are not people I want to date...I started out online with a head shot, but when an in-person date was set up, they would ghost me...In addition to my photo of me with my wheelchair, I post pictures of myself parachuting and other active photos, so they know I am not interested in someone to take care of me...It is all about how you present yourself. I have gotten more confident, and if a date cannot see all that I am, it’s their loss.”

Another woman spoke about how she was married at the time of injury that left her paralyzed from the neck down, and her partner's comment, “What is the point of having sex if you cannot feel it like you used to?” was hurtful. She shared that her partner's perception was hard on her. “I practice trial and error now [to figure out what works for me], and my mind can do a lot.”

Another woman said she had a healthy sex drive before her injury changed her abilities. She indicated she can still have sex, but her sense of touch is different. So, she uses her other senses more because she says there are many other ways she can get turned on. She said she needs more foreplay now and is aware of more parts of her body, such as her neck, that can arouse her, and how she can get aroused cognitively.

Communicating with partners was key for all the women. “Dating,” said one of them, “Gives you the chance to weed out guys who are fake, who won't even approach me if they do not want to try to communicate with someone with a disability. Guys who do not listen and do not want to even try to do what I told them works for me, the relationship won't work, and I won't be turned on.”

Here are some things these women wish someone had told them about relationships:

* “Anything is possible. Don't ever let someone tell you that you can never have a relationship.”
* “I wish physical therapy/occupational therapy had told me that everything with sex is possible, you just have to try things differently.”
* “Don't take rejection personally. Change it. They reject me...they will miss out on my personality, my sense of humor.”
* “Rejection is hard, no matter what. Do not ever settle because you think you are disabled and won't get anyone better. You are worth it, go for the right person.”

Thinking about relationships from a male perspective, I recently read an article, “They’re Ready to Fight Again, on Artificial Legs,” *New York Times*, July 8, 2023, about male soldiers in Ukraine who had one or more limbs amputated. Many may think that once a soldiers’ limb(s) have been amputated they can’t continue fighting. The article talks about how some men intend to return to the war after rehabilitation. Yes, their assignments may be different, but that isn't stopping them from continuing to fight for their country, so they practice with their new prostheses and think about their futures. And they do have futures, including with their relationships. In the article one soldier’s wife shares her thoughts, “I do not see disabled people,” Oleksandra Kabanova said as she sat waiting for her husband, Oleh Spodin, to complete a physical therapy session. “I see superheroes…. He’s very sexy without a leg… People thought that girls would dump guys after their injuries,” she said fiercely. “No way! It doesn’t work that way.” This is an indication that having a disability doesn't mean you are undesirable.

What is possible for having a sexually satisfying relationship for those with disabilities? The key is tapping into the power of the mind and heart. In the TED Talk, “[The Relationship Between Sex and Imagination](https://www.youtube.com/watch?v=Z9zNFDR-OTU),” Gina Gutierrez talks about the power of imagination to enhance sexual satisfaction for all people – single or married, able-bodied or disabled.

Gutierrez says, “Sex is as much mental as it is physical. Imagination is the most powerful tool we have to expand our personal agency and capacity for pleasure.” She talks about how the brain is the biggest sex organ. “Women can turn themselves on with their thoughts because memories, fantasies, and focus matter. You can activate your own sexual imagination. There are thoughts that turn us on, but also thoughts that turn us off – stress, shame, insecurities, and the icky.”

Gutierrez advises people to imagine what gives them sensory pleasure, such as a smell that appeals to them. Imagine a kind of place such as a beach, and a person such as their girlfriend. She explains that “The more you flex this imagination muscle, the more you will understand what turns you on. A bigger definition of sex is that it is not just a physical experience, it is a mental experience...an avenue to an aliveness that contributes to your wellness...Let your imagination tell you a sexy story.”

In a nutshell, yes dear reader, it is possible to have a satisfying dating or married life and sexual relationship if you have a disability. I wish you all the best.

*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.*

**INFORMATION BRIEFS**

**GBH Presents: August Press Play Saturdays**

Watch episodes of the children’s animated series, *Arthur*, and learn about the importance of accessibility from a few of his friends! GBH is on the frontline on creating content for disabled kids and their family. Learn about GBH’s mission of inclusivity and accessibility.

**When:** Saturday August 26, 2023, 11:00 AM–12:00 PM

**Location:** *GBH Studio at the Boston Public Library, 700 Boylston Street, Boston, MA 02116*

[Register Here](https://www.wgbh.org/events/august-press-play-saturdays-in-person) for this **free** event!

Registration is appreciated but not required. Limited seating is available on a first come, first serve basis. If you require a seat, we encourage you to arrive before the start time of this event.

**PBS Disability Pride Month Documentaries**

In honor of Disability Pride Month to commemorate the passage of The Americans with Disabilities Act (ADA) that was signed into law on July 26, 1990, PBS is showcasing a selection of documentaries that look at the history of the disability rights movement and activists. Additionally, there are documentaries about artists and storytellers whose works explore the diversity of disability experiences.

Click [here](https://www.pbs.org/articles/disability-pride-month-and-the-disability-rights-movement/) to access the following documentaries:

**The Gang of 19** - Encouraged by civil rights movements of the 1960s, the Disability Rights Movement gained momentum leading to the passage of the Americans with Disabilities Act in 1990. Decades earlier in 1978, 19 individuals tossed aside their wheelchairs and blocked city buses deemed inaccessible for the physically disabled. Discover how this one act led to years of advocacy in Colorado and inspired the nation.

**Wonderfully Made**: Kashmiere Culberson is a recent college graduate who embodies strength and confidence. Kash does not allow her disability to limit her pursuit of happiness and self-love.

**Eat Your Catfish:** Paralyzed by late-stage ALS and reliant on round-the-clock care, Kathryn clings to a mordant wit as she yearns to witness her daughter's wedding. Drawn from 930 hours of footage shot from her fixed point of view, Eat Your Catfish delivers a brutally frank and darkly humorous portrait of a family teetering on the brink, grappling with the daily demands of disability and in-home caregiving.

**Creating an Inclusive Richard III**: In a July 2022 performance of Shakespeare's tragedy, *Richard III,*The Public Theater chose to stage a show that truly centered inclusivity and diversity. In a behind-the-scenes interview, Danai Gurira, Ali Stroker, and Monique Holt discuss how director Robert O'Hara prioritized diversity and inclusion in his production.

**All Riders**: Visit public transportation from the perspective of disabled riders in this short film from Victor Dias Rodrigues. The subway makes New York City tick, but getting around is a constant battle for disabled New Yorkers.

**The Beautiful Colors of Jeremy Sicile-Kira**: Jeremy Sicile-Kira uses painting to transcend his disability and communicate his dreams to others.

**Sensorium: The First Twenty**: Visionary composer Paola Prestini explores the intersections of disability, artificial intelligence and voice in an experimental multi-sensory opera with choreographer Jerron Herman and poet Brenda Shaughnessy. This version of the video includes ASL and captions.

**Subscribe to *Disability Issues***

Disability Issues is available without charge to anyone who finds it useful and interesting.

To subscribe and view Disability Issues on-line go to [www.disabilityvisibility.com/resources/disability-issues](http://www.disabilityvisibility.com/resources/disability-issues)

Or call 617-952-6927/voice or email cmmoran@partners.org