***Disability Issues***

**Vol. 43, No. 2**

**Spring 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).

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**From the Editor:**

Dear Readers,

In this issue, there are multiple articles about disability advocacy from various perspectives. In this letter from the editor, I’d like to talk about the part of advocacy that is education. Sometimes it happens spontaneously during a simple interaction with another. Recently, I was excited to attend an open house for a new cohousing facility that was built using universal design. During a tour, the tour guide proudly said a resident who is “wheelchair bound” can access all parts of the facility. I replied, “She is a wheelchair user, not wheelchair bound.” The tour guide appeared flustered and apologized for not knowing the correct language. I hope this interaction creates a lasting change.

As persons with disabilities, we often find ourselves educating those who are temporarily able-bodied, which is beneficial – up to a point. There comes a time when it’s important for those who are able-bodied to take responsibility for self-education, rather than expecting those with disabilities to be their educators. An abundance of resources are available to improve one’s knowledge about disability language and ableism. In the town where I live, I am involved with local organizations who are committed to advancing equity and inclusion for all. I am often the person these organizations ask to represent a disability perspective. After years of being an educator, I am starting to point people to educational disability resources.

A long-time member of one local organization recently asked me to write a disability-focused piece for their column because she said, “I for one do not even know if I am using appropriate and inclusive language in discussing [disability] challenges.” I couldn’t help but think that after all these years, there is still reliance on having someone who she referred to as an “expert” write the column, so I pushed back. I sent her some disability resources and asked her to write a first draft because, “as a non-disabled person, writing the article is an invitation [for her] to dig a little deeper to use disability inclusive language and understand challenges.” I offered to review what she wrote and provide comments. My intention is to support her (and others) self-education process instead of continually being relied on as the expert educator.

I’m sure each of us have our favorite disability education resources. Here are two of mine: the book, *Demystifying Disability* by Emily Ladau, disability rights advocate, speaker, and writer. And an article on intersectional oppression and able-bodied supremacy, “[Disability Justice – in the Workplace (And Beyond)](https://nonprofitquarterly.org/disability-justice-in-the-workplace-and-beyond/?mc_cid=27b09efcbd&mc_eid=7363e06858)” by Sonia Sarkar, published in *Nonprofit Quarterly*.

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.

**THE PCA CORNER**

**Pulling Back the Curtain: Life Before the PCA Program**

**By Ray Glazier**

More than one reader of this column has expressed an interest in the background of the columnist. Previously I have shared with readers of *Disability Issues* my life-changing experience of acquiring multiple disabilities, ‘[Formerly Clueless: A Disability Saga](http://disabilityvisibility.com/blog/wp-content/uploads/2020/01/DI-2020-Winter-PDF-Vol.40-No.-1.pdf)’, published in the Winter 2020 issue of *Disability Issues*. But this column will chronicle my PCA experiences. In particular, what life was like before the PCA Program was in place to support people with disabilities.

When I was seriously injured in a car crash at 26, I was very fortunate in three important respects: (1) I had already completed my undergraduate education and had my B.A. degree, (2) I had a great job with an exciting startup company, and (3) I was already married to a lovely, loving college classmate. But at the time there was not much precedent for someone with my care needs to live in the community – no PCA Program, no Centers for Independent Living, no Americans with Disabilities Act – not yet. Luckily for me, disability life was on the cusp of a monumental change, thanks to the tireless efforts of advocates like Ed Roberts and Judy Heumann, but it hadn’t changed yet.

When I returned to the office after seven months of hospitalization, my enlightened employer hired a former hospital worker to provide the help I needed to function in the high-pressure consulting firm. Years later the company would hire my home PCAs to help me part-time during working hours, paying them the prevailing PCA Program hourly wage, and letting them hang out in the vacant office next to mine.

My primary day-to-day caregiver was my wife, which turned out to be great mistake. She gave up and left me after three years of struggle. I quickly came to two realizations: (1) Caring for a quadriplegic while managing a household was more than a one-person full-time job, and (2) The empty bedroom in my apartment was an invaluable asset in attracting caregiver candidates. I resolved to always have more than one caregiver and to look for live-in folks who appreciated the rent-free housing that I was able to offer. As a single guy, I have always managed to have a home with more than one bedroom.

My first live-in caregiver arrangement after my divorce was with a married couple who responded to my newspaper ad; they were bluegrass performers who had landed a low pay extended gig in Boston. But Will and Fern soon found it difficult to keep up with taking care of me and the apartment in addition to their nightly performance schedule. So I moved my bed into the dining room in order to free up another bedroom and took in Harry and Steve, unemployed friends of a fellow quad I knew. But the hetero couple and the gay couple were soon fighting over whose crabs were on the toilet seat. After the situation devolved into complete chaos and everyone moved out in a huff, a young friend came to my rescue and served a stint as volunteer PCA while I renewed my recruitment efforts. I took out more ads, posted flyers, and spread the word to everyone I knew.

Eventually I found Sam and Sally, a premed undergrad couple with an elderly, yappy little terrier. They helped me move into the two-story single-family home I bought using funds from the auto accident lawsuit. They moved into the upstairs and I made the downstairs den my bedroom / office / rec room. Unfortunately, the move had interfered with their heavy class schedule, and Sally complained that she was being kept awake by the rumble of late night trains passing on the nearby commuter rail tracks. Having grown up in a tiny town bisected by the Pennsylvania Railroad, I was unperturbed by train noises in the night. But for this young student couple it was a deal breaker – How could they focus on studying organic chemistry in these conditions?

The next couple was a Museum School nude model and his girlfriend; he said he had just left Bridgewater State, the University I was led to assume. It turned out that he had just been released from Bridgewater State Hospital, a medium security state correctional facility. They were doing OK for me as PCAs and I was desperate at the time, so… Then my MasterCard statement came in the mail, and I spotted a blatantly bogus $80 mailorder charge that I could ill afford. "I was desperate!" said Bob when confronted. “You were that desperate for two ounces of anti-baldness potion?" "It's very important in my line of work to have a full head of hair."

About this time, I learned of the MassHealth PCA Program and my eligibility for it as a working person with a disability, even though my salary meant that I was otherwise not eligible for MassHealth, the Commonwealth’s Medicaid program for the impoverished. This so-called ‘Medicaid Buy-in,’ now operational in most states, had been created to address the reality that employers’ health insurance programs refused to cover PCA services needed by many workers with disabilities now joining the labor force. My personal and professional life began to converge as I became the resident expert on Medicaid Buy-Ins within the Health Policy group of the consulting company I worked for.

The Pennsylvania Department of Public Welfare reached out to the company, and to me in particular, for consulting help. Savvy consumers were suing the department over the lack of a Medicaid PCA program that would complement the solely state-funded Attendant Care Program. Such a jointly state and federally funded program could, the lawsuit claimed, expand PCA services and reduce the long Attendant Care Program waiting list. The first thing I told this potential client was that these vocal consumers and their lawyers were spot-on. Under contract to the PA DPW, I directed a three-year effort to design and implement the Pennsylvania Medicaid Waiver Attendant Care Program.

This and other disability-related research projects over the years required travel around the country. Sometimes I flew solo, making advance arrangements for on-site care with local PCAs who I first met when I got off the plane. Other times my home PCAs or junior staff members from the company traveled with me in exchange for a daily cash honorarium.

I hope this summary of my PCA experiences sheds some light on how monumental the PCA Program is for promoting independence and well-being for people with disabilities. Advocacy to maintain and enhance this program is essential. Let us all use our power and influence to continue improving the services for people with disabilities that advocates like Ed Roberts and Judy Heumann began.

To read more about Judy Heumann, *Disability Issues* published a review of her memoir, [*Being Heumman: An Unrepentant Memoir of a Disability Activist*](http://disabilityvisibility.com/blog/wp-content/uploads/2021/05/DI-2021-Spring-PDF-Vol.41-No.2-PDF.pdf) in the Spring 2021 issue.

*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.*

**A Woman of Valor: Arlene Germain**

**by Sandy Alissa Novack**

I recently had the privilege of interviewing Arlene Germain, co-founder of [Dignity Alliance Massachusetts](https://dignityalliancema.org/). The following interview has been edited to fit in *Disability Issues*.

**Sandy Novack**: Arlene, please tell us your first introduction to concerns about disability and aging.

**Arlene Germain**: I always had an affinity for older folks, mostly because of my relationship with my grandmother. When I was about 8 years old, my grandmother moved in with my parents and me after my grandfather died, and I shared a bedroom with her for several years. Sadly, my grandmother developed dementia, but we continued to have a close relationship, even when she eventually withdrew.

Both my parents had strokes later in their lives. My mother's stroke destroyed her short-term memory, so she could not be left alone. My father took care of her for years until he died suddenly. I was able to keep my mother in her home with caregivers for a few years, but eventually I moved her to a nearby non-profit nursing home. I visited her several times a week, mostly late at night since I often worked overtime, plus my mother and I were always night owls. What I witnessed during late night visits and when I stayed overnight when my mother was dying was an eye opener.

Over the past 20 years, seven of my family and friends have lived in nursing homes. Sadly, I have witnessed poor care and many injustices, not only to my loved ones, but to other nursing home residents. My loved ones suffered dehydration, malnutrition, over-drugging, aggression by another resident not addressed by the facility, intimidation by staff, bed sores, and many unnoticed health needs. They suffered inadequate care despite the efforts of many dedicated certified nursing assistants (CNAs). No matter how hard the CNAs tried to provide good care it was impossible because they were constantly under-staffed.

Witnessing the suffering and injustices my loved ones endured, and so many more residents still endure, is the reason behind my advocacy work.

**SN**: Can you tell our readers more about your advocacy work and how you got started?

**AG**: Because I saw many injustices, I called AARP to ask who was advocating for nursing home residents. They put me in touch with the National Consumer Voice for Quality Long-Term Care in D.C. I attended their annual conference and learned about [Family and Resident Councils](https://manhr.org/essential-information/managing-the-experience/family-and-resident-councils/), which advocate for residents nursing homes. I started a family council at my mother's nursing home. Over the years, I served several terms on the Consumer Voice Board.

In 2000, Greater Boston Legal Services attorney, Kathy Fitzgerald, was visiting family councils around the state to educate them about a bill to increase CNA wages. She noticed that the councils didn't know about one another, so it was her idea to link them up which was the beginning of the [Massachusetts Advocates for Nursing Home Reform](https://manhr.org/) (MANHR).

Kathy and her supervisor, Attorney Wynn Gerhard, ran MANHR and I was one of several co-founders. MANHR's goal was to advocate for improvements in the care, dignity and quality of life for Massachusetts nursing home residents, including supporting family-run councils. In those early years, we assisted nearly 30 family councils. MANHR's first initiative was supporting family council legislation. In 2004, Massachusetts became the third state in the country to enact family council law (MA General Law Chapter 111 Section 72Z, Circular Letter).

When Kathy moved out of state in 2004, I assumed a leadership position for the duration of MANHR's existence. MANHR achieved 501C-3 non-profit status in 2006 and was an all-volunteer organization until MANHR received a grant in its last two years of operation to hire an Executive Director, Alison Weingartner. For more than 20 years, MANHR represented Massachusetts nursing home residents and families as the only long-term care consumer advocacy organization in the Commonwealth. MANHR had a seat on nearly 20 statewide coalitions/committees and was sought after by local, national and international media for advocacy comments.

In 2022, as part of my legacy before retiring, MANHR merged with [Dignity Alliance Massachusetts](https://dignityalliancema.org/) as an educational branch. MANHR's website continues to be available as a resource.

**SN**: Arlene, can you say more about what Dignity Alliance focused on when the organization was first formed and what your roles were? (Full disclosure, I am a member of Dignity Alliance Massachusetts.)

**AG**: Dignity Alliance's first initiative involved protecting nursing home residents from being forcibly moved to other facilities to make room for COVID patients who were being moved out of overcrowded hospitals. To stop this unjust practice and find another solution to hospital overcrowding, Dignity Alliance wrote letters to Governor Baker and other officials, and published a letter to the editor in the Boston Globe. We were successful and other venues were found to care for COVID hospital patients. Throughout the pandemic and as its ongoing mission, Dignity Alliance strives to help elders and people with disabilities in the community and in long-term care facilities.

I am a co-founder of Dignity Alliance, a Board member, and Coordinating Committee member. I also lead the Nursing Home Facilities Work Group, which addresses nursing home issues. I have to say it is hard to retire. I want to support Dignity Alliance through some of the current legislation issues. We are at an important juncture with nursing home finances. Advocates have been working for decades to increase transparency on how nursing homes spend the billions of Medicare and Medicaid dollars, and now real progress is possible with potential national and state transparency ownership requirements.

**SN**: Has your attitude about aging and disability changed as you contemplate retiring?

**AG**: All my life I have valued relationships. Life is precious and it is important to live the way one wants to. Aging definitely gives us a wider perspective on life.

**SN**: When you look back at your life, can you tell our readers what being devoted to advocacy for elders and people with disabilities has meant to you?

**AG**: I have cared for many relatives and friends in nursing homes. I feel that my efforts honor them and, hopefully, have made an impact to enhance the lives of all nursing home residents. I feel good about turning over a body of advocacy work to Dignity Alliance to strengthen their efforts. Advocacy is definitely a journey, and I am glad MANHR's journey continues through Dignity Alliance.

**SN**: What advice do you have for elders, younger people with disabilities, their families, friends, and caregivers going forward? What words of mission, hope, and inspiration do you want to pass on to our readers?

**AG**: Advocacy is not easy. It is emotional, requires strength, and it takes years. But there are a lot of people behind you, so never give up!

My partner, Ellery Schempp, is a physicist and an advocate. He started advocating when he was 16. He lived in Pennsylvania and protested mandated Bible reading in public schools, because he thought it wasn't right that his classmates and friends of different religions were forced to read one Bible chosen by the state. His protest turned into a 1963 landmark Supreme Court decision responsible for eradicating Bible reading in public schools. We are both advocates, and we understand about standing up for what matters.

[Dignity Alliance Massachusetts](https://dignityalliancema.org/) welcomes volunteers for its various work groups and endeavors. Please visit their website for more information and to join with others who are standing up for the dignity of people with disabilities, elders, and their caregivers.

*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.*

**Challenges I Confronted Getting My Rights Under the ADA**

**By Penelope Shaw, PhD**

Disabled from Guillain-Barre Syndrome, I have both lower and upper extremity impairments. I use an electric wheelchair because I cannot walk. Both my fingers and hands are contracted. My shoulders do not work, so I am unable to raise my arms.

In 2018 I was one of four plaintiffs in a Title II lawsuit who was trying to get my unmet rights to access as a person with a disability provided in my town. We sued Braintree, Massachusetts for noncompliance with the ADA.

We alleged multiple violations including a rear-entry ramp access to Town Hall, impassable sidewalks, dangerous curb cuts, inaccessible businesses, and inaccessible paths and playground equipment.

As plaintiffs we were represented by a team of lawyers and advised by an expert witness knowledgeable about the ADA and the rights of persons with disabilities. We filed our lawsuit in the U.S. District Court Boston. We went to mediation, but we were not satisfied with the outcome. Finally, in 2020 we signed a settlement agreement which has actually yet to be fully implemented because of the pandemic.

In the meantime, I continue to encounter access barriers, such as an extremely dangerous steep immediate-turn curb cut onto a sidewalk which I feel unsafe using so I drive in the street instead. Once a police officer saw me go onto this street and yelled at me for not taking the sidewalk, claiming the sidewalk was safe. I knew better. Using the curb cut might cause my wheelchair to tip and possibly be injured. In my local neighborhood, I must drive in the street when trash cans block sidewalk, which may have been put out too early or left out, emptied, longer than they are supposed to be on trash day.

There are inaccessible businesses in our town. Some in a small plaza at the top of a ramp which is too steep to safely drive up. At another location, there is a business I would like to frequent that is at sidewalk level but can’t because stairs in the front block access. Also, the button you ring to request service is inaccessible.

A second place I sought ADA accommodations was at a prestigious Boston hospital where I am a patient. I needed communication accommodations because of my upper extremity impairments. For me, the hospital's online portal is unusable. With overlapping fingers, I make numerous mistakes, and unlike in email, in the portal I cannot forward what I am typing to myself as many times as necessary to make corrections before sending.

I cannot easily make phone calls because I am unable to raise my shoulders. Instead, I must use my right shoulder to hold a phone up to my ear and mouth. I do this only rarely and briefly because it's painful. On one winter day, for example, I used my elbow to call 911 to ask the fire department to come rescue me because my wheelchair was caught on ice on a sidewalk.

Since my fingers overlap and my hands are contracted, I cannot use a smartphone because it’s too wide for me to grasp and also too slippery. Instead, I use a flip phone with a keypad. I made it clear to my physician that I cannot open links on my flip phone. But I continued to receive messages from her office staff with links that I could not open. I made a request of my physician to use email for communications but at first that failed. I then contacted the Disability Program Manager in the Office of Patient Advocacy. I asked to use email for communication as an ADA accommodation since I cannot use the online portal or make phone calls. I was told that the hospital does not permit the use of email because it’s not considered secure. The manager offered to assist me with making appointments, but I needed more than this.

During this process I received a several-page letter with guidance about communicating which I was to agree to. It included that my physician would email me if the messages were brief. But the letter also had four examples of when I would have to call her office, which I am physically unable to do. So, I didn’t sign or return the letter as instructed. The Disability Law Center (DLC) in Boston was interested in looking at my case. But, in the end my primary care physician agreed I could email her, so I did not ask the DLC to intervene.

My physician later scheduled a telehealth call, informing me that she would send an email with a Zoom link for it. But her office staff was not told that the appointment would be virtual. I received a text message on my flip phone from them with a link to open and check in to the appointment. I couldn't open the link. I then received a voicemail from her office about what would be involved for my in-person check-in for the appointment, when it would actually be virtual. After the appointment I received a letter in the mail from her office saying I'd missed the appointment which was not true. The challenges were endless.

As we know the ADA requires healthcare providers to accommodate the individual needs of persons with disabilities including communication ones that work for the individual. This experience of what I confronted at a major Boston hospital validates the research of Dr. LisaLezonni, a professor at Harvard Medical School, about how accommodations for patients with disabilities do not come easily, and sometimes are not even provided.

The above are just two examples of the many challenges I have as a person with physical disabilities trying to get my rights under the Americans with Disabilities Act. It is often not easy.

*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*

**We Have a Right to be Safe**

**By Shirley Paceley**

We cannot solve a problem that we are not brave enough to talk about. The problem is this: People with disabilities experience sexual violence more often than people without disabilities 3 to 7 times more often.

**What is sexual violence?**

Most people think that sexual violence is rape, but it is much more than that. Anytime someone uses their power and control over another person through unwanted or harmful sexual actions, that is sexual violence. It can include things like forcing someone to listen to or watch something sexual without their consent. Coercion can look a lot of different ways, from physical force to verbal threats and manipulation.

**What can I do if I am a survivor?**

If you are a person who has experienced sexual violence, please know that you are not alone, and it was not your fault. If you are having difficulties because of this trauma, there is help available. See the resources at the end of this article.

**People with disabilities can be (and are) part of the solution!**

People with disabilities are smart and capable and strong! We know best what needs to happen so we can be safe and so we can access victim services. People with disabilities are leaders in the movement to end sexual violence against people with disabilities. Here are a few of the things we have done to make changes:

* Work on policies and procedures in disability agencies.
* Teach classes on healthy relationships.
* Speak at conferences about sexual violence.
* Make videos to train parents and staff and victim services.
* Testify for changes in laws that are good for survivors.
* Speak at Take Back the Night Events.
* Work or Volunteer at Rape Crisis Centers.
* Work with teams of people to make systems changes that are good for survivors.
* Be part of Ad Campaigns.
* Help a friend who is being bullied, threatened, or touched.
* Speak Up about your rights to be safe.
* Train law enforcement

I wonder, what you might want to do to help end sexual violence against people with disabilities?

**Where you get help if you or a loved one is being (or has been) sexually victimized?**

Rape Crisis Centers offer free and confidential help. You can get their services even if the violence happened a long time ago. You can also receive services if someone you care about is victimized. It is okay to ask for help!

* [**RAINN**](https://www.rainn.org/about-national-sexual-assault-telephone-hotline) (Rape Abuse Incest National network) is a National Sexual Assault Hotline that is confidential and available 24/7. Call **800-656-HOPE (4673)** to be connected with a trained staff member from a sexual assault service provider in your area.
* Listing of locations and contact information for [**Rape Crisis Centers in Massachusetts**](Rape%20Crisis%20Centers%20in%20Massachusetts)**.**

You can learn more about this subject in ***SHINING A LIGHT: Creating Pathways to Equity, Safety, Healing, and Justice With People with Disabilities*** by Shirley Paceley, which is available on Amazon, in print and Kindle formats, and also available at BookShare (for readers with print disabilities).

*Shirley Paceley began her work with people with disabilities in the early 1970s, and quickly became aware of rampant abuse and neglect. She has trained thousands of people on effective strategies for trauma-informed responses that support survivors with disabilities and hold offenders accountable. She is a visionary: a disability rights activist, consultant, counselor, international trainer, and published author.*

**LOVE & INTIMACY CORNER**

**When You Lack Disability Clarity, Go for Graciousness**

**by Ms. Love**

Recently, I was in line at the grocery store, sitting on the seat of my rollator walker with a basket full of produce. Only one check-out lane was open, and it was the one with a sign indicating it was the accessible check-out. There were a few people in line in front of me – one had a large shopping cart full to the brim with groceries and three more had a medium amount of groceries. I knew the line wouldn't move quickly. It was taking longer to check-out than it did to shop. The line slowly inched forward, meanwhile five more customers got in line behind me.

As the customer in front of me began putting her items on the cashier’s conveyor belt, I felt a presence to my left and glanced over. A man with a full-size shopping cart was angling in behind me. I told him the end of the line was behind me and to the right. In an angry tone, he bluntly said the check-out lane is for people with disabilities and since he has a disability he can cut the line and go next. Of course, I had been waiting in line for over 20 minutes, leaning heavily on my walker because it’s hard for me to stand. I told the man he could see that I too have disabilities, but it doesn’t give me the right to cut in line.

Then it was my turn to load my groceries on the conveyor belt. The man moved in right behind me, and the young couple who had been in line behind me let him. He never asked the couple if he could cut the line, and the couple never spoke up and said he couldn’t. Since his tone was angry and his manner was defiant, the couple may have been afraid to say anything.

As I walked home with my bag of groceries on my walker seat, I kept thinking about my check-out experience. Yes, there is lane for people with disabilities that is wide enough to easily accommodate a wheelchair or walker, but people without disabilities can also use that lane to check-out. This is especially true if it’s the only lane open because the store is short staffed. Sure, you can ask someone if you can go in front of them, but I don’t think the accessible check-out sign means that someone with a disability is automatically able to cut the line.

As I continued walking home, I recalled a time a few years ago when I was using a cane. I was on the subway, and it was a hot day. Passengers who looked able-bodied were sitting on seats with priority for those with disabilities, so I was standing. Despite seeing that I was using a cane, no one offered to get up and give me their seat. Due to the heat, I suddenly felt like I was going to collapse. I told the young man sitting in a seat with priority for the disabled that I was not feeling well and asked if he could get up so I could sit down. He quickly got up and moved further back into the subway. I felt much better sitting down until it was my stop to get off and go home where I could rest.

While I am a strong advocate for disability priority, I wonder about the man at the grocery store who cut in line without asking the people who had been waiting in line for a long time if he could go in front of them. What does an accessible sign mean and how should people who need disability priority ask for what they need?

As a member of the *Disability Issues* editorial board, your Ms. Love did what she often does, I discussed my grocery check-out experience at our next meeting. Board members speculated on various possibilities of what the man’s motivation may have been. In the end, we agreed that people have different ways of acting and speaking up about disability related situations, including the couple behind me in line who let the man cut in front of them without saying anything to him. We also agreed that we didn’t know what the man in the grocery stores’ situation was or his level of ability to wait in line.

One editorial board member mentioned seeing a sign posted at an accessible parking spot at her local grocery store parking lot, “Customers with disabilities, please proceed to the front of the line.” There was no clarity on what line the store was referring to. Did it mean customers with disabilities could cut the check-out line? Maybe the man at my grocery store had seen a similar sign somewhere and thought it was okay to cut the line. The board member did say she thought the “proceed to the front of the line” sign was a vestige from the early days of the pandemic when there were often lines to enter the store because they were limiting the number of people they let inside. The main point is, people who see the sign can interpret it in many different ways because it’s not clear.

As part of our discussion on this topic, I mentioned a conversation I had years ago at my hospital when a staff person asked me when it was okay to use a bathroom accessible stall if you are not disabled? Some board members felt it was never okay and others said it depended on the situation. We all agreed that people with disabilities are not bathroom monitors and if someone is using the accessible stall – even if they look able-bodied – they may have a justifiable need for using the accessible stall.

There is a lack of clarity on who can use accessible restrooms, grocery check-out lanes, or dressing rooms in clothing stores. A board member said she sometimes she’s seen a group of teenagers using the larger accessible dressing room because they like to twirl around and comment on each other’s outfits. There’s also a lack of clarity on what to do if you have a disability and need to use the accessible dressing room. Do you knock on the door and ask them to leave – not knowing for sure if one of them has a disability – or ask a store employee to intervene, or just wait until they leave?

In the end, board members agreed there is a lot of complexity and confusion about how to interpret signs and various ways to act or respond. Given that, maybe we should give some grace to the man in my grocery store story, grace to the seemingly able-bodied person using an accessible restroom stall, grace to the person using the accessible dressing room, and anyone else. We all have our moments when we question why someone is doing something, but it isn't our job to police them. Since the signs sometimes confuse us more than help define their meaning, grace can be the path forward.

*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 BOOKSHELF**

**Children’s Disability Literature**

**By Mary Grimley Mason**

I recently wanted to buy a picture book for a friend’s grandchild and with the help of a children’s librarian found the perfect book. It made me wonder if there were equally charming books available for a child who had a disability and who might be embarrassed to read and see stories that made them feel excluded. With the help of another librarian, I found a large collection of children’s disability literature. Much of this bounty is due to the Schneider Family Book Awards given yearly since 2004 by the American Library Association (ALA). It recognizes “authors and illustrators for the excellence of portrayal of the disability experience in literature for youth.” It includes stories that focus on young children in grades one to three, middle grades and young adults. At least six awards are given each year.

The award was founded by Dr. Katherine Schneider, who was blind, and had been helped through school as a child by a librarian of the Michigan Library for the Blind who provided books in Braille for her. In founding the award, Dr. Schneider Intentionally allowed for a broad interpretation by her wording, the book “must portray some aspect of living with a disability whether the disability is physical, mental or emotional. The criteria emphasize “it must portray the disability as part of a full life, not as something to be pitied or overcome.”

The books fall into two categories: those that address a child with a specific disability such as impaired vision or loss of hearing and secondly, a more general group of books about being comfortable with differences in yourself or in others.

***My City Speaks*** by Darren LeBeuf and illustrated by Ashley Barron is an example of the first category. It is about a young girl, who is visually impaired, spending a day with her father in the city she loves. They travel to the places they go together: the playground, the community garden, the market, an outdoor concert.

As they go, the girl describes what she senses. The city “rushes and stops, and waits and goes.” It “pitters and “patters and drips and drains” It “echoes and trills” and

 is both “smelly and sweet.” Her city also speaks, as it “dings and dongs and rattles and roars.” And sometimes, maybe even the best times, it just listens. (ProQuest)

***El Deafo*,** a graphic memoir by author and illustrator, Cece Bell, is another book about a specific disability. It fits into the category of books for the middle school child. Cece chronicles her hearing loss at an early age and her experiences of going to school with her very powerful and awkward hearing aid, the Phonic Ear. The Phonic Ear gives Cece the ability to hear – sometimes things she shouldn’t – but also isolates her from her classmates. After some trouble, she is finally able to harness the Phonic Ear and become “El Deafo, Listener for All.” And more importantly, declare a place for herself in the world and find the friend she’s longed for. (ProQuest)

The second category of books is those which emphasize being comfortable with differences – your own, and those of others. A memorable one for young children is:

***Just Ask: Be Brave, Be Different, Be You*** written by Supreme Court Justice Sonia Sotomayor and illustrated by Rafael Lopez. In a Letter to her young readers, Sotomayor writes of growing up with juvenile diabetes and often feeling different. She explains that we are all different and that notion is empowering. She writes, “If you ever wonder why someone is doing something different from other kids, *Just Ask.***”** “An affirmative, delightfully diverse overview of disabilities.” (Kirkus Reviews)

***I’ll Walk with You***, words by Carol Lynn Pearson and Art by Jane Sanders is a poem, based on a children’s song. The theme, brightened by bold and colorful illustrations, is that “Everyone deserves to be loved, no matter how they look, where they come from, or what their age and abilities are.” Citing different times of feeling excluded, the poem returns to a refrain, “I’ll walk with you and talk with you. That’s how I’ll show my love for you.” Known for her heartfelt poems and stories, Carol Lynn Pearson’s I’ll Walk with Youlends itself to being read together with a loved one though it could be enchanting just looking at it as a picture book.

Children’s disability literature not only provides delightful reading for disabled children, but it also has been shared with nondisabled children who learn to recognize that people who seem different are just like themselves.

*Mary Grimley Mason is a Ph.D. 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.”

**READY & ABLE**

**New Spaulding Podcast Gives a Platform to New Voices**

**By Tim Sullivan**

As podcasts have grown in popularity the ability to provide in-depth reviews on complex issues is profound. However, for many within the disability community and providers who support them, there has been an absence of voices to speak directly on issues that matter to them. As part of Spaulding’s mission and work as a center of advocacy and research through its model system designations in Burn, Spinal Cord and Brain Injury, podcasts represent a new opportunity to create more channels to share information to benefit all.

This Spring, Spaulding launched Finding Strength: The Spaulding Rehabilitation Podcast, which aims to show how research can have real world meaning and impact for people. Monthly episodes will be inspired by research conducted out of the Spaulding Research Institute and stories from people with lived experiences.

The Spaulding production team made it a priority to make the content accessible and relevant for clinicians, researchers, patient populations and families. The podcast serves as a new extension of the charge model system sites to serve as centers of dissemination for new research, advocacy and education. Spaulding Model System program hold regular events each year from lectures, awareness walks, participate in community events and research recruitment among others. The podcasts represent an exciting new opportunity to connect with a broader audience in an entirely new way.

The first three episodes are now live!  **Episodes 1 & 2** are a special 2-part kickoff inspired by the *New England Journal of Medicine* article “From Survival to Survivorship – Framing Traumatic Injury as a Chronic Condition,” featuring guest speakers Jeffrey Schneider MD, Spaulding Burn Injury Program Medical Director, Diana Tenney, Burn Survivor, Advocate and She is past-President and Board member of the Burn Survivors of New England, Dave Estrada JD, United Spinal Association as a peer mentor, board member, and former executive director of its Greater Boston chapter and a program manager at the Spaulding New England Regional Spinal Cord Injury Model System and the Exercise for Persons with Disabilities Program, and Juan Hererra-Escobar MD, MPH, Research Director in Long Term Outcomes in Trauma at Brigham & Women’s Center for Surgery and Public Health.

In **episode 3**, Joseph Giacino PhD, Director Spaulding Rehabilitation Neuropsychology Service, Disorders of Consciousness Program, Nicole Godaire, CEO, Brain Injury Association of Massachusetts and Tracey Macarty, mother of TBI survivor, discuss clinician’s ability to predict outcomes after moderate to severe brain injury.  For the May 1st episode, Alan Jette, PT, PhD, MPH, FAPTA Professor Emeritus, Boston University, MGH Institute of Health Professions and Sarah Skeels, BS, MPH, Tufts University, were invited to discuss the development and use of a tool that measures function after spinal cord injury: the Spinal Cord Injury Functional Index / Assistive Technology (SCI-FI/AT).

To listen and subscribe to stay connected to the groundbreaking work coming out of Spaulding’s research labs, available on Spotify, Apple Podcasts, Google Podcasts and iHeart! New episodes are released the first Monday of each month. The production is a collaboration amongst Spaulding’s three Model System programs and the Rehabilitation Outcomes Center at Spaulding.

Follow us on [**Spotify**](https://open.spotify.com/show/19uf6qxbqoAZKoqguy9gQ9?si=itVSivxFQzCU2OAaojKe2Q), [**Apple Podcasts**](https://podcasts.apple.com/us/podcast/finding-strength-the-spaulding-rehabilitation-podcast/id1672657817), [**Google Podcasts**](https://podcasts.google.com/feed/aHR0cHM6Ly9hbmNob3IuZm0vcy9jNjc0ZmI2NC9wb2RjYXN0L3Jzcw), or [**iHeart**](https://www.iheart.com/podcast/269-finding-strength-the-spaul-109124377/)

Learn more at [**https://spauldingrehab.org/research/about/podcast**](https://spauldingrehab.org/research/about/podcast)

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

**INFORMATION BRIEFS**

**Annual Adaptive Recreational Fair**

The Massachusetts Department of Conservation and Recreation’s [Universal Access Program](https://www.mass.gov/orgs/universal-access-program) is hosting our [Accessible Recreation Fair](https://www.mass.gov/event/dcr-uap-annual-adaptive-recreation-fair-2023-06-10t100000-0400-2023-06-10t150000-0400), Saturday June 10th, from 10 a.m.–3 p.m. at Herter Park/[Artesani Playground](https://www.mass.gov/locations/artesani-playground-wading-pool-and-spray-deck) in Brighton.

Join us rain or shine for a free, fun-filled day celebrating accessible outdoor recreation in Massachusetts state parks! **Pre-registration is highly recommended, especially for use of equipment.**You can pre-register [online](https://forms.office.com/g/z9pUzpeYh3), or by calling Universal Access at (857) 319-2168. Please pre-register to request an ASL interpreter or other accommodations. In case of severe weather, call (857) 319-2168 for a recording of the fair’s status.

Family-friendly, accessible, and inclusive activities include cycling with an assortment of adaptive cycles, hiking and letterboxing with all-terrain wheelchairs and walkers, face painting, kite decorating, sidewalk chalking, golf and other equipment demonstrations, adaptive birding and fishing booths, bubble blowing and games, music, and more. Smokey Bear will be visiting the fair, too!

Come meet an array of regional adaptive recreation organizations and learn about accessible, adaptive, and inclusive recreation opportunities in the greater Boston area and beyond. Learn about adaptive equipment like hiking wheelchairs, beach wheelchairs, and adaptive bikes and trikes. Find out about upcoming adaptive summer programs like swimming, fishing, horseback riding, kayaking, exercise classes, nature activities, and hikes!

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