***Disability Issues***

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*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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**Table of Contents:**

**From the Editor** | Marianne DiBlasi  
**Ready & Able: Ensuring Equality in Cancer Care for Patients with Disabilities**| Cheri Blauwet, MD  
**I Am a Dreamer: A Refresh on Housing for People with Disabilities**| Sandy Alissa Novack  
**Reflections Inspired by Disability Awareness Months**| Marybeth Barker  
**What I Learned About Life from Becoming Disabled** | Penelope Ann Shaw  
**Technology: For Better or For Worse!**| Joan Burrows  
**Love & Intimacy Corner: Inclusive Fashion A-Z**| Ms. Love  
**Information Briefs:**  
• Runway of Dreams Hosts 7th New York Fashion Week Event  
• MASS MoCA Exhibit Explores the Deaf Experience  
• Get Outdoors This Winter!

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**From the Editor:**

Dear Readers,

In November, I attended a [webinar](https://www.wgbh.org/forum-network/lectures/building-bridges-to-belonging) hosted by WGBH in partnership with Cambridge Forum. The speaker was social psychologist, Geoffrey Cohen who discussed his book, [*Belonging: The Science of Creating Connection and Bridging Divides*](https://www.goodreads.com/en/book/show/60165404)*.* Cohen indicated that belonging is the feeling of being a part of a group that values, respects, and cares for us. Based on research, even fleeting experiences of belonging increase our sense of well-being and self-worth.

Since the webinar, I’ve been reflecting on isolation, belonging and how that relates to the disability community. Many times, people with disabilities are relying on their own ingenuity to navigate healthcare, housing, employment, technology, and relationships. Often, we are on our own to advocate for and create opportunities where we can flourish. It’s lonely, confusing, and exhausting – the antithesis of belonging.

Community is the antidote for going it alone. Connecting with others in the disability community who tell it like it is provides a sense of solidarity and belonging. Having a disability presents unique challenges, but learning how others have navigated hurdles can inspire fresh perspectives and creative ways to approach situations.

It is with this belief in the power of community that *Disability Issues* publishes articles written *by* people with disabilities *for* people with disabilities. We strive to foster a sense of solidarity and belonging within the disability community by sharing stories of personal lived experiences, people who are trail blazers, innovative ideas, common frustrations, and useful resources. We are grateful to you, our readers, for being part of the *Disability Issues* community. You are not alone. We are in this together.

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**

**Ensuring Equality in Cancer Care for Patients with Disabilities**

**By Cheri Blauwet, MD**

[Cheri Blauwet, MD,](https://spauldingrehab.org/physician/968/cheri-blauwet) of the Department of Physical Medicine and Rehabilitation at Spaulding Rehabilitation Hospital and Brigham and Women’s Hospital, is a board-certified physiatrist who is also a Paralympic gold medalist in wheelchair racing. As a person with spinal cord injury, she has used her personal experiences in healthcare and medical background to advocate for greater health equity for people with disabilities.

Dr. Blauwet and others [published a commentary in *The Lancet Oncology*](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(23)00406-0/fulltext) regarding the prevalence of ableism in oncological care. In this Q&A, Dr. Blauwet discusses her motivations for pursing this work and her plans for dismantling the existing obstacles.

**Q: What are your sources of inspiration for fighting ableism and improving oncology care for persons with disabilities?**

My interest regarding the impact of ableism on the healthcare that we as clinicians provide and the health outcomes that we see is both personal and professional. Professionally, I am the chief medical officer at Spaulding and my clinical training is focused on enhancing function for people with disabilities. As a result, I am responsible for all the quality and care that our clinicians provide, and it’s my duty to reduce bias and improve health equity for this population. Personally, I have experienced a spinal cord injury and am a wheelchair user myself. I have experienced the healthcare system extensively throughout my life, and so I am aware of the effect that ableism can have on care. I also understand how unfair it is when providers treat patients differently because of their disability status, and so I have developed a deep personal passion for this type of work.

**Q: What are the current issues with ableism in cancer care?**

One prominent example concerns the decision to treat cancer patients with antineoplastic drugs, such as chemotherapy. Doctors calculate a rating based on performance measures that can indicate whether a patient would be able to tolerate what can be a difficult treatment course. Using a wheelchair results in a lower rating.

Unfortunately, such current performance measures for people who use wheelchairs are outdated and inherently ableist. Healthcare services have evolved alongside society, and what it means to be a wheelchair user today is much different than what it was in 1950. It no longer makes sense to base a treatment decision on if someone is a wheelchair user or not, as legislation has moved forward the lives of people with disabilities and allowed many wheelchair users to live very full and healthy lives.

Recognition and screening are also important in oncology. Both cognitive biases and structural ableism can have a negative impact on access to basic cancer screening and diagnostics. For example, getting a mammogram if you cannot stand can be difficult. For a clinician, if they are not aware of their cognitive biases or have not heard of the concept of ableism, this can unconsciously affect how they give treatment for persons with disabilities. Another example is the unconscious bias that someone with a disability is not sexually active, and so in that scenario, a physician may be less likely to screen a patient for sexually transmitted illnesses that may increase the risk for certain kinds of cancers.

**Q: What is your top recommendation for tackling these issues?**

In our [Lancet paper](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(23)00406-0/fulltext), we make several recommendations including improving outreach, funding, and data collection for cancer-care and cancer research organizations. But one piece that I would like to especially highlight is the intent to incorporate ableism and disability awareness into clinical training. Whether you’re a medical student, a resident, a fellow or a faculty member, integrating this understanding into the delivery of health care is vital.

We as a medical community have to view ableist tendencies in the same light as prejudiced or sexist stigmas and biases, and attempt to eliminate them from healthcare delivery, particularly within oncology. The world is evolving and it is important for medical treatment to advance as well.

**Q: How do you imagine the educational process on ableism in oncology will proceed?**

This will have to be a team effort, where everyone works together to create lasting change. I think that we need multiple stakeholders, including leaders in oncology care to make national policy recommendations. This also encompasses physiatrists like me, and requires us to understand how all aspects of the cancer journey impact function. We should be thinking proactively about how the fields of physiatry and oncology can work together to optimize function throughout the continuum of oncology care including diagnosis, treatment, recovery and long-term health impact. Policy-wise, health service researchers and health policy experts should legislate methods for reducing biases. We are seeing this in real-time as just recently, the U.S. Department of Health and Human Services has proposed an update to strengthen the Americans with Disabilities Act.

One example where this could make an impact is with high exam tables at an OB-GYN clinic. Having a policy that ensures at least one table is able to accommodate people in wheelchairs will allow doctors to more easily perform pap smears and is a specific case where policy change can positively impact access to care.

**Q: What are the next steps you hope to take?**

As a physician, it’s important for me to consider how I can use my voice to enact change. For oncologists and healthcare leaders, advocating for both professional societies and leaders within the specialty to consider whether ableism exists in their treatment is paramount. This raises awareness, and in that same vein, is complemented by the publishing of papers, with research helping us to better understand the data that is related to ableism in oncology care.

Within every specialty of medicine, ableism can present itself. Making physicians aware of how ableism could be prevalent in their daily work is important. Providers in all medical specialties should talk to experts in these patient populations and work towards implementing the best practices for our patients, particularly for those fighting cancer.

*Cheri Blauwet, MD is an Attending Physician at Brigham and Women's Hospital/Spaulding Rehabilitation Hospital. She is an Assistant Professor of Physical Medicine and Rehabilitation, Harvard Medical School.*

**I Am a Dreamer: A Refresh on Housing For People with Disabilities**

**by Sandy Alissa Novack**

*“I am a dreamer. For a dreamer is one who can*

*find his way by moonlight, and his punishment is that he*

*sees the dawn before the rest of the world.” ~* Oscar Wilde

I am a dreamer, as are you if you are a person with disabilities, because people with disabilities spend a lot of time dreaming of possibilities. One commonly shared dream is about housing that is designed for us. Sometimes, I can practically taste what it would be like if my dream of living in a real home came true. But then I open my eyes and the reality of current housing for people with disabilities, or rather the lack of it, steamrolls over me.

Turning dreams into reality often requires the energy and persistence advocacy. An article from Shelterforce, “[Disability Justice and Equity in Housing](https://shelterforce.org/2023/06/12/disability-justice-and-equity-in-housing),” recognizes the need for advocacy to evolve and include the intersections of different oppressions, such as disability, race and class, which are deeply intertwined. The title they suggest for this intersectional activism is, *Disability Justice Activist*. Anyone who refers to themselves with this title, the article explains, understands that racism, ableism, and all the other “isms” are strongly connected, and that we don't need to set aside any part of how we identify. We can include all our identities. Whatever our gender, race, culture, religion, language, education level, recently disabled or not, physically or otherwise disabled, temporarily or permanently disabled, younger or older. How we identify, and *all* the ways we identify, we are allowed to be. This is justice. This is empowering.

Where can we find an example of housing that recognizes accessibility is not just limited to physically accessible? Individuals in the disability community have a wide range of various types of disabilities, including physical and non-physical. Where can we find housing design that doesn’t limit us to living only with people who have the same disability?

Let me refer you to another article in Shelterforce’s housing series, “[Developing Housing That Welcomes People with Developmental Disabilities](https://shelterforce.org/2023/07/25/developing-housing-that-welcomes-people-with-developmental-disabilities).” Though the article focuses on people with intellectual and developmental disabilities, I feel the concepts apply to a wide range of disabilities. The article states that while some people with developmental disabilities may need group homes, others do not. With this understanding, the article references housing designs that focus on accessibility, affordability, and inclusion.

The housing model that [those] working in disability justice are advocating for is characterized by units that are home to a mix of disabled and non-disabled residents, with communal spaces and activities where all residents can mingle. These units incorporate universal design principles regardless of whether the residents of those units are physically disabled or not, while a third-party service provider offers support to individuals who need it… Developments that follow this model...are united in their emphasis on accessibility, integration, and autonomy. This is in opposition to more restrictive settings...that segregate residents based on their disability and restrict the autonomy of their residents.

The article references, Kelsey, a nonprofit housing provider based in San Francisco that puts the needs of people with all types of disabilities front and center in their work. They gather groups of people with disabilities to ask for feedback when they are thinking about a new housing project. People with and without disabilities are part of their staff. When they began a housing project in 2022, they reserved 25% of the units for people with disabilities with rents expected to range from affordable for lower income residents to essential workforce housing.

Some of the design features are:

* Soundproofing and indoor air quality control and ventilation for people with sensory sensitivity, including people with intellectual and developmental disabilities and people with respiratory conditions.
* Lights that can be dimmed for people with visual challenges with their disabilities, including people on the autism spectrum and people with migraines.
* A sensory garden.
* Staff to help applicants complete their application, move, as well as help paying rent and utilities for those with cognitive disabilities.
* Plain language in documents, such as leases.
* A space for caregivers to rest.
* An inclusion concierge staff person who has “expertise in disability, inclusion, access, culture, and an understanding of the different services that people with disabilities need in their homes."  I think this is an excellent idea!

These are fresh ideas by people with disabilities and disability-friendly organizations. This is work being done by Disability Justice Activists who are breaking out of the dominant housing model which requires people with disabilities conform to institutional-type housing or living in generic inaccessible apartments. They are leading the way with collaboration and innovation, showing the rest of us what’s possible. Here in Massachusetts, we too can design creative housing and have people with disabilities involved every step of the way. How refreshing! How just! How right!

*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.*

**Reflections Inspired by Disability Awareness Months**

**By MaryBeth Barker**

***Disability Pride Month***

During July’s Pride Month, I found myself reflecting on my deepening appreciation of the disability community. I am increasingly aware of the positive impact disability activists both past and present have on my life. Their willingness to be visible, to make their voices heard, to demand accessibility, and other civil rights is central to the steep hill I climbed on my way to making peace with my disability and finding pride in that identity. Though my process may have been arduously slow, today I find myself mostly at peace with my disability as an individual and unmistakably proud as a member of the disability community.

I became disabled at age 58 due to the sudden onset of an autoimmune disease, Sjogrens. This is a notoriously difficult disease to diagnose, and in my case, it was even more difficult because of its atypical presentation. It took close to two years to get an accurate diagnosis during which time I lived in a state of uncertainty about what was causing the neurological symptoms of tremors, difficulty walking, loss of balance and vision changes. The most disabling symptom was the internal sensation of being tossed around like a buoy on a rough sea whenever I stood or sat upright.

During that time, I held fast to the hope that my medical providers would soon discover the reason behind the inflammation in my brain (encephalopathy) that caused these symptoms. Though they were certain it was an autoimmune condition they were unable to identity specifically which one. Consequently, for a long time I received less effective, generic steroid based therapy. Once I had a diagnosis, I could begin a therapy that was specifically targeted to Sjogrens.

From onset to diagnosis, I vacillated between trying to accept the new physical limitations as my new normal and resisting the condition. Friends and family encouraged me to fight like hell and not give in to the disease. Although I knew mobility aids would be helpful, I worried that asking for assistive devices would undermine my effort to maintain my remaining ability and interfere with my eventual recovery. For longer than I care to remember I struggled to walk without an adequate mobility aid and found it difficult to sit unsupported due to ataxia in my trunk.

I felt fearful of the way my disability was changing the dynamics of my relationship with my husband and daughters, and my self-image as I experienced one loss after another, including my ability to remain employed. Barely able to contribute at home, having to ask for help from others, and finally taking leave from my job as a social worker left me feeling anything but proud of the way disability was affecting my life.

Ironically, I had been working with people living with disabilities for years as a health educator and social worker. I was not a stranger to the concept of disability pride or culture, which only added to my inner conflict and feelings of failure. I knew many people with disabilities who had challenges and lived rich, interesting lives. I considered myself an ally, never imaging that one day I would need to face the daunting task of making peace with my own disability.

With the correct diagnosis and treatment, the bobbing sensations gradually diminished and have become manageable. My mobility improved but did not return to baseline. Sjogrens is a chronic, evolving and debilitating disease. Though I continue to experience complications related to Sjogrens, today I live reasonably well with my disability by using a wheelchair and adapting my home with stair lifts and other features.

Over the years my understanding of disability pride has evolved. Though I grieve the loss of my mobility, I have never felt ashamed of the stagger in my gait or tremor in my hands. But I can’t say I ever felt proud of these characteristics either. Does allowing myself to grieve what I lost by becoming disabled, or admitting that I’d rather be able to walk than not, mean I lack disability pride? Maybe I’m not fully evolved yet, but I cannot deny the loss I feel because of my disability. Yet, at the same time, I feel disability pride in the ways I, along with and because of learning from other people with disabilities, have transcended the stigma and limits society places on us. I am proud to be part of a movement and a community that demands visibility, dignity, equal access and recognizes the humanity in people of all abilities.

***Disability Employment Awareness Month***

During October, I reflected on when I stopped working, which was four years after the onset of my illness. Prior to stopping completely, short- and long-term disability benefits and my husband’s income, allowed me to take to take several paid and unpaid leaves from my job which spanned several years with the same employer. Fortunately, my employer always welcomed me back. I returned part-time, first in a supervisory position and later as a manager.

In retrospect, although my employer was willing to, and tried to, accommodate my needs, the changing nature of my disability made it difficult. I was uncertain of what I needed and what to ask for. I don’t recall if I was connected to physical or occupational therapists at the time but if so, perhaps their expertise would have been helpful. If I had been outfitted with the correct wheelchair and customized positioning that I have today, I think I may have been more successful.

Despite working with the disability community, I didn’t understand how fluid a state of disability could be until I experienced it myself. I thought asking an employer for an accommodation was a one and done thing. I was not invited to, nor did I feel comfortable, returning to the well to ask for additional accommodations to meet my evolving needs. Perhaps the human resource department could have checked in to let me know it was okay to ask for adjustments as things changed. A good practice for all human resource departments to engage in.

A year after I took leave for what I thought was the final time, my employer invited me to return to help with the startup of a new program that was well suited for my skills and experience. I was ambivalent, but I accepted and found the work both rewarding and restorative to my sense of self. Once this goal was accomplished, I voluntarily gave up my position in 2015 at age 62. For several years, I grieved the loss of my career. As I grew older, my peers began to retire, which helped. I also grew into appreciating the time retirement allows me to contribute to the world in different ways, to rest more fully, and pursue creative endeavors. I’ve found great pleasure as a volunteer baby cuddler in the Special Care Nursery at Mass General Brigham. I serve on my local Commission on Disability, Human Rights Council and on the Bruce Freeman Rail Trail Advisory Committee representing users with disabilities. In warm weather, I swim daily in the pond where I live and create mosaics of the creatures and beauty I see. That might sound like a lot but there are plenty of days in between when I do nothing but lay on the couch, read, and sleep.

As I reflect beyond my own experience in the work force, I am deeply appreciative of those who advocate for change and a climate where people of all abilities can reap the benefits of being gainfully employed. For those unable to be employed, finding the right volunteer position can make a difference. Having a purpose beyond oneself helps to foster feelings of worth and well-being. Employment and volunteer work are sources of pride and I believe that pride is a force multiplier.

*Marybeth Barker, LCSW, MPH worked in public health research and as a social worker for over 30 years. She retired from Commonwealth Care Alliance in 2015. She is a member of the Concord Commission on Disability, a volunteer in the Special Care Nursery at Mass General Brigham, and an Airbnb super host. She enjoys swimming, adaptive cycling, and creating pond-inspired mosaic art.*

**What I Learned About Life from Becoming Disabled**

**By Penelope Ann Shaw**

Twenty-two years ago, at age 58, I became unexpectedly disabled. Not only did I learn a lot about disability, but about life in general. I learned that medicine is not perfect. Physicians at my local hospital couldn't make sense of my symptoms - falling and being unable to stand up independently. They told me I was lying and wanted to put me in their psychiatric unit. I refused. Instead, they put me in the Medical-Surgical unit.

Soon I was unable to breathe on my own and was put in intensive care on life support, which convinced them I wasn't attention seeking. After several months I improved so was removed from life support and was transferred to a respiratory rehabilitation hospital where I had a tracheostomy and was put on a feeding tube. Almost a year later, I was transferred to the nursing home where I now live.

Originally, I was diagnosed with Polymyositis. After 9 years, in 2010, I went to the Mass General Hospital teaching hospital in Boston for a consultation and was told I'd been given the wrong diagnosis. My actual condition was Guillain-Barre Syndrome (GBS), a rare neuromuscular disorder that caused quadriparesis - paralysis of both legs and weakness of both arms.

Becoming disabled was a major event. My life, which I had taken for granted, had definitely been disrupted. Unprepared for this change, I was in disbelief, bewildered, somewhat disoriented. I had no idea what to make of what had happened. Later, I became more aware that dramatic life changes can happen to anyone and for many reasons. They can occur from severe natural disasters - wildfires, hurricanes, tornadoes, earthquakes and floods. People can lose their homes, family members, friends and livelihoods. Lives that others may have similarly taken for granted can be interrupted.

How had my life changed? My body lost functionality and was not responding the same way. I could no longer walk, wash or dress myself. Paid staff provided my personal care. I was taken out of, and put back into, bed with a lift. I couldn't cook, but I could feed myself. I learned that if people need help it's okay to ask for it. Sadly, I was no longer able go to a local art center studio to do my favorite leisure activity of creating art on paper. I had to acknowledge that I could no longer develop film and print photographs, do watercolors, woodblock carvings or monoprints because they all required me to stand and walk.

Having survived a life-threatening medical crisis, I began the long process of adaptation where I accepted and learned many things:

First, I accepted the initial losses of my home, car, and way of life. When I was provided with an electric wheelchair in 2010, I was able to go places and learned about the importance of environments, both natural and built. Would there be barriers, or would my trip be enabling and accessible?

In the hospital, I learned about the importance of technology - ventilators, tracheostomies, hospital beds. In the nursing home, I learned about alternating air mattresses, floor lifts, elevators and vehicles with wheelchair lifts for travelling distances.

I learned the importance of problem-solving, figuring out how to do things differently. For example, I now use my right elbow to hold a phone up to my ear because my shoulder muscles do not work at all. I discovered an innovative way to open milk cartons by using the prongs of a fork because I no longer have fine motor skills.

I learned to set different goals for my life. For example, accepting I could no longer go swimming because my wheelchair does not have the driving range of a car, which is needed to get to the pool.

I learned to identify as a person with a disability. I learned about the importance of the disability community. From these role models, I learned perspective and an optimistic way of thinking and living with high expectations, focusing on capacity not limitations. I learned what is possible.

I benefited from my new colleagues' education and learned about the importance of civil rights for people like me, not just civil rights for others. I learned about the ADA and my right to accommodations as well as my right to autonomy and control over my life. I benefited by my colleagues' practical advice, knowledge of resources, how to be a self-advocate and activist. Belonging to this community I got to know people I would not otherwise have met. I learned that community is power.

In my neighborhood, I learned that some people have stereotypes about people with disabilities. I encountered people who seemed to feel sorry for me and think I'm suffering because I use a wheelchair. Others were overly solicitous, praising me like I'm someone out of the ordinary. I found this annoying because, although I can't walk, I feel that in most ways I’m like everyone else. Fortunately, most individuals I meet are just friendly and treat me normally. I wish the larger society understood that those of us with disabilities are unique individuals. Being disabled does not predict whether we will, or will not have, a quality life.

Unfortunately, I also learned that life can be demanding in ways I was unaware of. As a person with a disability, there are always obstacles to overcome. I sometimes find the daily work of disability exhausting. Despite the challenges, I learned that those of us with disabilities can adapt physically, psychologically and emotionally.

In conclusion, I confess there’s a part of me that does not completely understand what happened. When I go to write my return address on an envelope, I have to stop myself from writing the address where I was living when I became disabled. Unconsciously I still live there.

In many ways becoming disabled expanded my knowledge of the world. I was taught new lessons. I learned that life is ever-changing, and my life will be a continual process of evolving and gaining new insights.

*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.*

**Technology: For Better or For Worse!**

**By Joan Burrows**

Is technology better or worse for children, adults, older adults, and people with disabilities?  All groups may benefit in small ways because of technology. There are better and faster ways to accomplish some things, but I fear there are also many difficulties and frustrations.

As I get older, I find it difficult and sometimes impossible to understand or know how to use new technology. I cannot get questions answered when I’m talking to an automated voice.  In many instances, people with certain disabilities are left out by technology and are no longer able to navigate automated systems to take care of their needs like they used to. It’s frustrating and stressful when a disability limits what you can do for yourself, and now there are even more hinderances from something new that is supposed to help. Technology is not Accessible for All.

Last week I tried paying my bills over the phone, as I’ve done before. After I gave the automated system the amount I wanted to pay, the 'voice’ confirmed my payment of "one thousand" rather than the "one hundred" I had clearly stated. There was nothing I could do to correct this 'voice'. I called the company that I made the payment to, then the bank to tell them about the problem. The bank said the company should do a reverse transfer, but the company wouldn’t do it. Instead, the company said they would send me a check for the overpayment. Since I no longer drive, a friend had to take me to the bank so I could deposit the check. What a time consuming and frustrating hassle.

I recently made another call that I thought would be quick and easy. I wanted to update my credit card information with a company. It took me a half hour to get the computer on the right page. I have my landline phone in one hand so a woman can guide me through the process. Then, she sends a code to my cell phone. Well, I still can do three things at once, but it is not easy. I clicked all the places she told me to and voilà, the new card number was on the computer screen! Unfortunately, it went downhill from there. I began getting frustrated and so was the woman on the other end of the phone. She finally gave up and said she would call back later. She did not. I will not use their services anymore.

Like most people, especially older adults and those with disabilities, I am trying very hard to stay independent. Situations that take away some of our independence and create feelings of helpless and stress are challenges we don’t need. The technology that is supposed to make things better and easier doesn’t always. The people who were so smart to develop all the new technology, need to focus on fixing it, so it is usable for all!

*Joan Burrows studied music in New York City and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.*

**LOVE & INTIMACY CORNER**

**Inclusive Fashion A-Z**

**by Ms. Love**

I was impressed with a recent Institute for Human Centered Design (IHCD) webinar on people with disabilities and fashion. I’m excited to share some highlights with you. The full program, “[IHCD Global Webcast: Inclusive Fashion w/ Sinéad Burke](https://www.youtube.com/watch?v=QmJooFCWWMk)” can be viewed on YouTube.

The IHCD program was titled, “Inclusive Fashion: Building a Holistic Ecosystem Beyond Product.” It was a stimulating and enchanting opportunity to listen to educator, advocate and author, Sinéad Burke, who joined the webinar from Dublin, Ireland. Sinéad identifies as queer, disabled and a little person. She is the Founder and CEO of [Tilting the Lens](https://tiltingthelens.com/) and is a consultant on accessibility. Dispelling the myth that accessible design cannot be functional and beautiful at the same time, Sinéad Burke spoke from her experience of working with global fashion companies, such as Gucci and Ralph Lauren, to illustrate how innovative, accessible design could benefit all.

To set some context, Sinéad began by sharing definitions of various disability models:

* Eugenics: disability not valued at all.
* Medical: people with disabilities need to be cured to be like the able-bodied.
* Charitable: people with disabilities are seen as always in need.
* Social rights: we are disabled by the built environment and society.
* Justice: acknowledging that disability is one dimension, but it is intersectional and includes the most marginalized in society.

She discussed how language shapes society and our thinking by using euphemisms, such as differently abled, special needs, and physically challenged. Or how about the ableism behind psycho, crazy, paralyzed, crippled, and blind spot? The next time you read a book, articles, etc. see if you can catch other examples. Sinéad spouted statistic after statistic, and fact after fact, astounding me with her breadth and depth of knowledge about disability. How does all of this apply to fashion? Per the talk's title, it is the whole ecosystem that needs to be inclusive – the people, places, and promotion, not just the product being sold.

For the *people* part of the talk, she spoke about the “need to audit and adapt the recruitment and employee onboarding journey, addressing accessibility and inclusion throughout the business to employ people with disabilities while creating a workplace culture that maximizes their success.” This includes the job description. If it says the person must be in the office full-time, is consideration being made for the transportation issues that an employee with disabilities may have? Or when reviewing employment applications, are some being discarded because there is a spelling mistake without taking into consideration that the applicant might have dyslexia.

For the *places* part of the talk, Sinéad mentions that fashion runways need to be accessible so people with physical disabilities can be runway models. She cited the statistic that 43% of people with disabilities cannot shop in person due to lack of accessibility issues inside a store. She is an advocate for everyone being able to enter and leave a building easily, comfortably, and independently, including being able to escape in the event of fire or emergency. Sinéad points out that making a building accessible when it’s being designed and built is less costly.

Further, Sinéad discusses how design elements should be reviewed, including signage, wayfinding, furniture, fixtures, waiting in lines, ordering, and more. She also makes the point that we should consider choosing color combinations that have contrast, or using soft and mild colors for people who are color blind or have vision impairments. Continuing our crash course on inclusive fashion, she asks if we have ever tried to buy a product online, but the company’s website is inaccessible. Companies have lost $6.9 billion dollars each year to competitors.

As for the *promotion* part of the fashion ecosystem, Sinéad spoke of how Vogue magazine has featured people with disabilities. This includes Sinéad herself on the cover! “There is a phrase,” she says, “If one can see it, one can be it.” She explained that making things accessible also means having content in more than one format. There is Braille, but she says British Vogue is also available in audio format.

Following Sinéad's comprehensive discussion on the ecosystem of fashion, the following panelists added their perspectives on inclusive fashion and disability:

* Jay Calderin, Founder and Executive Director of Boston Fashion Week
* Teppei Maeda, Founder of KIYASUKU
* Aaron Rose Philip, Model and Advocate
* Rebekah Taussig, Writer and Educator

**Jay Calderin** teaches at the School of Design at Massachusetts College of Art and Design and at the Museum of Fine Arts in Boston. He teaches his students to consider who isn't in the fashion picture. “People often design for the 'ideal' body; we need to walk toward more inclusive design for the variety in human bodies.”

**Teppei Maeda’s** Japanese company Kiyasuku is an online-only business that does alterations for people with disabilities, a custom process for each person. “I don't want people with disabilities stuck in sweatpants all the time because they do not have inclusive fashion.” When he talks to other businesses, Teppei says he “doesn't want to leave anyone behind.” He shared, all the staff have children with disabilities, so they understand what it is like to put on clothes with a disability or what it is like for a caregiver to put on clothes for someone with a disability.

**Aaron Rose Philip** identifies as Black, disabled, and a transgender woman. She said growing up she never saw herself in the fashion magazines where models were all White and non-visibly disabled. As a model, she was the first Black woman with visible disabilities signed with a major agency but said she “does not want to be the only one...People with disabilities can love fashion like anyone else.” She wants to see herself and people with all types of disabilities represented on runways and billboards.

**Rebekah Taussig**, author of the book, *Sitting Pretty: The View from My Ordinary Resilient Disabled Body*, tells us she grew up using a wheelchair, including once having a pink wheelchair decorated with stickers. She comments that clothes were designed for people who walk and stand, which she cannot do. She has issues trying on clothes in stores. For example, not being able to reach high enough to pull something off a hangar or getting her wheelchair into a dressing room. “You have a right to dress as you feel to tell your more inclusive story, how you want to identify...including your wheelchair in photos as beautiful...You can claim your narrative. There is a power to it.”

I applaud the speakers who are using their voices and bodies to create a fashion ecosystem where people with disabilities can express themselves and be seen as fashionable, trendy and beautiful, because we are.

*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*](mailto: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**

**Runway of Dreams Hosts 7th New York Fashion Week Event**

Adaptive clothing stole the show at [New York Fashion Week](https://sports.yahoo.com/runway-of-dreams-hosts-7th-nyfw-event-debuting-victorias-secrets-1st-adaptive-intimates-line-at-all-levels-of-the-fashion-industry-we-need-to-see-disability-represented-182205244.html?guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_sig=AQAAAK3dCs5Ut9QcfNPc7Mj7CBVb7zb7KjQLFfNipbTPOpCiRjNqrjPiHGYrNn_KBLRj-wewP4C2KLSJO_6wTJBa_Kp5jRQlNbkigCGOXKqMmCjBS6YqqHiN4CYtoKSKdgfD05yDEpgh_rShpIASmsHT0V32NzYPZKcEOJ40AJPs6Lw5&mc_cid=cfb7cb0883&mc_eid=6595e6377b&guccounter=1). The show, aptly named A Fashion Revolution,highlighted innovative work from big-name as well as up-and-coming brands that are making adaptive and universally designed fashion. The models included people with various types of disabilities.

In a first, [Victoria’s Secret](https://www.vogue.com/article/victorias-secret-makes-their-adaptive-fashion-debut-on-the-runway-of-dreams-during-nyfw?mc_cid=cfb7cb0883&mc_eid=6595e6377b) debuted an adaptive line featuring bras, underwear, slips, tights, and more in fun, bright colors true to the brand. The collection became available to purchase in October. Other brands that were featured on the Runway of Dreams included Tommy Hilfiger, Zappos, JCPenny, Target, Steve Madden, Kohl’s, Adidas, French Toast Adaptive, and Stride Rite.

**MASS MoCA Exhibit Explores the Deaf Experience**

[*In What Way Wham? (White Noise and Other Works, 1996-2023)*](https://massmoca.org/event/joseph-grigely-in-what-way-wham-white-noise-and-other-works-1996-2023/)*,* by artist Joseph Grigley, is a new exhibition at the Massachusetts Museum of Contemporary Art (MASS MoCA) that centers on the deaf experience. The exhibit explores the visual representation of speech and sound in the form of installations, sculptures, photographs, films, and books.

WBUR Arts Fellow Solon Kelleher visited the exhibit and writes about his experience in the article, [At MASS MoCA, artist Joseph Grigely shares his experience of being deaf](https://www.wbur.org/news/2023/10/03/mass-moca-joseph-grigely).

The exhibition runs through March 2024.

**Get Outdoors This Winter!**

Winter is almost here. Time to lace up those skates, put on some skis, strap on snowshoes, and ride a kicksled because DCRs Universal Access Winter Recreation Programs are up and running. There is something for just about everyone at locations across the State.  Check out the list of [upcoming 2023/2024 Winter Events](https://www.mass.gov/info-details/adaptive-program-schedule).

The Universal Access Program (UAP) offers adaptive, accessible programming seasonally at state parks, pools, and rinks. We partner throughout the year with [All Out Adventures](https://alloutadventures.org/), [Easterseals Massachusetts](https://www.easterseals.com/ma/), [Holyoke Rows](https://holyokerows.org/), and [Waypoint Adventure](http://www.waypointadventure.org/) to run our programs. Some of the programs are supported by [Spaulding Adaptive Sports Centers](https://sasc.spauldingrehab.org/).

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