

[View this email in your browser](#)

# DisABILITYissues

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

Vol 41 • No. 4 • Fall 2021



## TABLE OF CONTENTS

**From the Editor** | Marianne DiBlasi

**Mass General Brigham, Committed to Investments in Workforce Development** | Tim Sullivan

**PCA Recruitment Strategies and Tips** | Ray Glazier

**A Disability Declaration of Independence** | Penelope Ann Shaw

**Voiceless** | Sandy Alissa Novack

**Communicating from the Heart** | Joan Burrows

**Dolls and Stuffed Animals: Marking Time, Place and People** | Ms. Love

**The Bookshelf:** *Golem Girl* by Riva Lehrer | Review by Mary Grimley-Mason

**Information Briefs:**

- Waypoint Adventure: Accessible Hiking and More!



## *From the Editor...*

Dear Readers,

Do you enjoy writing and feel passionate about sharing disability-related stories with people in the disability community? If you do, I invite you to consider joining our fabulous team of *Disability Issues* editorial board members or being a guest writer who contributes one or more articles.

The editorial board members meet four times a year via a phone conference line, so there's no need to worry about transportation. At our meetings, we brainstorm, discuss, and plan the upcoming issue of *Disability Issues*, while also enjoying some laughter and camaraderie. Board members are comprised of people who have various types of disabilities and disability allies.

If you are interested in learning more about writing for *Disability Issues*, please send an email to Colleen Moran at [cmmoran@partners.org](mailto:cmmoran@partners.org) or call 617-952-6927 and I, the editor, will get in touch with you. I look forward to hearing from you!

In this issue, we bring you articles related to various forms of communication. Whether we are expressing ourselves by speaking words; using a body part to type or write; using non-verbal body language; or creating art, what we are communicating has power and

significance. As the editor of *Disability Issues*, I am honored to share the beautifully crafted words of our editorial board members and guest authors with you, our readers.

As we draw near to the end of October and National Disability Employment Awareness Month, I draw your attention to the article about Mass General Brigham's JobLab as an example of a program that enhances job skills and employment opportunities for people with disabilities. In conjunction with increased job skills, it's also essential that workplaces are accessible for employees with disabilities, not just places that are open to the public. To learn more about the history of accessible workplaces and current bills that are pending in the Massachusetts House and Senate which would enforce accessibility in workplaces, I refer you to an article by disability activist, Carol Steinberg, "[Mass. lags badly in workplace accessibility for disability community.](#)"

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.*



**MASSACHUSETTS' LARGEST EMPLOYER**

# **Mass General Brigham**

## *Committed to Investments in Workforce Development*

*By Tim Sullivan*

Before the pandemic began, locally in Massachusetts and across the Nation, was experiencing a strong run of economic success and a consistent decline in unemployment rates. However, the opportunities for persons with disabilities still lagged far behind at more than twice the unemployment rate of over 8%. The reasons are many, including real and perceived barriers to opportunity. As the state's largest healthcare system and employer with over 80,000 staff, Mass General Brigham understands the responsibility to broaden recruitment outreach and benefit from recruiting from often-overlooked talent pools. All types of businesses are evaluating what the "new normal" will be post-pandemic. This is an opportune time for organizations to refresh and revitalize workforce development to be more inclusive.

Since October celebrates National Disability Employment Awareness Month, it's an ideal time to spotlight creative workforce development programs for people with disabilities.

Before the pandemic began, locally in Massachusetts and across the Nation, was experiencing a strong run of economic success and a consistent decline in unemployment rates. However, the opportunities for persons with disabilities still lagged far behind at more than twice the unemployment rate of over 8%. The reasons are many, including real and perceived barriers to opportunity. As the state's largest healthcare system and employer with over 80,000 staff, Mass General Brigham understands the responsibility to broaden recruitment outreach and benefit from recruiting from often-overlooked talent pools. All types of businesses are evaluating what the "new normal" will be post-pandemic. This is an opportune time for organizations to refresh and revitalize workforce development to be more inclusive.

Since October celebrates National Disability Employment Awareness Month, it's an ideal time to spotlight creative workforce development programs for people with disabilities.



Elyse Forbush - Director of Nutrition and Food Services at Spaulding Boston, and Olivia Gaffney - JobLab participant.

One program is **JobLab**, located at Spaulding Hospital Cambridge and part of the Mass General Brigham system. JobLab is an innovative training suite with classroom space, kitchen training area, mock storefront, computers, interview rooms, and a quiet work zone. There is no cost for participants, and companies benefit by getting trained employment-ready candidates from a broad spectrum of the community. Participants receive support from and connections to community-based organizations, including CVSHealth, Jewish Vocational Services, MassHires, Massachusetts Rehabilitation Commission, Partners for Youth with Disabilities, and soon-to-be included Boston Public Schools and the Project Search program. The

goal is to grow even more partnerships in the coming years.



Elyse Forbush training Olivia Gaffney on foodservice methods at Spaulding.

“Our system is committed to inclusive workforce development programs that reflect the communities we serve. Those with disabilities often need to be creative, determined, and flexible to navigate a world that isn’t always inclusive for them. These are skills we search for. Programs like JobLab enable us to foster those skills and recruit strong candidates. By breaking down those barriers and creating these pathways to opportunity, I’m hopeful we can create a model for others to follow,” said Rose Sheehan, Chief Human Resources Officer for Mass General Brigham.

### **JobLab Goals:**

- **Employment Training:** Increase competitive employment

outcomes for people with disabilities.

- **Job Retention:** Improve function through ongoing support to maintain employment.
- **Business and Government Relationships:** Educate and build on expertise and resources that each partner brings to the table.

For managers, having the opportunity to engage candidates and learn their systems in settings like JobLab is invaluable. Elyse Forbush, Director of Nutrition and Food Services at Spaulding Boston has collaborated with many programs around the city to recruit job-ready individuals to join her team and said, “With JobLab, these organizations and programs will have the opportunity to train potential candidates in a hands-on simulated training site. In this setting, job coaches will be able to identify and enforce skills needed to gain real employment in support service departments across the network. With employment as the goal, for some, it will be the first real chance to have a job. The energy, personality, ideas, and dedication they bring enhances my team and supports the work we do for patients, families, and our colleagues.”

If you are interested in careers at Mass General Brigham and workforce development for the community with disabilities, contact **Colleen Moran**, Director of Workforce Integration at [cmmoran@partners.org](mailto:cmmoran@partners.org).

In October, *Chronicle* ran an episode about the future of the workforce which, according to Governor Baker, will require matching skills to jobs. One segment featured, [MassGeneral Brigham’s Spaulding Rehabilitation’s JobLab Creates Employment Opportunities](#), which shows the JobLab program in action!



*Tim Sullivan is Director of Communications at The Spaulding Rehabilitation Network, which is committed to creating public-private partnerships focused on providing new opportunities for underserved populations.*



# The **PCA** CORNER



## **PCA Recruitment Strategies and Tips** *By Ray Glazier*

In March 2020, a long-term live-in PCA was forced to leave at the very onset of the COVID-19 pandemic. It took more than a year of trying a variety of personal recruitment efforts before the situation was resolved. As a result, I have become well-versed in PCA recruitment strategies and offer some tips on what I learned.

I have begun to realize that recruitment is an ongoing necessity because PCA turnover is inevitable, given the low pay, slim benefits, and absence of a career path. The only room for advancement is outward because there is no upward ladder. MassHealth and the 1199SEIU union local could improve this situation by creating PCA job classes with different levels, perhaps based on tenure, such as PCA 1,



PCA 2, etc. But I digress...

Consumers and their surrogates may have noticed, as I have, that the PCA labor market appears to have rebounded with expiration of the pandemic federal unemployment benefit supplement. I have seen more potential PCA candidates posting their availability to work in my town on the MA PCA Directory. <https://www.masspcadirectory.org> For employer searchers new to this valuable tool, you need to create a free account, registering with your four-digit MassHealth PCA Program Employer ID number. Candidate PCAs can freely post their available towns, times, days, types of tasks, languages spoken, special training, certifications, and experience. This is a simple process for candidates to click on a checklist and respond yes or no to questions about smoking status, CORI check, and comfort with pets in the home.

Consumers or surrogates can then search the database by town and preferred language and can also enter any other specific parameters in an 'Advanced Search' with options like 'comfortable with pets.' I have been surprised to find the pet issue to be a deal-breaker because there are two cats in my home. Some candidates are allergic to cats, while others are leery of possibly being tasked with cleaning a litter box.

# Directory Basics Video



*[Click on Video Screen to go to Mass PCA Directory website.](#)*

While the PCA Directory is highly useful (and free), I have also found Craigslist to be a productive source for PCA candidates. However, Craigslist Boston Help Wanted ads require a posting fee and appear on the site only for a limited time. There are many online tutorials for coaching about posting ads on Craigslist. A crucial point is selection of the job category; usually 'General Help' is where PCA candidates will look for work, rather than in 'Medical/Health,' which caters more to credentialed professionals. For the same reason LinkedIn, while free to post, is not a likely source of PCA candidates.

To avoid wasting money on your search for candidates: There are several subscription websites for homecare worker placement, but I have found them to be of little help in finding PCAs. Folks who post their availability on these sites seem to want only cash payment under the table, so they prefer not to work within the PCA Program, which withholds income taxes from workers' wages. Some illegal immigrants take this approach.

Do you have an unoccupied room in your home and need some PCA help? List it for free as a 'room with paid part-time work' on Craigslist under 'Housing / Rooms & Shares'. Someone needing housing may be grateful to find a home with a built-in part-time job. Similarly, college student housing offices in your area may accept listings like this, but I personally have found their process to be cumbersome and generally unproductive.



Another free service for job posts is available on Facebook Messenger, if you have an account, and most people do. If you need to create one, accounts are free. As with Craigslist, you cannot include your email address or phone number in the Facebook Messenger posting. It's important to know they spot your email address when your post uses the '@' sign or your phone number by your use of numbers and hyphens.

**Tip:** Avoid having your entries flagged as 'unacceptable' by spelling things out, for example, '(at)' instead of '@' in your email address and 'six one seven...' instead of '617...' simply to spell out your phone number.

Whatever posting methods you use, be certain to include your proximity to public transportation for candidates who do not have cars. But describe your position without your street address or the 'gruesome details' of your personal care needs. Best to cast a broad net by describing your needs in general terms, then discuss the details with folks who inquire. Choose to whom you will disclose personal information. In an initial phone call, you might want your first inquiry to be about COVID vaccination status.

The best sources are personal contacts and referrals – and they're also

free. Job seekers are often advised that personal contacts are the best source for finding a position. That also works in reverse. Spread the word about your PCA opening amongst your family, friends, neighbors, fellow congregants within your faith community, and fellow students if you are in school.



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

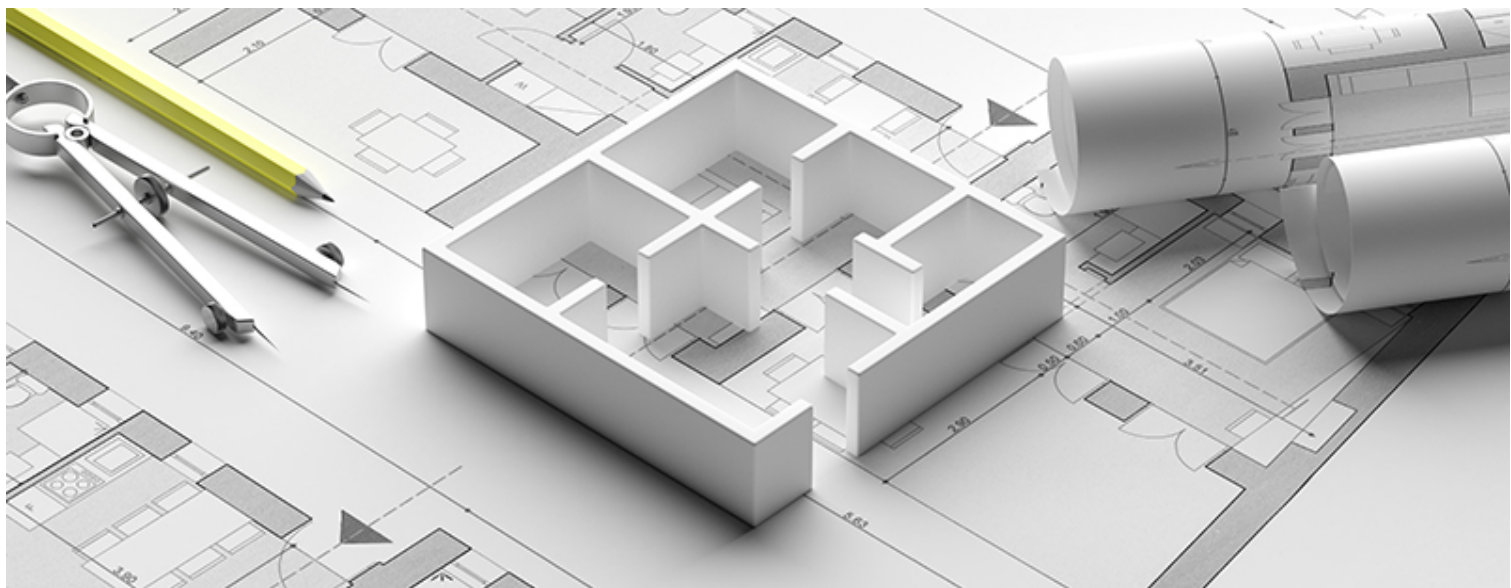


***By Penelope Ann Shaw***

As those of us in the disability community know well, the Supreme Court in its 1999 Olmstead decision recognized that over-reliance on nursing homes for long-term services and supports is a disservice to

the public, and in fact illegal - a form of discrimination under Title II of the Americans with Disabilities Act of 1990. States have been lax in implementing programs to provide these services and supports in local communities. So, I feel the time has come for the disability community - which has the knowledge, skills, experience, and resources - to take a direct role in getting people with disabilities and seniors out of institutions and into their own homes. We need to design and manage locally owned and operated, non-profit community-based housing, care, and services options.

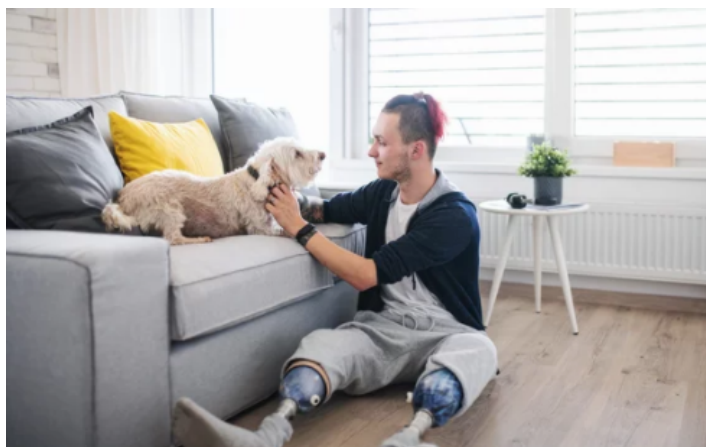
I propose that disability advocates form workgroups to find funding from research grantors, foundations, and philanthropies to develop the design and implementation of a pilot model. This model would include accessible private apartments and appropriate services that would allow individuals with both lower, and even high-care needs, the choice to live outside dehumanizing institutions. The workgroup would also need to create a management structure and define direct care workforce roles and training in an affordable cost-effective model.



I recommend seeking funding for a demonstration project from the National Institute on Disability Independent Living and Rehabilitation Research. This agency is well-known to support research to maximize independent living and the full inclusion of people with disabilities of all ages into society. It is important to note that the model should be designed similarly to what individuals currently living in their own homes with personal care assistant services are receiving. This model,

however, could not accommodate individuals who are at high risk of elopement, or who are combative and require more supervision and specialized care.

Long-term, I suggest there be advisory boards led by individuals with disabilities for these new independent living settings. Members of these boards should include consumers, other persons with disabilities, family members and representatives of disability, senior and personal care assistant organizations including local ADA commissions. The responsibilities of advisory boards would include providing advice and guidance on policy and direction for programs, expertise in the philosophy of independent living, required PCA skills and training, as well as oversight of regulatory, vendor, and overall fiscal issues including budget and operations. Board members could also provide resources, legal and technical assistance.



**Here are some of my initial thoughts about how a new community-based home and services model might look.**

- There should be a small building with accessible private

apartments. The building would have a central area for PCAs to congregate and be available to consumers when called. These PCAs would be hired and trained by individual residents with a focus on the principles of the disability independent living philosophy - to live a dignified life like everyone else with autonomy, and self-determination through choice and control.

- Care and services would be flexible, person-centered, tailored to the preferences and varying needs of residents. Consumers would make their own decisions and direct their own services, rather than receiving services from caregivers who think they are the experts in other people's needs.
- Some PCAs would be available around the clock 24-hours a day to assist individuals who do not need 24-hour help with daily living, but who need 24-hour access to assistance. This aspect of my suggested model is essential, as one of the biggest reasons why many people must live in nursing homes is because they require assistance with daily living both days and nights due to their functional limitations. We can eliminate this barrier to community living.
- At the request of residents, informal unpaid care from family members and volunteers from local organizations would be welcomed, as has always been the case in private homes.
- The model would require a paid manager to oversee the day-to-day building and business issues including maintenance and housekeeping of common areas, oversight of outside vendors, and budget. The manager would be available to address the concerns of residents and should preferably be a member of the extended disability community.
- Payment sources for housing, care and services could include Medicaid, Medicaid HCBS waiver programs such as Money Follows

the Person and Community First Choice, the Program for the All-Inclusive Care for the Elderly, and the Balancing Incentive Program among others. Money should be given directly to individuals so they can hire and pay their own PCAs, as is currently done by those living in their own homes.

- Consumers in this model would pay for their rent, utilities, laundry, furniture, linen, and food expenses themselves.



## **The benefits of this model - or a similar model - would be numerous.**

- It would expand the availability of home and community-based services.
- Since this model is not a skilled nursing facility, there would be reduced costs. No physician services. No nurses. No director of nursing. No consultant pharmacist. No dietician. No activities staff. Being cost-effective, the model would be viable as a non-profit.



- Through cost savings, consumers could offer living wages, benefits, and reasonable working conditions to their PCAs. Hopefully, recognizing the value of PCAs' work and treating them fairly would promote quality assistance and increase job satisfaction.
- Individuals with disabilities and seniors would benefit personally by having more choices for living outside institutions in true homes. They would be empowered to manage their own care. They would be living in community-dwellings with access to leisure and civic activities, creating greater opportunities for more meaningful and fulfilling lives. They would be empowered, have a sense of belonging, higher quality of life, and overall improved well-being.
- Expanded opportunities for home and community-based long-term services and supports would create conditions where people can reach their full potential and live purposeful lives in their neighborhoods. Benefits include disability direction; enhanced independent living; activities of choice in the community; autonomy; dignity; equality; self-determination; managing one's own care; social justice; maximum inclusion and integration.

Those of us with disabilities are well-suited to design such a pilot at-home model. We have already demonstrated our capabilities, resourcefulness, and expertise by running our own organizations. We have the ability to make real change by reimagining and reshaping community living through disability-directed programs.

We must have bold leadership to tackle the challenge of systemic institutional bias and deliver solutions. Becoming effective leaders as providers of housing and services is a way to make a tangible change and well-overdue difference in fulfilling the promise of Olmstead for equity and justice. In this way, we can help end discrimination and

promote inclusion - a human and civil right.

All of this is possible. We need ideas for a disability-led, consumer-centered model of housing to be put into action by those of us with lived experiences of these issues. We need to become engaged and develop a model that puts our values into practice.

## The future is ours.

---



*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.*



## **Voiceless** *By Sandy Alissa Novack*



I am eleven months into an episode of having little to no voice. After

many hours of voice therapy, I am pleased that my voice has started to return. I continue to work hard every day to achieve a balance between speaking and resting my voice.

During the pandemic, before going to in-person medical appointments, I wrote down the medical issues I wanted my physicians to know about and help me with. I did this to protect a voice that often couldn't come out, or if it did, was very strained. This shifted responsibility onto the medical provider to read my summary before asking me questions. For most of my replies, I nodded "yes" or shook my head "no." Other times, I jotted down a response on the pad of paper that I carry with me everywhere.

My primary care physician handled this process so well that at the end of one visit I wrapped my arms around myself and pointed to her. I was trying to express gratitude for her ability to maintain connection despite my voicelessness. Not only was I voiceless, but I was wearing a mask so she couldn't see the big smile on my face, and I couldn't give her a hug of appreciation at the end of the visit. She did not accurately interpret what I was trying to communicate but it was close enough, so I nodded. I am learning that communication is not always perfect, especially when one is voiceless. I empathize with people in the U.S. whose first language is not English and who must rely on non-professional interpreters to translate medical information.

Telemedicine also had its ups and downs. One doctor seemed to understand my broken, hoarse speech all the time. Another doctor tried hard to understand, and he got most of what I was saying. However, at the end of the visit, he recommended we suspend future telemedicine appointments until my voice was back. A third doctor could not handle my pained voice at all and seemed annoyed with me. She kept saying she could not understand me and needed to see me in person. Since this doctor was sheltering in place at home during the pandemic, I don't know if an in-person visit was possible. But even if we did meet in her office, what would she see? Just me wearing a

face mask over a mouth that could not project any better in person than I could virtually. Not being heard during a medical appointment is not only demoralizing but is also unsafe.

While voiceless, I was able to continue doing some volunteer work, partly because I like to write. For example, to write this article I do not have to say a single word; I just write my thoughts onto the page. For Zoom meetings, I sometimes communicate by typing messages into the Chat. This isn't perfect though because many Zoom attendees cannot read chat messages while listening to others talk. Therefore, some of my comments went unread. Still, I was able to stay engaged with no or little voice, mostly by communicating in writing.



Having a sense of humor lightens the day. When I first started voice therapy, I was asked what my goals were. After presenting my true goals, I quipped that I wanted to be able to sing opera. The therapist said, "Oh, you were a singer before this voice issue?" I replied, "No. But why not start singing as soon as you help me get my voice back."

The voice therapist knew from the start she was working with a client who had a sense of humor! Humor was also helpful when I was first referred for voice therapy and had no voice at all. I was given the phone number for the voice therapy department and told to call and make an appointment. I wonder if people ever stop to hear such comments come out of their mouths. The ability to think of what you are saying and to whom you are saying it to is no small feat. Having sense of humor and laughing at the absurdity of the situation helped.

Along with many frustrating experiences of being voiceless, I am

pleased to recount a moment of satisfaction and joy. I was asked to give a virtual oral testimony at a State House hearing on an issue that is a concern for many people with disabilities in MA. After consulting with my voice therapist about whether it was advisable, I registered to give an oral testimony.

I wrote my testimony out and rehearsed it in my head to make sure it did not go over the three-minute time limit. Mostly, I just hoped upon hope that when it was my turn to speak, a voice would find its way out. As if hoarding words to spare my throat, I tried not to say much before testimony time. I was sure about my words of advocacy and passion for the issue, but what if I opened my mouth and nothing came out or only extreme hoarseness? I reassured myself by having a backup plan; I would submit written testimony and still be heard whether a voice came out of me or not.

Many people were giving oral testimony. Part of me listened to their points and counterpoints, but all of me was wondering about the questions of the day: Would my voice, which has advocated at past State House hearings, be audible today? Can someone advocate without a voice?

My name was called, and like a horse leaping out of the starting gate my voice broke free and I was off! I was in a race to complete the entire testimony before my voice gave out and the allotted three minutes were up. I heard words coming out of my mouth, but I knew my voice was not strong. Still, I tried to enunciate each word clearly and at a slow enough pace to be heard by the legislators. I did it! It was the first time in many months that I spoke for a full three minutes without stopping. I felt like I had just won the Kentucky Derby, and it was exhilarating!

But what exactly had I done? I had managed to speak but was my voice audible enough for others to hear? I quickly emailed someone who was attending the hearing remotely. Did you hear me speak?

Was I audible? Did it fall flat? I hit "send" and within minutes a return email arrived. She told me I had been "awesome!"

For the next few days, my throat was very sore from my three-minute version of the Kentucky Derby. At my next voice therapy appointment, my therapist and I were quite pleased that I was able to give a spoken testimony. There is still a lot of work ahead to get my voice fully back, but I remain intent on communicating in *every* way I can.



*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.*



*An ongoing series of articles about Walter Kiver who lived with Muscular Dystrophy (MD); as did his son, daughter, and grandson. Articles are written by Joan Burrows, Walter's wife, in memory of her beloved husband who passed away in 2001, to honor his legacy of living life fully and helping others while facing his own challenges.*

## **Communicating from the Heart**

## ***By Joan Burrows***

Walter and I loved to talk. Soon after we met, we began having long conversations on the phone. Walter was alone, stuck in one room and I was divorced with one of my three children still living at home.

Later, Walter and I moved in together. We still talked a lot and got to know about each other – or childhoods, parents, and families. Walter and I both liked to sing, so I often played the piano, and we sang. He liked Country music and I liked Broadway show tunes and pop music. We learned about and grew to like each other's music. Walter even learned the French version of "Dites Moi" from the musical, *South Pacific*!

About three years into our relationship Walter attended Middlesex Community College and graduated with high honors. It was during this time, I noted he seemed disoriented at times. One day he hit his head entering the van. He had never done that before. I also noticed Walter didn't finish his favorite meal of clams, so I made a doctor's appointment. The doctor said everything looked okay but ordered a blood test for the following day.

The next morning, I told Walter it was time to get up for his appointment. Little did I know his response was going to be the last words I would hear for a long time. He said, "I don't compute." I thought he was being funny (he had a great sense of humor), but within a few minutes he was no longer responding so I dialed 911. The fire department was one street over and came fast! The doctor said Walter had pneumonia along with his already collapsed lung. They had to put Walter on a respirator, or he wouldn't make it.

A long day turned into a long night. Somewhere about 3 a.m. Walter awoke! His daughter, Marcia, and I rushed to his bedside. His eyes showed fear and confusion. We assured him and told him the doctor said the respirator would only be short-term. Walter began pulling his

arm out from under the sheet. Marcia noticed he was writing some letters on the sheet. She was an expert on his new way of communicating right from the start! Walter asked us questions. We didn't have all the answers, but we told him what we knew. After a bit, he calmed down and so did we. Nurses came in and out to check on him and the respirator settings. Walter began to 'write' to us again using his finger to write letters on the sheet. The nurse was truly amazed because she had never seen anyone do that.

One nurse tried hard to read Walter's finger writing; others did not have the patience. I told the head nurse that he needed to be heard just like anyone else. But still not everyone, not even doctors took the time. So, I spent most of my time there. They let me sleep in the big waiting room off Walter's room and I could hear when the respirator alarm went off. I always got up and went into his room.

The weeks went on. They were going to try to wean him off the respirator and talked about performing a tracheostomy. We asked several doctors for advice and trusted his doctor at the Muscular Dystrophy clinic when he said, "Go to a Boston hospital." We did! After two weeks, Walter had a tracheostomy. He was finally able to turn his head without pain *and* he could eat! Eventually, he even got some of his voice back, which no one thought he would because his vocal cords had been damaged by the long intubation. We left the hospital about two months later, in time for Thanksgiving. As Walter said "goodbye" in a soft voice, the two speech therapists said very quietly to me, "We did not think he would ever be able to talk again."

Back home, Walter resumed his role as chairperson of the Acton Commission on Disability. Walter ran the meetings and spoke on local cable shows with a panel of other members. One day the cable station sent over a video of one of the shows. I asked his daughter and his grandson to come and watch it with us. It was to be a celebration of sorts. After a few minutes of hearing himself talk, Walter left the room. I did not understand, but Walter told me he was extremely



upset at the sound of his voice. Walter never watched any more tapes. It was too sad for him.

After that, we pursued getting help with other ways for Walter to communicate. He went to several appointments at Boston hospitals. He tried to use eye movements to print out letters on the computer. It did not work. After several trips, he was given an alphabet board. When Walter was laying down in bed, he did not have the strength to lift his hand and point to the letters. When sitting up, he was able to use one arm to support the other, but it was very slow. Walter went back to writing with a pencil when sitting up and using his finger in bed. It worked! Some PCA's were better than others at understanding him, but they all tried hard. We also placed a buzzer under his hand so he could alert someone when needed.

When Walter could no longer hold a pencil, he used his finger to write on a table or a pad of paper. One day when he was sitting in his chair, he began making letters on his pant leg, "h a v e I t o l d y o u I a t e I y t h a t I l o v e y o u." I answered, "yes."



---

*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.



***Dolls and Stuffed Animals:  
Marking Time, Place, and People***  
***By Ms. Love***

During the pandemic, have you found yourself thinking about who and

what you value? What anchors you to memories of the cherished people, places, and special occasions in your lives? Many of my anchors are my stuffed animals and dolls.

I got my Thumbelina doll from family when I was four years old. I remember the day I took her to nursery school with me. I sat in the back seat of the carpool station wagon with other nursery school children. My legs were stuck straight out in front of me to better balance Thumbelina on my lap. She had an adorable face that I loved to kiss and a soft body I loved to hug close to me. She did have a hard dial sticking out of her back. If I turned it, she would move her arms and legs for a little while. But my mother removed the dial so I could hug Thumbelina more tightly. Thumbelina was only going to nursery school that one day for Show and Tell, but back at home, she and I were inseparable.

Perhaps in training to become the Ms. Love you now know; over the years my collection of dolls and stuffed animals has grown, as does my love for them.



One year, my mom got me twin bears by sending in proof-of-purchase seals from the paper towels she bought. Another year, I got proof-of-purchase seals from a friend who bought Sara Lee bagels. I mailed them in to get a stuffed polar bear with a bagel in its stomach area.

An older child in my neighborhood once saw my stuffed animals and, with obvious disgust, said that I was too old for childish things and I should get rid of them. We soon parted ways and I certainly kept all my dolls and stuffed animals. The older child was not an anchor in my life, but my dolls and stuffed animals were. As a college student, I was

given bears to place on my dormitory room bed. Then, there is the bear I was given by my first beau, and the bear friends gave me to celebrate my first job after graduating college. Nowadays, these dolls and bears live with me in my apartment. They are joined by other stuffed bears, squirrels, dogs, and even a penguin. All are anchors to the people who gave them to me and the loving relationship we shared.

There is a tutoring business in my neighborhood with a storefront that makes me smile because there are five extra, extra-large stuffed animals sitting on a couch! Each has a note with a certain number of points written on it attached near their ears. I assume the points mean that students who are being tutored earn points for their studies. When they earn a certain number of points, they can take home one of the stuffed animals. I frequently pass by this window and stand there beaming at each one of these animals. I imagine they have lots of stories to tell about the people who walk by their window. I wonder if they ever talk about me. I wonder if they wish I were younger and needed tutoring for school so I could earn enough points to bring them home with me. I wonder if they know that I am happy some lucky students get to bring them home. I wonder if they know I wish those lucky students never outgrow them and, like me, they too grow up with seeing wonder in the world and knowing how to love.

Each doll or stuffed animal marks a memory to a certain time and place; and people who cared about me, just as I cared about them. Of course I keep them, and I always will. What marks memories for you of times, places, and special people in your past or current life? In the article, ["What Owning 75 Pairs of Earrings Does for Me: And how every earring somehow changed me"](#) the author, Caroline Leavitt, shares another perspective on what and why a person values certain items.



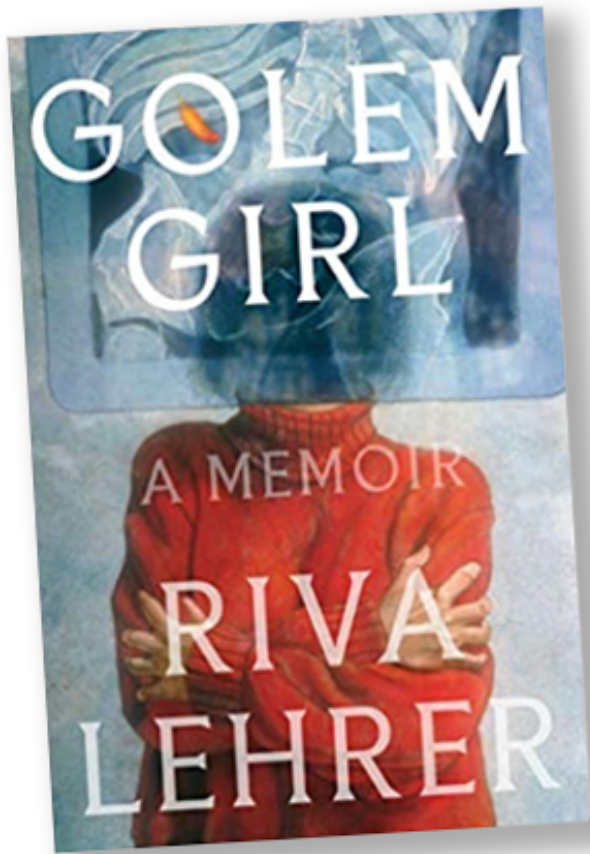
*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions, and suggestions to Ms. Love at [DI.LoveandIntimacy@gmail.com](mailto:DI.LoveandIntimacy@gmail.com)*

*Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy and may be edited.*

---

# The Bookshelf





## ***Golem Girl***

by Riva Lehrer

***Review by Mary Grimley-Mason***

*Golem Girl* is a memoir by artist and writer, Riva Lehrer. She writes about her extraordinary journey of living with a severe disability. She learns that rather than trying to be “normal” she can accept her condition as an opportunity for creativity and recognition of the multiple variations of the human body and mind. She discovers this through the development of her art.

Born with Spina Bifida in 1958 in Cincinnati, Ohio, Riva’s childhood was dominated by her mother’s intense drive to make her daughter “normal.” After multiple orthopedic operations, she was able to walk without crutches and disguise the signs of her disability.

Growing up, her mother taught her many things that a young woman should know, including a detailed description of sexuality and reproduction. However, she warned Riva that though she was outwardly an eligible sexual partner “boys are just not interested in girls like you,” implying that Riva would probably stay unmarried.

Despite these warnings and enduring endless medical interventions, Riva tells her story as one who sees the world with curiosity, humor, and enjoyment. She attended the Condon elementary school, which

believed disabled children should have the same educational opportunities as all children and be treated as fully part of normal society. Lehrer writes, "We were kids being kids, making friends, fighting enemies, forming cliques... not freaks or outcasts." During her eight years at the school, Riva enjoyed classmates with many different handicaps and felt no exclusion. She also discovered her own interest in art.

Although Riva was protected by a loving family and this inclusive education experience, she was still aware that society saw the disabled person as different and as she describes it, as a "monster." With ironic humor, she sees herself as part of the ancient Jewish legend of the golem, described as "an image endowed with life, 'a man-made creature' fashioned from the earth and often portrayed as a monster." Riva embraces the image of a golem for herself, ultimately connecting it with her creativity.

Riva's relatively tranquil life in high school was interrupted by the tragic death of her mother who, suffering from extreme pain from a botched operation, took her own life with an overdose of medication. Riva was devastated. Throughout her memoir, she returns to stories from her mother's life and how they relate to herself.

During her college years at the University of Cincinnati, Riva began to find herself. She majored in art history but was really interested in developing her own emerging talents as an artist. Though she felt she was not like the other art majors, she was surprised when the department offered her free tuition to continue for a Master of Arts. She was pleased but decided not to accept it.

By this time, Riva had ignored her mother's warning about being sexually ineligible. She writes, "For the first time in my life, I had deliberately broken the bounds of normalcy." She had her first love affair with an architectural graduate student who was able-bodied. They were together for eleven years despite often living in different

locations. They both explored other relationships and Riva discovered her bi- sexuality with other women partners. She moved to Chicago, took classes at the Art Institute of Chicago, and found the students there seriously engaged in art and politics. She also discovered the work of Frida Kahlo, whose self-portraits often showed a disabled body. Her partner introduced her to Lesbian Queer culture and Riva felt welcomed by this community. But later, in retrospect, she writes, "I was still a golem made from mud."

**"Disability is the great billboard of human truth," she writes. "Add it to any discourse and we can see what humanity really values."**

It was not until she found "disability culture" that Riva ended her search for accepting herself as a disabled person and as an artist. After experiencing new physical problems and two operations, she joined a chapter of the Spina Bifida Association, a connection she had always avoided. She experienced a new perception of herself; "I'd believed I could visit the world of disability while holding myself above it." She discovered an inclusive identity that embraced race, queerness, class, and national origin. She also became politically active for disability rights and other oppressed groups.

The turning point for Riva's work as an artist was when she joined Chicago's "Disabled Artists Collective." Here she felt at home with artists, writers, and performers who rejected any shame imposed on them. Instead, they celebrated their creativity and inclusiveness. Riva developed her own sense of portraiture, which had been evolving for some time. Each portrait was collaborative and included meeting with the person several times before she began the painting. It was a mutual experience and offered a new perception of the human body and portraiture. Her subjects were people with "severely challenged bodies", mostly members of the collective who were enthusiastic about her work. So too was the art world's reaction to her inventive art form.



Riva became a well-accepted artist with regular exhibits of her work and a member of the faculty of the Art Institute of Chicago.

In her 2019 epilogue, Riva celebrates the achievements of Disability Culture and what it reveals about human nature. "Disability is the great billboard of human truth," she writes. "Add it to any discourse and we can see what humanity really values." She feels the movement has made great strides for justice.

However, in a second Epilogue, written in 2020 after the Pandemic and the reaction to it, she is concerned that the movement has been weakened and "will be shoved back to the eugenic horrors of eighty years ago."

Nevertheless, she is hopeful. "Disability finds new ways to do things", she writes. "Sometimes it is the monster who saves us." She concludes, "It takes a monster to face down the dark."



*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."*

INFO BRIEFS • INFO BRIEFS • INFO BRIEFS



## **Waypoint Adventure: Accessible Hiking and More!**

Fall hiking is here! [Waypoint Adventure](#) is offering accessible **day hiking** opportunities at various locations across Massachusetts from October through December. Enjoy the fall foliage as you explore accessible trails. Assistive equipment will be available for use.

**Hiking Program Cost:** \$20 per participant. Two or more guests of program participant may attend at no charge.

**Registration is required.** To view the full schedule of upcoming programs and to register, visit [Waypoint Adventure's Program Sign-Up Site](#). A Waypoint staff person will reach out prior to the program to connect about the day and do a brief intake so the participant has a successful program experience.

**For more information:** Contact Steve at [sdasman@waypointadventure.org](mailto:sdasman@waypointadventure.org) or 603-489-3313.

To learn more about the organization and view the wide range of fun

indoor and outdoor accessible adventure programs, visit [Waypoint Adventure](#).



Editorial Board (L-R): Sandy Alissa Novack, Raymond E. Glazier, Joan Burrows, Marianne DiBlasi, Mary Grimley-Mason, missing: Mary Jane Fietze.

**Editor:** Marianne DiBlasi

**Editorial Board:**

Joan Burrows • Mary Jane Fietze • Raymond E. Glazier  
Mary Grimley-Mason • Sandy Alissa Novack

**Contributing Writers:**

Joan Burrows • Raymond E. Glazier • Mary Grimley-Mason • Sandy Alissa Novack  
Penelope Ann Shaw • Tim Sullivan

**Advisory Members:**

Bill Henning • Ruth Kahn • Oswald Mondejar

**Graphic Design:**

Louise Martling, Eleventh Hour Design

[www.11th-hour-design.com](http://www.11th-hour-design.com)

**Mass General Brigham Liaison:**

Colleen Moran

<http://spauldingrehab.org>



*Disability Issues* • Vol. 41 • No. 4      Fall 2021

**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 [massgeneralbrigham.org](http://massgeneralbrigham.org)

The *Disability Issues* newsletter is a free and independent publication. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

**To Subscribe:** The *Disability Issues* newsletter is available without charge to anyone who finds it useful and interesting. To subscribe, visit [Disability Visibility](#) and enter your information in the Subscribe to Disability Issues form.



Share



Tweet



Forward



*Copyright © 2021 Disability Issues, All rights reserved.*

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.

**Our mailing address is:**

Disability Issues C/O Public Affairs  
Spaulding Rehabilitation Network  
300 First Avenue

Charlestown, Massachusetts 02129

Want to change how you receive these emails?

You can [update your preferences](#) or [unsubscribe from this list](#).

[www.disabilityvisibility.com/resources/disability-issues](http://www.disabilityvisibility.com/resources/disability-issues)