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DisABILITYissues

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

Vol 41 • No. 2 • Spring 2021



TABLE OF CONTENTS

From the Editor | Marianne DiBlasi

Ready & Able: Staying Active "Virtually" | Tim Sullivan

The PCA Corner: PCAs and Animals | Ray Glazier

Walter's Place: Music is an Expression of the Heart | Joan Burrows

Love & Intimacy: The Reckoning | Ms. Love

The Bookshelf: Being Heumann: An Unrepentant Memoir of a Disability

Activist | Mary Grimley-Mason

Disability and Identity | Penelope Ann Shaw

Dreaming of Community: Families Creating Together | Ed Pazzanes

Information Briefs:

- Boston Area Crisis Center Webinars



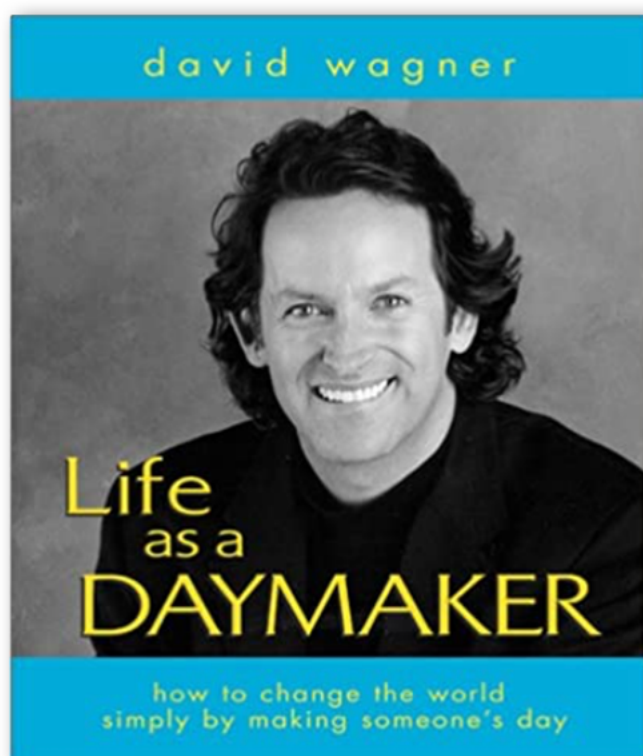
From the Editor...

Dear Readers,

Recently I was on a call with a friend who told me she ran into another friend who was having a hard day. To brighten her friends' spirits, she gave her a bouquet of daffodils from her garden. My friend casually mentioned, "I love being a Daymaker!" I asked, "What's a Daymaker?" She replied, "It's doing something nice for another person. It makes my day happier, and I think it makes theirs happier too." I was intrigued! I had never heard the phrase "Daymaker" before and wanted to know how she came up with it.

My friend told me she became a Daymaker after reading David Wagner's book, *Life as a Daymaker*. As soon as our call ended, I ordered the book. (I later learned Wagner has a [Daymaker Movement](#) website.)

This small, thin book is packed with gentle wisdom, encouragement, and many suggestions for ways to spread kindness. Wagner describes a Daymaker as, "a person who performs **intentional acts of kindness** with the intention of



making the **world a better place**” – for ourselves and others.

Being a Daymaker sounded like a fun and easy way to spread positivity so I gave it a try. As is my nature, in my early days of being a Daymaker, I made it very complicated by working hard to do something “big” that would have a profound effect. I became frustrated, which made being a Daymaker difficult to sustain. When I noticed this pattern, I decided to relax and play a game with myself by asking, “What is the simplest Daymaker thing I can do today?” I began noticing how opportunities to be a Daymaker flowed easily into my life.

One example is: The other day, I picked up shoes at the cobbler. Instead of running in and out, I slowed down and asked, “How was your weekend?” I saw his eyes light up as he told me about his garden and the plants he is growing in the greenhouse, getting them ready to put in the ground on Memorial Day weekend. We chatted for a few minutes about gardens and vegetables, both of us smiling underneath our masks. When I left the store, my heart was full of more joy, and I trust his was too.

Wagner weaves quotes from various people throughout his book. One of my favorites is from Mother Teresa, ***“Kind words can be short and easy to speak, but their echoes are truly endless.”*** If I apply this to my visit with the cobbler, I imagine the next few

customers who came into the store felt his joy, then they too may have spread joy to others, and in turn, they may have spread it to even more people. I enjoy the image of "joy echoes" reverberating out into the world from our one small interaction. For myself, I went home feeling happier and on my next Zoom call, I laughed more easily and brought lightness to the meeting. It gives me hope to believe each of us has the ability to change our own lives and the lives of everyone around us with something as simple as engaging in intentional acts of kindness.

As you read this issue of *Disability Issues*, I invite you to think of it as a Daymaker scavenger hunt full of clues for intentional acts of kindness. What are acts of kindness you can give to yourself? Which ones are kindnesses to others? When is kindness received? How is there potential for someone to act with more kindness toward themselves or another? What other Daymaker experiences do you find?

With hope for changing the world simply by making someone's day.

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.



READY & ABLE



Staying Active "Virtually"

By Tim Sullivan

Since the pandemic began in the spring of 2020, businesses and organizations of all types have had to rethink how they offer services. For those that provide recreation and fitness opportunities, this presented a whole additional level of challenges. For the Spaulding Adaptive Sports Team, they recognized it was critical for the physical and mental health of their participants to find a way to offer programs.

Spaulding Adaptive Sports Program started offering virtual classes online to participants several times a week to exercise virtually together from the safety of their homes. Since it launched, these programs have had more than 1,000 participants who have benefitted from virtual classes like yoga, boxing, dance with Parkinson's, exercise for stroke and traumatic brain injury, and more. "These programs were critical for supporting the health and wellness of an even broader

community when so many were isolated and unable to participate in their regular fitness and community activities,” said Mary Patstone, Spaulding Adaptive Sports Program Director.



The yoga program in particular is unique in that it is offered to both the community and current patients. The Virtual Yoga program is a partnership with the Spaulding Burn Model System and Spaulding Adaptive Sports Centers has grown tremendously. Virtual yoga and meditation classes are offered 10 times a week, benefiting more than 100 people per week since last summer.

This is much more than just a typical yoga class; each class is staffed by an instructor specially trained in adaptive yoga, a virtual host to manage the technology, an on-site physical therapist for hybrid classes, and a safety coordinator to help participants – anywhere in the country – receive urgent medical help if needed.

Studies have shown that practicing yoga can help reduce pain, calm nerves, improve flexibility, and help healing for both patients and caregivers – regardless of the type of injury or illness. It's no secret

that yoga increases muscular flexibility and strength, but it is also a proven treatment for back pain, knee pain, circulation issues, PTSD, and other chronic pain conditions. Yoga helps to ease the stress, anxiety, and depression that can create and reinforce pain.

"Many of my patients tell me that yoga has helped advance their recovery," says Dr. Jeffrey Schneider, Medical Director of Burn Rehabilitation at Spaulding Rehabilitation Hospital. "I'm grateful that we're able to offer this program to help people with their unique recoveries."

For more information on programs from Spaulding Adaptive Sports Centers call 877-976-7272 or email at

SpauldingAdaptiveSports@partners.org



Tim Sullivan is Director of Communications, The Spaulding Rehabilitation Network & Partners Continuing Care.



PCAs and Animals



By Ray Glazier

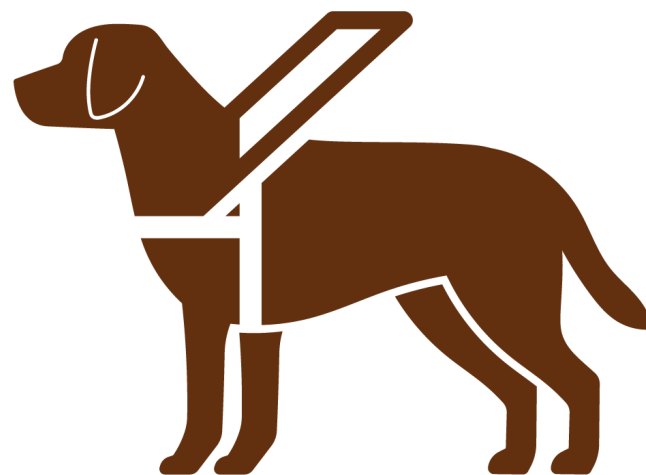
Most households have at least one animal of some kind – a dog, a cat, a bird, a fish, a reptile, or whatever. And their care can pose a problem for consumers and surrogates alike if there are no able-bodied household members to provide care in situations where the consumer owner is not able to perform all the necessary tasks independently. MassHealth frowns upon PCAs providing pet care like cleaning litter boxes or walking dogs unless the animal is actually a service animal. But... in my humble opinion, almost any dog is an emotional support assistance animal, providing unconditional sloppy kisses. However, emotional support animals are not considered service animals according to Massachusetts law or the ADA, although the right to keep them is recognized under both the Federal Fair Housing Act and the state fair housing law. And just to be clear, service animals are not simply pets designated as such. No true service animal user wants strangers petting the animal, for example, a guide dog while it's working for its owner/handler.



Practically speaking, the definitions of 'service animal' and 'emotional support animal' are both a bit fuzzy around the edges. The strict legal definition of 'service animal' only applies to dogs in both federal and

state law, although Massachusetts only recognizes “a dog that accompanies an individual with a sensory and or physical disability.” Federal law allows for a broader definition of service animals under the Americans with Disabilities Act (ADA). [The ADA defines service animals](#) as “dogs that are individually trained to do work or perform tasks for people with disabilities.” But the ADA (not Massachusetts) also recognizes miniature horses as service animals. Service animals should be permitted to accompany the person with a disability pretty much anywhere – doctor’s office, restaurant, bus, train, plane, hotel, movie theater, etc.

“However, animals whose sole function is to provide comfort or emotional support are not [emphasis added] service animals.” **“People are not required to possess any certification or identification for a service animal. Service animals are not required to wear a vest or badge.”**



Beware of phony internet 'certification' schemes and sales of bogus identifying paraphernalia. [All direct quotes above are from 'About service and assistance animals' at Mass.gov.]

So, where do PCAs come in? A consumer might, for example, ask a PCA to walk his/her pet ferret during a defined work shift and record that time as PCA hours. The ferret is by no means a service animal. This is not in the consumer's Care Plan, but then neither was travel to last week's Red Sox game. The basic premise of the MassHealth PCA Program is that the consumer is approved for a certain number of PCA service hours based on evaluation of care needs. The consumer decides how to allocate those hours to what specific tasks and at what specific times. That said, the PCA could decline if the animal care task

felt objectionable or demeaning. The consumer might then need to call on an able-bodied friend or family member to help out with pet care.

Service animals and assistance animals aside, there is definitely something to be said for a pet as a modulating influence in a consumer's home, and I speak here from personal experience. My two live-in PCAs, both of them adult men, fawn over Dobby, our not particularly attractive household rescue cat, giving her hugs and petting even when she decidedly is not in the mood for loving. The guys talk to her, project their moods onto her, tell her their troubles. She puts on her Yoda face and appears to listen intently. Then Dobby blinks knowingly, yawns, stretches and ambles to the window to check out the birds at the feeder on the back deck, her day's work done.



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



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.



*Music is an Expression of the **Heart***

By Joan Burrows

My husband, Walter Kiver, loved Country music and sang along with his favorites. He always had the radio on his wheelchair tray tuned to Country station. I did not know a lot about Country music, but I learned. We sang, "On the Road Again" when we got our first van. Walter also learned many of my favorites show tunes and other music. We enjoyed singing exuberantly! Remembering the music Walter and I created together brings a smile to my face.

Music is an expression of the heart and has always been a huge part of my life. These are some of my heart-memories of music.

Growing up, my family was very musical, and we sang often. Mom played the piano and Dad the banjo-mandolin. Every Sunday, we listened to Opera on the radio. Because the Operas were spoken in their original languages of Italian, German, etc., mom told us what was happening as the story unfolded.

One of the family stories that was retold over the years was about a time when I was 3-years old. The doctor entered the home for a house call as the song, "The Isle of Capri" was playing. He heard a child singing and asked if it was my older sister, Nancy. My mom said it was 'the baby,' Joan. I was lustily singing while rocking back and forth in my crib. Mom often played music on the radio and I loved to sing! In kindergarten, I was chosen to sing a solo at the Christmas show

and I loved every moment of stardom. When my mom's sewing circle met, I often made an appearance and sang for the ladies. Mom told me I was a 'ham.'

At age 5, I began taking piano lessons. The next year I saw my first Broadway Show in New York City (NYC). This became a regular event. From age 6 through Music School, this became my favorite thing to do. We sang show tunes after the plays – *South Pacific*, *The King and I*, *Carousel*, and more. I wanted to take voice lessons but was told I had to wait until 16 because of concerns about injuring my vocal cords. During my senior year of High School, I was chosen for the lead in Gilbert and Sullivan's *Patience*. I was thrilled! I loved every rehearsal and every performance.

Music helped me get through school. Although it was undiagnosed, I was a child with Dyslexia and ADD; two words not known to educators at that time. Music and sports were the only two areas where I felt successful. After High School, I attended Mannes Music School in NYC and took drama lessons with a private teacher. I majored in voice, minored in piano, and took theatre, theory, and ear training courses. While living in New York, I auditioned for some Broadway shows and saw many operas. It was wonderful to experience the full grandness of an opera performance, rather than just listen to it on the radio. I love all the songs, stars, and memories of the performances I saw. I used to sing them often but, sadly, my voice can no longer sing them. I still love listening to them though.

My first husband, Edward Burrows, played piano and there was always music playing in the house. My three children took singing and piano lessons. When my oldest daughter was about 6, she expressed an interest in playing the piano. Her friends wanted lessons too, so I became a piano teacher. I ended up giving piano lessons for more than fifty years, long after my daughter and her friends stopped taking lessons. Now I teach a 68-year-old friend and a 9-year-old using Skype. I enjoy sharing my love of music.



My newest neighbors are a mom and her three daughters. As I recover from health issues, they've been helping me a lot. To my delight, I learned they are all musicians and play piano, cello, violin, and flute. They also enjoy singing. One day, the girls were at my house and when they finished helping me, they asked if they could play my piano. Of course, I said, "Yes!" They had fun and I was thoroughly enjoying listening to the music. On the next holiday, I asked if they would come over and play for me, which they quickly agreed to. Mom came too and she thoroughly enjoyed hearing the girls play as they used to when they were younger. The next holiday, more music, followed by four birthdays with music and also cake!

I learned they have a piano upstairs but do not play it because the people living below them complain. One of the girls plays the cello and was finishing treatment for a hand injury. She was excited to begin playing again, but when she did, the neighbors downstairs began banging on the walls and playing the TV loud. The girl was in tears. I quickly invited her to come down to my place and play anytime she wanted. She did and she still does. I love it! Sometimes it is "dinner music" for me. Sometimes a friend is here. When my sister calls, she

loves hearing the music playing in the background.

During the last few months of Walter's life, he was in a coma and I often had music playing. I brought a tape recorder into his bedroom and played our favorite music for him. It helped me and I hope it helped him. I sometimes sang along with the music. The song I sang most frequently to Walter was the love song, "Always" by Irving Berlin, that croons, "I'll be loving you, Always.... Not for just an hour. Not for just a day. Not for just a year, but Always".

always



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.



The Reckoning

By Ms. Love



When I was little my dad and I used to watch cowboy or Western shows together. At that age, I just liked to see the cows, horses, and the good guy win at the end.

As an adult, however, watching repeats of some of these shows, I notice many of them come with some sort of reckoning. A family member grieving over the shooting of their loved one confronts the killer with a gun, or the men who corralled another mans' cows and branded them as their own is brought to justice by going to jail or being run off the land.

As I write this article, it is December 2020. This past month, I have been sick with a virus (no, not the pandemic's coronavirus). Because of the fever or fatigue from being sick plus the constant news about illness and death from COVID-19, I am having intense thoughts about people I've lost during the pandemic and throughout my life. I am thinking about people from my past and wondering how they are doing, which led me to google a few online. Maybe it is not a good idea to google people while having a fever since what you find out can lead to a reckoning *with* reckoning. But I did and I can't forget what I found in my internet search.

Let's start with Lorraine, a friend from high school decades ago. Not

only was she smart and very artistic, but she was kind and a great listener. My grandfather was very sick at the time. I visited him often with my parents, but I don't recall my parents ever asking how I felt about my beloved grandfather being ill. Lorraine kindly listened when I told her how my grandfather was doing and how I was feeling. In my virus-filled state, I wanted to let Lorraine know that I have never forgotten her kindness, so I did an online search. I found a good amount about Lorraine online. It seems she lost her second husband to cancer a few years ago, yet is surrounded by a large, loving family and many friends. She now lives in a part of the country far away from me.

I found three phone numbers attached to her name and last week I tried to call her. Two of the three numbers were not in service. The third, however, reached a voicemail with a woman's voice saying, "This is Lorraine, please leave a message." After all these decades, I couldn't be sure if this was my Lorraine's voice, so I left a succinct message with my name, phone number, and said I was looking for Lorraine H. and hoping I had reached the right person. Thus far, no one has called back. Is it because my googling on the internet gave a phone number for the wrong Lorraine? Is it because so much time has passed, she forgets who I am? Is it because she remembers who I am but so much has happened since high school that she would rather let go of the more distant past?

If googling had given me a clear address for Lorraine, I would drop her a short note, but internet searching isn't perfect, and I only found partial address information. I plan to call the number one more time. If I get the answering machine again, this time I will leave a longer message and say, if she is the Lorraine H. of my high school, the pandemic is making me think of people I have known, and I want her to know that over the years I have thought of her from time-to-time. I want to thank her for her kindness and let her know that I regret we didn't keep in touch over the years. She doesn't need to call me back if she doesn't want to, I just want her to know that when I have

thought of her over the years a smile always comes on my face. This will be a good kind of reckoning for me; one that is very satisfying because I am getting a chance to express gratitude to someone who influenced my life.

The other two people I googled are more difficult reckonings – two men I dated in two different decades who both asked me to marry them. For one, I found an obituary and learned he died four years ago. The obituary describes his death as “sudden,” but I know his family had health issues, as did he, so perhaps those were the contributing causes. Some of the so-called facts in the obituary I know are untrue because I had been a part of his life for multiple years. He had an openness to people with disabilities because of his first-hand experience with the disabilities in his family of birth. He never experienced my disabilities and health issues, but he was interested in learning about them. I had loved him. A reckoning happened when our relationship ended. Now, I am left continuing to reckon with all the questions and issues that were never answered or addressed during and at the end of our relationship. Perhaps the final reckoning is something that needs to end since he can no longer explain anything. Perhaps the larger moral is, I shouldn't google people, especially while I am dealing with a virus, because I may learn new information that has repercussions on my heart.

Nowhere is that last sentence clearer than when googling the other man who was the first man I ever dated. I loved him dearly, but I was young and wanted to know him longer before considering marriage. Also, we had a few significant stumbling blocks that he wouldn't discuss with me, which included his attitude toward disability, religion, and sex. If I could go back in time with the benefit of age and life wisdom, perhaps we would be able to address those issues. But there are no time machines and I learned he is now married with multiple children. What could have been or might have been, most definitely wasn't at the time. Perhaps I should never have googled him and revisited this relationship. Unlike the Western TV shows, this reckoning

didn't have a gun; just me with a computer, a stubborn virus, intermittent fever, and a pandemic that has already taken the life of a dear friend. Reckoning upon reckonings.

Dear readers, if the pandemic is pushing you to have your own reckonings, please know we are not alone. I've read articles about people who are facing their mortality during the pandemic and are writing wills. **If you are finding yourself addressing some reckonings right now, be gentle with yourself.** Regardless of what happened in the past, you are now living the best life you can at this moment, and that is enough.

If you read this column often, you know your Ms. Love likes music. In consideration of this column today, I thought you might appreciate the following songs:

- "[Somebody That I Used to Know](#)", performed by Gotye.
- "[Send in the Clowns](#)" performed by Frank Sinatra. The song isn't specifically about clowns; it's about human foibles, regrets, love, and second and third chances we sometimes get in life to get it right.

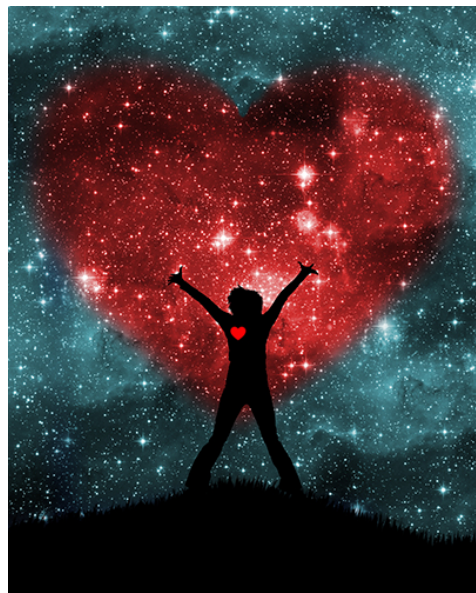
If you are in the mood for something other than music, you may enjoy the article, "[Touch & Pleasure Are Essential: Here's How to Give Them to Yourself](#)." As the pandemic continues and many of us are missing hugs and other types of touch, this article is especially relevant

March 2021 Addendum: During the past few months, your Ms. Love opened up Pandora's box of reflecting on the past, which has burrowed into my soul. The reflections continue, but I notice my thinking has shifted. Despite the difficult ending of relationships with the two men I wrote about, I realize they each confirmed something I already knew about myself – I have a lot of love to give.

While I hope your reckonings aren't as knockdown and drag out as

mine were, if you do revisit the painful parts of past relationships, I hope it may eventually give you some peace, like I now feel. I suggest giving yourself plenty of space and time to process your emotions and, please, be very gentle with yourself. You may discover that even the relationships which had a sad ending may reveal hidden gifts.

Although the last few months were challenging, I'm grateful for the gift of remembering that I was in love and was loving. Moreover, I remind myself of other people I have loved over the years and those who have loved me. Who wouldn't want to be reminded of that?! Going forward, here is what I choose to focus on regarding past relationships and for future relationships – loving fully.



The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com. Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.

The Bookshelf

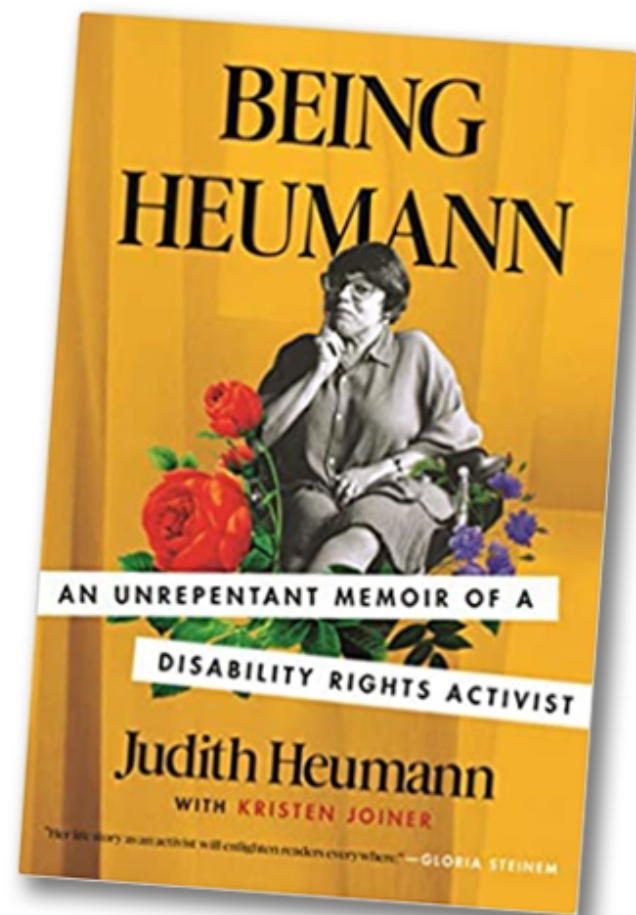


Book Review:

Being Heumann: An

Unrepentant Memoir of a Disability Activist

by Judith Heumann and
Kristen Joiner



By Mary Grimley-Mason

In the dedication of her autobiography to her parents, Judith Heumann writes: “To my mother and father for the belief that I could do anything.” That belief became her life’s philosophy.



Paralyzed at eighteen months from polio and using a wheelchair most of her life, Heumann became a leader in a fight for equality for herself and all people with disabilities. She succeeded in bringing about social change, recognizing the shared humanity of all people.

What makes Heumann’s story so special to read is the way she brings us intimately and transparently into her life and her fight against discrimination. Judith was born in Brooklyn. Relying on a wheelchair for mobility, Judith played outside with other children who were from immigrant families like her own. Her Jewish German father and

mother, survivors of Nazi Germany, refused to accept any discrimination against her disability. Her mother insisted that she attend classes in grade school although the school system argued that her wheelchair might be a "fire hazard." Years later when Judith graduated from Long Island College, her father ignored the college president's insistence that his daughter could not receive her degree on stage with the others. Without discussion, her father calmly turned her wheelchair around and bumped it up the steps so Judith could receive her diploma on stage with her fellow students.

Heumann became a leader in the Disability Rights Independent Living Movement, eventually joining Ed Roberts at the Centre at Berkeley, California. It was from there that in 1977 in San Francisco she led the longest takeover in U.S. history of a government building. This peaceful occupation of the headquarters of the U.S. Department of Health and Education eventually resulted in the federal recognition of the civil rights of people with disabilities in the American with Disabilities Act of 1979.

The occupation lasted almost a month. Heumann described the group of protesters as "soldiers in combat." They were joined outside the building by hundreds of supporters, who supplied encouragement, food, and necessary medications. The Black Panthers sent hot meals to the protestors and the Salvation Army contributed mattresses. Heumann's extraordinary leadership skills became clear during this episode of her life. She led the protesters in planning their strategy and in discussions and negotiations with the government officials still coming to their offices. She insisted that every voice should be heard, a principle she held throughout her life of activism. She believed that coming together, working toward a common goal, was the only way to change wrongs in society.

"The way society thinks about disability needs

to evolve, as too many people view disability as something to loathe or fear.

By recognizing how disabled people enrich our communities, we can all be empowered to make sure disabled people are included."

— Judy Heumann, Disability rights activist and author

Many of the group who prevailed in the Sit-In had known each other since meeting at Camp Jened, a summer camp for people with disabilities in the Catskill mountains of New York. The camp was recently featured in the award-winning documentary, *Crip Camp: A Disability Revolution*, showing on Netflix that tells the story of Camp Jened and the people who attended. The camp culture was influenced by the counterculture hippie values of the late 1960s and the seventies. The young people who ran it believed in a less structured and more relaxed atmosphere. The campers loved it! For the first time, they felt a part of society and free to be themselves. Experimenting with marijuana and developing romantic attachments for the first time was part of their liberation, but also learning that they could work to make their lives better and fight against discrimination. Judy attended Camp Jened as a camper from ages 9-18. She then became a counselor and inspired campers to become socially active and her camp friends often came together to fight for change.



After the struggle for the American Disability Act was won, Judith went abroad working with the World Institute on Disability and while there, visited her father's birthplace in Germany. Her international work eventually included membership in the World Bank and an international human rights treaty intended to protect the rights and dignity of persons with disabilities.



Time in Washington in the Clinton Administration found her the head of the Office of Special Education and Rehabilitation Services. She was nervous about taking such a demanding job but was encouraged by her husband, an activist born in Mexico, who she met and married in 1992. He was her constant cheerleader. In that position, Heumann became "the highest-ranking disabled person in the US government."

In her closing chapter, Judith Heumann returns to 'her story' and how her family taught her to see her disability as a challenge to take advantage of all opportunities. She also acknowledges the important group of friends from the Jened camp who believed that "we can design our cities and our society in a way that fosters belonging and community rather than segregation and isolation." The Obama administration backed their policies and made a difference for the

disability community, especially with the Affordable Care Act. Although Heumann says their activities received an assault from the Trump administration, she notes that the disability community “kicked into high gear in multiple ways.”

In the conclusion, she urges her readers to “Become an activist.” She quotes Shirley Chisholm, the first black congresswoman, who said, “You don’t make progress by standing on the sidelines, whimpering and complaining.” Working together, Judith Huemann concludes, “We are leaders of inclusiveness and community, of love, equality, and justice.”



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."





Disability and Identity

By Penelope Ann Shaw

Who am I? How do I see myself? These are questions with deep meaning, existential questions about my presence on this planet. To answer them I had to reflect on my life.

My early formative life experiences laid the groundwork for my whole life. I grew up in Bloomfield Hills, Michigan, which was a privileged, wealthy, white town where the famous Romney family lived. Rejecting these values, I balanced my experiences by spending a lot of time with my maternal grandparents who were ordinary, kind, loving, and liked everyone.

I made the choice to be educated in public schools, except for two impactful years when I, a young Protestant girl, resided at St. Mary's Academy in Monroe, MI. I was sent there by my father for being a rebellious 12-year-old who didn't want to go to school during 7th grade. I saw firsthand the caring work of the nuns with needy children

and older people in nursing homes. Prayers for the deceased was my Buddha experience; an introduction to suffering, old age, and death.

In high school, I volunteered at an orphanage. During and after college, I worked at Ypsilanti State Hospital for the so-called mentally ill on deinstitutionalization. I also worked or volunteered for, an afterschool program for low-income children, and a food pantry, and a shelter for people who were homeless.

These combined experiences increased my consciousness of social issues. But it was my two native-born French high school teachers who taught French classes that influenced my career choice. Wanting to be like them, I fell in love with the differences of people and cultures of the world. I spent my college freshman year at the University of Grenoble and my junior college year at the University of Strasbourg, both in France. I earned a doctorate in French Language and Literature. In my professional life, I was an academic at several universities where I both taught and administered programs for students studying French and English to Speakers of Other Languages.

But it was other work I found to be most meaningful; being a Peace Corps trainer for French West Africa and directing a program in the Dominican Republic, using USAID funding to develop and implement a training program for people who were homeless. This program provided individuals with the English language and employment skills so they could find work in the burgeoning tourist industry and afford housing.

My faculty appointment in the Mason Program at the Kennedy School of Government at Harvard was very personally powerful. I taught mid-career international government officials who were on leave from their work in diverse government departments such as education, healthcare, central banking, and transportation. They came to Harvard to earn a master's degree in public administration to acquire more knowledge and skills in their respective fields. Upon returning to

government positions in their countries of origin, they could apply this education to improve the lives and well-being of their people. I was excited to offer them academic support. Among my responsibilities was to make sure their English language and writing met the Harvard standard for graduate-level academic papers.

Career choices combined my two interests: 1) foreign languages and cultures, and 2) improving the daily lives of others. I feel these experiences helped shape how I responded later in life when I identified as disabled, and what it meant to self-identify as disabled. In 2001, the third phase of my life was beginning at age 58 when it was disrupted by an acute phase of Guillain-Barre syndrome. I was not expected to live, but I did. It was a very long recovery, which resulted in being permanently paralyzed, a significant mobility disability.

In 2006, I advocated for fair fares from the Massachusetts Ride transportation for persons with disabilities. I was published in the *Boston Globe* and was then asked to join with disability activists on the board of the Disability Policy Consortium of Massachusetts. I now identify as disabled, but it is only one part of my identity. This is not all that I am. I incorporated this facet into earlier ones.

Being a public advocate and activist, I have been in the news occasionally. I am now a speaker and published writer. As society still marginalizes us people with disabilities, we continue our struggle for full access and inclusion, our civil right to reasonable accommodations, and equity. Self-identifying as disabled is a political statement, a form of resistance to empower myself rather than to feel powerless. I have new goals and roles in society, including being a plaintiff in an Americans with Disabilities Act Title II lawsuit against the town where I live. We are working to improve access to town services for children and adults with disabilities.

I have benefited by describing myself as disabled. I am confident in my identity. I am part of an empowered community with common

interests. I meet new and interesting people with a commonality of lived experience about how disability affects our lives. I have a sense of belonging where I can process my concerns. My work provides me with both instrumental and social support. I have gained resources and tools, intellectual stimulation, and opportunities for living well. As an advocate and activist, I have developed new skills and had new insights about life. This has resulted in having a meaningful, interesting existence – medically, functionally, socially, politically, and an overall more satisfying life.

At age 77, the answers to my crucial questions about self-representation and figuring out who I am have become clear. I think of myself as a person who has continued my lifelong interests. My life is a journey of reflection and discovery to find myself, of growth, and a search for identity, which is an existential quest to define myself. I have learned that identity is a process always in the making, influenced by unexpected events one could never imagine, like a disability. It is complex, fluid, mutable, ever-changing, and evolving.

Who am I? This is who I am: I am still the same Penny, the person who from a young age was interested in difference and social justice in its' many forms. To identify as disabled is not something to be feared. It is only part of my identity.

This is my story.



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



**Dreaming of Community: Reflections
from *Families Creating Together*
By Ed Pazzanese**

Although progress has been made in understanding that individuals living with a disability have many strengths, we need to acknowledge their contributions and their right to confront stereotypes that can limit them to reach their full potential. It is a human right to fully participate in all communities, workplaces, homes, and educational settings.

Families Creating Together (FCT) founded in 2008 is an inclusive Expressive Arts Program that welcomes and includes children of all abilities. Our mission is to provide inclusive community opportunities in the arts for children and their families.

One of the exemplary residency programs designed for 25 participants which was created by Jody Steiner was called, *The Power of Our Stories: Sign Language, Movement and Visual Arts*, featuring Ayisha

Knight Shaw, a Storyteller / Actress / Teacher. She and Wendy Jehlen, an award-winning dancer and teacher, co-lead families to finger spell their names, play non-verbal theatre games and create informal storytelling performances.



"In a world where people are continually in a process of defining themselves and their communities, arts programs can be an integral part of building community. In every neighborhood, issues of identity and belonging, of respecting different ages and heritages, and of learning demographic ways demands public venue. Arts programs bring elders and youth together to learn, create and change." Quote

from "Culture Builds Community: Elders Share the Arts" by Perlstein, Susan. *Generations*: Winter 1998/1999.

Visit [Families Creating Together](#) to learn more about their award-winning multigenerational, creative arts programs which serves children of all abilities and their families.

Edward Pazzanese has 40 years of experience teaching Visual Art / Mixed Media to children of all abilities. Settings include at Dorchester House (History Mural Program), Community Art Center (Cambridge, Mass.) Dorchester Center for The Visual Arts, Brookline Public Schools, Nantucket Island School of Art and Design. In 2008 he founded Families Creating Together. He holds a BFA. from Mass. College of Art and a Master of Education from Wheelock College.

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Boston Area Rape Crisis Center Webinars

[Responding to Disclosures of Sexual Violence](#)

Wednesday, May 12, 3:00–4:00 p.m. ET

Closed captions and ASL interpretation will be provided with this webinar. In this free webinar for providers, learn how to support survivors of sexual assault, harassment, and abuse. Presenters from the Boston Area Rape Crisis Center (BARCC) will cover the impact of

sexual trauma as well as BARCC's SEEK (safety, empowerment, empathy, and knowledge) model for responding.

For more information and to register, visit <https://barcc.org/events/details/responding-to-disclosures>.

Bystander Intervention to Prevent Sexual Violence

Thursday, June 17, 11:00 a.m.–12:00 p.m. ET

Closed captions and ASL interpretation will be provided with this webinar. In this free webinar for anyone who wants to make their communities safer, you will learn tools and skills you can use as an active bystander to prevent sexual assault, harassment, and abuse. Presenters from the Boston Area Rape Crisis Center will talk about what you can do and a wide variety of strategies you can use.

For more information and to register, visit <https://barcc.org/events/details/bystander-intervention>.



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Disability Issues • Vol 41 • No. 2 Spring 2021

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

Spaulding has been awarded a Model Systems designation in three specialty areas - Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by U.S. News and World Report in its Best Hospitals survey with a #2 ranking in 2018-2019. Spaulding was recognized in

2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit www.spauldingrehab.org

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.

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