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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.

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From the Editor...

Dear Readers,

Last week, I had the great pleasure of attending the Institute for Human Centered Design's (IHCD) international webcast where they discussed the newly released film, *Best Summer Ever*. The storyline is about young love, high school cliques, and following your heart. The movie is a teen-genre musical with people of all abilities and various types of mobility devices performing in eight elaborate song and dance numbers.



The webinar began by showing *Bigger than Us*, a behind-the-scenes short



documentary about the making of *Best Summer Ever*. After the documentary, it was a special treat to be in conversation with the two leading actors, Shannon DeVido and Rickey Wilson Jr., and co-producer/co-screenwriter, Andrew Pilkington (shown in the photo, courtesy of [Zeno Mountain Farm](#), the movie's film studio.)

The movie is making history for being the first-ever Screen Actors Guild registered feature film made by a majority of cast and crew members with disabilities. This award is something to celebrate, and it's appalling that this is the "first-ever" film in history to hire this many talented professionals with disabilities.

About 20% of Americans live with disabilities, yet only about two percent of screen roles depict disabled characters – and those parts have generally gone to non-disabled actors. Watching this Glee-like teen musical reminded me of seeing Kevin McHale, the actor who played Artie Abrams, a wheelchair user in the TV show, "Glee," walk across the stage on his two very able-bodied legs to receive an award. This was a show that promoted diversity and inclusion and I felt tricked by their casting choice. Maybe I shouldn't have, because it's so rare that a person with a disability plays the role of someone with a disability, but I believed the actor had a disability. Maybe those of you who have keener "disability radar" than me picked up on it sooner and were saved from being tricked.



Given my “Glee” experience, I was delighted to see the cast of disabled actors in *Best Summer Ever* in roles such as auto mechanics, policemen, football players, and sportscasters. The storyline for these actors had nothing to do with their disability; they were playing characters in a film. As Pilkington said during the IHCD webinar, “The story can just be the story. The story doesn’t have to be the disability.”

In the *Bigger than Us* documentary, I was even more delighted to see many crew members working behind the scenes were people with disabilities, from leading characters, producers, and screenwriters to boom operators and grips. In the film industry, participation by disabled crew members is practically non-existent. Co-producer and independent filmmaker, Pilkington, commented that he is usually the only person with a disability working behind the scenes. He went on to say, “This type of film is valuable. Success for *Best Summer Ever* could help push the movie industry to hire more crew and cast members with differing abilities.” May this film be a turning point for integrating talented professionals, who happen to have a disability, into each aspect of moviemaking.

If I’ve piqued your interest to watch *Best Summer Ever* it is available on these platforms: [Amazon Prime Video](#), [Youtube](#), [Vudu](#), [Apple TV](#), [Google Play](#).

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.



Getting Active "Virtually" Any Way Possible

By Tim Sullivan

Like so many things since the onset of the pandemic, finding new ways to deliver services, provide support, and enjoy activities requires adapting. For the team at Spaulding Adaptive Sports Centers (SASC), that is par for the course. Each day the SASC team finds solutions to allow their participants of all abilities to enjoy a wide variety of sports and recreation all year and throughout New England. As Spaulding reopens programs and services, the team at SASC has used their skills, experience, and ingenuity to create multiple options for people to be active and socially connected.

“Adaptive sports and recreation are so much more than the activity; it is about being with others and the connections our clinicians create to allow our clients to enjoy that sport and activity. This past year and a half forced us to find different ways to create the spirit of camaraderie that is at the core of our programs. Fortunately, through our donor-

supported programs and lessons learned, we expanded our ability to offer rich experiences whether onsite or online,” stated Mary Patstone, Executive Director, Spaulding Adaptive Sports Centers.

The benefits of fitness and exercise, especially for persons with disabilities, are well documented. Reduced activity combined with isolation and lack of social connections can create substantial barriers to overall health and wellness. The COVID-19 Pandemic only exacerbated those risk factors. For the team at SASC, they knew their services were crucial to the health and wellness of their clients, so they created new ways to enable participants to enjoy being socially and physically engaged.

When in-person sessions were not allowed during COVID-19 lockdowns, the SASC team created social events such as viewing parties on Zoom, virtual meet-ups, virtual exercise sessions, and videos for clients to practice that helped bridge the gap. It also allowed the SASC clinicians to learn important lessons that they could use to expand services and reach clients for whom travel posed significant challenges.

As the summer of 2021 allows for expanded in-person activities, the SASC has created an expansive “hybrid” list of onsite activities and virtual offerings. There are ample opportunities for people of all abilities to restart their sport, learn a new one, and have some fun. The SASC operates in three regions: Boston, North Shore, and Cape Cod. Each location offers a mix of core and specialty offerings.

“We deeply believe there is a sport and activity for everyone. We offer a diverse mix of sports and will find a way for people of any ability to connect in some way. The best way to recharge your spirit and improve your health is to spend some time during this summer season connecting with others and reclaiming the feeling of joy we all need. We look forward to welcoming you back soon,” concluded Patstone.

For more information about the following programs or to register, please call 877-976-7272 or visit: spauldingrehab.org/adaptivesports



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

In-Person SASC Programs

Core Programs

- Cycling
- Kayaking



Specialized SASC In-Person SASC Programs

Boston

- Rock Climbing
- Outrigger Canoeing
- Sled Hockey

Cape Cod

- Mountain Biking
- Yard Games

North Shore



- Target Sports/ Archery
- Tennis
- Archery
- Therapeutic Horseback Riding starts in September

Virtual SASC Programming

- Fitness Programs
- Inclusive Fitness Training
- Upper Body Pump
- Floor and Core
- 30-min Fitness
- Cardio Conditioning Class
- Adaptive Boxing
- Yoga Programs
- Movement and Meditation



Specialized Virtual Programs

- Found Sound
- PWR! Moves for Parkinson's
- Dance with Parkinson's



The **PCA** CORNER



PCA Retention

By Ray Glazier

As any experienced PCA consumer or surrogate knows, a good PCA is hard to find. And likewise, any PCA knows that a good boss is hard to find. So, the pointers offered here actually work in both directions. The PCA situation is a part-time partnership, so treat it as one. A partner who is treated with care and respect has good reason to stay in the relationship.

Make sure that the other party knows that you value her or him as a human being, not simply as a way to get out of bed or to earn a paycheck. Show your concern about the person's family members and friends in a non-intrusive way. What are their major concerns? Educate yourself about hobbies and favorite activities and engage with this topic in mind.

Tips for creating a harmonious partnership with your caregiver or your consumer:

- In the very beginning, clearly define the expectations – tasks and timetable, then live with it until there is mutual agreement on changes.
- Write down this understanding for both of you to sign – an informal contract.
- Periodically review and update this document as either party feels necessary.
- Treat the other person as you would want to be treated – *the Golden Rule*.
- Don't make unreasonable demands of time or money above what you agreed upon.
- Exercise extreme patience, don't react hastily, let events unfold to their conclusion before passing judgment.



- Hold your tongue – sharp words cannot be unsaid. There is no “do-over.”
- Surprise the other party with unexpected rewards – a kind word, fresh fruit, a flower, their favorite candy, a small favor – just some little thing that shows you really care.
- Don't be too picky about things that aren't crucial – choose your battles.

A cautionary tale: A clinical psychological friend was visiting a paralyzed, home-bound patient and remarked on how the home was so perfectly organized and spotless, immaculately clean, and tidy (unlike mine). My friend was also puzzled that there appeared to be a new PCA answering the door each week when he came to call. I pointed out that these two facts could be linked.



Raymond E. Glazier, Ph.D. is a longtime consumer in the MassHealth PCA Program 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.



Love & Our Medical Providers **By Ms. Love**

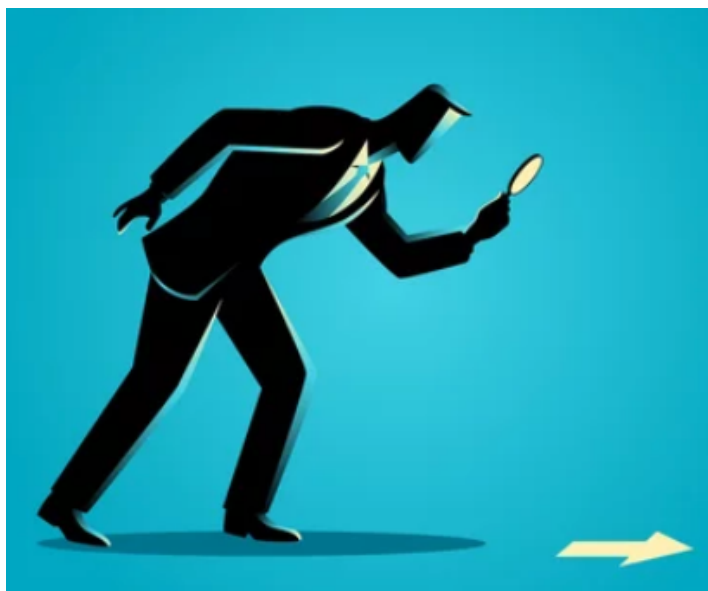


Dear readers, over the years your Ms. Love has written about love between parent and child, love of friends, dating relationships, and much more. But, as people with disabilities, we have never really discussed love and our medical providers.

When I was growing up, my family had the same doctors for decades. In fact, the obstetrician who attended my birth was still seeing me as my gynecologist decades later. He and my mother traded mystery books, and when he retired, he let my mother pick one of the paintings he painted that hung in his office as a keepsake of their long

relationship. Since my mother died, the painting now hangs in my home as a tribute to the relationship I had had with this doctor. Today, people frequently change jobs and move, requiring them to change doctors. Additionally, medical offices are set up so when you're sick, you see whichever doctor is available. Given these changes, it is nice to think about the long-time connections and caring relationships we still can sometimes have with our medical providers.

For example, I have been seeing my rheumatologist for 17 years I am not good at guessing people's ages, but I would guess he may be nearing retirement. Since the pandemic has turned his solo practice on its head, I wonder if he's considered retiring early and closing his office. That would be too bad on many levels. First, there aren't as many solo practitioners around as there used to be decades ago. Due to insurance bureaucracies and economy of scale issues, group practices and hospital offices dominate in the urban area in which I live. A new rheumatologist might put me on the patient assembly line of fifteen-minute-only appointments in a large office where many providers could take turns seeing me. My current rheumatologist sees me for extended-length appointments regularly. With him, I am not on an assembly line and he specializes in my diagnosis. Not only does he see more patients with my diagnosis than any other doctor in MA, but he also concentrates on the more complex patient presentations.



By seeing me for extended-length appointments regularly, he can stay on top of my condition and treatments. Over the years I have repeatedly been amazed at how my rheumatologist reminds me of Paul Drake, the private investigator for Perry Mason in the old Raymond Burr episodes of the popular television show.

He puts together disparate clues to understand my rheumatological situation as well as other body systems' issues that have escaped the understanding of some of my other medical providers. He is a smart, smart man, and he's just plain nice. No matter how sick I am, I always feel that I am in good hands when I see him.

Plus, I like connecting with people who are important in my life and I have loved learning bits and pieces about his life over the years. So often we know little to nothing of the personal lives of our medical providers. Therefore, I cherish, the little details I have learned about this doctor, including the fact that at the beginning of his professional life he was a physician for a circus, and discovering he grew up in the same city as my father.

Provider relationships do not always have to be as long as the one with my rheumatologist to touch my heart and be meaningful. I have been fond of four physical therapists. All have been from the same physical therapy office, which speaks volumes of the type of therapists they hire. In the past, I've gone to other therapy offices where they act like all patients are sports players and highly athletic. The one I go to now does treat athletic folks, but I also see people who look like me and use a walker. The therapists try to adjust exercises precisely to my capabilities. One therapist literally saved my life when I was having a severe reaction in her office because of a new medicine I was taking. Eventually, she had to leave the therapy practice due to a health condition of her own. Another therapist made me laugh a lot; she left the therapy office when she began raising a family. A third therapist I connected with left to start a small practice closer to her home. Alas, now I face saying good-bye to yet another therapist from this practice: She is leaving next week to get married and is moving out of state.

Each of these physical therapists made out-sized contributions to my physical functioning, but just as importantly, they loaned me their vision that my functioning could improve, and I could maintain other

functioning. When you are deep down in a hole, and someone not only throws you a rope to climb out but climbs into the hole to hoist you up with kindness, encouragement, and cheerleading, it is a form of love.

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Next week, when I must say goodbye to Jamie, I will wish her happiness in her new life with the man she is marrying, and I will give her a pandemic hug from a distance with the best smile I can muster. It's hard to have to say goodbye to professionals who have made vast differences in my well-being, but I know they must move on. Still, I am very thankful that they were "loaned" to me and gave of themselves so fully, trying over and over again to get my body to a better place. I will miss Jamie's ability to make my body ache as if I am in Army boot camp, yet inch-by-inch I am able to creep to a better place of functioning. I will miss the respectful way she listens to stories of new aches and pains. I will miss the way she shared the details of her wedding as if, perhaps, I am as important in her life as she is in mine.

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



Building Your Own Accessible Home with Habitat for Humanity

By Sandy Alissa Novack



According to a November 2020 report by [Habitat for Humanity](#), one in seven households in this country pay half or more of their income on housing. Yet as pricey as homes can be, we all deserve homes for shelter, to house our family, and just to rest our weary heads. In the [fall 2018 issue](#) of *Disability Issues* my colleague, Ray Glazier, wrote about buying and renovating an old house to meet his accessibility needs.

Tina Pedersen, who graced our pages in the [spring 2019 issue](#) as Ms. Wheelchair Rhode Island, has taken the idea one step further and built her own accessible home by remodeling an already existing home and working with Habitat for



Humanity. I recently had the opportunity to interview her about it.

Tina, please explain to our readers what kind of home you had before and why you were interested in or needed a new home.

Tina Pedersen (TP): My husband and I rented our previous home. It was supposed to be a rent-to-own, but within the first year I became paralyzed, and our two-floor home wasn't accessible, so it wasn't something we wanted to buy. The search for accessible housing began and it was endless. My wheelchair never fit in the bathroom or the landlord didn't want permanently accessible items, including a ramp in front of the building. So, we had to make do; constantly shifting everything from place to place to get by.

Did you have any luck finding an accessible home that was already built? Were there any on the market? If so, did they have the accessibility features you needed?

TP: Finding an apartment or home that fit all my needs was not possible. We had so many realtors, friends, and even working with all home grants and programs, but no one could find me what I needed. Adaptable is not accessible and finding something for a family that is not in a group setting doesn't exist. It raised the issue of availability for accessible homes. I am working on fixing that, starting with Rhode Island where I live.

Tell us about the process with Habitat for Humanity.

TP: I reached out to Habitat for Humanity and started the long process, which began two years ago. We just wanted a simple one-level home that was fully accessible. We passed the interview process and then had to wait for land or a home to remodel to become available. Finally, we received word in March 2020 that a home to remodel was available, but it may take some time. We did not start working on the home until July 2020. Volunteers for Habitat for Humanity are only available on Saturdays, so doing a huge job like this was going to be a long process. Given the pandemic, we had to add safety guidelines and we knew it was going to be even more difficult. I was given permission to use my own crews during the week, which allowed us to have smaller crews working at one time. We completed the project during the pandemic and moved in on December 24, 2020.

How long was the whole process of applying, building, etc.?

What was your role throughout the process? Was your husband or other relatives involved in building the house?

Have you ever designed and built a home before?

TP: The whole process was 2.5 years, but so worth it! My role was to put in sweat equity hours, gather teams to work, coordinate donations for needed items, and guiding compliance with the ADA. I put in over 1,000 hours, along with my son and volunteers.

My husband was working crazy hours during the pandemic, so he did what he could. I didn't have any experience with renovating a home for accessibility. This experience changed my life. We learned so much and we know every nook and cranny of the house. It has been the best home improvement class ever!

Did you get to pick your building supplies, such as what material the accessible ramp is made of?

TP: I had a lot of say in matters, but it came down to who donated items and what worked best for the price.



Did you pick where you wanted to live or did Habitat for Humanity? Is your neighborhood accessible, so you can run errands at the post office, store, etc.?

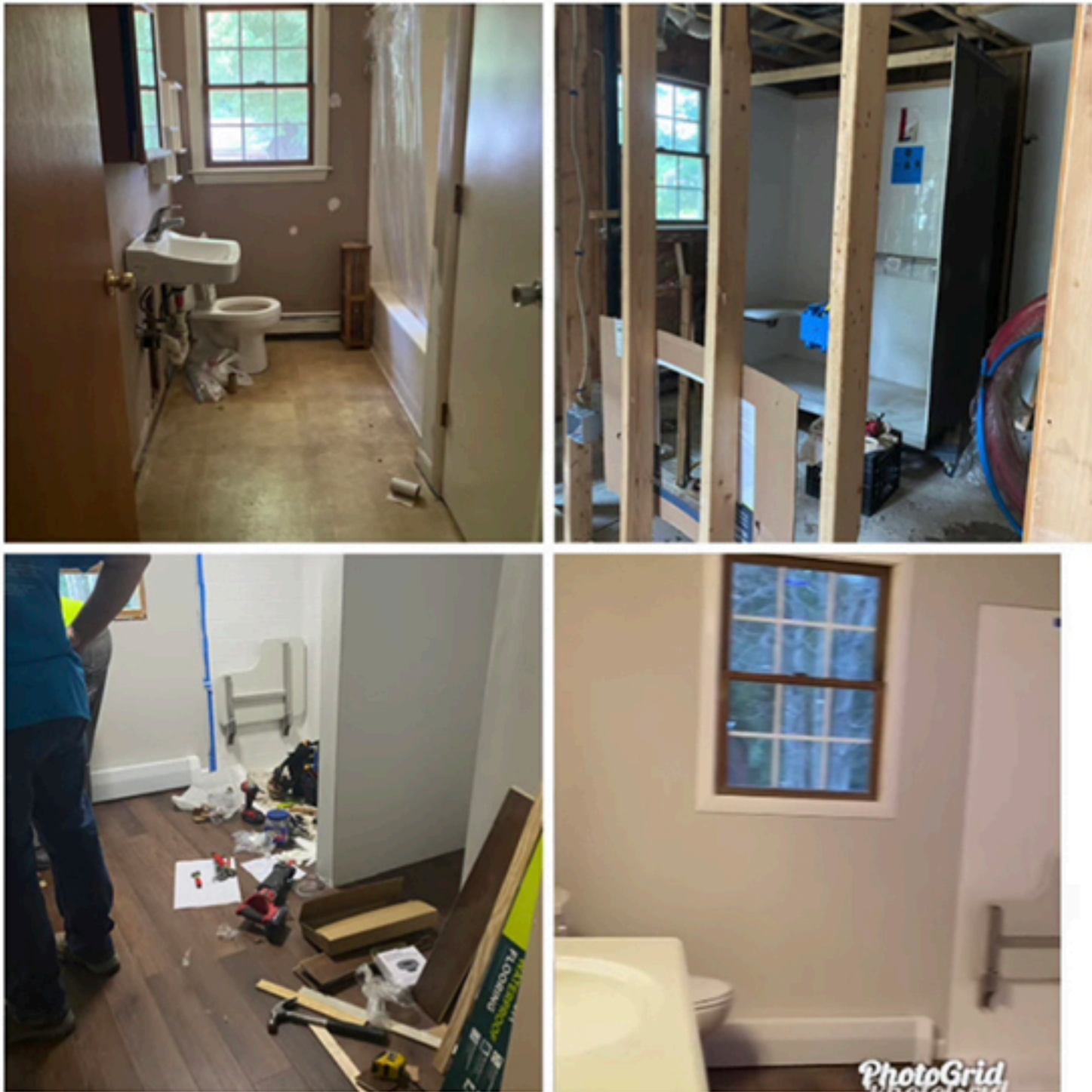
TP: The house was chosen by availability only. We are living in Burrillville, RI on a beautiful cul-de-sac. My neighbors are amazing. They have been welcoming and helpful since the start of the entire project. The area around me is great, but accessibility is poor in Rhode Island in general. But at least many of the places are willing to work with me on becoming accessible and welcoming to all. The organization I founded, [RAMP – Real Access Motivates Progress](#), is truly helping this process.

What indoor accessibility features would you like to share with us? What other features do you like?

TP: My kitchen is fully accessible, and the layout is purposeful with how I cook and what I need. This includes the stove being close to the sink. The corner cabinets with built-in Lazy Susan's are convenient. We were also gifted accessibility items like a voice-activated microwave, a sensor trash can, a vacuum that sucks up dirt so no need for a dustpan.



The bathroom has a roll-in shower, shower seat, grab bars, and a sink I can roll right up and park my wheelchair. I chose a side-sliding barn door, which provides a 40-degree opening into the bathroom.



The bedroom has an accessible closet and a custom-built vanity that my wheelchair fits under. Also, there are plenty of electrical outlets and room to charge my electric wheelchair and other medical equipment.

Our parlor is very open and set to be fully functional. It opens to the dining room, so it is easy to get around in my motorized chair.

We were also gifted a chairlift so I can enjoy my finished cellar and do my own laundry.

What is your favorite space in your new home and why?

TP: My favorite is the new bathroom. After spending six years

dragging myself onto the floor and sliding around just to use the shower or toilet, this bathroom is a dream come true!

Since you moved in, what have you noticed about your ability to be independent as compared to living in your previous home?

TP: My stress level has gone down, and my increased independence has built up my confidence. Because of the pandemic, I've been staying inside more. I also contracted COVID-19 from a delivery person. Fighting COVID-19 is hard but being able to use my bathroom and live in my home with greater ease has been life-changing.

How many homes per year does Habitat for Humanity build?

Did they build fewer homes during the pandemic?

TP: My entire remodel was done during the pandemic. Habitat can do one or two homes a year if land and houses are available. Unfortunately, that is not always the case.

Would you recommend Habitat to others who have accessibility needs?

TP: Habitat for Humanity is meant to help give people a step up. You do need to pay for your home and there are qualifying factors. You need to work on the home, take financial classes, participate in home improvement classes, and more to meet all their criteria. I know that many people think it is a free home. Some drop out when they find out it is not free and there is work involved.

What else would you like readers to know about Habitat, what it takes to build a new home, and what it feels like to finally move into your new accessible home?

TP: It felt great to prove so many people wrong and show them how much I can accomplish from my wheelchair. Swinging a sledgehammer became my new free therapy and showing everyone different ways to accomplish tasks was an accomplishment. I appreciate my home even more because it was my blood, sweat, and tears that went into

creating it.

Please see the Info Briefs near the end of this newsletter for information about **Habitat for Humanity's** free resources and support for homeowners.



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.

Happiness is...
By Joan Burrows



During a recent visit from my fifteen-year-old neighbor, she asked me, "How does one find Happiness?" Her question prompted me to reflect on my childhood and my life with Walter.

As a child, I had lots of friends. I recall being happy, except for the times when my mom punished me, or I fell and got hurt, or was sick. Music was always playing in the house from the radio or piano. As a family, we all sang and enjoyed the music. Music is still my "go-to" place for a lift when I'm feeling down. The flowers and birds in my yard bring a smile to my face every day. My friends and neighbors are also important to me, and now that we can once again safely hug each other – that is happiness!

My husband, Walter, had some rough times growing up. He had a stern Mother and a disease no one knew he had. He also had some vision and hearing problems. I don't know if he saw doctors who didn't diagnose him or if he just didn't see a doctor. I do know his type of Dystrophy was hard to diagnose because it begins with the facial muscles. I know at some point Walter's dad built him a better way to access their home. It may have been when he was in his teens and his legs were weak.

Walter began dating a girl in High School. She became pregnant and they got married. A girl was born, followed two years later by a boy. Walter adored his children. His wife went to work at a local restaurant and paid little attention to them. Walter's daughter, Marcia, told me many sad stories about their childhood. She and her brother often asked their dad to get a divorce.

One night Marcia came home to see her dad on the sidewalk in front of their house. It was raining and he could not get up. The two

children talked, and decided that Walter's son, Dennis, would move in to take care of his dad, and Walter's wife would leave! After a few years, Dennis began taking a double-major at college and wanted to move in with his girlfriend, so Marica, her husband, and their baby son moved in and took over the caregiving role.

Marcia was very young when she gave birth to her son. Her doctor told her that both she and her son had Muscular Dystrophy. It was only then that the family learned Walter also had Muscular Dystrophy. No counseling was offered to support the family. At the time, Walter was working at a mill factory in his town. Early one morning, Marcia found him sitting at the kitchen table. He told her he'd been sitting there all night because he wasn't able to get up and go to bed. Walter left his job and spent his days in his room. Soon he could not get out of bed and his care became more demanding. Dennis helped whenever he could.

Where Walter got his will to live and enjoy life, I do not know. I do know playing music, especially Country music (his favorite!), talking to his sister in NY every day, and playing with his grandson brought him great happiness. I also think his sense of humor brought him happiness. The first time I experienced his humor was a few weeks after I began working at the day program where Walter was now attending. One day while I was collecting song sheets after a group sing-along, I came to Walter and he did not release the papers. I thought he might have a problem with his hands, so I didn't want to pull harder. I looked up to see two eyes that indicated he was playing a joke on me. I began calling them his smiling eyes.

Everyone learned to see the smile in his eyes; his facial muscles would not let him smile any other way. One morning I was training a new caregiver and I had to run to the car to get something. When I came back, she was upset and told me, "He wrote with his finger that he could not breathe! I was just coming to get you." Walter sometimes needed his trach suctioned, but not this time. I looked at him and then

told her to just look at his eyes. She did; and she saw his smiling eyes. He was teasing her. I told him that this was not the time! Thankfully, the girl stayed, and she quickly began to enjoy his sense of humor.

Years later, Walter needed a feeding tube because his swallowing muscles no longer worked well. He was no longer able to eat one of his favorite meals - cheeseburgers. Later, he could no longer use a pen to write and communicate his needs. Yet, despite all these challenges, this man found happiness. It is one of the many things I loved about Walter.



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.





Aging Well: What the Disability Community Can Contribute

By Penelope Ann Shaw

The world population is aging. People are living longer. The preeminent geriatric and gerontological literature are replete with articles on this subject. While reading them I was particularly struck by points the authors made about negative beliefs that many adults have about aging.

The feelings and beliefs they described included people being anxious about and fear aging because they see it as a phase of life characterized by illness, decline, age-related disability, loss of independence, life-space constriction, isolation, depression, and even possibly a nursing home placement. This is a fatalistic narrative of late-life progression which alleges nothing can be done about it.

Many of these fears are misperceptions. It is essential to confront this narrative with a more positive optimistic view, recognizing that older adults are a diverse group with diverse experiences of aging. Aging is not necessarily something to dread.

Knowledge about aging can buffer negativity. Individuals are living

longer, and also on average, are healthier and more productive for longer. There are positive benefits to an increase in the average lifespan. The AARP profiled a woman at age 114 who had only given up driving at 97. Her story opens up new ways of thinking. Everyone can maintain a quality of life as they age. We routinely see older adults providing care for family members, working, traveling, volunteering, taking classes, golfing – actively leading their lives.

There are risks for disability at any age. Although aging is a risk factor for disability, disability is not an inevitable consequence of aging. Some people may lose strength and may develop physical, cognitive, and sensory deficits but with these changes, and despite the possibility of needing some type of assistance, these individuals can live well. Research shows that because of advances in medicine and rehabilitation, the expectation for those aging into disability to live to late life is the same as for their peers without disabilities.

Much has been written about the concept of successful aging. Initially, the primary focus was on how to maintain health and increase the number of functional years. The concept has now evolved from a biomedical approach to a wider understanding of physical, social, and psychological adaptation processes in later life.

What can those of us in the disability community contribute to this conversation about reframing aging?

We can provide a positive narrative of our experiences of living with disabilities for those who are new to disability. We can be age-defying role models and be vocal about saying that successful living does not require the absence of disease and disability. We can do this by sharing our personal stories and strategies for having active lives.

Those of us in the disability community can share our positive philosophy of living with impairments which have many dimensions. That we know we are people first, not our disabilities. That we are not

defective and that our patterns of everyday living are close to typical ways of living in society. That disability is normal and an aspect of human variation. That it is possible to moderate the effects of disabilities and lead actively engaged lives of purpose in productive ways, despite functional differences.

We can do this by sharing our strategies of focusing on our strengths and abilities. By having high expectations for ourselves. By knowing disability is socially constructed; that it is the environment - attitudinal, social, architectural, political, and cultural that disables people.

By virtue of our lived experiences, we must share with those who are newly disabled that we have the expertise to manage our care. That we are resilient. That we are problem-solvers. That we can advocate for accommodations. That looking at life with a social-existential perspective is empowering. That we have resolve. That we persevere. That we have collective power. That we have hope. That when accepting assistance, we retain our autonomy by making our own choices about when to accept and when to decline help.

We can also let them know that we are not isolated, but socially connected and integrated into our communities. That we see continuing opportunities for involvement by helping others. That we know the value of peers who can offer acceptance, encouragement, practical information, and resources. That we are empowered by our awareness of local, state, and federal policies that protect us from discrimination and exclusion. We can master the challenges of aging well. Let this new narrative about aging be widely publicized

In these ways, the disability community has a lot to contribute to optimal aging, most especially, the moderating effects of our mindset. We encourage older adults who age into disability to identify themselves with the disability community.

Personally, at age 78 I think about my own aging and mortality. Like most people, I hope for the prolongation of my life. As I age with a significant disability, I have advantages. I already accept bodily

differences. I am accustomed to loss and limitations. I benefit from the skills I developed to adapt to functional challenges and my familiarity with community supports and resources. I focus on my abilities. I maintain a sense of personal agency. I manage my care. I prioritize my goals by selecting what is most important. I am a proud member of both the disability community and a member of the larger world, where I know how to live successfully. I still make a contribution.

In many ways, I do not feel old. I do not expect my aging trajectory will be all that different from that of those who age without a disability. I already know how to have an active life with a disability, which is helping me to age more easily. As for my mortality, I am a realist. I have lost many people close to me. I have a future time perspective. I am aware that death is part of the human condition and we are all existentially vulnerable. When I die, I will miss this life. In the meantime, I am enjoying my life, immensely, and am still benefiting from the opportunities life offers.



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.





Home Maintenance and Improvement Tips

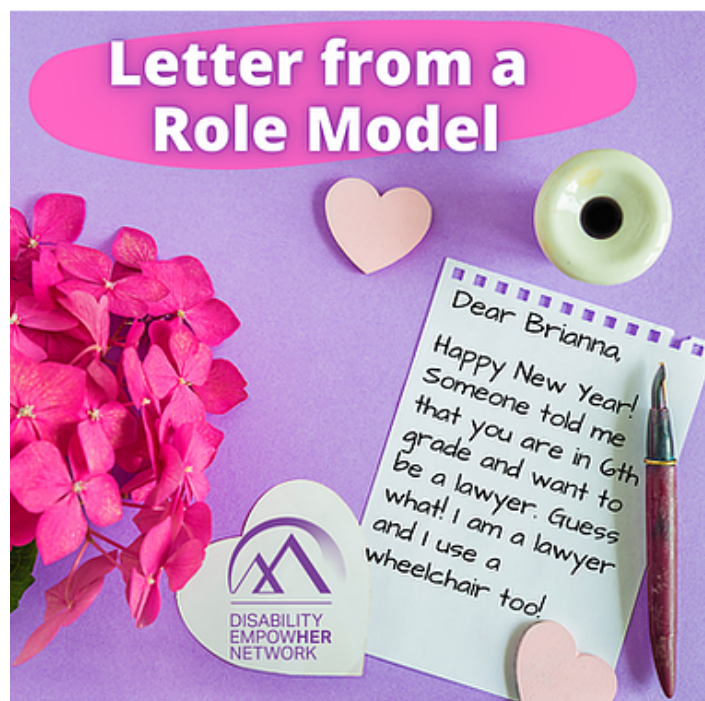
The [Habitat for Humanity](#) website has information to help homeowners whether you bought it, built it, or are renting it. Their free downloadable 53-page guide: [Home Maintenance and DIY Tips](#) is a collection of more than 150 do-it-yourself (DIY) home maintenance and improvement tips to care for your home inside and out – on a budget. Here are a few excerpts from the guide:

- Homeowners in a hurricane zone should take extensive photos of their home before a storm hits, which can make documenting damage easier.
- Contractors are expensive. Take some classes to learn some basics to keep your costs down. Things like unclogging a drain, replacing a faucet, changing a fuse or resetting a circuit breaker, painting, exterior upkeep, etc. can save you money... On the other hand, find a reliable handyman you can trust to do minor repairs quickly and correctly at a reasonable price so you can call on the person as soon as a small problem arises.
- Search secondhand stores – like [Habitat for Humanity ReStore](#) – before going to a regular retailer. Many of these types of stores sell new items that people just never opened. You often find more interesting and unique items.
- Write down directions on index cards for maintenance on various items, especially the things you do only occasionally. Put the index cards in plastic and attach them to the item.

Leave Words of Inspiration for Habitat Homeowners

Before the drywall is hung, it's a longstanding tradition for Habitat for Humanity volunteers to write messages on the beams that frame the Habitat home they've just helped build. It's a meaningful way to seal in love, hope, and courage as the walls come together to become a family's home.

Habitat for Humanity invites you to help families celebrate stability, self-reliance and the start of a brighter future in their new home when you post your virtual Beams of Hope message to encourage new Habitat homeowners. [Write your inspiring words to a Habitat family today!](#)



Disability EmpowHer Network: Letter from a Role Model

Disabled girls often do not have disabled adult role models to be positive influences in their lives. **We're changing that!**

[Disability EmpowHer Network](#) connects girls with disabilities from across the country to receive a personalized letter from a positive disabled woman role model!

We match girls with role models based on their backgrounds, interests, disabilities, and personalities!

[Teen Vogue](#) and [Spectrum Life Magazine](#) have highlighted Letter from a Role Model because of the incredible impact this program has had on girls with disabilities and their families, as well as the Role Models!

Do you know a girl who could use a letter? [Tell us about her here!](#)

Are you a disabled woman interested in being a role model? [Sign up here!](#)



[Audiobooks to Celebrate Disability Pride Month](#)

Kendra Williams, Co-founder and Executive Producer of "Reading Women," a podcast that features books by or about women, is thrilled to celebrate disabled, chronically ill, Deaf, and neurodivergent authors and their amazing audiobooks! As a disabled person herself, she loves to promote authors from the disability community to the wider bookish community.

Visit <https://bookriot.com/disability-pride-month-audiobooks/> for descriptions of Kendra's suggestions of audiobooks for your Disability Pride reading list, which include:

- ***Haben: The Deafblind Woman Who Conquered Harvard Law*** by Haben Girma
- ***Growing Up Disabled in Australia***, edited by Carly Findlay, narrated by the Editor
- ***Sitting Pretty: The View from My Ordinary, Resilient, Disabled Body*** by Rebekah Taussig, narrated by the Author
- ***Act Your Age, Eve Brown*** by Talia Hibbert, narrated by Ione Butler
- ***The Collected Schizophrenias*** by Esmé Weijun Wang, narrated by the Author
- ***Golem Girl*** by Riva Lehrer, narrated by Riva Lehrer and Cassandra Campbell
- ***The Kiss Quotient*** by Helen Hoang, narrated by Carly Robins



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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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