***Disability Issues***

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**Summer 2022**

*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

**Mass General Brigham** is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. Mass General Brigham is an integrated academic healthcare system, uniting great minds in medicine to make life-changing impact for patients in our communities and people around the world. Mass General Brigham connects a full continuum of care across a system of academic medical centers, community and specialty hospitals, a health insurance plan, physician networks, community health centers, home care, and long-term care services. Mass General Brigham is a non-profit organization that is committed to patient care, research, teaching, and service to the community. In addition, Mass General Brigham is one of the nation’s leading biomedical research organizations and a principal teaching affiliate of Harvard Medical School. For more information, please visit [**www.massgeneralbrigham.org**](http://www.massgeneralbrigham.org).

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**In this issue:**

**From the Editor** |  Marianne DiBlasi
***Love & Intimacy* | Once Upon a Time at the GYN's Office**| Ms. Love
***Walter's Place* | Making a Difficult Decision**  |  Joan Burrows
***The PCA Corner* | Transitions** |  Ray Glazier
**Crossing Streets Definitely Can Be Dangerous**  |  Penelope Ann Shaw
**Traveling While Disabled**  | Marybeth Barker
***Ready & Able* | Sumer Travel Fun for All** |  Tim Sullivan
**Connecting to Nature with Forest Bathing**  |  Shelley Yen-Ewert
***The Bookshelf*|  Beauty is a Verb: The New Poetry of Disability**  |  Review by Mary Grimley Mason
**Information Briefs:**
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**From the Editor:**

Dear Readers,

We begin this summer edition of *Disability Issues* with an article about the accessibility or, more accurately, the inaccessibility of many OB-GYN practices, followed by a reflection piece on companioning a loved one to an abortion 30 years ago. The recent Supreme Court ruling to overturn Roe v. Wade has sparked many memories and people sharing their stories. Members of the disability community are a diverse group of individuals with a wide range of perspectives on many topics, including abortion. As a person with a disability and as editor of *Disability Issues*, I’m curious to hear what people in the disability community are saying. I learn from listening to other experiences that are both similar and different to my own.

I recently read two articles that raise up voices of people with disabilities about abortion and I offer them to you below for your consideration. If you want to hear other voices, there are many more articles that offer various perspectives. If you google “people with disabilities share views about abortion” you will find a plethora of articles to choose from. As individuals and as a community, I believe we are stronger when we listen to and learn from each other, including perspectives that are different from our own.

“[How do people with disabilities feel about abortion? New poll sheds light for the first time](https://19thnews.org/2022/05/how-people-with-disabilities-feel-abortion/?utm_source=The+19th&utm_campaign=372b780862-19th-newsletters-daily-0510&utm_medium=email&utm_term=0_a35c3279be-372b780862-382844702).” An exclusive by Sara Luterman, May 10, 2022. *The 19th News*.

“[With Roe v. Wade Overturned, Disabled People Reflect On How It Will Impact Them](https://www.npr.org/2022/06/25/1107151162/abortion-roe-v-wade-overturned-disabled-people-reflect-how-it-will-impact-them?utm_source=npr_newsletter&utm_medium=email&utm_content=2022626&utm_term=6891521&utm_campaign=news&utm_i.d.=43663717&orgid=430&utm_att1=).” By Shruti Rajkumar, June 25, 2022. *NPR*.

In this edition of *Disability Issues*, we also offer you two articles that further expand on topics published in *Disability Issues*, Spring 2022, one on advice for having difficult conversations with a PCA caregiver and the other on street safety. Since summer is typically vacation season, we bring you two articles about vacation adventures, one about a trip to Scotland and the other about accessible recreation in Cape Cod. Finally, we leave you with two contemplative pieces, one on Forest Bathing and the other, a review of an anthology of disability poetry.

Be well and stay safe this summer.

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.

**LOVE & INTIMACY CORNER**

**Once Upon a Time at the Gynecologist's Office**

**By Ms. Love**

Once upon a time, a long time ago, my friend, Francesca, was able to step up on a narrow scale to be weighed at her gynecologist's office. She was able to push open the door to the ladies' room and fit inside the stall to give a urine sample. She could also climb up on the exam table by herself for pelvic exams and tests.

Over the years, Francesca periodically changed where she went for her OB-GYN care and she noticed exams were becoming painful. Very painful. Still, she faithfully scheduled her routine and acute visits, exams, and tests. Every time Francesca tried to talk with medical providers about being in so much pain, she was ignored, or pooh-poohed away, and was told that others also have pain with exams and testing. The older Francesca got, the longer that pain lasted, often for days after her appointment. The older she got, the more she tried to ask questions about the life stage she was in – what to expect as she aged? How to handle situations (such as perimenopause)? What her options were? Although Francesca went to a good-size practice with multiple female gynecologists and other staff, she was told to go online and google answers to any questions she had. That didn't sit too well with Francesca because she wanted answers based on her unique health concerns.

Increasingly, Francesca was aware that she was a one-of-a-kind in the OB-GYN practice she was going to at that time. Specifically, year after year she was the only one in the waiting room who was not pregnant or holding a newborn. The waiting room was jam-packed with magazines, brochures, and pamphlets about being pregnant, being a new mother, breastfeeding, and finding babysitters. You name it, the waiting room had it for these new moms. Francesca knew the material well because at each visit she hunted through all the reading material looking for information about her stages of life. The older she got, there wasn’t a single flyer that met her needs.

The only place she found any age-appropriate material was in the exam room. It was a one-page sheet about menopause and calcium levels of various foods, but it had been xeroxed so many times the copies were hard to read. When she mentioned this to her gynecologist, she received confirmation that this was the only material they had about menopause. Over the next few years (Francesca checked), it was always the same over-xeroxed one-pager on calcium levels that were offered in the practice.

As Francesca went from ambulating on her own to using a cane and then a walker, she was aware that no other patient ever looked like her. No one was visibly disabled at an older age. No one else stepped outside the practice because they needed an accessible bathroom that had turn-around room for a walker. Year after year, she didn’t hear anyone else ask the medical assistants if there was an accessible scale and accessible exam table they could use. When Francesca asked for these things, the answer was always the same, “No.”

She was tired of asking for an accessible scale and exam table because, in this day and age, she not only needed them for her disabilities, but she also expected them. She did not feel safe climbing on and off tables on her own and she had it with others grabbing her to pull her on and off the exam table like she was a rag doll.

During the current pandemic, the day came when her health required yet another pelvic test and she let out a wail of pain. She was still doubled over with pain when her doctor called her later in the day to discuss the test results. You wouldn’t think much good could come out of the pandemic, right? Actually, something great came out of the pandemic for Francesca. The pandemic is when she found her power.

After the doctor told her the test results over the phone, Francesca asked if the OB-GYN practice was at least going to get an accessible table that would meet her needs and also benefit women in their last months of pregnancy or those who were pregnant with multiple babies. The doctor said. “No, we are not getting one” and challenged Francesca about her need to have an accessible table, reminding her that they always helped her on and off the table.

Francesca was fed up being treated like a “have-not” because no one paid attention to her needs for accessibility and pain-free visits. Of being a have-not because she didn’t get the accessible exam table or scale she needed. A have-not for needing information about the gynecological stage of life she was in and not getting that either. Of feeling like a second-class citizen because able-bodied people got what they needed.  She had put up with it for years, but no longer. This time, she stood up for herself.

Politely, but firmly, and very, very sure of herself after all her years of being treated as a “have-not” in multiple OB-GYN offices, Francesca told the doctor, that yes, she did receive help getting on and off the table, but her body was in great pain because they pulled and dragged her on and off. She announced her plans to find another OB-GYN practice that met her accessibility needs and that saw many patients who were her own age.

Francesca has not looked back. It was the best decision she made during the pandemic; leaving behind a medical provider who wouldn't see her or meet her needs and a practice that focused its attention on serving patients who are in the able-bodied majority. Francesca found herself an OB-GYN practice at a local hospital that sees people of all ages and abilities and has accessible scales, tables, and bathrooms. She found an OB-GYN nurse practitioner who listened to her history of pain and immediately committed to working with Francesca to educate her on what was possible and how they would work together going forward.

The nurse practitioner didn't wave a magic wand and turn Francesca into the Cinderella of the gynecology office. There were no glass slippers, no luscious, bejeweled gown, or Prince Charming. But darn it all, my friend never walked taller than the day she walked out of her first meeting with the nurse practitioner, who listened attentively to her GYN needs and extended an offer of partnership going forward. I couldn't be any prouder of my friend.

If your needs for accessibility, your stage of life, or your questions are not being addressed at your OB-GYN office, make some phone calls and find out who else can provide you with the care you deserve. At this point in the pandemic, they say there is a medical staff shortage because staff are looking for better pay, benefits, commutes, and more. But patients can look for better conditions too; so don't settle for less than what you need in a medical practice and provider.

**Additional Gynecological Resources:**

* The [KIND Clinic](https://www.bidmc.org/centers-and-departments/obstetrics-and-gynecology/programs-and-services/gynecology/programs-services/kind-clinic) at Beth Israel Deaconess Medical Center, Boston, MA. Phone 617-667-3738. The first clinic in New England to specialize in gynecologic care for women over the age of 21 with intellectual and developmental disabilities.
* “[America Lost its Way on Menopause Research. It's Time to Get Back on Track.](https://www.washingtonpost.com/opinions/2022/04/28/menopause-hormone-therapy-nih-went-wrong/)” An opinion by Sharon Malone and Jennifer Weiss-Wolf, April 28, 2022. *Washington Post*.

*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.*

**WALTER’S PLACE**

*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.*

**Making a Difficult Decision**

**By Joan Burrows**

When the U.S. Supreme court issued its ruling to end federal protection of abortion rights, memories from some 30 years ago came flooding back of the time when Walter’s daughter, Marcia, asked me to go with her when she was having an abortion. She made this very personal, and difficult, decision after many discussions and much consideration.

At that time, she had one son who was about 20 years old. Marcia loved her son and loved caring for him. But in the twenty years since she gave birth to him, she had lost a lot of functionality from having Muscular Dystrophy and was now using a wheelchair. Marcia was in her 40’s, had a job, and was not prepared to have another child. She and the man she was involved with did not want to marry. Multiple people in her immediate family also had Muscular Dystrophy – her son, brother, and father, and it was very likely the baby would too. Once we talked about what having a baby girl would be like, but the probable negatives were daunting. I would have loved to help her care for a baby, but I was taking care of Walter so my time would be very limited.

As part of her decision-making process, Marcia saw her doctor and had several appointments with a psychiatrist. She also spoke with her dad, me, her son, and perhaps some close friends. I believe we all told her the same thing – it was her decision. I do recall thinking what a very difficult decision it was. Ending a life, or possible one, who is part of you…I cannot think of a more difficult thing to do. Her decision to have an abortion was not made lightly. For her, it was the right one.

When Marcia asked me to go with her, of course, I said “yes” but I did not anticipate all the emotions I would feel. The images on the news of people on the steps yelling at people that they were “baby killers” and “murderers” was now real as I pushed her wheelchair up the ramp. I wanted to yell back at them.

Once inside, she checked in, waited, and then had another meeting with a doctor and physiatrist. She spent about 30 minutes with them before she came back and told me she was going in for the procedure. I wanted to hug her, but her look said, “No.“

I waited in the waiting room while people came in and went out. I wondered about each situation. Some were alone and I felt sad for them. I waited a long time. When Marcia came out, I wanted to hug her, but decided not to because the look on her face said, “Let’s get out of here.” Marcia got in the back seat of the car. I put her wheelchair in the trunk, and we drove away. The road was straight with frequent traffic lights. After only a short distance, I heard Marcia say, “You just went through a red light.” I had no idea! But it did lighten things up a bit because we talked about what we would say if a policeman stopped us. Marica’s sense of humor was ‘out there’…so I won’t tell you what we said!

I got her settled in at home and a friend was already there to stay with her. All went well, though we never talked about whether she had any long-term emotional effects. We probably should have, but we didn’t. I am not sure she wanted to because, knowing Marcia, if she wanted to talk with me, she would have. Maybe she talked with her friend who was closer in age. I hope so.

Marcia went on to head the Personal Care Unit at NE Independent Living and helped many people in ways others could not. Her personal experiences of living with Muscular Dystrophy, as well as living with her dad, son, and brother made her exceptionally skilled at understanding and helping others.

Marcia and her son have both died but they left me with good memories, love, and much admiration for all they accomplished in their short lives…as did Walter. I learned a lot from each of them. They are very special people who inspired me to become a more thoughtful and empathic person.

*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 PCA CORNER**

**Transitions**

**By Ray Glazier**

Regular readers of this column will recall that the last installment recounted the dilemma of my friend ‘Bob,’ who contacted me for advice concerning his longtime PCA and sole caregiver ‘Sarah,’ who I thought was exhibiting symptoms of caregiver burnout. Bob said he tried supplementing the MassHealth PCA Program hourly wage of $17.71 with a few more dollars per hour from his Social Security check. Sarah was not impressed.

Note: the previous installment of ‘Bob’ and ‘Sarah’ is published in the PCA Corner section of [*Disability Issues*, Spring 2022](http://disabilityvisibility.com/resources/disability-issues/disability-issues-archives/).

Next Bob bit the bullet and had a sit-down, heart-to-heart talk with Sarah, telling her it was obvious to him that she has been off her game. Bob told her that her help is invaluable to him and his well-being. She shrugged. Bob said that it pained him to see her suffer so obviously. Sarah looked down at the carpet. He asked what he could do to make things better. She grunted and rolled her eyes towards the ceiling. Bob explained that the wage supplement he gave her was all he could manage, actually cutting into his budget for meals. Sarah mumbled something unintelligible, looked at her watch, and stood up to leave.

Bob found their conversation totally unproductive and unsatisfying. So he regrouped and laid out an action plan for keeping Sara as a caregiver, especially because that was his ultimate objective all along. He felt sure that in the right set of circumstances the old relationship could be resurrected. Sarah had not given him anything to go on, but Bob seized upon another piece of my advice: He hired a second part-time PCA to share the workload. The new recruit, ‘Emily,’ was cheerful and energetic, a breath of fresh air.

Sarah was immediately jealous and made no secret of her resentment at Emily’s very presence. The hostility weighed heavily on Emily, who gave her notice after only four weeks. Bob was now between a rock and a hard place, so he again turned to me for advice. Based on what Bob told me about his conversation with Sarah and his description of her reaction to hiring Emily, my takeaway was, that Bob’s relationship with Sarah is irretrievably broken.

Maybe Sarah should have expressed her discontent more directly, using her words instead of acting out. Probably Bob should have confronted her as soon as things went wrong, then taken remedial action; better yet, he should have fostered open dialogue from the get-go. However, at this point it is probably best for both persons to part ways on friendly terms and move on, lessons learned. So that was what I told Bob, as gently as I could.

**Epilogue:** Bob gave Sarah a month’s termination notice, but she decided to leave just as soon as Bob could find a replacement. Bob persuaded Emily to stay on after all, with the understanding that he would be hiring another part-time PCA to share the workload. Bob paid for Sarah’s train ticket back to her hometown and they shared tearful goodbyes, promising to stay in touch.

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

**Crossing Streets Definitely Can Be Dangerous**

**By Penelope Ann Shaw, PhD**

Only a few days after my article on street safety was published in [*Disability Issues*, Spring 2022](http://disabilityvisibility.com/resources/disability-issues/disability-issues-archives/), I was hit in my power chair by a car while crossing the street at the intersection I described in the article. I had good reason to think it was safe to cross the street since I was in the crosswalk and had the walk signal.

The driver stopped and came over to apologize. A bystander called 911. Police and Fire came. I was asked several questions: Are you okay? Do you want to go to a hospital to get checked out? I did not notice any problems, so I responded that I was okay and didn't need to. I tested my chair and couldn't find anything wrong with it either, so I left the scene of the accident and continued with my errands.

About 12 hours later, I was in terrible pain and decided an emergency department hospital checkup was warranted. Between that visit, and a second a couple of days later to my own hospital, I discovered that I had several fractures – of a knee, leg, and pelvis. For a couple of weeks, I took a strong painkiller but took myself off it as soon as I could because it was an opioid.

Later, I noticed that the left arm of my power chair was damaged, so I had a technician come to evaluate it. When he checked out the chair it turned out to be drivable, but he told me that the whole frame of my chair was bent and needed to be replaced. He cautioned me to be careful when driving it.

The police report said the driver was given a verbal warning for not yielding to a pedestrian in a crosswalk. The problem was, even though I had the light, the driver did also. He had not run a red light; he had the green traffic signal. Being parallel to me, the driver turned right into the crosswalk where I was also given a “walk” signal to cross the street. When he took the right, he didn't see me.

This accident happened because my Town has concurrent walk signaling which gives pedestrians a walk signal and the right of way at the same time motor vehicles are given the green light to go. The driver and I were in the same place at the same time. People have been killed by this traffic flow system.

I write this piece not only to warn readers of the dangerousness of concurrent traffic signaling but because I learned a few additional things that might be useful to people with disabilities if they encounter something similar. I worked primarily with the driver's auto insurance company. I learned about possible insurance claims for the following: If I was employed, I could have filed a claim for lost wages. I could file claims for ambulance service, uncovered medical expenses, and - in my case - repair of my power chair.

It was suggested that I find a personal injury lawyer to represent me, which as of now I have not done. Surprisingly, I learned from a letter I received in the mail from Medicare – one of my health insurers – that If I obtained a financial settlement federal law requires that any monies I am due, both Medicare and Medicaid can recover money from personal injury lawsuit settlements. For example, these expenses could include hospitalization, outpatient medical visits, and rehabilitation costs.

Luckily, I was not killed in this accident. I suggest it is imperative that everyone become concerned about traffic flow systems and public safety. Recently, several articles have been published in newsletters about an increase in pedestrian deaths. An article by Jenni Bergal was published in PEW on June 1, 2022, [*Wheelchair Users Say States Should Spend New Road Money on Safety*](https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2022/06/01/wheelchair-users-say-states-should-spend-new-road-money-on-safety?utm_campaign=2022-06-02+SW&utm_medium=email&utm_source=Pew&subscriberkey=00Q0e00001g4NOqEAM)*.*

I believe concurrent traffic signaling is very dangerous and we should provide protective street crossing via pedestrian-only phases or, at the very least, lead time for pedestrians so drivers can clearly see them in crosswalks.

In the meantime, I go to the same places as I did before the accident, but I avoid the dangerous intersection by taking roundabout routes. I no longer put myself in a crosswalk where drivers can turn right at the same time as I am crossing to prevent possibly being hit again.

*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.*

**Traveling While Disabled**

**By Marybeth Barker**

I like to travel but I have no interest in going to resorts, whether they are designed for those with disabilities or the non-disabled. Although I wouldn’t be opposed to sitting in a shady spot on a beach that has icy cold drinks and snorkeling, I much prefer the *idea* of taking the road less traveled. I like staying in a neighborhood B&B and experiencing a bit of local life instead of staying in a large hotel.

But my life is changing due to my disability. The actual experience of taking the road less traveled is vastly different than my imagined idea of what it will be like. On a recent trip to Scotland to attend a wedding, I imagined myself roaming the city streets of Glasgow, taking in the architecture and local culture. I imagined going to pubs with live music at night.

But my actual experience of “roaming” meant constantly scanning for the nearest curb cut and hopping my wheelchair over potholes and cracks in the pavement. Meanwhile, my husband is taking in the vibe of the city. He notices the cafes and scans the menus on sidewalk blackboards that block my path. He takes in the boutiques and galleries that I ignore lest I roll into a ditch while looking around. I’m not unhappy roaming the city streets, taking in the sounds and smells, and the ways things are different from home, but I am reminded that traveling is not what it used to be. In my actual experience, going to pubs requires going up or down a flight of stairs and the music doesn’t start until 10 pm. So even if I could get inside, I would not be able to stay awake to listen to the music. I am disappointed in myself. I fall so short of who I imagine myself to be.

It occurs to me that I’m suffering from a version of “social media-induced low self-esteem.” Before I left on vacation, I researched tips on wheelchair travel in the UK. I began to follow strangers on Instagram, mostly women, cheerful women who use a manual wheelchair like me. They posted pictures of their glamorous selves wheeling thru streets with city lights and music spilling out onto the sidewalk behind them. Photos sitting under twinkling lights sipping a cocktail with one hand while doing a wheelie with the other.

I’m sure I’m not alone in seeking images of people who are like me, especially if you have identities that are different than mainstream society. I suppose it’s the nature of social media to post photos on both sides of the disability spectrum – images of attractive people performing superhuman feats like climbing stairs in a wheelchair while juggling or photos of the dark side with close-up shots of pressure wounds and urinary catheters.

I laugh at myself when I realize how silly I’ve been to fall into this self-esteem trap. You’d think I’d know better; I just turned 69 and I’m not in middle school. But just the same, whether my travel exhaustion is from simply getting older or from the challenges of navigating in a wheelchair, the combination of aging and disability is no joke. Are there Instagram posts for that? I’m afraid to look.

There’s no doubt about it, I found traveling hard, but not so hard that I’m willing to stop. But next time, I’m going for the accessible beach with snorkeling and icy cold drinks. Never at a resort though, at least not yet.

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

**READY & ABLE**

**Summer Travel Fun for All: Accessible Recreation**

**at Cape Cod’s Nickerson State Park**

**By Tim Sullivan**

In 2017 the Spaulding Rehabilitation Network, in partnership with the Massachusetts Department of Conservation and Recreation (DCR) launched the McGraw Center for Adaptive Sports at Nickerson State Park in Brewster, MA on Cape Cod. Now starting its 5th year, the program provides persons with physical and cognitive challenges and their families the opportunity to experience the beauty of Cape Cod’s trails, ponds, bogs, and vistas in a more accessible way than ever before.  The program is open to Massachusetts residents and travelers alike.

The McGraw Center is a first-of-its-kind collaboration between Spaulding Rehabilitation Network’s Adaptive Sports Centers and DCR. The Center was made possible by a generous donation from Melissa and David McGraw, the Donald C. McGraw Foundation. Spaulding, a member of Mass General Brigham, has a long history of creating collaborations to bring accessible resources to the broader public.

“*Our goal has always been to bring the joy of sports and recreation to as many people as possible. To be able to offer these in such a beautiful setting makes the McGraw Center truly a special place,*” said Mary Patstone, Executive Director, Spaulding Adaptive Sports Centers. “*Being here also brings awareness to the thousands of people who travel to Cape Cod to visit Nickerson State Park and the Cape Cod Rail about adaptive sports. They see are participants and equipment and realize that they or a family member can benefit and end up trying it for themselves.*”

Adaptive cycling, seated yoga on Cliff Pond, kayaking, hiking, and swim lessons are among the McGraw Center’s most popular programs. In addition, Nickerson State Park has a wide variety of accessible camping options for guests to enjoy the park and all Cape Cod has to offer during the summer. The McGraw Center was featured in 2019 on NESN. You can watch the segment, “[NESN Celebrity Sports Series - McGraw Center for Adaptive Sports](https://www.youtube.com/watch?v=GReUZBctfjs)**,”** on YouTube.

For additional information on programs, please visit [Spaulding Rehabilitation Network’s Adaptive Sports Program](https://spauldingrehab.org/conditions-services/adaptive-sports) or call 877-976-7272 or email SpauldingAdaptiveSports@partners.org.  Accessible parking is available at the Nickerson State Park main gate on Route 6A.

“*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 in this summer season connecting with others and reclaiming the feeling of joy we all need*,” concluded Patstone.

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

**Connecting to Nature with Forest Bathing**

**By Shelley Yen-Ewert**

Do you notice:

* The movement of grass?
* The different textures of flowers?
* The sounds of wind?
* The smells of your potted plant?
* How the air against your skin can change from moment to moment?

While I’ve always enjoyed being in nature, I never took the time to notice these things until I started practicing forest bathing. In the beginning, I found it hard to slow down my mind. Now I regularly notice these things. Each time, I find the impact of forest bathing is different. Sometimes I’m simply more aware. Sometimes I feel calmer. Sometimes joy, acceptance, or grief come up. Sometimes I get insights or feel more creative. Through these experiences, my relationship with nature has deepened.

Research has shown a range of benefits from being around nature, including looking out a window at nature or being in a room with potted plants. This includes, but is not limited to decreased stress, lower blood pressure, and increased creativity and problem-solving. Perhaps there can also be a benefit to the environment when people connect to and care for nature.

In the 1980s, a tech boom in Japan led to the rapid growth of cities. As steel, concrete, and glass took over green spaces and people worked longer hours inside, they experienced increased stress and stress-related health issues. The Japanese government created “shinrin-yoku” also known as forest bathing, to reduce stress, help people reconnect with nature, and protect Japan’s forests. While forest bathing could include water, actual bathing isn’t usually involved! The word “bathing” here means being immersed in the atmosphere. In forest bathing, we are immersed by using our different senses to connect with nature. Through this connection, we are also restoring our relationship with the natural world.

The term “forest” is used, but forest bathing can be done in any natural environment. By the ocean, in a city park, even in your own home. At home, you can do forest bathing in a backyard, on a balcony, or inside your home looking out the window, or with flowers, potted plants etc.

Try this out. Pick a potted plant, a tree, or something else you enjoy in nature. Use any of your senses to get to know the plant. Touch it and notice the different textures. Does the plant have a particular smell? What details do you see? Are there any sounds you hear?

You can also contact a forest bathing or forest therapy guide who can support you through this experience, which is similar to how meditation teachers guide meditation sessions. Guides can hold forest bathing sessions in-person and virtually, where participants join a video call in whatever environment they choose. Guides offer sessions to individuals and groups. In a session with a forest therapy guide through the Association of Nature and Forest Therapy, you will be offered different invitations or prompts to help you connect more deeply with nature. You will also have the opportunity to listen to other participants’ experiences and to share if you wish.

Sandy Novack, *Disability Issues* editorial board member, shares her forest bathing experience:

*“I participated in one of Shelley’s first group forest bathing events on Zoom in October 2021. Some participants were participating in their backyard and at least one was in a park. Given the pandemic, I chose to stay inside my apartment and sit in the middle of my houseplants. I was able to practice new ways of being among them. It was very peaceful. At the end of the event when each person shared their experience. We all wanted to keep practicing forest bathing on our own. I have always enjoyed going for walks and looking at nature around me. Since being introduced to forest bathing, I pause more often during my walks to take in the smallest detail of a tree, a squirrel eating a nut, or the ivy growing on the side of a house. In inclement weather, or if you must stay indoors for health reasons, forest bathing is also possible by looking at photos or videos of nature on your computer. It is a pleasant way to take a break during the day, slow down, and appreciate the wonders of the natural world.”*

Shelley is currently offering some free forest therapy sessions both virtually and in-person, depending on location. Shelley will work with you to ensure accessibility. If you are interested, contact shelley.foresttherapy@gmail.com.

*Shelley Yen-Ewert is a certified forest therapy guide through the Association of Nature and Forest Therapy.*

**THE BOOKSHELF**

***Beauty is a Verb: The New Poetry of Disability***

**edited by Jennifer Bartlett, Sheila Black, and Michael** **Northern**

**Review by Mary Grimley Mason**

Disability Literature comprises a vast body of writings: individual memoirs and autobiographies, collections of stories, essays, discussions of classics, such as Moby Dick, children's literature, and more.

Out of all this bounty, I discovered *Beauty is a Verb: The New Poetry of Disability* (Cinco Puntos Press, 2001). This anthology on disability poetry combines a survey and analysis of different stages of disability poetry with a selection of the poetry itself and with several essays by the poets.

Using the social model of disability, where having a disability usually marginalizes the person in society, the anthology traces the development of a "poetics of disability" that aims to put poetry into the mainstream of the American literary text and also helps to acknowledge that disability is a normative part of the human experience.

**Part One of the anthology, "Early Voices,"** has poems written as far back as the 1930s and into the 1950s where the actual disability is often not clearly mentioned. An example is the poem, "Motive" by Josephine Miles (1911-1985). Miles, well known as a poet and academic, developed degenerative arthritis s a young child and was severely disabled, even unable to use a wheelchair. However, she described the physical results from her disability as "productive limitations" and chose not to be involved in issues around disability or identity politics. As illustrated in "Motive," her poem does not specifically mention her disease and impairment but does eloquently capture both the grim reality of her environment and at the same time, the touching moment that brings joy and excitement to her life.

*A window in the shadowed room where I lay*

*Opened on a dark brick wall*

*And high beyond the sooty block*

*Of buildings stood in rain.*

*Heat in bones under blankets burned*

*With aspirin, Keeping me warm,*

*What else? Grandfather shrugged,*

*Stepgrandmother reheated the hot milk.*

*Later she brought also a small box*

*Which turned out to be filled with six small bottles,*

*Of perfumes, assorted, six colors,*

*Oho! There is something to life!*

**Part two of the anthology, "The Disability Poetics Movement,"** focuses on poets and their work that was influenced by the politics of the disability movement and the passage of the Americans with Disabilities Act in 1992. The poetry often becomes more specific about a disability and expresses the effect it has on the poet. Vassar Miller in "If I Had Wings or Love" (1991) foreshadows this change in one of her poems:

*I'm either a monster*

*In search of a horror movie to be in*

*Or else I'm a brain floating within a body*

*Whose sides I must touch while*

*You glance discreetly away.*

The poems in Part Two represent a wide variety of ways the poets absorb their disability as part of their poetics. Wry humor, for instance, can be an outcome. Hal Serowitz' poem, "A Step above Cows" is an example:

*I read somewhere that a cow*

*can only walk upstairs but*

*not down. Even though I have*

*Parkinson's, I'm a step ahead*

*of a cow. I can walk up or down*

*without much trouble. And the*

*one time I fell, I was walking up*

*but lost my balance and fell down,*

*which proves that I'm not*

*a cow, because for a split second,*

*I had the choice of where to fall-*

*up or down-and unceremoniously*

*took the down route, because it*

*takes you faster to where you*

*want to go-at the beginning*

*of the stairs, so I could do it right this time.*

**In Parts Three and Four of the anthology, "Lyricism of the Body" and "A New Language of Embodiment,"** many of the poems have not previously been read as part of the poetics of disability but they still use the narrative and lyric form, and often celebrate the non-normative, as demonstrated in "Beach Baseball" by John Lee Clark.

*Even when I fold my white cane in half*

*To double my chances, my batting average is a joke.*

*I am much better in knowing which smooth stones*

*the ocean wants back from the shore,*

*But when there is a metallic crack and a rainbow*

*cleaves my mental sky, I see something*

*falling from one blue into another and then a gasp*

*of what I like to think of as pure white.*

*Beauty is a Verb: The New Poetics of Disability* is not only a welcome addition to disability literature but also an exciting new addition to the genre of poetry.

*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.”

**INFORMATION BRIEFS**

**Accessible Recreation Programs and Activities**

DCR’s Universal Access Program is dedicated to providing outdoor recreation opportunities in Massachusetts State Parks for visitors of all abilities. Accessibility is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs. Visit the [Universal Access Website](https://www.mass.gov/orgs/universal-access-program) to keep up-to-date with our activities! Pre-registration is required for all programs.

DCR offers many kinds of trail experiences for our visitors. Across the state you will find a variety of trails from wheelchair accessible trails, to easy hikes, to more rugged hikes. You can explore places close to home or further afield with attractions like ponds, streams, waterfalls, mountain tops, picnic areas, and vistas. For further information please visit the [Accessible Trails Page](https://www.mass.gov/info-details/accessible-trails) on the DCR website. If you are looking to spend some time in nature and would like to read trail recommendations, visit [Everyone Outdoors](https://everyoneoutdoors.blogspot.com/p/covid-era-trail-recommendations.html). We can’t wait to see you out on the trails!

**Accessible Kayaking with All Out Adventures**

Join All out Adventures for kayaking across Massachusetts! Kayakers will paddle together in a small pod. There will be 1 hour 15-minute timeslots to allow for time to get set up and recreate on the water. Instruction, adaptive equipment, and assistance as needed provided.

 **D.A.R. State Forest,** Goshen

Wednesdays, July 6 - August 24

**Cochituate State Park,** Natick

Tuesdays, July 12- August 2

**Quinsigamond State Park,** Worcester

Tuesdays, August 9 - August 30

**Cost:** $8 per participant. One guest of a program participant with a disability can attend at no charge.

**Register:** Call (413) 584-2052 or Email info@alloutadventures.org

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