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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,

I recently participated in a writing your life legacy workshop. The facilitator guided us on various ways we could share the legacy of our life experiences, wisdom, and values to loved ones while we are alive. I chose to write a poem and called it, *Learning to Trust*. I am inspired to share it with *Disability Issues* readers because it is well suited to the theme of family and life challenges of living with a disability reflected in many of this issues' articles.

In life, there are always unexpected twists and turns. When disability is part of your life experience, there are additional layers of uncertainty about what the future will be like. In the following poem, I share one of the ways my parents and I learned to respond to the uncertainty of living with a disability.

This week I read an article, "[My disability made it hard to accept my gender identity. Here's how I made peace.](#)" The author, A. Andrews, shared their life wisdom in the style of a cartoon. I wonder what life wisdom you have learned and what style you would choose to express yourself. Maybe you too would choose a poem or a cartoon, or maybe a letter, video, piece of art, or....

# *Learning to Trust*

## *by Marianne DiBlasi*

A baby is born with a lump on her back  
and misshapen legs.

“Spina Bifida”, the doctor says,  
as he tells the mother terrifying stories  
about what her child’s future might be.  
“I’m scared, confused and overwhelmed”,  
the mother cries as she cradles  
the baby close to her heart.

The parents take their baby home and say,  
“We will trust our baby and maybe  
the doctors will be wrong.  
We will treat her just like  
all our other children.”  
And so they did.

When their two-year-old daughter came home  
from the hospital using crutches and wearing  
new full-length steel braces on her legs,  
the mother reached out to help  
her child go up the stairs.

“No mama, I do!” the child exclaimed.  
And the mother trusted her child.  
She watched as the child climbed  
the stairs, doing it her way.

When the child turned seven, her father  
taught her to ride a bike, just as he had

taught all his other children.  
Trusting her father, the child tried multiple ways to get on the bike before succeeding.

Tossing her crutches on the lawn, she learned to fly like the wind. The wheels of her bike became wings, carrying her faster and further than she'd ever gone before.

Throughout the child's life, the parents and child learned from and with each other about trust. Together, they trusted their way into the unknown future by making one choice, one experience at a time.

They learned not to live in fear of what might be, but to trust in the possibilities of what might be.



*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.*

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## **Adopting Children and Raising a Family** One Couple's Story

***By Charlie Carr and Karen Langley***



We identify as Charlie Carr and Karen Langley. I self-identify as a person with a disability in as much as someone would say, for example, they are a person of color. In other words, my disability doesn't define me. We are both white and have had long professional careers that generally tend to intersect around disability-related issues. We've lived in Methuen for over 35 years.

When we decided to adopt children, we were both new to the system and knew very little about community resources. Karen took the lead and began by using the Massachusetts Adoption Research Exchange (MARE) which was extremely helpful and provided us with actual stories, pictures and other information about children that wanted to be adopted. There was bias against people with disabilities in the broader systems, especially private organizations like Catholic Charities. They explicitly made clear that they would not work with a family where the parent has a disability. So, we stayed with MARE and Karen brought home binders filled with children ready for adoption.

In our early 40s at the time, we begin to realize that our only options were to adopt children from the Massachusetts Department of Children and Families (DCF) who were living in their foster care system. After several months of looking through binders and at hundreds of children we landed on two siblings, a brother, and a sister ages 7 and 6. Both are African American and had been in foster care most of their lives. We opened a case with DCF and had a very progressive social worker who didn't focus at all on my disability other than to ask if I was comfortable if some type of situation arose that was an emergency. It's important to say that we were very lucky to get this particular social worker because DCF had an institutional bias against people with disabilities adopting children through their system. Since I am a paralyzed person using a power wheelchair, that included

me. The social worker disclosed that her father had a significant disability and had raised her and her siblings, so she wasn't biased. I was prepared to file a legal complaint if I was denied based on having a disability but, thankfully, it never came to that.

DCF required a lengthy process of preparation including 10 weeks of group meetings that went into many details about the adoption process and the psychological baggage that most of these kids had and how it came out in their behaviors. Toward the end, I remember Karen and I each received a form that listed out about 15 common behaviors that other adoptive parents and DCF staff flagged as self-destructive or destructive. The only two that I said I couldn't handle were feces smearers and fire starters. I think we both agreed on them.

After meeting Quiana and Kareem at a Burger King, we kind of clicked and planned for visits and eventually overnight stays at our house. Finally, on the day they came to permanently live with us, the foster parent drove up to our house with them and two garbage bags stuffed with their life's belongings. Because they are brother and sister and were young veterans of foster care, they wanted to live in a house with a forever family. They had been bounced around and traumatized together for all the years of their lives. Stability felt good even if they had no idea who had just brought them into their home.

Karen and I learned by trial and error how to develop a family that was very diverse. We looked beyond race and disability and focused on the goal of creating an accepting and loving family. After about a year, we decided to legally adopt our children and go through the adoption process that included DCF, the court and us. So, in November 1996 Quiana and Kareem Langley-Carr were declared our children in Lawrence Family Court. Quiana was 8 and Kareem was 7. The whole process took about two years.

As they grew older, each had Post Traumatic Stress Disorder (PTSD)

behaviors and we spent years in family therapy. DCF could have been more forthcoming about PTSD triggers and sometimes violent behavioral outbursts. It seemed as though we spent half of our lives in therapy. It would take years before they felt strong attachment and love for me and Karen. The same was true for us.



Like most parents, we went to endless school/parent meetings and learned from the Massachusetts Federation for Children about resources available to get an IEP for our son who had been diagnosed with a specific learning and a psychiatric disability. Methuen public schools were not very good about including children with disabilities within their social/educational programs.

We soon became aware of the limitations and shortcomings, socially and educationally, of our public schools and incorporated an option for going to a private school.

We are truly a blended multi-racial family with two people who have significant disabilities and one who is LGBTQ. My disability has always been obvious given that I'm quadriplegic and use a power wheelchair. That's the only way my children knew me. Some questions, some testing, but generally, we were and are who we are.

Looking back, I think our children focus more on a loving and stable family and not so much on our physical or racial differences. There were some challenges but nothing that I remember being thought of as big obstacles in that regard. Our children grew up in the disability community and were immersed in the culture and grew to understand

the struggles for equality. This left an impression on them, especially as it relates to their own lives as people of color and LGBTQ stigma, marginalization and discrimination.

Now, as grandparents with two grown children who were adopted, we feel that bringing Quiana and Kareem into our lives is a blessing, but the journey has been a difficult one for us as parents and for our children. For those considering adoption, we would strongly recommend that you fully understand where the children came from and what types of behaviors they've demonstrated because of being bounced around in the system. If you choose to go through the Department of Children and Families (DCF), although somewhat improved, there is still a bias toward parents with disabilities who want to adopt. Unfortunately, to this day DCF will come into a family with Deaf parents and hearing children only to pull them away because "they are not suitable" simply because they are Deaf.



If you feel you have the desire to adopt, make sure you're prepared for difficulties and obvious changes to your current lifestyle. The rewards of adoption are incredible both for the family/individual and for the children. They may not be able to articulate it but all they really want is stability and love. Sounds simple but it's a lot of work. Truly a labor of love.

*This article was based on interview questions from Sandy Alissa Novack, Disability Issues editorial board member.*





## ***Pregnancy and Disability:*** **An Interview with Mary Grimley Mason** ***By Ms. Love***

*Disability Issues'* editorial board member, Mary Grimley Mason, sat down recently to talk with your Ms. Love about how earlier in her life she gave birth to three children as a person living with a post-polio condition.

**Ms. Love:** Mary, our readers would like to hear about your experience of having a disability and being pregnant. Although you had your children decades before the passage of the ADA, I think you have an important perspective that can inform women with disabilities who become pregnant today and their partners. Can you set the scene for us of the birth of your firstborn?

**Mary Grimley Mason:** I was in my 30's, living in France and teaching 11<sup>th</sup> and 12<sup>th</sup> grades at the American School. I was a graduate student at Harvard University, studying English Literature, but planned to spend a year abroad in France to enhance my experience and studies. My husband had a grant to write and spent the time in France with me.

My one year abroad stretched into three. During our third year in France, we had an unplanned pregnancy. As a child, I had become disabled with polio, which I handled with crutches and braces. Decades later, the pregnancy was difficult because I had pain and I felt a lot of pressure in my body from the heaviness of carrying the

growing fetus. Muscle pain with the pregnancy caused me to move more slowly. I probably experienced more pain and fatigue due to my polio. I used crutches to walk but had little power in my legs, which made being mobile with the extra weight more difficult. I remember having an x-ray during labor. They were looking for any obstruction from the polio that would impact giving birth. Fortunately, there wasn't an obstruction. If there had been, I would have needed to give birth by Caesarean section rather than have a vaginal birthing experience.



With my first pregnancy, I had a lot of assistance. In addition to my husband, my mother came to France to help and I had a midwife with me in the labor room. My first-born daughter was born in January 1960, and after pregnancy, I went back to being more agile and fluid in my mobility.

**Ms. Love:** Was your son was born two years later?

**Mary:** Yes. At that point, my husband was teaching, and we were living in a small town near Portland, Maine. We had a little apartment on the second floor of a farmhouse outside of town and there was no elevator. Since I couldn't carry my little girl, it was a test of my ability to cope. I really did need help, but I was lifting my daughter on my own. I had strong arms then, but I had to be very specific in my movements and figure out my techniques for safety – for myself and my daughter. The limitations due to my disability were compounded by my second pregnancy.



With my second pregnancy, the doctor said I should come to the hospital alone. A common policy at that time was, no one is allowed to be with the mother during labor. The doctor was very concerned about my safety and wanted to induce labor, so I didn't go through labor as I had for the first birth in France.

When my son was born, we moved into town and lived in an apartment on the first floor of an 18th-century house. We hired a woman to help me, but it was very hard to find someone.

**Ms. Love:** Was your youngest daughter was born in 1967?

**Mary:** Yes. By then, my husband and I were both teaching in Cambridge, Massachusetts and I was writing my Ph.D. thesis. Early in the third pregnancy, the doctor told me that while abortion was against the law at the time, because of my polio condition I could get an abortion. I was surprised he said that. "Absolutely not," I told him.

I do believe one should have a choice.

For my third pregnancy, my water broke, and the doctor told me to take a taxi and get to the hospital quickly. After I gave birth, I went home and felt fine, but then later it had a bad effect on my health. I had terrible pain with muscle spasms. I needed a couple of months of help from a nurse to recover from that.



A while after giving birth to my third child, I had my “tubes tied,” so I would not get pregnant again. An insurance company can’t prevent someone from having a procedure, but they can refuse to pay for it... or try to refuse! My health insurance company tried to refuse paying for my procedure because they considered it an abortion. My doctor intervened and threatened to resign if I could not have the procedure. The doctor argued with the insurance company and said I needed the tubes tied to be healthy because of my polio. Even today, medical providers often need to advocate for their patients to get what their patients need.

**Ms. Love:** Additional words of wisdom for our readers?

**Mary:** I would tell others, “Get help and as much help as you can.” Since I had a full-time job, I could afford it. Even though taking care of my first child was hard, it was very rewarding and very special. In the future, I hope insurance will cover help for those who need it after giving birth.

For some of my pregnancies, the health care system sealed me off from my husband and others, making giving birth a medical matter. I believe pregnancy with a disability should be considered a natural event, but you also need a professional provider that understands

issues pertinent to disability.

I think more awareness is needed of what the health care system can do to help make things easier for a pregnant woman who has an underlying disability. Also, what can be done to make life easier and safer at home after the family leaves the hospital.

Finally, don't allow stigmatization due to your disability.

### **Additional resources on pregnancy and disability.**

Anne Branigin. "People with disabilities face much higher risks during pregnancy. Researchers are only beginning to understand how." *The Lily*, December 28, 2021.

- A new study that fills in gaps about the health risks pregnant women with disabilities face.

The Lurie Institute [for Disability Policy] receives a four-year NIH grant to study pregnancy health care disparities among Black women and Latinas with physical disabilities. Brandeis University, The Heller School for Social Policy and Management.

- A grant to support research toward advancing pregnancy experiences for women with disabilities.

### **A Note to *Disability Issues* Readers from Ms. Love:**

Your Ms. Love is planning to publish more articles on the topic of OB/GYN issues and disability, and I welcome your input. For inspiration, the following article is about a doctor who asked patients to weigh in on how they would "design/optimize a visit to the gynecologist's office," He sent a tweet asking people what they see as "problems, frustrations and solutions" and the responses poured in.

Julianne McShane. "How Would You Change Your OB/GYN Visits? This Tweet Got 3,000 Responses." *The Lily*, December 8, 2021.

As a person with a disability, if I were asked what I'd like to see in an OB/GYN office, I would want an accessible exam table and scale. Please send me your ideas of what you would like to see and experience as a person with disabilities and why (or what your family/friend would want for you). Your responses might be included in a future article about disability and getting OB/GYN needs to be met.

Send your responses to me, Ms. Love at: [DI.LoveandIntimacy@gmail.com](mailto:DI.LoveandIntimacy@gmail.com). Please include your name so I can give you credit for your ideas or let me know if you prefer to be listed as Anonymous. *I look forward to hearing from you!*



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

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





# **Rewards and Challenges: *Caregiving as a Spouse***

***By Mary Grimley Mason***

## ***Joan and Jim***

When Joan was told her husband, Jim, had Parkinson's disease, she said, "We had a lot of learning to do." They attended classes for caregivers, support groups, and classes on Parkinson's Disease. Joan remembers her role as a caregiver began when she took over driving the car. Jim had been tested and told that he could no longer drive safely. Joan says she gradually progressed over the seven years of his illness from a partner to someone who also had to make many decisions while always being supportive of his feelings.

As his cognitive skills decreased, she managed their finances and arranged for the higher level of care he needed. As Jim's symptoms increased, occupational therapists for a special program about Parkinson's came to the house. They also began looking at retirement communities and put their name on the list at a local senior living community.

It was not until Jim was hospitalized after he fell and broke his femur

that they decided he needed more continuous care. Joan put the house on the market. "I was lucky," she said, "it sold quickly." With the help of a moving agency, Joan moved herself and Jim to a two-bedroom apartment into their chosen retirement community. They signed up for special programs, including Palliative Care and Hospice. Jim particularly enjoyed the person in hospice who played the guitar and asked him how he was feeling. "Trapped" was Jim's answer to that question.

In fact, because of the Covid pandemic at that time, the feeling of confinement was felt by the whole community. All residents were restricted to their apartments for almost a year. On the rare occasions when Joan did leave the campus, she remembers feeling anxiety about whether Jim might need her. However, as restrictions lifted and when Jim was able to, Joan took him in his wheelchair to events on campus, such as a popular drumming class that many residents attended and enjoyed at their own level of participation. She and Jim also attended the Parkinson's meetings.

My own memory of seeing Joan and Jim together was when she brought him to dinner in the resident dining room after it reopened. They sat at a table with sympathetic friends even though it was not an easy occasion for Jim who sometimes experienced eating problems. I remember seeing Joan sitting beside Jim and affectionately reaching over to stroke his shoulder reassuringly. Sometimes, words are not necessary.

Eventually, Joan had to arrange for twenty-four-hour physical care to help Jim with all his activities of daily living, including helping him eat as his disease progressed. Joan is a Speech Pathologist and said, "It was hard to watch him being fed toward the end when he sometimes had bad coughing spells." She was always available to share time with him. It was hard when Jim began sleeping long periods of time so they couldn't spend much time together. As Jim's dementia increased, he became less responsive, but as Joan said, he always remained



sweet and appreciative, which made it rewarding to be with him.

Jim died peacefully on March 2, 2021. A few close friends attended the cremation with Joan at Mount Auburn Cemetery. As Covid eased, a service was held a few months later in their church in Lexington. His ashes were buried in one of the lovely garden centers at Mount Auburn. There is a plaque with his name on it and a space for Joan's name.

Joan remains an active member of the senior living community, contributing her thoughtfulness and special skills to groups and events. She is also an activist in the larger regional community.

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## *Sue and Jerry*

Sue and Jerry met in high school when Sue was eighteen. When they attended different colleges, Sue kept in touch with Jerry. They were married at their graduations in 1959. "Jerry was my best friend," she says, "and always has been."

After college, Jerry studied for the ministry at Union Theological Seminary and became a Methodist minister. They lived in northwest Philadelphia for forty-three years where Jerry was a much-loved pastor. Later, he trained for pastoral counseling, which became his vocation. Sue worked as a writer, primarily for custom-developed training programs.

In 2006, Jerry was diagnosed with Parkinson's Disease even though he only had a few symptoms. As they learned more about the severe effects of Parkinson's, they decided to move to a retirement community in New England because that's where their three sons lived. They moved into a senior living community in 2007 where they become active and appreciated members of the community.

At first, Jerry's life wasn't too affected by his condition. He even continued working as a counselor until he began losing his eyesight, which affected his ability to read and write. Sue took over driving the car and managing bills. When Jerry began using a walker, Sue began assisting him with other types of physical activities. This was the beginning of Sue's role as a caregiver.

Throughout the years, when they had to employ caregivers, Sue always remained an active part of the team. They began using professional care when Jerry needed help transferring from bed to a standing position and then to a wheelchair. At first, they had aides for just four and a half hours in the morning but as Jerry's needs increased, an aide was needed all day. When Jerry was safely in bed, Sue was able to take care of him at night and tend to his personal needs. When he needed help eating, she fixed his meals and ate with him. She enjoyed going with Jerry when an aide took him outdoors for a ride around the campus. Sometimes she read to him even though he was not able to respond. Sue said Jerry never complained and they were much endeared by his aides.

Sue spoke of some very difficult episodes they went through. One was a period when Jerry had severe hallucinations. Another was a frightening episode when he slept for two days and a night. "I thought he was going to die," Sue said. He did recover, but they checked with the doctor about his medications. Sue feels that bringing in the hospice system was a good turning point for them. The focus was no longer on trying to find cures, but on Jerry's comfort and calmness. Jerry rarely spoke so it was a wonderful surprise when he spoke after a friend came and sang for him. When Sue asked him if he had enjoyed the singing he said, "Yes, enormously" which thrilled her.

Jerry died on November 17, 2021. A memorial service was held for Jerry, who had been part of the community for fifteen years. Two weeks later Sue and her family invited everyone to gather and celebrate Jerry's life and to enjoy his favorite dessert of vanilla ice

cream with chocolate sauce and nuts!

Sue feels she has a lot of work to do to recover from her loss and to re-enter into being part of the world around her. "I thought I would not live past him." After our interview, Sue told me she was inspired to write down all her memories about the years Jerry was ill, which was helpful. Sue is gradually rejoining the community and she is much welcomed.

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*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."*



*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.*

## ***Family and Disability***

## ***By Joan Burrows***

A family is a complicated relationship – good and bad, happy and sad, just as all relationships are. A family where one or more members have a disability is the same, although with more challenges.

Sometimes there is an adult with a disability or a child(ren) with disabilities, and sometimes it may be both adults and children. Adults can set the way the family handles and deals with the disability. Hopefully, he or she was brought up with caring and understanding parents who were able to give them the best of life, love, and friends when they were a child, so they are better able to offer that to their own children.

When a child is born with a disability, society may not always help! Parents may turn away from the baby, as may relatives. “Welcome Baby” cards are few. If another child is born with the same disability, it is not easier for the parents, though perhaps it might be for the children.

I know a father with Multiple Sclerosis who had four young children. He participated in all the activities he could with his family. I know a mother whose family turned against her when her child was born with a disability. She commented that no one knows how difficult it is to know that your child will die before you. She was “Super-Mom” and gave her child all she could with love and care.

Then there is a family who had an 8-year-old daughter and wanted more children. After two miscarriages, they decided to try once more. Twins were born. The boy had Muscular Dystrophy and the girl had Cerebral Palsy. When the babies came home, there was a lot of love in the house and constant care. The older sister, now 9 years old adored the babies and played with them and helped her mom. I visited often. The family seemed to be doing well and I loved being involved.

About two years later, they moved to a bigger, more accessible home for the twins. Although they now lived further away from me, I kept in touch the best I could with phone calls. I sent some music for the oldest whom I had taught piano and later for the twins who also loved music. Just before the boy reach age 20 he died, which is too common for someone with Duchenne Dystrophy.

The mom gave all she had to her children and never accepted outside help. She said, no one could care for the twins better than she could. The twin girl is now in college. She is getting out, driving, and reaching her potential. Her older sister is estranged from her mom, which is sad, because her mother did what did from love, yet a little nine-year-old girl felt left out. It's easy to understand, but not easy to see.

When a grandfather, daughter, son, and grandson all have a disability, there are no "rules." How does a family deal with it? Walter Kiver is the grandfather, and this is his family's story.

For many years, the grandfather was not diagnosed with Muscular Dystrophy (MD) and neither were his daughter or son. At 20 years old, Walter's daughter had a baby who was diagnosed with MD. At this time, they tested the baby's mom and learned that she too had MD. After years of not knowing why she got so tired or why she could not climb the ropes in gym class and keep up with her friends, she understood why. She also watched her father, Walter, go from walking to using a wheelchair because he too lived with MD.

This family was fortunate. A doctor came to make a house call and stayed for two hours talking with Walter and told him he had much to offer the world. The doctor convinced him to go to the hospital to be evaluated and get a wheelchair. Soon, the doorway to his room was widened, the back door had a ramp, and Walter was off to an adult day center. He was very social, so this was perfect for him. Walter met people who helped him and one of them was me! He went back to

school and got his degree in Social Work graduating with honors. Walter went to various schools to talk with children from first grade through high school. He and I took courses from the State Office on Disability. We became Community Access Monitors and started a Commission on Disability in our town.

Walter's daughter and grandson followed in Walter's footsteps. His daughter graduated from Wellesley and worked her way up until she was managing the PCA program at Independent Living in Lawrence. Walter's grandson graduated from Mass Hospital School and then Gipps College where he wrote a beautiful story about his relationship with his uncle who was taking a double major in college. Sadly, his uncle (Walter's son) committed suicide and it was related to living with MD. If only he had been able to hang on a little longer, I believe he would have had a good future.

The grandfather, daughter, son, and grandson had challenges to deal with, and they also had a lot of love and care.

We all need help at times, yet sometimes it's hard to accept help. I believe that we are put on this earth to help each other. When we offer and receive help, we create a better, more loving world.



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*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.*





# A Typical Day in the Life of...

*By Marybeth Barker*

There was a touch of autumn in the air as I made my way up the stairs to my car on the stairlift. The lift moves unbearably slow but the birds flitting back and forth in the branches overhead against an exceptionally blue sky countered my usual tendency toward impatience. I was looking forward to having tea with my friend at the bakery.

My car was low on gas, so I stopped to fill up on the way. I pressed the help button on the pump, waited, then pressed again expecting to hear a voice from the intercom or see an attendant come outside. The cashier, visible to me through the window, didn't appear to see me. Assuming the button was broken, and the attendant had just not noticed me, I phoned to explain that I was outside, disabled and needed help. "Sorry, I'm the only one here and I can't leave the cash register" was the reply. Since my tank wasn't empty, I decided to move on to meet my friend.

I parked in the disabled parking space closest to the entrance. As I began transferring from the driver's seat into my wheelchair on the passenger side, I noticed a motorcycle parked on the painted stripes next to my vehicle and my wheelchair ramp deploys from the passenger side. After visually calculating the distance between my door and the motorcycle, I determined my ramp would likely knock the bike over. Shifting back to the driver's seat I backed out and easily found another spot. I was eager to meet my friend and the illegally parked motorcycle hadn't inconvenienced me too much, so I rolled on.

Jessie was holding a table for us outdoors on the back patio of the bakery. The bakery has an accessible front door, ramp, and indoor seating but I quickly discovered there was no accessible access from

indoors to the rear patio. I exited the bakery and wheeled myself around to the back of the building, squeezing between cars, past the dumpster, and over the potholed asphalt to the back. I still couldn't achieve full access to the patio, but we decided it was too lovely a day to sit inside so Jessie pulled a table over and we set ourselves up along the edge.

I considered complaining about the motorcycle and the lack of a ramp, but my friend and I had limited time and I wanted to relax into our visit and enjoy each other's company. I didn't want my disability to be the focus of our conversation or to spend the short time we had together on anything unpleasant. The motorcycle was still there when I left so I took a photo of the license plate. At the time, I wasn't sure what I would do or if I would do anything about it. However, later that day I called the police with the license plate of the motorcycle. I also emailed a letter to the manager of the gas station and the bakery.

I remember this day well because there was a time when these events might have soured my day. Perhaps because the weather was so nice and I was determined to enjoy it, or perhaps by then I had simply figured out that if I stopped to fight every injustice, I'd never get anything done.



In retrospect, I think during the early days of becoming disabled, the

fear of losing my autonomy ran so deep that I saw every barrier or attempt from friends or strangers to help me as a threat to my independence. Learning to negotiate the world with a disability has been a process. I had trouble sorting out when to accept or reject help and found many unsolicited attempts to help not helpful.

Inappropriate comments and gestures from well-meaning, but unenlightened individuals are common. Determining how best to respond is likely something every person works out individually.

I no longer bristle at someone for helping me with the door one moment, only to resent that no one is helping me with the door in the next moment, but I'm still working it out. It's taken nearly a decade, but I've come up with a few guiding principles:

- If there is a teachable moment opportunity, I take time to educate.
- If an unwelcome attempt to help places me in danger, I decline forcefully.
- Some barriers to access are best addressed later, by reporting them in writing.
- Finally, I don't let unenlightened people ruin my day. I problem-solve when I can and move on.



*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.*



## **Street Safety for all Pedestrians**

***By Penelope Anne Shaw***

As a power chair user, I frequently encounter safety issues when driving my chair. In winter, there is often snow and ice on sidewalks and in curb cuts. Once my chair got caught on ice and I had to call 911. Several men from the fire department came to push me off the ice and shoveled a clear path for me. Throughout the year, there are trash barrels, debris, broken sidewalks, and grates. There are also motor vehicles blocking sidewalks, which owners can be ticketed for. These hazards often make it necessary for me to go into the street to drive my chair. Being in the street with motor vehicles is especially challenging when it is dark outside, even when I'm driving against traffic. To address some of these problems (and more), I was a plaintiff in a Title II lawsuit. In a December 2019 settlement agreement, our Town agreed to address them but has never fully done so.

When crossing streets, I also encounter safety issues because of timing length and concurrent traffic phasing. There is an intersection near where I live that I find particularly dangerous to cross. Crosswalk buttons are completely inaccessible when I can't get

my wheelchair close enough to reach the button because of large piles of snow. On the positive side, this intersection does have accessible pedestrian signals with audible and tactile cues – beeps and vibrations – to let pedestrians with vision and hearing disabilities know when the "walk" sign is lit up. If one holds the button down the signal will orient the person to the direction, for example, "Crossing Washington Street eastbound".



## **Time to Cross a Street**

I am concerned about safety at an intersection because of the timing of crossing. When I cross the street from a pharmacy to get to a business on the other side, the process is as follows:

- Press the crosswalk button. An orange raised hand indicates not to cross.
- The image of a white figure walking appears on the sign indicating it is okay to cross.
- A number 9 indicates pedestrians have 9 seconds to cross the street.
- When the orange hand flashes with the number of seconds remaining, pedestrians are supposed to continue crossing. Sometimes I barely make it across in my wheelchair within the 9 seconds.

More than once I have seen a woman with 2 toddlers cross ahead of

me. These children walk slowly. I am reluctant to try to zip around the children for fear of frightening them. Instead, I wait for the next crossing cycle because 9 seconds is not sufficient for all of us to cross safely. I was troubled to hear the woman say to the young girl who appeared to be about three years old, "Hurry Dear. We only have a few seconds left to get across the street." According to our Director of Public Works, this timing length meets the requirement – a 7-second walk, a 9-second countdown, and a 4-second buffer. Is that enough for a woman with 2 toddlers and a wheelchair user?

Occasionally, if the street condition is poor, such as when there are piles of snow or ice, I have still been in the middle of the street when the signal times out. Under these conditions, I am dependent on the kindness of motor vehicle drivers to let me finish driving my chair across the street. I feel strongly that if the timing cycle at this intersection is not long enough to cross the street safely every time, it should be lengthened.

## **Concurrent Traffic Phasing and Turns**

[Concurrent phasing](#) is a traffic movement system created by engineers in which both motor vehicles and pedestrians have the light at the same time. The purpose is to increase traffic capacity and flow. I have found this system to be serious and even problematic, especially when motor vehicles make turns.

When I am at a nearby pharmacy and want to cross a street, around the corner on the left there are motor vehicles in the curb lane parallel to me. After pushing the crosswalk button, there isn't a pedestrian-only phase. Many of the vehicles turn right and encounter me in the crosswalk. This system causes motor vehicle and pedestrian conflict. In part, because there are neither yield-to-pedestrian signs at this corner nor lead-time for pedestrians.

With this system, vehicles frequently come very close to me, which is unsafe. It appears that the vehicle drivers don't even see me. This

might be because I am less visible in a wheelchair since I'm not standing up or maybe because the pole at the corner blocks their view. Often there are multiple vehicles in a row, moving at fairly high speeds that do not yield. They blow through, coming within inches, almost sideswiping me. This is frightening and dangerous and it puts me (and other pedestrians) at high risk of injury. Because of a rare neuromuscular disease, I am unable to turn my head to the left so I can only see vehicles when they are in front of me, increasing my vulnerability.

Possible alternatives for providing protected crossing with concurrent phasing include better-designed-more-visible crosswalks, yield to pedestrian signs, lead time for pedestrians, or a pedestrian-only crossing phase. City and town engineers need to address all these concerns – impassable sidewalks, street crossing timing, and concurrent traffic phasing. They should design solutions to improve safety for everyone, regardless of the mode of transportation – those walking, bicyclists, and wheelchair users.

Keeping sidewalks and curb cuts clear, having more reasonable timing for street crossing, and addressing the conflict between motor vehicles and pedestrians with concurrent phasing would improve the safety of persons with disabilities when traveling on sidewalks and crossing streets.

*Is there the will to make changes? Is this an ADA issue?*

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*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.*

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## **The PCA CORNER**

### **Burn-out and Retention Issues**

***By Ray Glazier***

By now most readers will have heard of the pandemic-inspired Great Resignation, in which many workers who are in demanding, low-wage jobs have reassessed the worthwhileness of their working lives and simply dropped out of the labor force. Unfortunately, PCA work is an occupation that is beginning to be affected by this trend. Now, more than ever, PCA consumers and surrogates can ill afford to take workers for granted. [Readers of this column can find tips on PCA retention in [Disability Issues of Summer 2021](#).]

Consider the situation of Bob [not his name], a consumer of my acquaintance, who writes:

After almost a decade, I'm having problems with my PCA Sara. [It could just as well be Sam; the name is fictitious.] She has been amazingly loyal, considerate, and helpful over the years – even sitting by my bedside during my hospitalization a few years ago, knowing full well that she could not be paid for those hours. Sara has provided pretty much all of my in-home care for the better part of eight years now. We have become really close – sharing confidences, knowing all about each other's families and each



other's quirks and preferences.

But lately Sara is moody and frankly uncooperative. Instead of doing what I ask, including when and how I want things done, she does tasks when and how it suits her. At first, I assumed that it was distraction or absent-mindedness. But then a pattern emerged. Yet I can't bring myself to talk with her about the problem. Surely, she must be aware of how this behavior frustrates and aggravates me because Sara knows me better than almost anyone

Lately I have actually considered replacing Sara, even though recruiting and training a new PCA is a daunting prospect. Truth be told, she is pretty much irreplaceable. I am at a loss as to what to do. You have more experience at this than I do, so give me some advice.

Here is my take and what I told my troubled friend more privately:

I can see two big problems right off – communication break-down and PCA burn-out. The first issue fuels the second, so fixing the communication break-down is part of the key to keeping Sara as a caregiver, especially because that is your true ultimate objective.

Examine your relationship with Sara with all the self-awareness and honesty you can muster. Are there any errors of omission or commission on your part that could account for this change in behavior? Is it possible that you had come to treat Sara more as a friend and surrogate therapist than a caregiver? Have you over-relied on her for your care because she was so available and so compliant? Should you have delegated certain tasks to other PCAs or even added another part-time PCA to take on part of the workload that she has been shouldering solo?

If the answer to any of these questions is "Yes" or even "Maybe," you have your work cut out for you. In some instances, the remedy is implicit in the question, if you can take the hint. Burn-out really burns deep, and neither hugs nor Band-Aids will help

the healing process. Can you figure out any way to give Sara a vacation with at least partial pay? Even if she doesn't have a family to support, chances are she needs that paycheck to pay the rent or make her monthly car payment.

Contributing to burn-out and the PCA turnover rate – above and beyond the sorry expected rate of 40 to 60 percent – has been the unfortunate late payment snafu that happened earlier this year. On January 1st MassHealth transitioned from three Fiscal Intermediaries to a single agency to process timesheet records from more than 40,000 PCA consumers and payroll checks for the entire PCA workforce of 55,000. A February 7th Boston Globe story [“Missing personal care attendant payments strain an already taxed workforce”](#) by Katie Johnston discussed the resultant late payment problem that created a major hardship for thousands of hard-working PCAs and may have caused many to seek other employment with larger and more dependable paychecks.

To continue our fictitious scenario, Bob feels certain that paycheck delays have contributed to Sara's mood change; he hopes it won't cause her to stop working for him. In that Globe article, Bob read with alarm about the experience of quadriplegic Charlie Carr, the former Mass. Rehab. Commissioner. Mr. Carr told the reporter that (quoting the article): “His afternoon PCA quit when the checks stopped coming and took a job as a delivery driver, he said, leaving him with a gap in caregiving for several weeks.”

Amen, Bob!

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Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA Program 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](mailto:RaymondGlazier@gmail.com) with questions, comments, or suggestions for future columns.



## **Normalizing Disability in the Workplace: A Benefit for Everyone**

A conversation with ***Zary Amirhosseini, M.Ed.***,  
Manager, Massachusetts General Hospital Disability Program

***By Stacey J. Drubner, JD, LICSW, MPH***



In the last few decades, the workplace has made progress with being

more accessible for people with disabilities. After 30 years+ since the ADA was passed, the hope is that we can achieve a more advanced phase of inclusion and normalcy. This requires mitigating [workplace ableism](#) (discrimination and stigma based on a disability), and moving away from “the idea that non-disabled people are more worthy than disabled people, more valuable, more talented.” The key to a paradigm shift lies in education, continued innovation, and authentic acceptance and normalizing.

So how do you know what to do or how to interact with someone who might be a person with a non-visible disability? Zary Amirhosseini recommends an open-minded and non-judgmental approach for all individuals.

- Be sensitive to a variety of employees and potential non-visible disabilities.
- Show flexibility and patience.
- Don't make assumptions regarding disability status. Being “different” may not signify a disability.
- Be open to understanding individual needs for thriving. For example, a person with a learning disability may require repeating information or an assignment.

Being inclusive and accommodating is the “human” and ethical thing to do, but research shows that it also benefits the workplace and taps into a skilled workforce population. Findings show:

- Companies that embrace best practices for employing and supporting more persons with disabilities in their workforce have outperformed their peers.
- Organizations that are disability inclusion champions benefit in the following ways:
  1. Exhibit better innovation
  2. Have greater productivity ratings
  3. Enjoy a more favorable reputation

#### 4. Perform above-average financially

The takeaway is that organizations can realize benefits through processes that “employ, enable, engage, and empower” people with disabilities.

When discussing benefits specific to the healthcare space, Zary points out that those with disabilities, or family members with disabilities, enhance the patient experience because they are aware of barriers firsthand. Beyond their medical industry skills, they understand the consequences of not having automatic doors, nearby parking, adjustable exam tables, or someone misinterpreting what it means to have a mental illness.

## **How to Normalize Disabilities and Make a Workplace More Accessible & Inclusive**

### ***Individual Level Considerations***

Zary emphasizes that being a good colleague to people with disabilities involves the same components as being a good colleague to anyone:

- Be patient, kind, open-minded, and understanding.
- Accept that you will encounter lots of different people in the workplace, including those with different cultural backgrounds, disabilities, ages.
- Disabilities are part of a person’s identity, but not indicative of everything about them.
- Focus on individual strengths – what they *can* do, rather than what they *cannot* do. What skills and specialties do they bring to the job?

### ***Etiquette and Communication***

People with disabilities are people first. It is not uncommon to unknowingly say or do the wrong thing or to avoid all engagement due to fears around awkward exchanges. Educate yourself on

acceptable communication and etiquette standards, and consider the following:

- Be open-minded and willing to make adjustments as needed.
- Acknowledge that not everyone has the same preferences for how they want to be treated.
- Use person-first language.
- Be respectful of devices and [Service and Support animals](#).
- Treat adults with disabilities like adults.
- You can offer help but take and respect the lead of the person with a disability.

### ***Etiquette Resources***

- CDC, Disability and Health Promotion: [Communicating With and About People with Disabilities](#).
- Work Without Limits: [Disability Etiquette Guide: Everyday strategies for effective communication with people with disabilities](#).
- [Respectability.org](#) Video: [Etiquette: Interacting with People with Disabilities](#).

### ***Organization Considerations***

Provide regular and standardized education to the workforce, with a focus on:

- Rights and resources
- Non-visible disabilities
- Appropriate engagement
- Consider a [paradigm shift from the Medical to Social Model of Disability](#).
- Hold discussions around disability regularly. The more we talk about disability, the more normalized and less stigmatized it becomes.
- Benchmark with other organizations that have achieved success with integrating disability into the workforce.
- Establish systems that allow for evaluation and improvement. The

Pandemic taught us that we can adapt more quickly than we did historically.

- Consider [Universal Design](#) modifications that can benefit the whole workplace, not just those with disabilities.



*Zary Amirhosseini, M.Ed., Manager,  
Massachusetts General Hospital Disability  
Program*

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## **Abilities Dance Presents the World Premiere of “Intersections”**

[Abilities Dance](http://abilitiesdanceboston.org) presents the world premiere of a reimagined “Intersections” show streaming live and in-person from the Multi-Cultural Arts Center in East Cambridge, MA, April 22-23, 2022.

Created by an all-BIPOC artistic team, this inclusive recital with an all-new music score redefines antiquated views around dance, showcasing the talents of a diverse, passionate company of performers. Disabled and nondisabled artists from across the country will infuse their artistry into this innovative ballet.

To maximize accessibility, audio descriptions will be provided (for blind/low-vision audiences), and captions and ASL interpretations will be provided (for deaf/hard of hearing audiences). These will take a



narrative form which complement the music. Contact Abilities Dance at [abilitiesdanceboston@gmail.com](mailto:abilitiesdanceboston@gmail.com) or 781-465-4032 if there is something they can provide to make the performance as accessible as possible!

Early bird tickets are \$25 until April 8<sup>th</sup>. General admission is \$35. Unlimited free tickets to anyone who needs it so that finances aren't a barrier to see the work. Tickets may be purchased at: <http://abilitiesdanceboston.org/events/intersections>.

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The [Anti-racist Collective of Avid Birders](#) is an inclusive, progressive birding group based in Western Massachusetts, that was established informally in June 2020. As of December 2021, they became a regional affiliate of the Feminist Bird Club. They center and celebrate the experiences of Black, Indigenous, Latinx and birders of color; birders of all genders and sexual orientations; and birders with disabilities. Their work is dedicated to making the outdoors—and birding in particular— accessible and safe for people who find themselves under-represented or unacknowledged in traditional birding communities.

Current meetings are both in-person and at virtual events. This space is meant

to build community among bird-enthusiasts who share values of inclusion, share resources to make birding a more equitable hobby, and support fundraising efforts.

If you have questions or comments, please write to: [FBC.WMA@gmail.com](mailto:FBC.WMA@gmail.com). Follow us on [Facebook](#) and Instagram @antiracist.avid.birders



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