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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...***

"It is a great privilege to be able to enjoy the bread-and-cheese of life — the simple pleasures, of which there are so many."

~ *Charles Edward Jerningham*

Dear Readers,

The calendar has turned to a new year and with it, a steep rise in Covid cases. Maybe like some of you, my holiday plans to gather with small groups of friends and family were canceled at the last minute. Thus, my holidays were quiet, and that quietness has continued into the new year. I'm limiting how much I go out and doing more reading, watching, attending events online.

Soon after the new year, I read an article that offered the question, "***What are the simplest things that bring you joy?***" During the bleak, cold days of winter and social isolation, I have taken this question to heart. I am paying attention to what simple pleasures bring a smile to my face and lighten my spirit. In true new year's fashion, I decided to journal about my experiences. Each evening (or the next morning), I reflect on the day and make a note in my journal of no fewer than 5 times when I experienced the simplest thing that brought me joy. Some days it's easy and other days I find

myself stretching to write down 5 moments. But I'm realizing that what I pay attention to seems to expand and I figure I can't go wrong with expanding joy.

As examples, I offer you some reflections that made it into my journal. Making a cup of tea and taking the time to breathe in the earthy aroma before the first sip. Making pizza with an assortment of my favorite ingredients. Noticing the daily growth of my amaryllis plant and its' glorious blossoming. Taking an afternoon nap, just because I want to. Appreciating a moment of laughter with a friend. Watching old reruns of Frasier (one of my favorite sitcoms) and laughing out loud at their antics. Being gentle and kind to myself when I am tempted to be self-judgmental. Getting into bed at night and snuggling under the warm covers, especially when it's bitter cold out.

I wonder what simple joys you would discover if you reflected on your daily experiences. If you are inclined to consider this question for yourself, I share the article that inspired me, [The Simplest Things That Bring Joy: Community Reflections](#).

In 2022, may you be safe and embrace the tiny (and large) joyful moments.

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.*





**The Baby, the Nurse,  
and LOVE**  
***By Ms. Love***



The Baby and the Nurse.

Once upon a time, in the state capital of Massachusetts, a woman gave birth prematurely at a hospital to an adorable baby who weighed only one pound and one ounce. The mother had a serious alcohol issue and didn't know she was pregnant until she gave birth to a baby girl. The baby was born with fetal alcohol syndrome and a birth defect called Spina Bifida, which occurs when the spine and spinal cord don't form properly. The birth defect affected the baby's back and hips and caused hydrocephalus, requiring the placement of a shunt in her brain. The mother saw the baby with a hole in her back (from the

Spina Bifida) and left the hospital. It is thought that the mother did not want to see how her drinking had contributed to the baby being born with so many complications, yet she declined to sign papers so someone could adopt the child.

Meanwhile, in another part of the same hospital, a respected nurse was working with some nice colleagues who shared their lives and dreams with each other. This nurse was not married and told her colleagues that she wanted to have children. One day a colleague suggested the nurse go to the Neonatal Intensive Care Unit (NICU) because there was a baby in the NICU who might become available for adoption. The nurse took one look at the little angel and said she wanted to adopt the baby if the biological mother decided to place the baby for adoption.

The biological mother was ambivalent about keeping the baby. She left the hospital without her baby, and it seemed like she wasn't coming back. Then, weeks later she showed up wanting to take the baby home with her. This cycle was repeated multiple times – leaving her baby behind, then asking to take the baby home. Sometimes, it was obvious to medical staff that the mother showed up to the hospital drunk. The doctors did not let her see the baby when she was drunk. One day, the biological mother did take the baby home with her for six hours. Soon after, she signed forms that allowed the baby to be adopted. The nurse moved ahead to adopt the baby and named her Emily.



Emily with her mother and the judge on her adoption day.

In the 1980s, a doctor told the adoptive mother that baby Emily would die either because she was born prematurely or from the hydrocephalus. The obstetrician who delivered Emily advised the adoptive mother to “pull the plug” on the baby because she would never walk or be able to do anything with her life. There was a law, Emily says, that said you could NOT pull the plug on a sick baby who could potentially have a good life. The adoptive mother knew about this law and told the doctor not to pull the plug. Oh, how wrong the doctor was to think that Emily would not live and live well!

Baby Emily is now a 33-year-old woman who lives in a group home in Westborough and attends a day program. It was my pleasure to recently interview Emily to hear more about her life and share it with you, dear readers. Emily uses a combination of walking with crutches and a wheelchair.



Emily dressed up for her 30<sup>th</sup> birthday party.

One of Emily's treasured activities is to tell people her birth story. She wrote her birth story to share with the area group homes and [Massachusetts Advocates Standing Strong](#). Part of her story includes her brother who is six years younger than Emily and has a mild form of cerebral palsy. Her mother adopted him too.

I began today's column with the traditional opening line of a fairy tale, "Once upon a time" but Emily's adoptive mother is no fairy tale heroine who lived "happily ever after." She was a nurse for 44 years at multiple big-name Boston hospitals. But when Emily was still young, she was advised to leave nursing because she had developed allergies and Multiple Chemical Sensitivity Disorder from wearing hospital gloves with powder and being exposed to hospital-strength cleaning products. There were times she was so sick, she couldn't leave the house. Eventually, she developed heart and other health issues. As a young adult, Emily moved into a group home in 2013. Sadly, Emily's mother died of ovarian cancer soon afterward.

I wish I had met Emily and her adoptive mother years ago. As a nurse, it's clear that Emily's mother had an inner strength when caring for patients and understood how the healthcare system worked. I bet she also used some of her nurse advocacy skills while raising two young children with disabilities. Emily was raised to be a strong, confident woman who doesn't let anyone put limits on what she wants to do. Emily is passionate about advocacy. She is certainly her



mother's daughter.

Emily keeps a notebook with stories and photos about her life. One special highlight is when she attended her high school prom and was voted Prom Queen. Emily has pictures of herself with Prom King from that night and tells me, "I was 4'4" and the Prom King was 6'2" and the captain of the football team. He knelt to take prom photos and dance with me. It was a memorable night!" These days Emily's social life is just as vibrant, and she enjoys spending time with her boyfriend.



The Prom Queen and King.

Emily told me about the many activities she's involved in. Before the pandemic, Emily participated in the Massachusetts Special Olympics'



swimming and cycling teams where she earned a gold medal in swimming for her speed. She hopes to continue training for the Special Olympics when the pool re-opens after the pandemic. Being an animal lover, she happily volunteered at an animal shelter. She does self-portraits with acrylic paint, which have been on display at the Boston Public Market. Emily shares her artistic talents with peers by helping them with arts and crafts projects. She helps her roommates learn self-advocacy and encourages them to try their hand at speaking up for themselves.



**Left:** Emily participating in the [Michael's Run](#) 5k road race.

**Right:** Emily displaying her [Explore-Prepare-Act Training](#) training certificate from Massachusetts Advocates Standing Strong.

Because of surgeries and time spent in rehabilitation, Emily was not able to complete all the requirements to attain a high school diploma. However, she attended the graduation ceremony with her classmates and wore a cap and gown. Emily is currently enrolled in a GED program to earn a high school equivalency diploma. Her favorite class is general science. Emily hopes to complete her GED in two or three years. She plans to continue her education at Quinsigamond Community College and study early childhood education. She wants to work with young children who are in special education programs.

I asked Emily if her mother gave her advice that she particularly values. She quickly responded, ***"Just because you have a disability, whatever you do, don't let it stop you. You can do***

***anything you want to do as long as it is not too dangerous. Use your heart and put your mind to it. There is always a way to do what you want to do based on your abilities."***

A baby, a nurse, and with a lot of love, we see how **LOVE** blooms.

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*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.*

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## ***The Chaos and Beauty of Thanksgiving***

***By Marybeth Barker***

For most of my life, I have lived in an able body. About ten years ago that changed. At age 58, I developed a disabling autoimmune condition, Sjogren's, which manifested encephalopathy and left me with ataxia (a balance disorder), tremors, and neuropathy. Today I use a wheelchair for mobility and fatigue. Though I have slowly come to self-identify as a person with a disability, like most people living with a chronic disabling condition, I have made my life and identity about far more than my disease. I volunteer as a baby cuddler at MGH, serve on my local Commission on Disability, and volunteer as needed on projects related to preserving the environment of the pond where I live and swim.



Arranging the many medical appointments and infusion treatments necessary to manage my disease feels like a full-time job. But I need my life to be about more than just the custodial care of my body parts. I want a full life, even if that means it's hard and messy at times. Messy is okay as long as there are moments when I feel purposeful. My Thanksgiving was all of that.

It was exhilarating to prepare for a two-week visit during Thanksgiving from my daughter, her husband, and my eight-month-old grandchild who lives in Wisconsin. I struggle with chronic pain and fatigue, but the mere anticipation of their visit was energizing. Physical discomfort easily took second place to the pleasure of setting up borrowed baby equipment, ordering toys, planning the Thanksgiving menu, and more.

Once the excitement of hugs, shuffling bags, hanging up coats, and discussing sleeping arrangements settled down I glanced at a new text message. The message was a call to rally support from local disability activists. I was conflicted because I wanted to respond, but I didn't want the intrusion right now. With pangs of guilt, I ignored the text and turned my attention back to being with my family.

Thanksgiving Day and the weekend that followed are a blur. The



house rocked with visits from friends and family, all vaccinated, boosted, and tested of course. Food was shared, stories were told, people came in and out as they took long walks along the trails around the pond. During the holiday and weekend, the entire family participated in playing with and caring for my granddaughter. The following week, her dad travels home to WI and my spouse and daughter go back to working remotely. This leaves me with primary responsibility of caring for my granddaughter.

I'm awestruck by my granddaughter, Ophelia, Filly for short. She is eight months old, very mobile, and in need of constant supervision. She wants to be free of restraint to crawl and explore. The only way to keep her safe is to join her by getting on the floor and scooting beside her. The baby can crawl faster than her old grandma can scoot so I'm happy when she pauses to play with a toy. But each time she pauses, the dog Rupert plops himself between us making it difficult to climb over or around him when Filly decides it's time to crawl again. I realize I'm desperate when I find myself trying to reason with Rupert as if he is an adult person and I am expecting to receive empathy from him!

When I need a break from floor play, I secure Filly on my lap in the wheelchair with an adapted device called Lap Baby. The velcro straps allow both my hands to be free so I can wheel her around the house as we sing or listen to children's music. "The Wheels on the Bus" seems to be her favorite song, which seems very appropriate! My phone is filling with messages and missed calls but I'm too busy by day and too tired at night to check them.





After one day, I'm exhausted so I ask a woman from the neighborhood to come over for a few hours a day to help. The baby doesn't nap unless she is being held. Thankfully, we fall into a routine. I rock Filly to sleep each afternoon then carefully transfer both of us to my bed. With my "grandmother's helper" on board and our two-hour daily naps, I make it through the week.

By the Wednesday after Thanksgiving, I am actually looking forward to my intravenous infusion appointment. Sitting in a recliner where I can read and nap for four hours with an IV in my arm is an appreciated respite. I finally check my phone messages and see there is a petition in circulation to stop trees from being cut down near the pond to make space for an accessible path, which they say people with disabilities don't really want. The petition misrepresents the position of the local Commission on Disability and falsely speaks on behalf of people who are disabled. I'm rattled but decide not to respond at that moment. I will pen a thoughtful reply once my life returns to normal.

I return to the text message that came in last week when my daughter and family were arriving. It's asking for support to oppose a holiday light show planned on the grounds of the former Walter E. Fernald State School. Not long ago, hundreds of disabled children and adults were warehoused there. They were starved, neglected, and subjected to state-sanctioned medical experiments. Local activists have been asking the town of Waltham to relocate the holiday show to a different location out of respect and in recognition of its history of injustice. Their requests for a plaque, museum, or monument have gone unanswered.

I get drowsy and my thoughts drift back to a memory of visiting a museum in Berlin Germany. The Germans erected a monument and museum on the site of the former Nazi "euthanasia program," which commemorates the lives of 300,000 adults and children with mental

and physical disabilities or chronic illnesses who had been murdered there. My sleep is disturbed.

When I return home, Filly is tired and fussy. I darken the room and we retreat from the world to the rocking chair. I softly sing to her until she's asleep in my arms. My time with her will come to an end in a few days so even as exhausted as I am, I cherish every moment I get to spend with my precious granddaughter.



*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.*

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## **My Father's Greatest Gift**

*By Ray Glazier*

My father was a working man, a small-town barber who had little worldly goods to leave me when he died at 83 after becoming paralyzed in a freak accident. In my boyhood and especially teenage years, we were at loggerheads: He was an Archie Bunker prototype – stubborn Republican, ultra-conservative, inherently racist. But he was supportive of my academic ambitions despite my Meathead-like liberal views. When I became paralyzed from a brain injury in an auto accident at age 26, he rushed from Ohio to Pittsfield, sitting with my

mother at my bedside for weeks as I lay in a medically induced coma that he didn't comprehend.

My paralysis devastated and baffled him, but I came to understand paralysis far too well. I was fortunate to be able to return to work the week after I was discharged from seven months in the Massachusetts General Hospital Rehabilitation Unit. I had made considerable progress from my initial post-coma status – total quadriplegic, ventilator-dependent, looking like a Holocaust survivor at 99 lbs. In my attempts to speak, no one except my wife could understand what I said and my valiant attempts to walk were fruitless. At first, my father and other family members and friends were supportive of my illusory notion that all this was a temporary state of affairs; in fact, doctors were also complicit in this.

As time went on, the devastating truth began to sink in; I was a wheelchair user for life, unable to propel the chair because I only had the use of one weakened arm and had a life expectancy of 15 years according to the insurance actuarial tables. (I celebrated my first 'Survival Day' in 1983, 15 years after my injury. I am now 38 years past my expiration date and counting.)

The world was full of architectural and attitudinal barriers, as well as emotional pitfalls. Crossing a street in those pre-ADA days meant rolling my wheelchair along the sidewalk until finding a driveway (the only curb cut), going into the side of the street, and rolling along until there was a driveway on the other side, then crossing without a crosswalk or traffic light. People stared or averted their eyes wherever I went; total strangers commiserated awkwardly with my wife. I was a stranger in a strange land, a pariah in a most unfriendly environment.

I became depressed, suicidal, and quit my job. My wife couldn't take it any longer and left. After hospitalization following a nearly successful suicide attempt, I flew back to Ohio. Home is where they always have to take you in. My parents embraced me. My diminutive mother

provided my personal care and my father helped me face the outside world with the knack for humor that he had developed to entertain patrons of his barbershop.

When people stared at us on an outing to the mall, my father ogled back and sometimes made silly faces. When people totally misinterpreted what I was trying to say, he made a joke of it, offering some outrageous alternative misinterpretation. When it turned out that the allegedly accessible restaurant was up a flight of stairs, he threw up his hands and laughed. When I looked sad, he pinched my cheek and told a joke. He accepted me – wheelchair and all – and he showed me how to hold my head up and face the music.



When I returned to Cambridge and went back to work, I hired attendants and began to travel around the country, sometimes solo in connection with my work on government projects related to disability. I visited the White House West Wing during the Clinton administration, but Bill wasn't home.

Hotel reservations for wheelchair rooms sometimes weren't honored. Arriving to the hotel late at night after a delayed and prolonged flight from Boston to D.C., I was told that the accessible hotel room I had reserved was already occupied. The manager offered me a better room, but the bathroom door was 6 inches narrower than my wheelchair. Next, he escorted me to the presidential suite, with pillars



in the archway, a commanding view of the city, and even a wet bar. Again, the bathroom was off-limits, and I desperately needed to empty my bladder. I pulled out my handheld urinal and threatened to pee right there and empty it into the wet bar. The hotel manager caved, evicted the interlopers, and put me in that sole wheelchair room. My Dad would have been in stitches with laughter.

Then there was the time the airline assured me that they had not taken my power wheelchair apart on a flight to D.C. But the baggage guys delivered it down the jetway at Reagan National with the seat facing backwards. Or the innumerable restaurants who told me they were wheelchair accessible but turned out to have just a step or two, so they routed me through the kitchen. I guess they meant it was accessible for convenient deliveries. Believe me, you don't want to see the kitchen of most restaurants.

You gotta laugh at the wheelchair life otherwise, it would literally be maddening. My father gave me the gift of learning to see the humor.



*Raymond E. Glazier is proud of surviving over half a century as a quadriplegic, during which time he earned his Ph.D.; Ray is a longtime consumer in the MassHealth PCA Program. He is currently the founder and Principal of disAbility Research Associates in Belmont, MA, as well as a sitting member of the Mass. Architectural Access Board.*



# Managing a Multiple PCA Workforce

*By Ray Glazier*

Consumers with substantial healthcare needs and the quantity of approved PCA Program hours to address those needs, (or their surrogates) must hire multiple PCAs for the practical reason that no single PCA could possibly work all those hours. Even if a super-human PCA was able to work more than full-time each week, the PCA Program limits each PCA to no more than 50 hours per week (including double-counted night hours) unless the consumer or surrogate obtains overtime approval. Approval is applied for through the Personal Care Management (PCM) agency.

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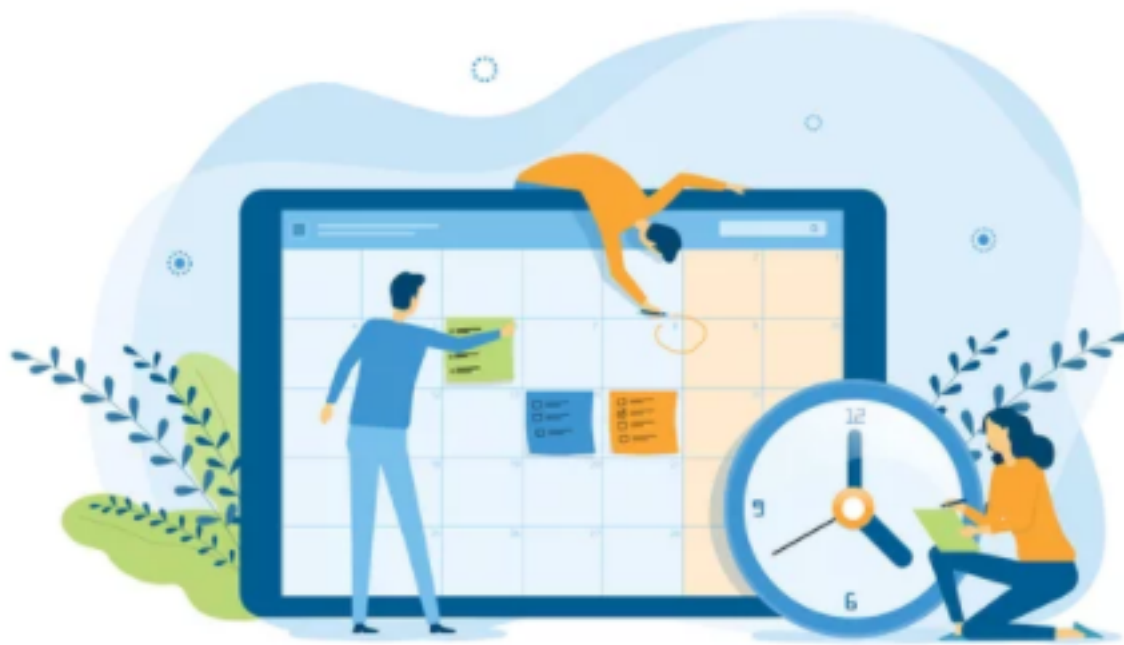
Managing a multiple PCA workforce presents special challenges for the consumer or surrogate, a situation with which this author is well acquainted. It is all too easy for one person to assume that another is attending to a standard household chore like putting out the trash or emptying the dishwasher. So, it is important that there be a publicly posted schedule of responsibilities. Each PCA needs to know who is supposed to be doing what and when.

This is so that everything gets done and there is no wasted duplication of effort. Approved PCA hours are so precious that none should be wasted.

There are several special considerations in the management of a

multiple PCA workforce. Avoid scolding a worker, for example by saying, "Sam does this so much better than you do." In fact, scolding is generally counter-productive. Instead, you might suggest: "Sally has a good way of doing that. You might ask her to demonstrate her technique." Be aware of workforce composition and workforce dynamics. A male PCA may not take kindly to what seems like instruction from a female PCA, or vice versa. The same dynamic may apply in cross-ethnic or interracial situations. It is beneficial to be attuned to the sensitivities and biases of each of your workers.

If you or the consumer for whom you are a surrogate has sufficient PCA hours, consider dividing the day into different shifts. For example, morning, afternoon, and evening or getting out of bed, lunch, supper, and bedtime – whatever works best. The important thing is day-to-day consistency and clearly defined expectations.



You will probably want to avoid scheduling two PCAs in the same time slot to avoid duplication of effort. However, you might intentionally decide to schedule an overlap for training purposes; often the most efficient and effective trainer of a new PCA is a trusted and experienced one. And yet you will want to avoid perpetuating errors from one 'generation' to the next by having a less effective PCA act as trainer.

Oftentimes a good current PCA is your best contact for recruiting quality PCA candidates through that person's friends, family members,

and acquaintances when you are in hiring mode. This is especially true if you have always acted in good faith and demonstrated to the current PCA that you are the stellar employer that each of us aspires to be.

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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 the founder and Principal of disAbility Research Associates in Belmont, MA. Contact Ray at [RaymondGlazier@gmail.com](mailto:RaymondGlazier@gmail.com) with questions, comments, or suggestions for future columns.*



*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.*

## **Unexpected Friends**

***By Joan Burrows***

When the counselor at the hospital told me, "Now that Walter is on a respirator, you need to decide if you want to be a wife or a caregiver." I said, "I want to be both." But I was told that would be almost impossible and if I wanted to be Walter's wife, we needed to hire people. In preparation for Walter to come home, I spent several nights



in his room and received several days of training on how to use the respirator. At home, I had the local visiting nurses on-call but, reluctantly, realized I needed more help. I called the Independent Living Agency in Lawrence. They guided me in evaluating how many hours we would need – 24/7 – and how to place an ad. I decided to be Walter's caregiver overnight and ran an ad for help during the day.

The first person to reply lived a short distance away and had wanted to be a nurse but stopped her training to begin a family. She was fantastic; caring and willing to learn. Years later, she drove with us to Washington, DC. The hotel had an adjoining room and she helped Walter every day, especially with getting up in the morning, going to bed at night, and with transfers from the wheelchair. We were so lucky to have her as our first caregiver because it encouraged us to continue getting more help. Many years later her daughter brought her children to visit us.

I can't recall the order of Walter's other caregivers. We had many kind, good people, and a few who were not so good; they didn't stay long. Percentage-wise, I estimate 95% were great, caring people. One used to comb Walter's hair and tell him, "You look like Errol Flynn." Most of them were women but we also had three men. One was a middle-aged man and Walter enjoyed having conversations with him about typical male topics. We became friends with many of these fantastic people and continued seeing them even after they stopped helping with Walter's care.



We hired a young woman with a 4-year-old daughter who played with my 2-year-old granddaughter while she was working. Later, I taught piano at a private school that her daughter attended. Her mom stayed with Walter and I drove her daughter home. She came on holidays too, and it was a given that she and Walter would watch the New York Thanksgiving Day Parade. She is a grandmother now and lives in Tennessee. She recently came for a visit and brought a lovely hanging basket for my garden. On other occasions, I have visited her and her grown-up daughter who is a mother with a son. Where does the time go?

One was a teenager, a senior in high school. When she responded to the ad, I told her about the job. It did not dissuade her, so I set up an interview. She was sweet, kind, and eager to help. Later that day her mother called to tell me she thought the job would be too much for her daughter, but the teen would not be deterred. She worked here for two years, then went to England for a semester. We often received cheery postcards from her. When she returned to finish college, she frequently stopped by to sit and talk with Walter. If I did not have help in the evening, she would help me (for no money). She is now an acupuncturist with a degree in California and works with seniors. I sometimes receive calls asking for a reference, which I happily and glowingly give. In a recent email, she told me she was coming to the

east coast for a conference and would call me to set up a time for a visit.

I can still see another lovely young woman sitting on the terrace with Walter, talking and holding his hand as I returned home from shopping. We frequently went to movies together and occasionally out to lunch (before Walter got a feeding tube). When I went swimming in the lake, she and Walter sat together on the shore where I could see them laughing and chatting away. Years later, after Walter died, she attended a conference in Boston and came for a visit. When my granddaughter began taking violin lessons, she loaned her a violin. Now the woman is married, lives on the Cape, and has invited me to visit.

Another woman came to us with experience in home care. In addition to her job, she helped friends get an occasional break by taking care of their severely disabled child. She worked here for many years and was with us when Walter went into a coma near the end of his life. At that time, she came in every morning, kissed him on the forehead and said, "Good morning, Walter, it is Donna." I was overwhelmed the first time she did this. I had seen her skills and her caring, but not like that. She moved to Florida a few years ago and I took her to lunch before she left.

Walter was mostly in a coma during the last few months of his life. Some people asked why I didn't move him to a facility. It was because his caregivers knew what to do and the way he liked things. They also knew who he was as a person and that was an amazing comfort to me.

Each caregiver is an important part of my life because without them Walter could not have remained home, the place where he gave and received so much love. Their support helped keep me going and their friendships still do! These people are a continued connection to Walter. Last month one of these special people died unexpectedly. I lost a

good friend and a super caregiver for Walter.

How did these strangers in our employ become such good friends? After a lot of reflection – Walter was the reason. Everyone loved him and I was part of the strong connection he made with people. If it weren't for Walter, I am not sure some of these people would have become friends. We were in our 50's and many were thirty years younger than us. It is hard to imagine becoming friends if we had met under different circumstances. Our love and care for Walter was the thread that wove together our friendship, and it still remains.

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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.*



## **Mass General Brigham Invests \$50 Million in Community and Mental Health**

An Initiative Focused on Increasing Access for Patients and Builds on Existing \$175M Annual Community Health Investments

***By Tim Sullivan***



This past October, Mass General Brigham announced a \$50 million investment in a new *comprehensive community and mental health strategy* to improve the health of the communities it serves. In partnership with 20 community-based organizations, the initiative targets programs to improve mental healthcare capacity, workforce development, chronic disease management, as well as nutrition security and equity.

**“The pandemic shined a light on long-standing barriers and inequities in healthcare.** At the same time, the mental health system across Massachusetts reached a breaking point with dramatically increased need for care and limited capacity. This new community health strategy will address mental health, chronic disease, and food and nutrition insecurity by working with Massachusetts community health centers and organizations to significantly increase our services in communities with the greatest needs.”

— *Anne Klibanski, MD, Mass General Brigham President and CEO*



**Increasing Capacity and Building the Pipeline of**

# Workers to Address the Mental Health Crisis

The pandemic exacerbated the number of individuals needing mental health support. Emergency departments are overwhelmed by the number of individuals seeking psychiatric care, and many patients are experiencing unacceptable delays in receiving treatment. Mass General Brigham is partnering with community-based agencies and schools of higher education across Massachusetts including Bridgewater State University, William James College, UMass Boston, Salem State University, Quincy College, and Boston College to create scholarship and loan repayment programs, fellowships, stipends, and salary supplements for those in the mental health field. The programs will help increase the pipeline of new mental health staff in Massachusetts over the next several years and build the capacity and expertise of the licensed and unlicensed mental health and addiction workforce, recovery coaches, and mental health specialists.

"We are extremely grateful to Mass General Brigham for this five-year funding commitment to expand mental health and substance use disorder services in communities of color. Identifying and meeting this critical need is a great example of what happens when you use an equity lens," said Michael Curry, president and CEO of the Massachusetts League of Community Health Centers. "Community-based health centers are the perfect partners to help address how these issues relate to the lingering trauma of systemic racism, reduced access to healthcare and social services, and the recent devastation of the COVID-19 pandemic."

Mass General Brigham is also partnering with the Massachusetts Association of Mental Health to immediately develop and implement programs to increase pediatric urgent services. In addition, we will partner with the Corey Johnson Program for Post-Traumatic Healing to provide trauma-focused mental health support, specifically in the Roxbury community.





chronic disease, improving heart health, and addressing substance use disorders that lower life expectancy and disproportionately impact racial and ethnic minority populations.

“Beginning this year, we will start to build new capabilities to increase chronic disease management and promote nutrition security and equity in our Community Health Centers and Primary Care practices in Revere and Mission Hill,” said Elsie Taveras, MD, MPH, Chief Community Health Equity Officer for Mass General Brigham.

Mass General Brigham will also expand its successful mobile health initiative, launched during the pandemic, to bring care to patients who have difficulty accessing a hospital or a community health center and address emerging needs. The mobile health program will continue to provide COVID testing and vaccinations as well as expand to include:

- Screening and management of hypertension
- Substance use disorder treatment and harm reduction
- Community outreach, engagement, and linkages to social support services
- Social risk factor mitigation such as the distribution of care kits and home health monitoring equipment

The mobile program will immediately focus on Lynn, Chelsea, Revere, Everett, and Greater Boston including Charlestown, Dorchester, Roxbury, Mattapan, and Jamaica Plain. Taveras said, “We are focusing on communities with some of the highest rates of cardiometabolic disease and substance use disorders in Massachusetts.”

The full story can be viewed at [Mass General Brigham Invests \\$50 Million in Community and Mental Health](#).

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





INFO BRIEFS • INFO BRIEFS • INFO BRIEFS



If you are entertaining political aspirations, "bravo!"  
The disability community could use more  
representation.  
Here are a few tips to get the ball rolling.

**Representation Counts:**

# Tips to Launch a Political Career

1. **Hire an experienced campaign manager with political savvy:** You are likely going to receive a great deal of attention—wanted and unwanted—and a campaign manager can prepare you mentally for the grueling life of a campaign.
2. **Get used to asking people for money:** You don't need to be wealthy to run for office, but you do need the financial resources to get your message across and pay your staff.
3. **Have a social media strategy:** Recruit friends and colleagues to volunteer on your campaign, network with their social circles, and ask them to promote you on social media. For a more coordinated and less volatile social media effort, hire a professional social media manager.
4. **What you communicate matters:** Unless you are a proficient and experienced writer, hire a professional political speechwriter to assist you with campaign messaging and speeches.
5. **Be visible and be heard in your community:** You have an opportunity to make a significant impression through public appearances. Appearing at public events demonstrates a confidence that the voters need to witness and feel so they are inspired to vote for you.
6. **Have a message with universal appeal:** The disability issues that your platform addresses do not necessarily exclusively benefit the disability community. Policies that promote better access and inclusivity allow everyone to shine and advance the society as a whole.

For more resources to launch a political campaign, view the full article by Jillian Day at [Representation Counts: More People with Disabilities](#)





## **Transportation Initiatives that Improve Accessibility**

All people deserve the right to travel. But a disability can make it difficult to drive, fly or use public transportation. Fortunately, various transportation initiatives to improve accessibility for people with disabilities are underway. And these initiatives are making it easier than ever before for those with disabilities to get where they need to go, as quickly and easily as possible.

Here are three transportation initiatives that improve accessibility for people with disabilities.

**Self-Driving Cars:** Autonomous vehicles, aka self-driving cars, transform the way people with disabilities get from Point A to Point B.

They include a wide range of technologies to streamline transportation.

**Public Transportation:** Traveling by bus, train or other forms of public transportation is a must for many people with disabilities. However, enjoying accessible public transportation remains a persistent problem across the United States. Initiatives to enhance the accessibility of public transportation for people with disabilities are ongoing.

**Education:** Earning a college or university degree in public health can help people with disabilities become advocates for transportation accessibility. Colleges and universities offer public health degree programs both online and in traditional classroom settings. Anyone can enroll in one of these programs to build the skills they need to become successful advocates for transportation accessibility for those with disabilities.

To read more details about each of these initiatives, view the full article by Adrian Johansen at [Transportation Initiatives That Improve Accessibility](#)

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