***Disability Issues***

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**Winter 2023**

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

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

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**From the Editor:**

Dear Readers,

Happy 2023! At this time of entering a new calendar year, I remember learning that the month of January is named for the Roman god Janus, the god of two faces - one looking ever backward, one looking ever ahead. The two faces of Janus represents transition, crossing a threshold, of moving out of one time into another.

In January, there is collective energy to engage in a process of taking stock of our lives, reflecting on the past year and dreaming of where we want to go. I have mixed feelings about the tradition of making a New Year’s resolution. I am a reflective type of person, so I’m drawn to the intentionality and thoughtfulness part of making a resolution. On the other hand, making a resolution feels like it requires me to look at myself with eyes that focus on what I am lacking, how I can self-improve, or how I am deficient in some way that needs to be corrected. This is where I get stuck and resist making a resolution. It reminds me too much of societal messages saying that people with disabilities are broken and need to be fixed. As a child, I internalized these messages and have devoted much time and energy to internalizing my wholeness, value and worth.

On New Year’s Day, I got together with a friend for brunch and afterward, we went for a stroll through a park. Our conversation turned toward reflecting on the past year and what we wanted to welcome going forward. Neither of us wanted to make a resolution or add more tasks to our lives, instead, we gravitated toward expanding what offers nourishment to ourselves and others – kindness, peace, joy and ease, freedom. It was a soul-enriching way to enter 2023.

Since it’s still January, you may still be reflecting on the past and looking forward to the year ahead. Perhaps you will find this way, or something similar, to be an enriching way to welcome the new year.

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.

**A Travel Adventure to the Deep South**

**By Marybeth Barker**

Traveling can be both pleasant and perilous. When my friend, Peggy, suggested we take a trip together to the Deep South to learn more about Blues music, which we both enjoy. I was thrilled but nervous. Since becoming a wheelchair user seven years ago, I have not traveled with an able-bodied person other than my spouse.

Peggy and I often meet for lunch and go to local music venues. I have my own adapted vehicle, so if I ensure a place is accessible, I don’t need help when meeting up with friends. By design, Peggy had only experienced being with me in environments that enabled my independence. I wasn’t sure she understood just how inaccessible the world could be.

I wanted to take the trip and pondered over the kind of and level of help I might need. I worried that I may have grown so used to my husband anticipating barriers and knowing what help I needed without having to ask for it, that I was no longer aware of what kind of help I needed. I wondered how much of the unsolicited help I accepted from my spouse was habit versus necessity. I readily accept help from my husband, Irwin, to save time, energy and reduce risk of injury. Was it okay to do the same with a friend or should I put extra effort into doing things independently? These were the thoughts swirling around my brain as I tried to come to a decision.

I decided to talk with Peggy about the help I might need, such as getting my suitcase in and out of the car and lodgings. There would be restaurants, museums and attractions that were not accessible. As we explored various venues and learned about their accessibility (and lack thereof), Peggy remained undaunted and a willing travel companion. I offered to take the lead in finding the right vehicle to transport my wheelchair and accessible lodging. At home, I have an adapted vehicle. When traveling, I can walk to the rear of the vehicle and stand long enough to lift my lightweight manual chair in and out of the rental car. With a mutually agreeable plan in place, we commenced reading, researching, and sharing information about “The Deep South.” We eventually came up with an exciting and accessible itinerary. I found the right car for easy in and out and an Airbnb with a porch lift for meant for luggage but able to carry me as well.

When traveling with Irwin, he typically handles the details. With this trip, I found myself taking pleasure in managing the details, presenting paperwork, wayfinding, and tipping the disability service personnel at the airport. This forced the assistants to address me directly, not my companion, which doesn’t always happen when I travel with my husband. Being unfamiliar with disability assistance, Peggy stood back and observed this new experience. As we zipped to the front of the line at security, I saw Peggy smile each time the agent unclipped the black straps in the maze that most travelers must wind their way through.

We flew to Memphis, toured the National Civil Rights Museum, Beale St, Sun Studio and a took a tour of the city on a Mississippi River Boat. After two nights in Memphis, we picked up our car and headed down Highway 61 toward Mississippi. From our Airbnb situated on the bank of the Sunflower River in Clarksdale we made our way to the King Biscuit Blues Festival in Arkansas. We took day trips into Tupelo, Oxford, Indianola, and other small towns in the surrounding area significant for their place in the history of the Civil Rights Movement and famous Blues artists.

Peggy schlepped my suitcase in and out without complaint. I volunteered to do all the driving after we accidentally ended up with Jeep Wrangler instead of a car. Peggy wasn’t comfortable driving what is technically a truck but since I grew up driving trucks, I rather enjoyed it. This put the suitcase thing in perspective. It was just something she could do, and I couldn’t, like the driving the Jeep.

It was evident that Mississippi is one of the poorest states in our nation. Sunlight shines through the gaping holes in abandoned warehouses along empty streets. Barren store fronts, faded signage, boarded up buildings and empty lots tell the eerie story of days gone by; better days for some but not for most. But walk the streets and you’ll also find freshly painted murals of old Bluesmen brighten the alleys and specialty shops selling harmonicas, guitars and Blues memorabilia show up in the most unexpected places, celebrating the rich history of the Delta Blues. A new red brick building, housing the new Delta Blues Museum, rises in contrast against the ruins of a once thriving cotton commerce.

Funded by public and private dollars urban renewal is focused on economic development through tourism and raising the profile of Delta culture, its music, and its meaning in history. Buildings of all types are being repurposed as small shops, music venues and tourist lodging. The shop owners and other locals are among the most welcoming, helpful, and talkative people I have ever met. Many are direct descendants of the enslaved people who built this nation. Posters advertise performances by local musicians who are the proud grandchildren and great grandchildren of the original Delta Bluesmen.

A wheelchair user might think one of the poorest areas in the country would not be good for accessibility or tourism. But I found the area accessible for reasons having nothing to do with elevators and ramps. In general, the Delta is completely flat. I was easily able to traverse the sidewalks, even those with potholes and cracks, in my wheelchair. Most of the restaurants and music venues are located at street level. A small hop over the threshold will get you inside almost any business. Mississippians take pride in their hospitality and apply it eagerly to this widely embraced movement of economic development through tourism. They will go the end of the world to accommodate you. In the few places that were not accessible in the conventional way, merchants were eager to accommodate in unconventional ways.

Traveling to Mississippi with my abled bodied friend held many surprises, including that I was able to do it. It was so worth shaking things up and testing my independence in a differently accessible environment and relationship.

*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.*

**A Grand Vision: Advanced-Technology Batteries for Electric Wheelchairs**

**By Penelope Ann Shaw**

The news is ablaze with articles about the advent of electric vehicles. Electric vehicles have advanced-technology batteries. These batteries can store a lot of energy, giving owners a driving range more than 200-300 miles on a single charge.

As a user of a battery-powered electric wheelchair, I am intrigued and jealous of the range these batteries provide. I was told that my current chair has a mileage limit of 8-10 miles, and that is only under ideal conditions.

Given my limited range of distance, I am lucky to live in the center of my town. Driving only a short way, I can get to many essential places, such as the Town Hall, local public library, post office, two pharmacies, a grocery store, several restaurants, a clothing and general merchandise store, a nail solon, an arts and crafts store, and the local farmers market during summer,

In addition to distance, several other conditions draw energy from my batteries, such as driving up inclines, driving fast, and going out in extremely cold weather. I have actually seen the battery indicator on my chair dropping dramatically, which left me uncertain as to how much power I had left. Suffering from range anxiety, I had to go directly home to avoid an emergency.

As for charging, electric-vehicle batteries can be charged in 30 minutes, whereas charging times for electric-wheelchair batteries can take much longer. In my case up to 6 hours. I assume most power-chair users would like to charge their batteries at home with a normal household electrical outlet. I assume most would also like the ability to charge their batteries at charging stations in the community; like electric vehicle owners can do. Having advanced-technology batteries for wheelchairs would be transformative for many people with mobility disabilities.

In my case, better batteries would benefit me in numerous ways. Emotionally, I would have peace of mind and the ability to focus on my driving experience. I would have confidence that I could go out a distance, roam around, return home and go out again the same day if I wanted to. I wouldn't be worrying that my battery energy was being extinguished. I would also have the freedom to drive fast knowing speed would not use up all my battery energy. Longer range would allow me, for example, to go to my town shopping plaza, which is currently too far for me to go to.

Twenty years ago, an ambulance brought me to a specialty respiratory rehabilitation hospital in my town. I was taken there for treatment because I had a tracheostomy. Later, I was transferred to the nursing home where I now live. Thus, the town where I live is not a place I knew before I became disabled. I regret never having the opportunity to see the hospital from the outside or being able to drive through the town to fully get to know it. Having these opportunities would be real treats.

How many miles on a single charge would allow me to accomplish these goals? As I said, electric-vehicle batteries can get 200-300 miles on a single charge. I would like a minimum of 15-20 miles. 25-30 would be even better.

Another benefit advanced-technology batteries would give me is speed. In cold winter weather I could drive fast to my destination without worrying about using too much battery power. Currently, I must drive slowly to preserve power. Sometimes I need to stop and go into a store to warm up before finishing my trip. Unlike people who drive in cars and can turn their heat on to keep warm, I’m exposed directly to the elements and get very cold.

Additionally, better batteries would give me more independence and productive use of my time. The local paratransit service I must use for long distances has limitations. I must schedule my trip both ways the day before, which doesn’t give me the flexibility to decide to go somewhere at the last minute. Since paratransit service can be unpredictable, possibly arriving earlier or later than I would like, I need to schedule extra time on both ends of my trip. Sometimes I waste a whole day on a single appointment or errand.

To fulfill my vision, we electric-wheelchair users need people with expertise in electrical and materials, such as chemistry scientists and engineers to research and develop advanced high-energy density batteries for us. I hope some experts will take on a project of this sort which would improve the lives of many people. Perhaps these experts could meet our needs by adapting the same battery materials used for electric vehicle batteries. Experts at the U.S. Energy Department Advanced Research Projects Agency might be able to provide advice on such a project as well.

Very importantly, those of us who use electric wheelchairs should be engaged as experts, partners, and collaborators in the project. Having the opportunity to share our lived experiences and expertise directly would promote the acceleration and success of a project.

I do realize that the market for advanced batteries for electric wheelchairs is small compared to that for electric vehicles. Hopefully, manufacturers will be mindful of the cost since people with disabilities are generally not wealthy.

What other innovations do I think would benefit individuals who use electric wheelchairs? In my opinion, the ability to drive our chairs in rain or snow and making it standard to have bright headlights on our chairs so we can drive safely outside at night would be valuable innovations.

*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*

**Inflation Tips and Tricks**

**by Sandy Alissa Novack**

In times of rising inflation, we all benefit by sharing our latest “finds” of how to reduce expenses with each other. In one way or another, we have all known hard times and it’s a kindness when people share potential resources that can reduce the impact of inflation on your well-being. Below I offer some tips to start percolating ideas.

**Groceries:**

* Buy in bulk. Sometimes I hear shoppers complain that they live alone and can’t use more than one item, so they feel left out of BOGO sales (Buy One, Get One Free). Not necessarily true. Items such as canned goods have long expiration dates so you can use one now and use the other later. Another option is to share the cost of buying BOGO items with a neighbor. Same thing for mega-packs of toilet paper, paper towels, 10-pound bags of potatoes and other products. You pay less per unit item for larger packages with more items than what you immediately need, but they will keep for a long time, or you can split the purchase with a neighbor.
* For some people, it is easier on their health and disabilities to shop at only one store. For others, they may shop at various stores to get items on sale. For others, grocery delivery is their preferred option. Delivery can add to the cost of groceries, but if it spares strain on your health, consider honoring your well-being and save money in other ways.
* Ask about community options for food, including local food pantries. If you aren't sure if you qualify for SNAP, also referred to as food stamps, ask and apply. Every little bit of help serves to meet your health and dietary needs. If you receive Meals-on-Wheels or eat at congregate meal sites, let others with disabilities and older adults know about it. They may be hungry or not feel well enough to cook and interested in these options.

**Staying Warm:**

* If your house or apartment is drafty, dress in layers indoors, not just when you go outside. You can stay warm while keeping the temperature lower and paying less for heat. Use draft blockers at the bottom of doors and windows or use plastic sheeting on your windows to keep chilly drafts from coming in. When the sun is shining, open your curtains during the day to let the sunshine warm and brighten your home. In the evening, close curtains to keep the heat in. Stay warm by eating hot soup and sipping tea.
* If you are concerned about being too cold, go to your town or city's warming center until your home is warm enough to return to. You can also make arrangements to stay with a relative or close friend who has heat.
* Contact your utility company. Tell them about your age and disability needs and concerns about large bills this winter. They may ask for proof of severe health or disability to keep your service going despite economic hardship.
* If you don't ask for help, you won't get it, so please ask for what you need. You may be eligible for various kinds of assistance. The cold snap we had in December was severe and dangerous. It is imperative that you keep warm and safe, inflation or not. If you have a case manager, social worker, or resource worker at your doctor's office, independent living center, or elsewhere, ask them about resources you might be eligible to receive.

**Gift-Giving:**

* In the U.S., we are bombarded with advertisements on the internet, television, newspapers etc. telling us to shop for all sorts of items. After a while, we start to think that everyone around us can afford cruise vacations, the newest electronics, etc. Most of us cannot afford to keep on endlessly buying things. Shut off the social media and stop reading magazines about pricey “must have” items.
* When you feel pressured or frustrated about wanting to give gifts to yourself or to others, remember that you are very rich in being you, just the way you are. When I was a child, I asked my dad what he wanted for his birthday. Every year he told me to just give him a card. “How about a new winter hat?” I would ask. “Don't need one, thank you.” “Is Mom going to make you a birthday cake?'' “Yes.” “Did she already ask you what flavor you want this year?” “Uh-huh.” “What can I make for you?” “Make me a card.” After years of these types of conversations, I learned what comes from the heart can be more valuable than what comes from a store.
* If there is someone you really want to give a gift to and your budget is tight due to inflation, paying for medical bills, saving for college, saving for a move, being on a fixed income or whatever other reason, here are some gifts to consider:
* Instead of a wrapped present from a store, give the gift of your presence, either in-person or on Zoom. One-on-one time to talk with, listen to, and share our lives with people who are important to us is priceless. Better yet, schedule a series of such presence-giving gifts, such as eating dinner together over Zoom each month.
* Bake a treat from scratch. Betty Crocker has her place in life, but no one has ever turned down one of my tea breads or other treats baked from scratch, such as homemade soups and chutney.
* If you want to give a gift to someone with disabilities, think about what would matter to their specific situation. Is it hard for them to remember everything their medical provider says at an office visit? How about giving the gift of your time to be a note-taker if they are comfortable with you sitting in on a visit? If they have cold or dry hands during winter, how about knitting a pair of mittens to protect their skin?

Challenging economic times requires being flexible and using skills to seek out ways to get healthy food on the table, stay warm, and maintain social relationships. You can support yourself by reaching out to loved ones and organizations for help in knowing what resources are available.

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**LOVE & INTIMACY CORNER**

**No Winter Blues Here!**

**By Ms. Love**

I like to tease my fellow Disability Issues' editorial board members that, as Ms. Love, I get to do research for some of my columns in Shangri-La or other places some of us might like to visit. Just between you and me, however, I am writing this column wearing a winter coat indoors in Massachusetts to keep me warm from drafts while the television weather forecasters once again announce the windchill in Boston. They are advising people to stay home because being outdoors for a long time could cause hypothermia. I feel like I’m in a real-life version of *Scrooge: A Christmas Carol* – Bah humbug to staying at home for the pandemic and staying at home for the severe weather.

So, what is your Ms. Love, and what are you, supposed to do? No, don't hide under your bedcovers, that won't solve much unless you have a fever. This past summer, I estimate that half of my apartment building turned over. That means I am still over-due for meeting many of the new tenants, which gives me some ideas for my “No Winter Blues Here” plan:

**Step 1:** While I still have electricity during the storm, I am putting on my face mask and walking back and forth in the hallway outside my apartment. I need the exercise since the weather is not conducive to walking outside. At some point, I expect some of my neighbors will put down their television remote control device so they can throw out their trash or get their mail; and there I will be. It’s never too late to introduce myself and potentially make a friend.

**Step 2:** I am going to take a suggestion from editorial board member Sandy Novack's article, “Inflation Tips and Tricks,” which is also published in this newsletter about baking for gift-giving. Before the storm, I accumulated all the flour and other ingredients needed to bake, but I could never find the time. Now is the time. Plus, one of my neighbors who moved out last summer told me how much she enjoyed smelling sweet aromas whenever I baked last winter. So, if my baking makes my current neighbors salivate, I could put some slices of baked goods in baggies and leave them at my new neighbors' doors to say “hi” and offer season’s greetings.

**Step 3:** Do you find yourself saying, when you have the time you will vacuum, file papers, get down on your hands and knees and scrub your floor until it sparkles? Um, well, let's not get *too* on top of things. Perhaps let go of the idea about scrubbing the floor on your hands and knees, but you get the idea. Throw yourself into cleaning up, redecorating, or renewing your living quarters. Maybe put some music on and dance your way around the room while dusting. It's amazing how exchanging your throw pillows for ones that were stored away in your closet suddenly makes your favorite chair more welcoming. Perhaps it puts you in the mood to sit in that re-decorated chair while sipping hot cocoa, preferably with those tiny marshmallows I love. I mean, that *you* love. Yes, you might love tiny marshmallows as much as I do.

**Step 4:** Your Ms. Love is almost single-handedly keeping Hallmark and the Post Office in business. I do type emails to friends, but I still very much believe in sending a physical card with a handwritten note inside to those I am close to. Sure, I can save emails but I treasure handwritten letters from relatives and friends throughout the years. I recognize their distinctive handwriting and enjoy memories of good friends and the times we shared when I re-read their letters. Those memories are pleasurable ways to spend hours or even days this winter.

**Step 5:** Here's the thing about eating popcorn: Often you share it with someone while watching a movie. Well, during both a pandemic and winter storms, no one is being invited over to share a bowl of popcorn with me and debate which movie we should watch. That can be a good thing because I know exactly what I want to watch, “Gunsmoke” re-runs, and I get to have a whole bowl of popcorn to myself. We all need some me-time sometimes so being alone can be a treat.

**Step 6:** Are disabilities and health issues weighing on you this winter? If you have painful muscles or joints, consider taking a long hot shower or bath. If you are handy with scissors, trim your hair or just your bangs, maybe give your mustache or beard a trim or new style. It can instantly perk you up to look your best or to see a new you. All it took this week was for me to part my hair on the left instead of from the middle and, woo-hoo, I felt like a new person.

**Step 7:** Always be on the look-out for the next opportunity to engage in life outside of yourself. Not only do I volunteer routinely, and remotely during the pandemic, but I also keep alert for one-time opportunities. For example, this week I got an email from AARP talking about Cupid Crew, “a volunteer-driven effort to connect with older adults at risk for isolation and send them love.” I signed up to have some Cupid Crew cards sent to me in early February to decorate and give to seniors in my community. After all, I am already *your* Ms. Love, so why not help others feel love, too?

I must run now because Gunsmoke comes on in 15 minutes and I haven't popped my popcorn yet. In addition to my suggestions, add your own beat the winter blues remedies. When you come up with some ideas write them down, so you don’t forget. If one doesn't work just move on to any of the others on your list. Or maybe remain open to serendipity. Sometimes what you think will happen doesn’t, but if you are in the mood for exploration and possibilities, that plan may lead to something exciting and unexpected.

*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.*

**THE PCA CORNER**

**A Perspective from the Trenches**

**By Ray Glazier**

Over the years this column has examined PCA matters affecting workers, consumers, and their surrogates from their respective points of view. In this departure from our usual format, we hear from one of the Personal Care Management agencies (PCMs). There are eighteen PCMs around the Commonwealth who administer the PCA Program for MassHealth. The Boston Center for Independent Living (BCIL, <https://bostoncil.org>) is a non-profit organization that serves people of all ages with a wide range of disabilities in the Greater Boston area. The group also advocates on PCA concerns.

An introductory message from BCIL Director Bill Henning:

“PCA matters are often highly charged, and rightfully so many times. But it’s important to know that the program, in thirty years, has grown from about 3,500 consumers to over 40,000, and its budget is touching $1 billion. There’s a lot of genuine support from MassHealth for the PCA program, notwithstanding some serious battles carried forward by advocates and PCA consumers over the years. And of course, there are regular individual challenges for consumers around Medicaid rules and regulations [MassHealth is the Massachusetts Medicaid agency.], along with the eternal difficulty of PCA worker shortages. But as a path to independent living, it’s the most important program we have for thousands of people with disabilities.”

BCIL Deputy Director Courtland Townes, III is also the PCA Program Manager. We interviewed him for this column. Our queries appear below with Courtland’s responses in **bold** type.

We asked him: About how many PCA consumers are served by BCIL and how many PCAs?  [By the way I am a BCIL PCA consumer myself.]  **“Not sure about how many PCAs, but we presently serve roughly 1200 or so PCA consumers between our OneCare and MassHealth Fee for Service programs.”**

How have these numbers changed over the years? “**The number of PCA Program participants has steadily increased. There has also been a marked increase in the number of PCA consumers who utilize a Surrogate to help them manage the PCA Program.”**

What are your responsibilities regarding the MassHealth PCA Program? “**I have direct supervision/support of program staff; ensuring that we are in compliance with our MassHealth and OneCare contracts; general programmatic oversight.”**

What challenges, issues, or difficulties do you have to deal with in carrying out these responsibilities? “**Providing direct face-to-face services has been challenging during the pandemic, and [there are] clinical staffing shortages, i.e., difficulty in hiring and retaining Registered Nurses [to perform consumer need evaluations] has also been a challenge.”**

What is your background?  Where were you born and where did you grow up? Education? Previous experience, and how it relates to your current job? **“I was born in Boston, moved to Florida at age 10 and then returned to Boston after college. I have almost always worked for non-profit organizations that centered on providing services/programs to the surrounding community.”**

Do you have a disability yourself, or do you have a family member or close friend with a disability?  **“I am a person with a disability.”**

Is there anything you would like to add about the MassHealth PCA Program and how it has evolved over the years**? “The program has continued to grow, and with that growth have come more bureaucratic requirements and oversight from MassHealth. The next change on the immediate horizon will be the implementation of Electronic Visit Verification (EVV).”**

Author Note: EVV, as most of us know, is a hot button issue for many consumers, who feel that this federal legislative requirement is a potential invasion of privacy for both consumers and PCAs. The [21st Century Cures Act](https://www.congress.gov/bill/114th-congress/house-bill/34/text), is a federal law, passed by Congress in December 2016, that in Section 12006(a) requires all state Medicaid programs to implement an Electronic Visit Verification (EVV) system for personal care services (PCS) and home health care services (HHCS). All states must implement an EVV system to avoid a reduction in federal Medicaid funding. EVV systems, replacing paper timesheets and the like, must electronically verify in real time the type of service performed, the individual receiving the service, the date of service, the location of service delivery, the individual providing the service, and the beginning and ending times of the service, according to CMS, the federal Medicaid regulatory agency.

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

**READY & ABLE**

***“*Clinics on Wheels” Offer Wide Array of Medical Screenings**

**to Greater Boston Communities**

**By Tim Sullivan**

Due to the pandemic, many people in the past few years have had to delay their medical care. For the communities with disabilities where accessibility and travel have always been added challenges to receiving regular medical care, the past several years have only served to exacerbate those issues. Throughout the health care spectrum, clinicians are seeing chronic disease management decline tremendously – which has led to sicker patients and negative outcomes. To address this broadly for all patient populations, Mass General Brigham has explored how to reach those populations disproportionately affected by these adverse outcomes directly where they live. Launching this Fall, after participating in community COVID-19 vaccine programs the last two years, the [Mass General Brigham Community Care Van](https://www.massgeneralbrigham.org/en/patient-care/services-and-specialties/community-care-van) program aims to bring preventative care and disease management resources directly to those in the community.

The Mass General BrighamCommunity Care Van program offers screenings and interventions for chronic health issues such as hypertension, diabetes, and substance use disorders, in addition to COVID-19 screening and vaccinations. The vans are staffed with multilingual and multicultural clinicians and support staff to better connect with the communities served by Mass General Brigham through the Greater Boston Area.

The expanded services on the vans identify targeted interventions for specific, widescale problems starting with hypertension and diabetes care. Clinicians can screen blood pressure, test for lipid and A1C levels, and provide physical activity assessments. Staff can also provide recommendations for additional physician follow-ups and a blood pressure care plan.

Staff on the vans also screen visitors for Social Determinants of Health (SDOH). These SDOH screenings ask patients about factors such as housing, access to healthy food, and personal safety. Connecting patients with resources for these issues can have a far-reaching impact on a variety of health concerns.

The vans’ [schedule](https://www.massgeneralbrigham.org/en/patient-care/services-and-specialties/community-care-van) is routinely updated with stops in Lynn, Chelsea, Revere, Everett, and Greater Boston including Charlestown, Dorchester, Roxbury, Mattapan, and Jamaica Plain. In 2023, the mobile vans will add substance use disorder (SUDs) services to their rotation. Clinicians on the van will provide initial screenings, make connections for patients to treatment programs and recovery coaching, as well as providing prescription-based treatment options.

“For the Mass General Brigham Community Health team, it is vital to be able to connect directly with community members and reach them where they live. For all of us to bring these vans to our communities and share our expertise is an important example of our mission in action,” said Priya Sarin Gupta, MD MPH, Medical Director, Community-Based Clinical Programs, Mass General Brigham.

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

**INFORMATION BRIEFS**

**DCR UAP Winter Schedule 2022-2023**

DCR’s [Universal Access Program](https://www.mass.gov/orgs/universal-access-program) provides outdoor recreation opportunities in Massachusetts state parks for visitors of all abilities. Accessibility is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs.

General Information

The Universal Access Program (UAP) offers adaptive, accessible programming seasonally at state parks, pools, and rinks. We partner throughout the year with [**All Out Adventures**](http://www.alloutadventures.org), **[Easterseals Massachusetts](https://www.easterseals.com/ma/)**, [**Holyoke Rows**](https://holyokerows.org/), and [**Waypoint Adventure**](http://www.waypointadventure.org/) to run our programs. Our East Boston skating program is supported by **Spaulding Adaptive Sports Centers**.

Our structured programs feature adaptive equipment, professional staff, and instruction and support. Friends, family members, and companions are encouraged to take part in our programs alongside participants with disabilities.

Check out our website to keep up to date with our activities!

<https://www.mass.gov/info-details/adaptive-program-schedule>

**FEMA Assistance for Accessibility Items for Homeowners and Renters**

If you or a member of your household use adaptive or accessibility items that were damaged by a disaster, you may be eligible for FEMA assistance. FEMA recognizes adaptive or accessibility items are an important part of your disaster recovery process and will enable you to maintain and/or re-establish your independence and quality of life after disaster.

[FEMA](chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https:/www.fema.gov/sites/default/files/documents/fema_updated-iappg-version-1.1.pdf) assistance for specific accessibility items does not count toward your Housing Assistance or Personal Property maximum awards, and is limited to the following:

**For homeowners:**

* Exterior ramp
* Grab bars
* Paved pathway to the home’s entrance from a vehicle

**For homeowners and renters:**

* Accessible beds
* Raised toilet seats and shower chairs
* Accessible refrigerators and washers
* Computers or adaptive technology, such as screen readers or adapted keyboards
* Motorized or manual wheelchairs, or walkers
* Visual and/or vibrating fire signals
* Assistance for other damaged accessibility items or medical equipment such as CPAP, oxygen supplies, and catheters may be covered by FEMA's Medical and Dental Assistance

For more information, visit [www.fema.gov/expanded-assistance](https://urldefense.proofpoint.com/v2/url?u=http-3A__www.fema.gov_expanded-2Dassistance&d=DwMFAg&c=ZQs-KZ8oxEw0p81sqgiaRA&r=UZNwpeF4C-NYF1f9u8p-lQ&m=tJjV0OZo7QoIX5xpU5c4tJcXEuap0kTf7ZxKDZldo1KXR8cbK_yG77v_7wij3fvh&s=d1Q3jsPls_wzhGMQkMnRg_igid5Y9kgtYRpuCoKIfkM&e=) or call FEMA's Helpline at 800-621-3362.

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