DisABILITY Issues

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,

Every Saturday morning from mid-June through the end of October, I spend my morning at the Cambridge Farmers Market, located on the Cambridge Common Parade. Going to the farmers market is a highlight of my week as it's hard for me to remember that up until 2020, I only attended occasionally.

The shift from occasional to regular patron happened during Covid when I realized I could walk safely to the market, stay outside, and participate in hand-sanitized shopping safety protocols. The parking lot was paved, which made it easy to use my wheelchair instead of my walker, and I could stop at any booth I chose. The market offers all have a paved pathway, but the narrow and wooden booths were set up on each side of the path, making the pathways crowded and challenging to navigate, especially in the wheelchair.

This summer, the Winchester Farmers Market moved back to the Town Common, which is a grassy area with paved paths. Although I like this less, about the Common's accessibility challenges, I like widened the footbaal, and we brainstormed possibilities to enhance accessibility for people with disabilities and seniors. I'm not sure if anyone ever acted on my idea of the paved walkway, creating more opportunities for people to walk, and roll, under protected shade.

Over the course of the Market season, I was delighted to notice a steady increase of people shopping at the Market who used mobility assistance devices, including walkers, canes, and wheelchairs. Most other bagpipes, where accessibility is enhanced for people with disabilities, it creates more universal access for all members of the community, including those who are not disabled. I wonder if those who shop with balance issues are not comfortable using mobility devices and parents who were pushing their children in strollers.

In the grand scheme of things, this may seem like a small victory for accessibility, but I believe that every action which creates more equity and inclusion is tremendous toward creating a kinder world for all.

Marianne Dillon, Editor

Marianne Dillon has been the editor of Disability Resources Monthly for over 20 years. She has also been a contributor of a column and editorialist in several with media. Her background is in sales & marketing and she is a graduate of Ithaca College. She is married, Mother of Christie Mason Kim Alexander Elizabeth Thompson Dillon

Mass General Brigham Accepts "Great Jobs Challenge" to Support Workforce Development in Health Care

By Tim Sullivan

Recently, U.S. Secretary of Commerce Gina Raimondo announced the winners of the "Great Jobs Challenge" to support workforce development in the country as part of the EDA's initiative Build Back Better Regional Challenge funded by President Biden's American Rescue Plan. The Great Jobs Challenge is a competition that invited regional coalitions to submit proposals to the Administration and will enable communities across the country to invest in innovative approaches to workforce development.

As the lead applicant, the Mayor of Boston's Office of Workforce Development (OWD) brought together partners from key organizations in the region including workforce development boards, community college academies, and OWD's individuals within the Greater Boston Region. Over 100 employers will create opportunities and partnerships with organizations in the region including community colleges, veterans and connect our residents with opportunities in healthcare, childcare and clean energy. The grants to the Boston Administration for Workforce Development and Mass General Brigham Employee Development and Retention Program.

"This Important Funding will connect participating residents with more than 4,000 living wage jobs and crucial support services," said Mayor Marty Walsh. "Our residents have been hit hard by the pandemic, and we are committed to partnerships with organizations in healthcare, childcare and clean energy. The grants to the Boston Administration for Workforce Development and Mass General Brigham Employee Development and Retention Program.

"Employment is empowerment and has numerous benefits for both the individual and the broader community. The Great Jobs Challenge grants, each day we see the positive impact a career can have on health and economic security for our residents," said Mayor Walsh. "Our partnerships by participating in this multi-sector grant award, made possible through the leadership of the Mayor's Office of Workforce Development and Mass General Brigham, will allow us to continue our work with Urban Slalom, a partnership we see as vital to our ongoing work to ensure that the people in our organization reflect the diverse communities we serve," said Mass General Brigham Recruiter, Chief Human Resources Officer, Mass General Brigham.

Sectors included in the awarded grant are Child Care, Clean Energy and Health Care, and tied to a "Backbone Organization," which will convene and coordinate the many employers and training partners in each sector. Backbone Organizations include the Massachusetts Health Quality Partners (MHQP) and the Massachusetts Port Authority. The Massachusetts Bay Transportation Authority (MBTA) and fulfill that role.

As part of this collective effort, Mass General Brigham plans to partner with Urban Slalom to train candidates to enter roles such as Patient Access Associates, Medical Assistants, Medical Coders, Patient Administrative Assistant, Phlebotomist, Pharmacy Technician and EKG Technician. Other health care employers, community colleges and workforce development organizations will also be invited to form collaborative effort with leads to build career pipelines programs and system capacity, which will benefit all health care employers. A special focus will be placed on the hiring and retention of Black and Latinx persons with disabilities. Through technology, employer and manager support, Urban Slalom and Mass General Brigham is dedicated to helping with a candidate's workplace success and growth.

Employers will also be asked to provide financial assistance that people of all backgrounds have some training expenses that our program them to serve as front-line health care workers within Mass General Brigham's Ambulatory Care Operations and Patient Care. Mass General Brigham, Urban Slalom and Grabble are skillfully to help these entry-level jobs, and residents gain the skills they need to qualify for these important career opportunities."

The 32 winning projects nationwide were selected from a competitive pool of more than 300 applicants. Projects span a wide range of sectors including, industry, and other stakeholders, these projects will solve for local talent needs and increase the supply of trained workers and help communities recover from the COVID-19 pandemic. Projects include supply chains, global competitiveness, and regional development. This funding will advance a broad range of sectors - including agriculture, advanced manufacturing, aerospace, biotechnology, clean energy, manufacturing, and information technology - complemented the design, development, implementation, and expansion of training programs that are tailored specifically to each community.

GOOD JOBS CHALLENGE BY THE NUMBERS

32	$500M	$1-1	
	50,000		
35	824	40	

"A trained workforce is essential to ensuring that the United States can compete and succeed in the 21st century," said Secretary of Commerce Gina Raimondo. "Thanks to the hard work of President Biden's Rescue Plan, the Commerce Department is able to make a down-in generation investments in industry-driven, and locally-led workforce training that will create good jobs, strengthen our regional and national economic growth, especially for underserved communities."

For information about opportunities at Mass General Brigham visit the careers page.

Tim Sullivan is Director of Communications at the Disability Rehabilitation Network.

PCA CORNER

Remembering Paul Spooner

By Ray Glazier

In a departure from our usual picture format, we take this column into a tribute of the life of **Paul Spooner**, a longtime supporter of the Disability Rehabilitation Network Center. Paul was only 67 when he passed away recently after a long battle with Parkinson's Disease. Paul was a PCA who currently worked the equivalent of several thousand of disability advocacy.

Paul was diagnosed with a rare muscular atrophy at a young age, which left him with a permanent disability and need for a power wheelchair. Paul was a PCA who currently worked the equivalent of several thousand of disability advocacy. Paul was diagnosed with a rare muscular atrophy at a young age, which left him with a permanent disability and need for a power wheelchair

The girls were musical and played instruments from age 4 to 8. Both girls were in the Suzuki Method of Violin and Cello. At age 8, the girls played with the Boston Symphony. The girls played the piano here and I loved it. I had taught piano for 50 years, so it was fun to hear their music and see their joy.

The Mom often brought down supper or treats. One day we were talking, and she told me that her daughter was trying to get back to playing cello after a hand injury and PT, but the people in the unit wouldn't let her because it was too expensive. I said I'd pay for her daughter was in tears. I suggested her daughter come down here to practice. Ona came and played for two years, sometimes the piano too. After a while, she told me she did not want to be paid for helping me because she was using my room to practice. I tried to talk her out of it, but she insisted. Ona was 12 when she started. She is now 14 and has got Suzuki books, music and compose. All in gift – it fills spiritually and enjoyable gift!

Now, in fall 2022, my upstairs neighbor and good friend is off to Budapest to follow her dream of studying cello and becoming the best cellist she can be. It's only been two weeks and I miss her, but I know she is doing what she has dreamed of for years. I miss her, but I am happy for her. Before she left, I wrote her a note saying she came at a time I truly needed someone and that someone was a bird, flying person. She was the left, she wrote me a note. She said I came into her life when she needed someone, and I listened and helped her like a Counselor/Mar Charge a few words she made the week

Now, her younger sister helps me, and I hope I help her. Her violin sounds beautiful! She also studies violin. I was a voice major in Music School and hope she will sing for me sometime. She will graduate from school in two years.

What helps people of any age, but especially older people who now feel that they are no longer needed or useful is to find a way to keep helping others. Give them purpose and happiness. I try to help those who do things for me and the young people make it easy. They are easy to please, appreciate being listened to and, in turn, they listen to many of my stories. Perhaps some have nowadays for them is their only time to be with someone who happened to live and who is about 70 years of being here alone.

I look forward to friends and music and helping others when I can. I love the birds, my flowers, and the clouds in the sky. But sure what else there is.

Happiness Is

A little vase of flowers from a friend.
New flowers on my desk from a neighbor in a morning surprise.
A special nectar drink from a neighbor one hot afternoon.
A clean refreshing shower after a sweltering surprise.
Children playing Kickball.
Children and friends filling bird feeders.

Baby cardinals chirping. Mama cardinal feeding her babies and pups at the birdbath
watching over her family.

Bouncy bubbles and lots of special sounds.
Hearing a little girl's laughter and her Mom's deep belly laugh.

The calls, cooes, and coers made.
Receiving a card with a lovely note from a friend.
A ride in a friend's car to the store or a movie.

A Peacock feather made by a boy who asked
for a special friend to have it. He said to his Mom
I thought he was just showing it to me, but
he said the feather was for me.
It is in my window where he can see it too.

Little joys that make a BIG difference in life.

Ivan Burrows studied music in New York City and later taught piano. She was a nursery school teacher in Boston, MA. She is a member of the Action Commission on Disability with Harlan Kizer. She is a caregiver for people with disabilities and seniors.

Disability and Poverty

By Penelope Ann Shaw

One day I was at a store where the cashier tried to do something nice for me. I mentioned that I was on a fixed income and that I lost all the benefits included discounts on purchases and assured me there was no cost to getting or using the card. She took down all my information for the application.

Less than 24 hours later I was notified that I did not qualify for the card. I learned later that the card was actually a rewards credit card Clearly, the credit reporting agency found I had no credit history and assumed I was a high risk. I was also told I could apply again in a year or use my debit card. I have never applied for a credit card.

This event started me because I felt it made me officially poor. My monthly income as a person with a disability living in a nursing home in Massachusetts is a small SSI amount ($30) and a small Massachusetts state supplement ($43.83) for a total personal needs allowance of $73.83/month. Over the past 60+ years the dollar value of $73.83 equals to less than $20.00 per month – a major difference.

My monthly 2 Medicaids cost/share service cost is $417.61 leaving me with $20 Minimum for all other expenses I might have. Luckily, I am legally allowed to accept gifts. So, the generosity of my friends makes it possible for me to have everything I need, including clothing and other necessities.

I began thinking about disability and poverty. I researched the subject and found many authoritative sources. An article from *The Georgetown Center for Poverty and Inequality Center for American Progress' Disability Justice Initiative,* "Advancing Economic Security for People with Disabilities" by Sarah Ludwig, "Disability and poverty experiences poverty at nearly twice the rate of their able-bodied counterparts. The U.S. Census Bureau American Community Survey 2015 found that 25.9% of Americans with Disabilities aged 18-64 are living below the federally defined poverty level.

Why are people with disabilities so often poor? Why is there so much income inequality?

From my reading, I learned there is persistent poverty among persons with disabilities of working age in part because of barriers to employment. Employers have discriminatory practices and are uncouple a failure of employers to accommodate their disabilities as is required by law, which leads to below minimum wages and outright discrimination. People with disabilities also obtain less full-time employment than their counterparts without disabilities.

A 2017 National Council on Disability report emphasized that people with disabilities are also more often poor in part because of the added costs of living with a disability. They have the costs, "medical, assistance, transportation, aids, assistive technology, services, supports, and other expenses." Medicaid covers medical, home and community care, phone and internet service for themselves and their children. These are even less affordable when their's is poverty.

But as those of us in the disability community know well, people with disabilities also often have significant additional expenses related to their disability. These can include home modification, personal care assistance, durable medical equipment such as hospital beds, floor lifts, ramps, and specialized equipment, such as wheelchairs, walkers, wheelchairs, walkers, large print or Braille materials, captioning, VRS interpretation, speech-generating devices, and accessible transportation. These can potentially be expensive.

I actually read about a woman with Cerebral Palsy whose way of getting barrayed her shoes and necessitated her having now shoes every month. For individuals living in rural areas where paratransit is not available, the cost of a taxi can be prohibitive, leading to a lack of private transportation. In July 2022 I read a New York Times article that said there was a heat wave in Texas where many people who are poor could not afford air conditioning.

For myself – as someone with a physical disability who is living in a nursing facility on Medicaid – all my durable medical equipment is paid for: my hospital bed, my alternating air mattress, a Hoyer lift, a wheelchair, a walker, and a commode chair. I have a wheelchair van paid for the cost of paratransit service and personal items.

Because of my disability, I need to buy several small items such as a canvas bag for my power wheelchair so I can carry things including porchex and Ziplock bags in case of unexpected rain to protect myself and the control panel of my chair. Because of my upper extremity impairments my hands are contracted and my fingers overlap, so I need a "Dycem" non-slip material to place on my table tray and arms through to prevent dragging my phone, because it is expensive disorders don't work, in order to write I use high quality gel ink pens and a special ergonomic pen holder. I need a special cushion for my wheelchair, I need an old-fashioned wooden cane to reach up and pull elevator buttons, knock on doors and slide things over on tables so I can grab them.

U.S. federal and state government public benefit programs provide some of these supports with disabilities. These include direct cash assistance SSI and SSDI, subsidized housing, SNAP food stamps, Medicaid, Medicare, and Medicare Part D prescription drug coverage and churches offers provide services like meal sites, food pantries, and homeless shelters. Some foundations have assistance programs that are focused on poverty issues. In Massachusetts, our state Rehabilitation Commission has a durable medical equipment reuse program. Some of these services are refurbished and offered free to people who request them.

Nowhere, too often these critical safety net programs are insufficient to assure that everyone with a disability can afford their basic needs! Many still experience financial hardship and material deprivations from the lack of spending power to buy basic necessities. Economic inequality can lead not only to an unacceptable lower standard of living including poor housing, inadequate nutrition, and lack of medical care, but also family business depends on her to be their sign-language interpreter, lower life expectancy, financial security would promote not only physical but psychological well-being of optimism, coping abilities, life satisfaction, and longevity.

What can the disability community do to help address the cumulative disadvantage of having a disability and also being poor?

Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a date and national advocate who uses her experiences to promote a disability culture that will expand the lives of children and adults with all types of disabilities. Dr. Spring Shaw is her daughter-in-law and a graduate of Wilde House Conservatory Tap Dance Conservatory Commission on Safety and Quality in Nursing Homes.

The Movie Theatre

"CODA" (Child of Deaf Adult)

Academy Award Best Film 2022
Streaming on Apple TV+

Movie Review by Mary Ginsburg Mason

This Charming coming-of-age film touches the heart and illustrates the challenges and adaptability of being with a family member who is deaf. Ruby, a seventeen-year-old daughter of the deaf Rossi family who live in a fishing town in Gloucester, Massachusetts. As the only hearing member of the family, Ruby is torn between helping her family as an interpreter and being the lead in pursuing her own dreams.

She has musical talent and in high school the music directors, Mr. Villalobos (Mr. V), urges Ruby to pursue her singing and arrange and apply to the Berklee College of Music.

Mr. V gives Ruby private lessons and arranges a duet at the school show's grand finale and Miles, another talented student who becomes a romantic connection. Despite these incompatibilities, Ruby is in a difficult position of deciding whether she should audition or stay with her family. Ruby's family is a close-knit community and her family business depends on her to be their sign-language interpreter, lower life expectancy. Financial security would promote not only physical but psychological well-being of optimism, coping abilities, life satisfaction, and longevity.

Ruby's dad (the audiologist) and her mom (the receptionist) are hearing and are supported by their son, Leo, who is a hearing dormant adult.

"CODA" is based on the 2014 French film "La Famille Bélier," which centers on a family with ten children, six of whom are deaf. Director, Sian Heder, saw the potential to cast the three main characters with deaf actors and make a film that was more authentic. It won three Oscars: best Supporting Actor, the father, Troy Kotsur; best Actress, the mother, Marlee Matlin; the second Oscar! and best Adapted Screenplay for Sian Heder.

The production was a collaborative achievement. It always had Interpreters on-site and a consultant who gave advice, particularly in the stunt scenes. The deaf actors often trained the production team, including business personnel and lighting technicians.

When Troy Kotsur won for best Supporting Actor, he gave a moving acceptance speech in ASL (American Sign Language) signed by an interpreter at the Academy Award ceremony. The audience showed its appreciation by clapping in ASL.

Mary Ginsburg Mason is a Ph.D. Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of "Life Thinks: A Memoir of Healing and Transformation" and "Sexual Abuse and the Disabled Women's Best Lives", and "Seeing Clare: Lessons from Mothers with Disabilities."

INFO BRIEFS • INFO BRIEFS • INFO BRIEFS

NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH

October is National Disability Employment Awareness Month.

This awareness month was created to educate the general public on the contributions of people with disabilities. Employment continues to be more inclusive in their hiring practices. NDEAM discussions were originally triggered by veterans with disabilities returning home after World War II. The theme of the "Disability: Part of the Equity Equation" Click here to learn more.
https://www.dol.gov/agencies/oasp/disability/ndeam

A strong workforce is the sum of many parts and perspectives, and people with disabilities are an important component. The theme, "Disability: Part of the Equity Equation," celebrates the essential role individuals with disabilities play in the workplace.

Disability is and always has been part of the rich diversity of our nation, and by extension, our workforce. During NDEAM, we celebrate the contributions of people with disabilities, past and present. We also commit to ensuring all workers, including workers with disabilities, have equitable access to jobs and the tools they need to work in inclusive, supportive workplaces going forward.

This year's NDEAM theme also honors the significant diversity within the disability community. All the organizations we work with are committed to advancing not only employment for people with disabilities, but also equity in how we do so. We want all people with disabilities, from all backgrounds, to have equal opportunities to work and thrive.

Organizations of all sizes and in all industries are encouraged to participate in NDEAM, and the Office of Disability Employment Policy (ODEP) is ready to provide information and tools about the spirit of NDEAM and how you can celebrate it.
Video: https://www.youtube.com/watch?v=CPSHqmqb8Ac

The Jackson guide to disability inclusion in the workplace

Creating Inclusive Workplaces for Employees with Disabilities

In an increasingly digital and remote working environment, it's important to focus on inclusivity. The *Definitive Guide to Disability Inclusion in the Workplace* explores the key aspects of disability in the workplace in depth, providing insight into how inclusive company policies and working styles tend to be (or tend not to be), as well as practical tips and advice. It also looks at the ways in which employers can to ensure a more inclusive culture. By making disability inclusive a priority, businesses can help drive motivation, engagement, and talent retention at work.

The guide covers important considerations, such as:

- **The have to phase** to protect people with disabilities
- **The disability employment gap**, its causes, and how it changes according to demographic groups
- **Practical steps to support disabled employees**
- **How to build a more inclusive culture** in the workplace

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Mass General Brigham is pleased to be an contributor 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 and communities everywhere. Our clinicians, researchers, and learners connect to all continuum of care across a system of academic medical centers, community hospitals, community health centers, home care, and community health centers, long-term care, and long-term care services. Mass General Brigham is committed to patient care, research, teaching and service to the community. Patient care, teaching, and service to the community. Mass General Brigham is one of the nation's leading innovator research organizations and a principal teaching affiliate of Harvard Medical School. For more information, please visit www.massgeneralbrigham.org.

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