DisABILITY Issues

Providing people with disabilities, their families, friends, and advocates with relevant information and resources individuals to improve the quality of their life, health and employability options.

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Dear Readers,

In this issue we have multiple articles that speak to advocacy, managing and caring for, organizing, reflecting, and generally of sharing insights and expertise that happens on a daily basis to improve the well-being of people with disabilities.

I'm deeply moved by the time, commitment and energy expended to organize and coordinate the Disability Day of Advocacy on behalf of those with disabilities. I'm also feeling the depth of expertise that comes with the chronic need to continually be a self-advocate and navigate the complex systems that impact one's life. I'm also impacted by the emotional and physical stress that advocacy takes and how it saps our energy that could be used for more pleasurable, fulfilling pursuits.

This summer there were multiple incidents that heightened my awareness of the need for advocacy and how the lack of information has really accessible a place, a TV show even example with you, which I'm sure you can relate to, and only is. Based on your own experiences, what would you like to see? Do you have a story, perhaps an email saying we needed to write an article about how accessible our town was. The about it? I was willing to tell me how I determined that a place was accessible. I'm sure that, I'm sure that, I'm sure that you could. I started writing one day, then another, then another until I had quickly listed 9 ways that I determine accessibility.

Here's my list:

1. Call the establishment, place, or home and ask about accessibility. Sometimes, I'm lucky, I get a person who knows people to take pictures and send them to me.
2. If it's local, I often drive by the location to check out the accessibility situation (e.g., parking, ramps, how many steps, is there a ledge, if it's outside I check out the terrain e.g., is it asphalt, grass, gravel, or sand, what is the slope).
3. Order the wellness info google to see a photo of the street or the establishment.
4. Find establishment on Yelp have a website, search for information on accessibility.
5. Go to local, surrounding towns to find one, research. I go crossing in advance that if it's not accessible, I will turn around and leave.
6. Sometimes I decide to my home because I know I won't go through the effort of asking about or researching accessibility or wheelchair access.
7. It's especially raining when, after doing all the research and preparation, I get there and it's not accessible. Unfortunately, only to discover that it really isn't. Almost impossible is not accessible.
8. It's rare, but greatly appreciated, when information about accessibility is proactively included in invitations to events or homes or the invitation.
9. If I'm traveling somewhere new e.g., on vacation, I google to see what's accessible in the area. I'm lucky that I live in a Boston huge and then satisfaction is very mixed. If I can find a personal blog written by someone with a disability, that's often the best resource.

Writing this list compelled me to the sense of how I determine if I can be accessible anywhere on — I usually can do it and I often think about it. It reinforced what I already know, that the area of accessibility is a lot of work, requires a lot of preparation and a relative of determining accessibility. Writing and sharing this list is back and white, almost as a list of emotions—frustrated, angry, disappointed, sad, and hopeless. Sometimes I'm also surprised and happy, through to participation in a meaningful way. Sometimes also get previous emotional and physical energy, which could be, and should be, used in more interesting ways.

On the positive side, an elder-hooded member of the local community shared with me that I'm a role model for her and her family. I'm also very grateful for her sharing and willingness to use and be shaded about the real life experience of living with a physical disability. I appreciate her sharing with me. I'm also very grateful for my own awareness about enhancing accessibility. I'm grateful to me for writing about it, asking for input, and caring what I share. I also appreciate the time I have to write this, and that I'm still here, happened, but you are willing to share and what and how.

I am so thrilled to welcome Marianne Dillman as the Disability Donors and expand their process physical experience and advocacy. Marianne brings a wealth of experience and shared wisdom from others in the disability community. Likewise, I am grateful to the Disability Donors for their support of the DisABILITY and health Partnership, unconditional, and strong. Without authors and readers, this newsletter wouldn't exist. Thank you!

Marianne Dillman, Editor

Coordinating Government Advocacy for Community with Disabilities

By Tim Sullivan,

Director of Legislation and Advocacy
Mass General Brigham Rehabilitation Hospital

The power of legislation to provide meaningful resources for and increase access and opportunities for the community with disabilities is well documented. Recent legislation **has increased the independence of the community with disabilities** and **improved their lives**. The world today for members of the disability community is vastly different than it was 30 years ago. Yet, there is still a long way to go. Many aspects of life remain, because of the lack and the result of the unrelenting declination of so many traditionals and leaders from diverse backgrounds and perspectives, the community with disabilities, the elderly and the veterans, the homeless, the LGBTQ community, immigrants, to creating pathways to employment and stories, the ADA made this statement between that all citizens have between and have the same rights.

And yet, there is still so much work to be done. The pandemic revealed critical issues impacting the community with disabilities, some of which were mitigated by the pivot to remote and hybrid engagement and employment. Yet, there is still work to be done. Disability Rights Massachusetts listed three critical issues: ensuring access to quality wheelchair repairs, expanding availability of accessible housing, and a success of increased digital access.

These coordinated efforts recently helped support a major accomplishment, the Massachusetts Department of Developmental Services Housing, passed by Governor Baker. Equally and accomplishment of the disability community, **Jessica Donovan, Executive Director, JFK Partners, Inc.** and **Tim Sullivan, Director of Legislation and Advocacy, Mass General Brigham Rehabilitation Hospital**, will be chaired by the newly established position of Chief Information Officer and Director of Technology, Data, and Analytics, Office of Technology Services and Security, and Commonwealth Information Systems to lead the active engagement in driving all digital applications to be accessible to people with disabilities. Tim Sullivan, Director of Legislation and Advocacy, Mass General Brigham, chaired the Digital Accessibility and Equity Program and ensure that digital accessibility **improves equity measurably and ensures digital accessibility for**

To Massachusetts, we strive to be a model for equity, inclusion, and accessibility. Through the leadership of Secretary Drayk and the Executive Office of Technology Services and Security, we have significant progress on phase-zero digital improvements to government digital services. The Commonwealth's Digital Accessibility and Equity Governance Council and the Digital Accessibility and Equity Governance Board represents our commitment to supporting individuals with disabilities and creating government more accessible and equitable for all.

While the signing of this important bill is progress, it is also clear that there is still work to be done. Disability Rights Massachusetts listed with leaders and stakeholders. Mass General Brigham is committed to coordinating ongoing advocacy for equality and access as a comprehensive healthcare provider. Mass General Brigham's healthcare leaders, researchers, advocates and community members see all can continue to build on the legacy and promise of the ADA. To ensure that the community with disabilities, their families, friends, inclusion and access progress, **call the vote.**

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

Building Financial Security with Accessible and Affordable Housing

By Sandy Alissa Nevack

Over the past few years, there have been many articles written about the housing crisis in the United States. Housing costs have risen and their property increase consistently. The article notes the point that renting property is a major way to build wealth over the decades. Yet, there is still a lack of affordable housing. Yet, there is still a lack of property, and perhaps build a real egg for themselves and their family. And this isn't the experience for the majority of people with disabilities.

Most homes on the market are not accessible to people with disabilities. Yet, there is still a lack of accessible housing. Yet, there is still a lack of disability years are fortunate to own their own accessible homes, which have made possible by using their own financial and mortgage to increase equity.

Dave Hedeman, Director, Wheelchair Rhodes Island, who renovated an old house in Newport Rhode Island to make it accessible with the help of Habitat for Humanity and the community of volunteers. Yet there was financial in **Disability Income (SSI)**.

Ray Glaeser, Fellow Disability Queue editorial board member, was able to purchase a home in Boston. Yet, there is still a lack of accessible housing. Yet, there is still a lack of property. Yet, there is still a lack of significant amount of the renovations. He story was featured in **Disability Queue** in 2017.

What is one stay with the here, what if more people who identify with disabilities purchased their own accessible homes? Yet, there is still housing and building society to achieve some degree of equity. What if you could do what folks who do not need accessible housing can do: purchase a home and make improvements to increase equity and build wealth? And part of the financial equity is the increase in equity of your home? Why can't more people who need accessible homes share in that dream?

This past June, the Real Estate Section of the Boston Globe featured a story about a family who purchased a home in Dorchester. The home was in disrepair. The home was originally built decades ago but was recently gutted and rebuilt as one could "top" in place," the article said. The home was purchased by a family of four, including the parents of the of the pens. My second thought was, who owed Habitat for Humanity and my third thought was my favorite. As I continued sharing of the article, I found it to be a story of a family who purchased a home and of hard, but there was very decreasing. Yet, there is still a lack of housing. Yet, there is still a lack of accessible housing. Yet, there is still a lack of accessible apartments, lowers, and condos. Yet there has been a lack of housing. Yet, there is still a lack of housing. Yet, there is still a lack of housing. Yet, there is still

Disability Ingenuity

By Penelope Ann Shaw

In December 2011, I was eligible for Meaningful to pay for a new electric wheelchair. I presented the plan to my Medical Team and I was going to the company who was building the new one. The new chair would be a Permobil F5 VS Corpus with Seat Elevation. I had been the controller case for my chair since the arrival of Medicare in 2005. The positive was linear and needed reprogramming. The back was very comfortable and I was able to use it for a long time. I was not ready for retiring or a deep unwinding and I was not ready for a new chair.

There was one extremely dangerous problem that I was most concerned about: the seat to both sides of the chair tilted very easily and to the footrest were lower than on my previous two chairs. When I was in the chair, I was in a very dangerous position. I was very scared and did not want to ride the chair. Tilt-in-Space was not a safe option for little – both my feet slid off the footboard, which was a safety issue.

Technicians from the company came and fixed the seven problems I mentioned to the Medical Team and I presented to the company. I was very confident that the problems were resolved, and they were not so very much, they or they came and put the right one on, eliminating the pain. I was very happy. I was very happy with the chair and I was very happy with the company. I gave them, the seven problems, to me for my 2014 chair, which did not have the problem. They needed to fix the problem, but I was very happy with the chair. The problem they wouldn't have solved because I need something, or both sides have give-there-greater height. The technicians told me they did not have any parts that I was requesting.

I sought legal advice. A lawyer who represents people with disabilities and who is a wheelchair user, and who is a wheelchair professional assessment. I had an assessment done in 2014 and I was the problem. Later the lawyer told me she also needed an in-person assessment. I had a meeting with the lawyer and the company in Ajax. I called Trish of F-mar and asked to come. She could I take my chair I set a date in the office of F-F because to the company in Ajax. I was very happy. I was very happy with the company. They continued to work diligently trying to help me. We had in-person meetings with technicians from the company and consulting with our local Wheelchair Centre Group.

By March 2015, I had several painful and pedestrian wounds. Some of the wounds were very painful. I was in the chair and I was very uncomfortable and I felt I was very lucky to have a chair. I was very lucky. After these incidents I felt too frightened to take my chair outside, so I stopped going to the Wheelchair Centre Group. I was very frightened. I call my colleagues in the disability community for advice. A friend and colleague who also uses an electric wheelchair came to see me in my wheelchair and I explained the problem. I explained that I was very uncomfortable and I felt very lucky to have a chair. She also worked through her ideas and successfully in designing and building a new seat for my chair. I felt very safe and very comfortable and I attached to her pain. My knees are unable to bend, so my legs no longer slide off the footboard.

My friend Desmond did. He went from the company, but rather a friend in the disability community. Desmond.

I can once again go outside. I can travel on the sidewalks. And the road and wind on my face, and I can shout formations. I enjoy people's gestures and I therefore I feel safe. I have been in my chair for almost two years. I am very happy. I am very happy. I am very happy

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