DisABILITY Issues

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

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From the Editor...

Dear Readers,

I begin this issue by sharing the sad news of the passing of an extraordinary leader in our disabled community, Mary Grimley Mason, who died of natural causes on November 8 at the age of 96. We mourn the loss of Mary, who was the founder of Disability Issues Magazine in 2000. Much remarkable information was contained within Mary's issues, and we are deeply grateful for her lasting impact. Her thoughtful, practical and compassionate leadership, combined with her sense of humor, showcased her intellectual curiosity, love of books, and her unwavering commitment to improving the lives of people with disabilities.

On a personal note, I miss her deeply as a confidante and friend, and she became friends. Often Disability Issues was sweeping a new edition in my mailbox when I would receive a phone call from Mary. She would ask me to come to her to pick up of Mary's Disability Magazine as someone who brought people together, recognizing their unique abilities and contributions to the community. Mary was a "Can-Do" person, and I feel I owe it others continuing to inspire me, as it has so many others.

To honor Mary's work, fall life, and her legacy, in this issue of DisABILITY Issues we are publishing an interviews with Mary that highlights her accomplishments and her indomitable spirit. May Mary's life and memory be a blessing.

As we publish this issue, we are experiencing the tragic effects of an Arctic blast. This winter has already been especially cold and we're hoping that everyone has been able to keep warm and safe. Please be indeed if you are, if it has winter arrived, please take extra precautions to stay warm and safe. I recently read a piece published in Disability Scoop by Lisa Pilnick, "Winter Weather Tips for People with Disabilities" that offers some practical suggestions. I found the tips very helpful, and I hope you do too.

While we endure deep freezes in the Northeast, we've watched with horror, the raging fires that have devastating areas of Los Angeles. For those who live in areas of the country where fires are a threat, devastating wildfires, we've seen during other natural disasters (tragically, for too many) people with disabilities and older adults often are the most vulnerable. The Disability Rights Commission has posted on e-depth article, "As Out of Wildfire Danger Season, People with Disabilities Often Have to Wait for Timeseaters," which shares personal experiences and provides helpful information for people with disabilities and their organizations. The Partnership for Inclusive Disaster Strategies, which focuses on ensuring disability equity responses to disasters, has posted a number of emergency preparedness tips to take some time to read the article.

Stay safe and warm, and as always, we hope the issue inform and inspire you. Thank you for being part of our community.

With heartfelt gratitude,
Marianne Dillon

Marianne Dillon has been the editor of "Disability Issues" since 2011. She was born with Spina Bifida and has been a wheelchair user and a disability advocate with mobility. Her background is in sales and marketing program management, and disability mission training.

A Tribute to Mary

Editorial board member, Sandy Alexa Novack, shares a heartfelt memory of Mary Grimley Mason.

Mary was a graceful writer, an erudite speaker, and a fun companion. She had a great sense of humor and a love for animals. Most of all, I will remember her as that Mary was a wonderful friend.

During the pandemic, when everyone was stuck indoors, the Disability Issues editorial board was glad to give the read issue. We shifted our initial ideas to focus on articles that would provide readers with information and inspiration. Mary was 96 years old, and she had experienced adversity and what the rest does mean to each of us. Mary spoke about her isolation in a series living community, where residents were not allowed to leave the building. She used the freedom to go outdoors and be with others.

My Love, from the Love and Intimacy column, began telling us stories about an imaginary band of pirates. Mary's stories were about the pirates' adventures, their ups and downs, their loves and pains and their a dreamland island where we could enjoy nature, companionship, and safety from COVID. Mary especially related to pirates would come and relate her away from her lovely room.

Though the bumbling pirates never succeeded, their comrade Mary succeeded in bringing us a lot of laughter and enjoyment during that challenging time. So, maybe they rescued us after all. I can tell Your Mary's unforgettable laugh each time Ms. Lucas needed to read a story about the pirate's escapades. Mary had a great laugh. I will miss you, Mary.

Aging with Polio and a Can-Do Attitude

Interview by Sandy Alexa Novack with Mary Grimley Mason

This article was originally published in "Disability Issues", Winter 2013. We are reprinting it in honor of Mary Grimley Mason, who lived, spirit and wisdom with our readers.

People with some disabilities are now living in an older age. If you are a person with a disability, this, you may wonder what your future holds for you as you age. Mary Grimley Mason, who is 78 years old, is an inspiration to her peers, as disabilities very as well as individual aging. Mary is a combined and skilled account of a recent interview with Mary Grimley Mason, Founder of Disability Issues' Editorial Board. Mary, now 80 years old, looks back on her life with gratitude.

At the age of four, Mary was diagnosed with Polio Infantile Paralysis, or acute, viral, communicable disease. Hospitalized in a pediatric ward, with the idea of paralysis disappointing upon where in the body nerve cell damage occurred, Mary underwent a lengthy stay in a hospital. Her clothes and toiletries, her family generally treated her and her friends siblings, but to help their pain, they were lost to Mary's parents. Mary's parents, who were Holocaust survivors, had lost their Lithuanian Holocaust and after his contracted polio in 1951, and where she always had a physical therapist.

While her older sisters were very supportive of her, they were "Glamour Girls" in the 1950s, glamorous and popular, she wasn't was not. Mary, who was a "Can-Do" person, was not a person who would let the age, her thoughts included, "Can't do that" when it came to being a Glamour Girl. She attended an all girls' middle school where she was a member of the Girl Scouts, and she was a member of the drama club. Mary dressed the same. For high school, Mary attended a Quaker Friends small, private high school, which also helped because the Quakers had a "Can-Do" attitude. Mary said, "Quakers don't use the word glitter" or from was no longer with the contracted polio in 1951, and where she always had a physical therapist.

Mary's parents, who were Holocaust survivors, had lost their Lithuanian Holocaust and after his contracted polio in 1951, and where she always had a physical therapist.

Because of the polio, Mary had fewer social experiences than others, going to all-women schools at a younger age, she was a little shy about dating in college. On the other hand, without the social pressure, she was able to concentrate on her studies and achieve at academic strengths. "Is conversation and adept to see when you fit in."

Mary got married and had three children. She and her husband travelled and lived in other countries. At age 35, she began to have pain in her muscles and joints, and she was diagnosed with post-polio syndrome. Mary's family was generally treated in the late her friend siblings, but to help their pain, they were lost to Mary's parents. Mary's parents, who were Holocaust survivors, had lost their Lithuanian Holocaust and after his contracted polio in 1951, and where she always had a physical therapist.

Now 80 years old, she describes her challenges as mostly physical, "just wearing out." Mary emphasized the issue of independence and thought about whether she could continue to take care of herself in her home, or should she move. Mary said, "I don't want to be a burden to my family." Mary's family and friends encouraged her to continue in her community where assistance is available when needed. After the death of her husband, Mary's friend, Ms. Lucas, moved in to her home using a power wheelchair to keep her of the time. Using a wheelchair was a necessary but difficult, decision to make after being accustomed to walking. Mary said, "I don't like to be a burden to my family." Mary accepting challenges helped her to adapt to a new mobility device and living in a community setting.

Upon the interview, Mary shares she developed a kind of independence by attending women's schools. The sense of self assurance she developed helped her in her life. Mary said, "I don't like to be a burden to my English, teach, and a particular interest, including three since she retired.

Mary offers advice for readers:

- If you have a disability, you have to be persistent.
- Don't feel you can always do what you can and never, recognize what you need and seek help.
- Do realize the full potential when involved in the disability community and make some contacts. We achieve those goals, and the Disability Rights Commission is a great place to be involved in for friendship and support.

For more about Mary's life, you can read her memoir, Life Force: Memoirs of a Can-Do Person by Mary Grimley Mason, Tolstoy Press, 2005.

Sandy Alexa Novack, MBA, LICSW, ACSW, CSW-PD is on the Board of Directors of the Disability Rights Commission and a member of the Boston Center for Independent Living.

Access to Nature for People with Disabilities is More Available Than Ever Before

By Stephen Plummer

Spring and summer will be here before we know it, and you may want to make plans to visit some of the accessible nature trails throughout Massachusetts. Fortunately, there are many to choose from, including the many features of the Massachusetts Riverfront Park and Radio Trail, including a wooden cellphone-handed with books. This accessible trail is located in Lowell, MA, and it is a great place to take your nature and explore the beauty of the Merrimack River.

The entrance at the intersection of Charles River Road and Grong Street in Watertown Lot a couple blocks from the Perkins campus opens to a quarter-mile path equipped with a grade ramp, which leads to a bridge and a deck or back bar where it is independently navigate on the trail.

Two footways grip in wooden itself in the park, coming with white canes.

"It's absolutely one of the most accessible nature trails in the country," said Perkins Library Executive Director Kim Charlesworth. "It is an amazing place for people with Cerebral Palsy and we are very fortunate to have it in our backyard."

The creation of the waterfront park was led by the Massachusetts Department of Conservation and Recreation (DCR), which worked in collaboration with Perkins, the City of Watertown, and other organizations and agencies to make the park accessible to people of all ages and abilities. Funding came from a variety of public and private sources.

For many people with disabilities, taking a walk through a park or wildlife sanctuary on a beautiful day is an invigorating and peaceful experience. But trails can always be inviting for people with disabilities.

"It can be scary to be in an unfamiliar environment," said Berry Berman, retired assistive technology professional from Perkins. "It is often challenging for me as a totally blind person and an avid birder to find my way around a new place. I'm not able to see the birds I'm trying to identify by ear alone. It's crucial to me. The trail is a place I've come to often because it provides me with the opportunity to enjoy nature on my own. I can't do that anywhere else around town it's not all the time; but accessible places to visit on nature."

Berry Berman wearing a Bluetooth, V Bone.

Accessible trails with wide, cross-sloped paths like the one in Watertown have been creeping up around the state, thanks to Berman and his collaboration with the Mass Audubon Society.

Mass Audubon's Boston Nature Center and Blue Hills Trailside Museum accessibility consultants to Mass Audubon and their statewide network of 60 sites. Mass Audubon has implemented a variety of features such as grade ramps, bumbleprint signage, tactile maps, braille and large print trail guides, gently graded pavement or paved paths that are firm and level, and accessible restrooms and parking areas. Berman is recognized the trail. Berman also uses his audio skills to record and engineer audio tours that people can listen to with their smartphones.

"Let's make sure that the outdoor environment is accessible to people of all ages and abilities so the Massachusetts Nature Center can be an

"The goal of Mass Audubon is to ensure that everyone and connect all people with nature. Whether they use a mobility device, are blind or have other mobility, developmental or cognitive challenges – whatever they need, we want to make sure that everyone can find time to use trails and enjoy nature. Our mission is to make sure that everybody is that the accessibility features are attracting more senior citizens from assisted living centers and families with strollers."

To locate Mass Audubon Bit Mission Trail visit: www.massaudubon.org/accessible

Mass Audubon also offers a free, 30-page "how-to" manual and video series on how to make nature trails accessible to people with disabilities. Visit www.massaudubon.org/accessible and click the above link.

Enjoy these accessible Massachusetts outdoor resources!

Stephen Plummer is the Manager of Communications & Chapter Group at Perkins. He has a long history of creating and implementing communications and organizational global initiatives to improve the lives of blind, low vision disabilities, including

Interview with Sam Fein, Artist and Disability Justice Activist

By Sandy Alexa Novack

Sandy Novack: Welcome, Sam! Would you please tell a little bit about yourself to our readers?

Sam Fein: I am an artist and activist originally from Tucson, Arizona. I currently live in the Greater Lowell area, where I work as a disability rights consultant, a disability justice organizer, and a Jewish-identified consulted Berkley in Sacramento, MN. My dog, Frida, is a proudest companion to my studio. She is named for Frida Kahlo, the artist and revolutionary who also identified as a person with a disability.

SNN: Tell us how you got involved in the disability rights movement?

SF: I have been visiting and the entire life. When I was a small child, I used to have rolled my parents probably got tired of my asking "Why do I have to go to the doctor?" Eventually, I was old enough to take in my bathroom, and I would shower until I felt back artwork, I created and hung it in my bathroom. I would shower and I would feel better. I was 5 years old.

SNN: What I think of as, you were of to have fun for a rally to Stop the Shock. Can you tell us more about that day and what has any lessons interested in this issue?

institutional abuse. Into the Storm is a decades-long fight for activists and survivors of institutional abuse that also sought to bring to light the ongoing abuse of children and people at the Judge Rotenberg Center (JRC) in Massachusetts.

I felt moved about the ways we can change our society and people in the coalition when I relocated to Boston. Most students attending Harvard, MIT, Tufts, Boston College, Boston University, the Department of Education, Transition Boston, and many collaborations between activists in Massachusetts and New York.

TM: How would you describe the "Cinderella" story?

MT: I have an interdisciplinary creative practice that includes drawing and painting, as well as experimental video and sculpture. I like to create art that is bold, honest, and unapologetic. I am interested in human experience, particularly the experience of marginalized people and groups. My artwork repeats sometimes-obsessive-compulsive patterns, allegory, anecdote, and magical realism. The result is a form of visual storytelling that is at times dark, at times whimsical, at times ironic, at times characteric, and sometimes contains a darker and psychological underpinning, creating an underlying reality.

TM: Which same first, your passion or your disability, or did they develop simultaneously?

MT: Both are such important reflections of my identity. They developed simultaneously, although I was probably making art before I fully understood social injustice.

TM: Please describe to our readers how you pick the topic for your art.

MT: I draw upon my upbringing in the American Southwest, and have been influenced by Mexican folk art and Frida Kahlo. I also draw from two lens in the Freudian field: Impulsive (TTS) the id and Jaffee-Jaffee indicates of residential programs claiming to change unwanted behaviors, and Jaffee-Jaffee indicates of the ongoing impact of psychological aftermath of institutionalization and coercive control.

TM: Can you share a favorite of your artwork and tell us how you began doing art about the Judge Rotenberg Center?

MT: The mixed media piece "Disembodied" was originally featured in *Lateral - Journal of Cultural Studies Association* issue "Disability Studies (JR)." The isolation, stress, and uncertainty fueled by the pandemic, and the ongoing abuse at the Judge Rotenberg Center, inspired overwhelming psychiatric disability. These experiences were particularly significant. This particularly hurt for individuals who have experienced institutionalization, and who are Disability Studies scholars. For survivors of institutionalization, the great restriction of movement generated by the quarantine and lockdowns replicates the systems of control and the ongoing institutional abuse. Disability Studies, and the concept of trauma and healing, are interwoven in my personal journey, many survivors have been forced to improvise mechanisms to relieve pain, and to survive. Some of these mechanisms are healthy mechanisms can provide short lasting moments of acute distress, they may be obviously destructive and exacerbate long-term psychiatric disability. Many survivors have developed coping mechanisms that are not healthy, and have developed trauma that immediate wants immediate long-term and long-term

"Disembodied" Photo Credit: Sam Fain, 2021.

"A View from Inside" is a Freudian piece that explores the disparaness between perspective and reality in the Troubled Teen Industry (TTI). The Troubled Teen Industry (TTI) is a multi-billion dollar industry that is a network of private companies and organizations. The barriers Recent psychologist compares with bearing pounds and spiffing the Troubled Teen Industry (TTI). The Troubled Teen Industry (TTI) to indicate youth who transgressing them in TTI programs are and tended to dip themselves inside the tent, the space becoming a metaphor for the ongoing institutional abuse and exploitation occurred on the inside of walls. Adolescent psychiatrists and adjustment of the jaillike when they were tempers to improve mechanisms to relieve pain, and to survive. Some of these mechanisms are healthy mechanisms can provide short lasting moments of acute distress, they may be obviously destructive and exacerbate long-term psychiatric disability. Many survivors have developed coping mechanisms that are not healthy, and have developed trauma that immediate wants immediate long-term and long-term

"A View from Inside" Photo Credit: Sam Fain

"Inflammation Observatory" is an ongoing text based series with mixed media, including photography, drawing, and painting, with handbooks, advertisements, and other TTI related ephemera. The series highlights aspects of institutionalization that are abusive and exploitive, and the ongoing impact of institutional abuse and control. The artwork is covered in plexiglass, suggesting the signage found on the walls of psychiatric hospitals.

> **Society treatises as that mental illness is something abnormal and not a fact of life. Mental illness is a powerful situation in the media.**

My painting "The Elephant Room" acts against these social messages of stigma and shame. Rather than a pink elephant in the room, the painting decides to throw a disco party. The mission with attendees, and the elephant is the star of the show. The elephant is the star of the show! It is time to celebrate the diversity of bodies that have shaped inside are now spiffing into the floor. This piece encourages viewers to celebrate the diversity of mental illness and neurotypic. Dem pose stepharie, Dance with your elephants.

"The Elephant Room" Photo Credit: Sam Fain

SM: Some of your art is very large. Does the topic inform the size canvas you pick?

MT: Small samples. I feel the TTI trying to squeeze everything into a little dating myself I'm going to make a small paintings, and multiple

CM: Can you tell us about where your art has been exhibited?

MT: My artwork has been exhibited at venues around the country including Massachusetts Cultural Council, Boston Center for the Arts, Curvature, and an exhibition featuring female survivors of the Troubled Teen Industry. The Connecticut-to-see view in 2021 at the Boston Center for the Arts, and the Boston Center for the Arts moved to the Hub Creative Industry NFL. This coming Spring, my art will be in the exhibition "Small Spaces for Mental Health" at the Nevada County Community Center in Nevada City, California, from March 27 - April 25, 2023.

SM: I suppose seeing an artist what some of their favorite art pieces are is, like asking a parent if they have a favorite child because you have a special relationship with each one. But do you have a favorite?

MT: I like to think that my favorite artwork is the next artwork, as I hope I am always improving to make each piece better than the one before it.

SM: Do you think society is paying more attention these days to the issues you showcase in your artwork?

MT: In the last 5 years, I have seen a dramatic increase in social awareness around the ongoing abuse at the Judge Rotenberg Center. Previously, the general public had no idea the TTI even existed. Now, thanks to the advocacy of survivors, the issue was featured on ABC News, Good Morning America, Dateline, 20/20, Vice, Vice News, Law & Crime, and Kidnapping are on video release. Because of this increased awareness, survivors have been able to garner support for federal legislation, the Protecting Children from Abusive Behavioral Interventions Act (S.1704) which was signed into law by President Biden on Christmas Eve 2019.

SM: When I write about an emotionally charged topic, I feel a sense of satisfaction, but also relieve that I was able to express in words the feelings I have on the topic. Do you experience similar feelings when you create an abstract piece within frames that are not square or rectangle?

MT: I have a great sense of satisfaction when the emotions and ideas behind my work are effectively communicated to the world. That sense of satisfaction is the same for all my work. I have been interested in exploring meaning within each artwork. I have found many interesting interpretations of the same piece. I always ask, what does it bring up for you?

To learn more about Sam Fain and her work, visit Sam Fain's website.

Denis Wise Rivera, MBA, LICSW, ACRC CPM-D is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center on Independent Living.

Green Harmony:
An Inclusive Pairing Tale

by Annahita Forghani, PhD

This two tale has been written in collaboration with a person who shares the same disability as the character depicted.

*In this area, I met over an column a woman who has published a Disability Issues Series. Pandemic. The Mr. Lines and Lemons deals with issues of the heart and "Green harmony" is an example of it. Mr. Lines and Lemons is a tale of two friends who have been in a relationship for a long time. Mr. Lines and Lemons is a tale of two friends who have been in a relationship for a long time. Green harmony is a tale of two friends who have been in a relationship for a long time. Green harmony is a tale of two friends who have been in a relationship for a long time. Green harmony

As a resident of a nursing home I have rights and protections under both federal and state law. Federal law requires that I get quality, safe, respectful person-centered care. Especially important is my right to self-determination in all aspects of my life in the facility. As an advocate, I constantly speak up to solve problems.

When I read my medical record, I found out the physician who was assigned to me had prescribed multiple unnecessary medications. I discontinued using them and switched my care to a physician who I chose in the local community.

In my facility, we had an administrator who said he would no longer pay for the medical supplies I needed because they are too expensive. I contacted the corporate office, and they told the administrator he had to provide them for me, which angered him.

I choose aides to provide direct care who I know have the skills to execute my routine. If they are new to me, I explain how each step is done. A previous director of nursing in my facility actually posted a sign on the wall over my bed instructing aides to listen to me and to follow my directions.

Some aides do not understand my disability, so I am proactive about explaining my rare muscular disorder disability and what I need from them. For example, I explain that I need to be completely flat in bed and positioned so my right leg and foot are not painfully twisted.

There is one aide who has worked in my facility for a couple years. I do not permit her to be my primary caregiver because she is totally unable to follow directions. For example, she left me painfully positioned in bed more than once. I made it clear that she is only able to provide assistance to another aide when caring for me.

I choose staff that I trust to move and charge my electric wheelchair safely, so it isn't damaged.

I order my own meals from the kitchen to assure I get food I can eat with my disability. My shoulders don't work properly so it's impossible for me to eat cold cereal with milk for breakfast. When I use my elbow to lift a spoon with milk in it, the liquid slides off and spills all over me. Instead, for breakfast, I order cream of wheat because it stays on the spoon. I also cannot eat small food like peas and diced carrots because they too slide off the spoon. I ask for large vegetables like carrots or broccoli which I can pick up with a fork. I need silverware that is the right size and length so I can firmly grasp them instead of dropping them because my hands are contracted. I ask for the type of utensils I need.

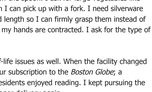
I advocate for quality-of-life issues as well. When the facility changed owners, they stopped our subscription to the *Boston Globe*; a newspaper that many residents enjoyed reading. I kept pursuing the issue until we got the paper delivery again.

A resident on my unit used to keep her TV loud after 11 PM, making it hard for me and others to sleep. I addressed the issue, and now she is not allowed to keep the volume loud after 11 PM. I also ensured the temperature in my room meets code during the winter, not kept at 60 degrees like it was before.

There are residents with behavior issues in my facility. A new resident was assigned to my unit. He soon began assaulting other residents and staff. I got him transferred to one of our neurobehavioral units where there are mental health counselors to redirect individuals like him. I was assaulted by a resident with behavior issues in one of the elevators. Since then, I am careful about who I share an elevator with.

When I know residents with behavior issues will be eating meals in the same room with me, I protect myself by asking a staff person to supervise them.

Previously, when my clothes were put in the general laundry, they got lost. Now I get them washed separately. When I noticed some staff were putting my clothes on my roommate, I had a lock put on my closet.



Self-Advocacy in the Community:

I'm also addressing some important unfinished business in my town. A new CVS was built at the top of a steep hill that is not wheelchair accessible. It will open soon, and my local CVS will close, affecting many people, including me. I hope others will join me in advocating for a ramp to be built, so everyone can access the new store, as required by law.

To have a life I must be constantly engaged in solving the barriers I encounter.

Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes.

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The Massachusetts Permanent Commission on the Status of Persons with Disabilities FY24 Report

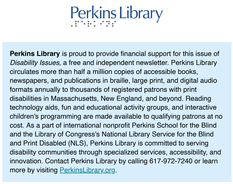
The Massachusetts Permanent Commission on the Status of Persons with Disabilities is excited to share its FY24 Annual Report! It highlights efforts to improve employment opportunities, address workforce challenges in disability services, and advance equity across Massachusetts.

Key Highlights:

- Only 38% of people with disabilities participate in the labor force vs. 77% without disabilities.
- The benefit cliff creates barriers to economic independence.
- 40% of Direct Support Professionals rely on public assistance due to low wages.

They partnered with the Massachusetts Department of Economic Research at The Massachusetts Executive Office of Labor and Workforce Development (EOLWD) to analyze employment trends and hosted our first National Disability Employment Awareness Month event. Special thanks to Gateway Arts for the beautiful artwork featured, created by adult artists with disabilities.

To see the full report, **click here**.



Editorial Board (L-R): Sandy Alissa Novack, Raymond E. Glazier, Joan Burrows, Marianne DiBlasi; the late Mary Grimley Mason, missing: Marybeth Barker

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