***Disability Issues***

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

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**Table of Contents:**

**From the Editor**| Marianne DiBlasi
**A Tribute to Mary** | Sandy Alissa Novack
**Aging with Polio and a Can-Do Attitude** | Interview by Sandy Alissa Novack with Mary Grimley Mason
**Access to Nature for People with Disabilities is More Available Than Ever Before**| Stephen Plummer
**Interview with Sam Fein, Artist and Disability Justice Activist** | Sandy Alissa Novack
**Love & Intimacy Corner: Green Harmony: An Inclusive Fairy Tale** | Annahita Forghan, PharmD
**Disability and Self-Advocacy** | Penelope Ann Shaw
**Info Briefs:**

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**From the Editor:**

Dear Readers,

I begin this issue by sharing the sad news of the passing of an esteemed member of our editorial board, Mary Grimley Mason, who died of natural causes on November 6 at the age of 96. We mourn the loss of our dear colleague and friend who joined the editorial board in 2009. Mary's invaluable contributions enriched *Disability Issues,* and we are deeply grateful for her lasting impact. Her thoughtful, practical perspectives shaped our editorial board meetings, while her articles showcased her intellectual curiosity, love of books, and unwavering commitment to improving the lives of people with disabilities.

On a personal note, I first met Mary at a conference in 2010, and we quickly became friends. When *Disability Issues* was seeking a new editor in 2011, Mary recommended me – and as they say, the rest is history. I am honored to be part of Mary's enduring legacy as someone who brought people together, recognizing their unique abilities and encouraging them to contribute their skills for the greater good. Mary's belief in others continues to inspire me, as it has so many others.

Mary journeyed through life longer than many, embodying her hallmark traits of courage, determination, wisdom, and generosity. She often described herself as a pioneer, and I wholeheartedly agree. Throughout her life, Mary broke through barriers and obstacles, paving the way and making it easier for future generations of people with disabilities to reach new heights.

To honor Mary’s rich, full life, we’ve included a link to her [obituary](https://www.deefuneralhome.com/obituaries/Mary-Grimley-Mason?obId=33711389#/obituaryInfo) and are re-publishing an interview with Mary that highlights her remarkable life and indomitable spirit. May Mary’s life and memory be a blessing.

As we publish this issue, we are experiencing frigid effects of an Artic blast. This winter has already been especially cold and we’re only partway through January. On these bitterly cold days, please stay indoors if you can. If you must venture out, please take extra precautions to stay warm and safe. I recently read a piece published by United Disability Services, titled “[Winter Safety Tips for People with Disabilities](https://udservices.org/winter-safety-tips-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 decimating areas of Los Angeles. Our hearts go out to all who have lost their homes and lives during the devastating wildfires. As we’ve seen during other natural disasters (tragically, far too many) people with disabilities and older adults often face greater risks, challenges and loss of life. CNN recently published an in-depth article, “[As the LA Wildfires Have Shown, People with Disabilities Often Have to Fend for Themselves](https://www.cnn.com/2025/01/18/health/disability-la-fire-evacuations-wellness/index.html#:~:text=According%20to%20the%20United%20Nations,have%20disabilities%20or%20mobility%20issues.),” which shares personal stories, exposes systemic failures, and highlights the work of the disability-led organization, [The Partnership for Inclusive Disaster Strategies](https://disasterstrategies.org/), which focuses on ensuring disability equity responses before, during and after disasters and emergencies. I encourage you to take some time to read the article.

Stay safe and warm, and as always, we hope this issue informs and inspires you. Thank you for being part of our community.

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 and marketing, program management, and disability inclusion training.*

**A Tribute to Mary**

*Editorial board member, Sandy Alissa Novack, shares a heartfelt memory of Mary Grimley Mason*

Mary was a graceful writer, an erudite speaker, and a fun lunch companion. She had a great sense of humor and a love for adventure. Most of all, I am proud to say that Mary was a wonderful friend.

During the pandemic, when everyone was stuck indoors, the Disability Issues editorial board had a call to plan the next issue. We shifted our initial ideas to focus on articles that would provide readers with important pandemic information. During the meeting, we shared personal experiences about what the lock down meant to each of us. Mary spoke about her isolation in a senior living community, where residents weren’t allowed to leave their room. She yearned for the freedom to go outdoors and be with others.

Ms. Love, from the Love and Intimacy column, began telling us stories about an imaginary band of pirates. These pirates were making to plans to rescue Mary and the other editorial board members and take them to a deserted island where we could enjoy nature, companionship, and safety from COVID. Mary especially wished the pirates would come and whisk her away from her lonely room.

Though the bumbling pirates never succeeded, their comical escapades brought months of laughter, offering much-needed relief during that challenging time. So, maybe they rescued us after all. I can still hear Mary’s unforgettable laugh each time Ms. Love revealed the next chapter 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 Alissa Novack with Mary Grimly Mason**

*This article was originally published in Disability Issues, winter 2014. We are re-publishing it in this issue to, once again, share Mary’s life, spirit and wisdom with our readers.*

People with some disabilities are now living to an older age. If you are a young person reading this, you may wonder what your future holds for you as you age with your current disability. It is hard to generalize, as disabilities vary as well as individual circumstances. What follows is a condensed and edited version of a recent interview with Mary Grimley Mason, a member of Disability Issues’ Editorial Board. Mary, now 85 years old, looks back on her life and its challenges.

At the age of four, Mary was diagnosed with Polio Infantile Paralysis, an acute, viral, communicable illness sometimes resulting in paralysis, with the site of paralysis depending upon where in the body nerve cell destruction occurred. For Mary, polio meant she now walked using crutches and braces. Her family generally treated her just like her three siblings, but to help treat her polio, they sent her to Warm Springs, GA (known for its warm, mineral spring water, and where Franklin Delano Roosevelt went after he contracted polio in 1921), and where she always had a physical therapist.

While her older sisters were very supportive of her, they were “Glamour Girls” in the 1940s, glamorous and popular; this wasn’t easy for Mary. Mostly Mary feels her challenges were the same as anyone else her age, her thoughts included, “I can’t do that” when it came to being a Glamour Girl. She attended an all girls’ middle school where students wore uniforms, which helped because all the students dressed the same. For high school, Mary attended a Quaker Friends small, private high school, which also helped because the Quakers had a value system that made things easier. They allowed “nothing glittery” so there was no vying for high fashion and everybody was treated the same.

The issue of mobility prompted Mary to attend a college with a small campus so it would be easier to get around. But in the post-WWII years when no one had cars, she felt restricted. Two professors advised her to transfer to another college where she would be more intellectually challenged. She transferred to Harvard just as cars were becoming more prevalent, and she states that Harvard was good at letting her park wherever she needed. Reflecting on this point in her life, Mary would advise others with disabilities not to undersell their capabilities intellectually or otherwise. Mary knew she needed to transfer from a small college and get a car for her mobility. “There is a lot you have to do, practically speaking, to self-advocate, to be pro-active.” You also either must have, or develop, a can-do attitude, “You have to do what you have to do, so just do it, and move forward.”

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 emphasis, Mary was pushed more into developing her intellectual and academic strengths. “You accommodate and adapt to see where you fit in.”

Mary got married and had three children. She and her husband travelled and lived in other countries. At age 39, she began to have more physical and personal challenges. A hairline fracture of a hip required her to temporarily use a wheelchair, something she had not had much experience with before. Her marriage also ended when her husband chose to focus on himself and left. In her typical style, Mary “just went on with life”.

Now 85 years old, she describes her challenges as mostly physical, “just wearing out.” Mary addressed the issue of independence and thought about whether she could continue to take care of herself in the home she’d been living in for 20 years. She recognized that she needed more help and moved into an apartment in a retirement community where assistance is available when needed. After the move, Mary transitioned from walking with crutches and braces to using a power wheelchair most of the time. Using a wheelchair was a necessary, but difficult, decision to make after being accustomed to walking most of her life. Once again, Mary’s practical approach to accepting challenges helped her to adjust to a new mobility device and living in a community setting.

Upon life review, Mary states she developed a kind of independence by attending women’s schools. The sense of self-assurance she developed helped her “find her voice”. She went on to get her PhD in English, teach, and publish six books, including three since she retired.

Mary offers advice for readers:

1. If you have a disability, you have to be persistent.
2. Don’t feel you can always do things on your own; recognize what you need and seek help.
3. She wishes she had gotten more involved in the disability movement earlier and made some contacts. She advises those with disabilities to reach out to people in the disability community for friendship and support.

For more about Mary’s life, you can read her memoir, [*Life Prints: A Memoir of Healing and Discovery*](https://www.amazon.com/Life-Prints-Healing-Discovery-Cross-Cultural/dp/1558612378/ref%3Dsr_1_1) by Mary Grimley Mason, Feminist Press, 2000.

*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.*

**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! Perkins School for the Blind students like to explore the many features of the Watertown Riverfront Park and Braille Trail, including a wooden xylophone marked with braille. This accessible garden and walking path allows people who are blind to easily enjoy nature and explore the banks of the Charles River.

The entrance at the intersection of Charles River Road and Irving Street in Watertown (just a couple blocks from the Perkins campus) opens to a quarter-mile path equipped with a guide wire, which enables people who are blind or have low vision to independently navigate on the trail.

Along the path, granite markers provide interesting facts about the area in both print and braille. Visitors can read about animals, plant life, Native American history, and the growth, development, and impact of industry on the Charles River over the decades. In addition to the braille and print signage, wooden blocks along the guide wire alert visitors to points of interest, including granite benches for taking a break and a wooden overlook extending out over the river. The trail also leads to a sensory garden area with boat-shaped benches for climbing and touching.

“It’s absolutely one of the most accessible nature trails in the country,” said Perkins Library Executive Director Kim Charlson. “It is an amazing treasure along the beautiful Charles River, 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 stakeholders to design a space that would be accessible to visitors 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 that's not always the reality for some people with disabilities.

“It can be scary to be in an unfamiliar environment,” said Jerry Berrier, retired assistive technology professional from Perkins. “It is often challenging for me as a totally blind person and an avid birder to find places where I can spend an hour or two or longer, all by myself listening to bird songs, if I choose to. This trail is a place I’ve come to often because it provides me with the opportunity to enjoy nature on my own. It’s a wonderful experience because it’s not all that easy to find accessible places to visit in nature.”

Accessible trails with wide, rope-guided paths like the one in Watertown have been cropping up around the state, thanks in part to Berrier and his collaboration with the Mass Audubon Society.

For the past fifteen years, both Berrier and Charlson have been accessibility consultants to Mass Audubon and their statewide network of All Person Trails. Features include multi-sensory elements such as guide ropes, braille/print interpretive signage, tactile maps, braille and large print trail guides, gently graded graveled or paved paths that make it easier for people using wheelchairs, and/or other mobility aids to navigate the trail. Berrier also uses his audio skills to record and engineer audio tours that people can listen to with their smartphones.

Half a million people visit Mass Audubon sanctuaries every year. Director of Adult Education and Accessible Programs Lucy Gertz said, “The goal of Mass Audubon is to boost that number and connect all people with nature. Whether they use a mobility device, are blind or have low vision, have developmental or cognitive challenges—whatever they need – it is the hope of Mass Audubon that they will enjoy time on our trails and experience nature. An added bonus is that the accessibility features are attracting more senior visitors from assisted living centers and families with strollers.”

To locate Mass Audubon All-Person Trails near your location visit:

[www.massaudubon.org/accessibility](http://www.massaudubon.org/accessibility)

Mass Audubon also offers a free, 70-page “how-to” manual and video that's available online for other organizations working to design their own accessible trails. It is available at the above link.

Enjoy these accessible Massachusetts outdoor resources!

*Stephen Plummer is the Manager of Communications & Graphic Design at Perkins Library. He has a long history of creating and directing marketing and publications in support of organizations' global initiatives to improve the lives of those with multiple disabilities, including visual impairment.*

**Interview with Sam Fein, Artist and Disability Justice Activist**

**By Sandy Alissa 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 Boston area and work as a community organizer at the Disability Policy Consortium. My art studio is in a converted factory in Somerville, MA. My dog, Frida, is a constant companion in my art studio. She is named for Frida Kahlo, the artist and revolutionary who also identified as a person with a disability.

**SN**: Did you go to art school, or are you self-taught?

**SF**: I have been making art my entire life. When I was a small child, I used to have night terrors. My parents probably got tired of being woken up in the middle of the night, so they eventually put a craft table in my bedroom, and I would draw until I fell back asleep. I studied art formally in high school and college, and ultimately attended art school for my Master of Fine Arts degree.

**SN**: When I first met you, you were off to New York for a rally to Stop the Shock. Can you tell readers what that was about and how you become interested in this issue?

**SF**: Within the field of disability justice, my area of focus is institutional abuse. [Stop the Shock](https://stoptheshock.info/) is a decades-long fight by activists to end the use of electric shock devices that are used as a form of behavioral control on disabled people at the Judge Rottenberg Center (JRC) in Massachusetts.

I first heard about the issue when I was in college and became active in the coalition when I relocated to Boston. Most students attending the JRC are from New York and their stay is paid by New York's Department of Education. Therefore, there is an ongoing collaboration between activists in Massachusetts and New York.

**SN**: How would you describe the kind of art you do?

**SF**: I have an interdisciplinary creative practice that includes drawing and painting, as well as experimental media and text. I strive to make art that is bold, honest, and unapologetic. I am interested in human relations and emotional conditions within social frameworks of power. My densely layered narratives integrate psychosocial research, allegory, anecdote, and magical realism. The result is a form of visual storytelling that is both comedic and bizarre. Bold colors, quirky characters, and whimsical scenes contrast a darker psychological underpinning, creating an upsetting reality.

**SN**: Which came first, your passion for social justice or art, or did they develop simultaneously?

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

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

**SF**: I draw upon my upbringing in the American Southwest, and fuse memory and imagination with present-day events. Recently my focus has been on the Troubled Teen Industry (TTI), the multi-billion-dollar industry of residential programs claiming to change unwanted adolescent behavior. These pieces explicitly address the emotive and psychological aftermath of institutionalization and coercive control.

**SN**: Can you show us examples of your artwork and tell us how you began doing art about the specific topic?

**SF**: The mixed media piece “Overwhelmed” was originally featured in *Lateral: Journal of Cultural Studies Association* issue “[Crip Pandemic Life](https://csalateral.org/section/crip-pandemic-life/overwhelmed-fein/)”:

The isolation, stress, and uncertainty fueled by the pandemic has challenged our collective mental health. For people with preexisting psychiatric disabilities, these repercussions are further magnified. This is particularly true for individuals who have experienced involuntary confinement in “corrective” facilities. For survivors of institutional abuse, the gross restriction of movement generated by the quarantine and lockdowns replicates the systems of total control to which they had previously been subjected. Facing an uncertain future and lacking access to community support systems, many survivors have been forced to improvise mechanisms to relieve traumatic symptoms on their own. While these self-soothing mechanisms can provide relief during moments of acute distress, they may be ultimately destructive and exacerbate long-term symptomatology. The artwork is an expression of being overwhelmed, and the conundrum faced when survival strategies that meet immediate needs threaten long-term well-being.

“A View from Inside” is a collaborative piece that explores the dissonance between perception and reality in the Troubled Teen Industry (TTI). An erected tent – a reference to wilderness programs—displays a series of banners sourced from TTI advertisements. The banners flaunt picturesque campuses with beaming youth and uplifting messages. The banners are held up by zip ties, a tool commonly used to restrain youth when transporting them to TTI programs. Viewers are invited to zip themselves inside the tent, the space becoming a barrier that replicates confinement. Handwritten messages are scrawled on the inside of walls. A slideshow projects photographs of the artists when they were teenagers in the TTI, reminding us of how young adolescents truly are.

[“Inflammatory Observations”](https://samfein.com/projects/inflammatory-observations) is an ongoing text-based series with material sourced from medical records, internet forums, program handbooks, advertisements, and other TTI-related ephemera. The series highlights aspects of institutionalization that are absurd and outrageous as well as systemic oppression, including racism and sexism. The artworks are encased in plexiglass, suggesting the signage found on the walls of psychiatric hospitals.

My painting “[The Elephant Stays](https://samfein.com/paintings/2019-present/view/7430593/1/7430594)” acts against these social messages of stigma and shame. Rather than ignore the elephant, the figure in the painting decides to throw a disco party. She moves with abandon, dipping and spinning with her elephant as a dance partner. The door to the closet is wide open, the stacks of boxes that had been stuffed inside are now spilling onto the floor. This piece encourages viewers to take ownership of who they are. Shame thrives on secrecy. Own your elephants. Dance with your elephants.

**SN**: Some of your art is very large. Does the topic inform the size canvas you paint?

**SF**: With smaller canvases, I feel like I’m trying to squeeze everything in. I keep telling myself I'm going to make smaller paintings...eventually.

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

**SF**: My artwork has been exhibited at venues around the country. Through a curatorial fellowship from ApexArt, I developed [The Corrections](https://apexart.org/fein.php), an art exhibition featuring female survivors of the Troubled Teen Industry. *The Corrections* was on view in 2023 at The Foundry in Cambridge, MA, and a portion of the exhibit later traveled to the Pratt Institute in Brooklyn, NY. This coming Spring, my art will be in the exhibition “Jewish Voices for Mental Health” at the Peninsula Jewish Community Center in Foster City, California from April 10 - June 25, 2025.

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

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

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

**SF**: In the last 5 years, I have seen a dramatic increase in social awareness around the Troubled Teen Industry and its dangers. Previously, the general public had no idea the TTI even existed. Now, thanks to the advocacy of survivors, the issue was featured on *NBC Nightly News* and documentaries like Netflix’s *The Program: Cons, Cults, and Kidnapping* are in wide release. Because of this increased awareness, survivors have been able to garner support for federal legislation investigating these facilities. [The Stop Institutional Child Abuse Act](https://www.stopinstitutionalchildabuse.com/sicaa) (S.1351/H.R. 2955) was signed into law by President Biden on Christmas Eve 2024.

**SN**: When I write about an emotionally charged topic, I feel a sense of satisfaction, but also release that I was able to express in words the intensity of the moment. Do you experience something similar when you create art about social justice matters that are close to your heart?

**SF**: I feel a great sense of satisfaction when the emotions and ideas behind my work are effectively communicated to the world. That said, I also enjoy ambiguity and invite viewers to find their own personal meaning within each artwork. I have heard many interesting interpretations of the same piece. I always ask, what does it bring up for you?

**To learn more about Sam Fein and view more of her artwork, visit** [Sam Fein’s website](https://www.samfein.com/)**.**

*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**

**Green Harmony: An Inclusive Fairy Tale**

**by Annahita Forghan, PharmD**

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

*In this issue, I turn over my column to a woman who has published in Disability Issues before, Annahita. The Ms. Love column always deals with issues of the heart and “Green Harmony” is no exception. At times, the people closest to us, such as family members and friends, don't understand or accept our disabilities. With information, patience and time those with disabilities can often help such people understand and relate to our disabilities. But sometimes it is clear that the relationship remains unpleasant and a person with a disability must decide what they should do then. These are the kinds of issues our heroine princess confronts in this fairy tale.*

*Yours in love,*

*Ms. Love*

Once upon a time, there was a market replete with tasty foods. A pretty princess named Leznupara[[1]](#footnote-1) was most fond of an unlabeled mysterious green gelato. She often limped her way home, eating this big green gelato after saying good-bye to her pal Macadamio[[2]](#footnote-2) as she pondered the possible flavors this green delectable could be.

One day, Leznupara came home and was so focused on identifying the gelato’s flavor – “Pista…” that she forgot to finish the gelato before her father, Giuseppe, saw her.

“Leznupara!” he shouted. “Once again, I catch you wasting time on that green garbage! Instead of working on curing your legs, you’ve thrown yourself into that nasty cone of snot! Shame on you times a million nine hundred. You are a disgrace to our family name!” Furious, Giuseppe locked Leznupara in the highest room of the tower to prevent further embarrassment.

Leznupara was devastated about losing the chance to figure out the gelato flavor she had almost uncovered. If only Macadamio knew how close she had come to figuring it out. If she identified the flavor first, she would win their bet, and he would bring her another gelato. If she lost the bet, he said he had something in mind, but it was a secret only to be revealed if he won. What did he secretly want?

Days went by and Leznupara was still locked up in the tower. She couldn't run and there wasn't even much space to walk. She had genetic polyneuropathy affecting her legs, meaning her immune system was attacking her nerves. And her nerves were dying faster because she wasn't exercising, risking muscle atrophy. As her feet, ankles, and legs weakened, she began to have a lot of trouble lifting her feet as she moved around, so she tripped and fell often. She also felt random pain for no reason and knew it was her polyneuropathy.

Damn her father, Giuseppe, for thinking her body was something to ashamed of. If she wanted to enjoy a stupid gelato mystery to keep herself positive, why did her father want to take that away from her too?

Her frustration grew, which didn't help the situation because stress aggravated her nerves even faster. She wanted to change her negative thought pattern, so she began using memories of Macadamio. She remembered the way they laughed and all the flavors of gelato they had tasted.

As difficult as it was, memories of Macadamio helped her to perform some plyometrics so she could at least salvage what nerves and muscles were left in her legs. Her legs had a much slower response than before. It felt as if she was trying to move through a heavy, sticky substance, like walking through molasses. Her legs eventually became stiff and her toes stayed curled. Consequently, she had less mobility. Sometimes she had no mobility at all. Her inflexible legs impacted her lower back and sometimes she experienced excruciating spasms that kept her bedridden. Each time Leznupara overcame challenges related to her polyneuropathy, she learned to embrace her abilities.

Thoughts of Macadamio sweetly distracted her from the pain, even though Leznupara knew she may never see him again. She wondered what Macadamio would have wanted if he won their bet of being the first one to guess the green gelato flavor. Would he have wanted her to buy a different gelato flavor? From a different seller? What if he wanted something else altogether!

BANG! Something flew through the window and whacked Leznupara's head. What in the world? She looked around the small empty room she was locked up in. A rock smacked her, but how? It must have come from the entrance to real life outside. She had to look before curiosity consumed her faster than she could eat a cone of green gelato. But she hesitated. Tentatively, she peeked over the windowsill.

She wanted nothing to do with the crowd of people below. It was one thing for her to accept these physical changes herself. It was another thing to get other people to accept it. She dreaded facing their judgmental eyes, knowing they would watch her as she limped. What about the friends she already had? Would they avoid her now that she had strange movements? Leznupara raised her head a little higher and her eyes were now fully gazing over the windowsill. Then, slowly she raised her head even higher, and her nose popped over the windowsill. Wow!

Leznupara noticed someone waving their hands wildly in the dark. Macadamio! She stretched her index finger in front of her mouth to let him know not to make a sound. If Giuseppe found out that Macadamio was there, she would never know what his part of the bet was! She looked for a way to get out. She used her arms to lift herself up through the windows. Far below, Macadamio pointed to a pile of hay that she could land on. Really?

Leznupara was losing the nerves in her legs, but not her brain. She carefully lifted her body over the window's ledge, using her arms to push her weak legs over. She saw a column of uneven bricks sticking out of the tower that she could grab onto as she climbed down. Because her legs were stiff and weak, they weren’t much help. At one terrifying moment, she slipped! Empathetic Macadamio yelled out to her in heartfelt concern as Leznupara hung on, holding her body weight with her arms until they were slightly numb. Finally, her slow feet found another ledge to stand on. By then it was too late. Out trudged Giuseppe with swollen eyes because he had just woken up. He began yelling utter nonsense at his inculpable daughter. She was fed up.

Leznupara had already climbed most of the way down, so she jumped the rest of the way. The hay came in handy at that point. She landed safely but stumbled as she started running. Macadamio ran alongside her, even though he could have run much faster. He slowed down even more to put obstacles in her father’s way while Leznupara ran ahead. Giuseppe shouted insults and threw hay, which ended up flying into his mouth so that silenced him. He tried to punch the hay with his fist but the sharp hay cut his dry skin so that didn’t help.

Finally, after running a few miles, Macadamio turned to face Leznupara. She began speaking. “I almost guessed the flavor of the green gelato earlier! It was a green plant. Argh, it was on the tip of my tongue before my father interrupted!”

“Not just any green plant, Signorina, it was PISTACHIO!” Macadamio laughed as Leznupara snapped her fingers in defeat. “Now that you’ve won, what was your secret end of the bargain?” Leznupara asked, exasperated.

Prince Macadamio thought about how to approach it. He had already planned it a million times in his head, but now there was a palpable texture to the air that wasn't there when he was planning it alone. Asking the Princess wouldn't do. He knew she was strong enough to refuse if she wanted to so, he stated it as a declaration.

“Kiss me,” he said.

Leznupara's eyes widened in shock. “Well why didn't you say so?!” They didn’t waste another moment and put their thoughts on hold for once, after all the thinking they did on their sapori a sorpresa[[3]](#footnote-3). They were now acting instead of thinking, and it was sweeter than they could have ever imagined or planned for. Even sweeter than their favorite green gelato.

Four romantic years later, Prince Macadamio asked Princess Leznupara to marry him with a green emerald jeweled ring. A few more sweet years later they gave birth to a green-eyed baby, who they named...can you guess? Pistachio. A baby full of mysterious journeys to come, as mysteriously as the gelato that had brought them together.

And they all lived sweetly ever after!

**Glossary**

1. *Leznupara (prounced Lez noo pah rah): The Princess Leznupara is aRapunzel spelt backwards. The author added an “a” at the end to make “Leznupar” sound like a feminine Italian name.*
2. *Macadamio (pronounced Mac a dame ee yo): The Prince's name comes from the macadamia nut.*
3. *Sapori a sorpresa: Refers to surprise/surprising flavors.*

*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* *Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy and may be edited.*

**Disability and Self-Advocacy**

**Penelope Ann Shaw**

As a person with a significant physical disability, I often must advocate for myself. Here are some of the ways I advocate.

A wheelchair company built a new chair for me and my legs slid off the chairs’ leg supports. At my request, a friend assisted me. She bought parts that added height, which solved the problem.

Once, I was hit by a car while in my chair. The driver’s insurance company told me the chair was damaged but usable if I drove carefully. When it came time to repair it the manufacturer said it was unsafe to drive because the frame was bent. I contacted the Disability Law Center in MA who assigned a lawyer to my case. She contacted the driver's insurance company and got the money to build a whole new chair. My concern is the whole process took almost two years.

I often ask for assistance. When shopping if I can't reach what I want, I am comfortable asking a stranger to hand the item to me. I do the same at my local public library. Since I can’t reach the electrical outlet from my chair, I am not able to charge my cell phone, so I ask someone to plug it in for me.

On one occasion I was driving my chair on a very narrow sidewalk and unexpectedly encountered a couch blocking the sidewalk. Unable to turn around and drive back to the curb cut to travel in the street, I called the town’s police dispatch to ask for assistance. They sent an officer to move the couch so I could get home.

I informed the town councilor about a dangerous sidewalk in our town with unsafe curb cuts and gaps in the sidewalk that could flip my chair. Because of these barriers, I must drive in the street alongside vehicles in this location. The councilor contacted the Department of Public Works, but the sidewalk has not been repaired yet.

**Self-Advocacy in the Nursing Home:**

As a resident of a nursing home l 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 need 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 onto 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.*

**INFORMATION BRIEFS**

**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](https://www.mass.gov/doc/annual-report-fy-2024/download).

1. [↑](#footnote-ref-1)
2. [↑](#footnote-ref-2)
3. [↑](#footnote-ref-3)