***Disability Issues***

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**Summer 2024 – Farewell Issue**

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

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

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**From the Editor:**

Dear Readers,

On behalf of the Disability Issues editorial board and myself, I am sad to announce that we have come to the end of an era. Funding for the newsletter's editorial, program management, and design expenses was not renewed, so this will be our final issue.  The editorial board and I have reached out to multiple people and organizations to inquire about funding that will allow us to continue publishing the newsletter and explore alternate media platforms, but unfortunately, we have not been successful.  We appreciate Spaulding Rehabilitation’s commitment to fund a final issue so we can say goodbye to our loyal readers.

For the past 15 years, Spaulding Rehabilitation has been an enthusiastic champion of Disability Issues and provided us with financial, administrative, and programming support. We are deeply appreciative for all that Spaulding has contributed to our success and stability, especially since 2018 when they became our sole funding partner.  Since the newsletter’s inception in 1977, this free and independent newsletter has relied on the generosity of financial underwriters. We extend our gratitude to CVS, Work Without Limits, Massachusetts Rehabilitation Commission, and Spaulding Rehabilitation for their generous support. Our funding partners made it possible for Disability Issues to publish a multitude of articles on a wide range of disability-related topics and share the dynamic personal stories of people who live with disabilities. This treasure trove of articles is still available for you to enjoy on our [archived issues](https://disabilityvisibility.com/resources/disability-issues/disability-issues-archives/) website.

Disability Issues has thrived due to the dedication of our talented editorial board members and contributors, who themselves live with disabilities. A hallmark of the newsletter has been its articles, written by and for people with disabilities in a down-to-earth style that champions timely issues within the disability community. The heart and soul of Disability Issues has always been to share stories about real-life experiences and offer practical wisdom to enhance the lives of those impacted by disability. We hope you have enjoyed and benefited from reading about the remarkable individuals and outstanding organizations we have featured.

We extend a heartfelt thank you to you, our cherished readers. Although we may not know you personally, we will miss you very much. *Disability Issues* was published quarterly, yet you were always in our hearts and minds throughout the entire year. Between publications, our editorial board and contributors paid close attention to people and situations, always keeping an eye out for stories that would be most meaningful to you. Your engagement and appreciation have been the driving force behind our efforts; inspiring us to seek out diverse perspectives on topics that impact the daily lives of people with disabilities. Thank you for receiving and valuing the stories we shared. Your support and connection have made our work truly rewarding.

I have had the honor of being the editor of Disability Issues since 2011. Reflecting on the past 13 years, I am incredibly proud of what we have contributed to the disability community.  As we bid farewell, we are delighted to present this final issue, filled with an abundance of articles for you to enjoy and benefit from.

With heartfelt gratitude, 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.*

**Celebrating the Spirit of Disability Issues**

For all of us at Spaulding, a deep commitment to the community with disabilities is core to our mission. From patient-centered care, educating the next generation of caregivers and ground-breaking research, everyday there is a focus to make life one day better for the people we are honored to serve. Another core tenet we hold is to be a fierce advocate for the community with disabilities. Since its inception, *Disability Issues* has been a vital platform to share resources, education and most importantly the voice of people with disabilities. For the past 15 years, Spaulding has been honored to help contribute resources to enable the publication to fulfill its critical role. However, like many media we all consume, the time has come to evolve and change the way we share information, news and resources.

We salute all the dedicated people who have made *Disability Issues* such a vibrant publication. At Spaulding, we know how important hearing from peers in the disability community can be. We have deeply valued the ongoing connection through *Disability Issues* to those in the community to share resources to promote life participation and independence in a variety of ways from healthy-living tips, to workforce development to advancing public policy.

The need to bring the stories, voices, and views of people with disabilities has never been more important and potential opportunities through new media options has never delivered more promise. [Spaulding](https://spauldingrehab.org/about/advocacy) is committed in joining with you to keep advancing the causes of access and equality and being a resource for all of those connected to disability. We extend our deep gratitude for the path forged by *Disability Issues* and the leadership of their Editor and Editorial Board. We look forward to opportunities the future will hold.

*Sincerely,*

*Spaulding Rehabilitation*

**Why Writing Your Life Story and Documenting Disability History Matters**

**By Sandy Alissa Novack**

When I was a child, my grandmother encouraged me to tell stories. There is power in telling one’s story; it lives on and is out there to stand the test of time. In my professional career, I went on to lead Holocaust survivors' support groups. I worked individually and in groups with many Holocaust survivors. Listening to these stories was a significant life experience for me as well as for the tellers of their stories.

For 19 years, I led a creative writing group at an elderly housing complex, and we published a book, containing both autobiographical as well as creative writing. The book was sold throughout the USA as well as in a few other countries. Though decades have passed, the book continues to be sold online. There is no end-date for a good book to read and learn about others' lives and dreams.

Now, I am the Vice President of the Board of Directors of the Disability Policy Consortium (DPC) and Chair of the Board's Advocacy Committee; and what do I want to do? Help tell more stories – *your* stories. I am a strong believer that history belongs to those who get written into history, and for too long that has not included many people with disabilities. DPC wants to change that for the residents of Massachusetts.

Why does your story matter? I have been writing stories for *Disability Issues* for almost two decades and discovered, everyone has a story that only they can tell, which should be told and preserved for history, or else it risks getting lost. I encourage you to write your story, the story that is unique to you and your life experiences.

During the pandemic, we lost many of our friends, family, colleagues and neighbors with disabilities. Many of them gave their time to stand up for the civil rights, the needs and desires of people with disabilities in the areas of medical, housing, education, work, or other spheres of life. Yet too many died without their efforts being documented. If you can write your own biography through the lens of disability as either a book or a chapter about a certain portion of your life, please starting right it now. If you write a chapter, it can be combined with chapters written by your peers to create a book. Please share your story about your life for the sake of documenting disability history and marking the future of life with disabilities.

For those who are unsure of how to begin writing your story, the first step might be to start with one disability related issue that is close to your heart. Share how it impacted you, why it matters to you, and what you tried to do about it. It does not have to be a success story. As many of us know, successes rarely come quickly or easily, if they come at all. That in itself is a story future readers need to read about. If your disability prevents you from writing your story, over the next few months DPC will be developing a plan to help you write your story, so we also want to hear from you.

No story is too short. No story is insignificant. Tell us about disability and the health care system, transportation, housing, dating, work, and any other aspect you want to share. If your story is about advocacy, it could be a blueprint for others to learn what issues you advocated for, what you did, and your vision for next steps. Let's face it, there is a disability angle to every single part of life, so your options on what to write about are wide open. There is no immediate endpoint to this project, so if you are not ready to tell your story now, feel free to tell it when the time is right.

Our goal is to place as many life stories as possible from people with disabilities in public libraries, disability study libraries, and other locations. In this way, we will develop the disability history resources to pass down to those who come after us. Whether you live on Cape Cod, in the Berkshires, North of Boston, or anywhere else in the state, your story is important.

If you want to tell your story, please send your contact information and email address to me, Sandy Novack, at mail@dpcma.org and put “Writing Our Disability History” in the subject of the email and I will follow up with you. If you don’t use email, leave a voice message for me with your name and phone number at the DPC office, 617-307-7775.

Since 1977, a treasure trove of life stories have been written by and about people with disabilities and published in *Disability Issues*. These newsletters will be contributed to DPC’s Documenting Disability History Project. Some of our older issues were not archived so we could use readers’ help. If you have newsletters that were published before 1991 or between 1998 – 2007, please let us know. We would like to scan copies of them for historic preservation. Please be aware, prior to 1991 the newsletter may have been published under the name *Together*, a publication of the [Information Center for Individuals with Disabilities, Inc](http://www.disability.net/index.html). If you can help, please contact us at disabilityissues@disabilityvisibility.com.

Thank you for your long-time readership and your help with documenting disability history.

Sandy Alissa Novack, MBA, MSW has been on the Disability Issues newsletter Editorial Board since 2005. She has written on emergency preparedness, housing, hospitals and universal access, and more.  She *is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**Why I Write**

**Penelope Ann Shaw**

Because I'm paralyzed, I often sit in my wheelchair up to 10 hours in a day. I usually ask to be transferred to bed after dinner, around 7 pm to avoid being in pain due to pressure on my legs. Being in bed works for me. I am warm and comfortable. It is a quiet self-imposed exile where I can focus, rest, have privacy, and escape from the problems of nursing home life. I enjoy looking out my window at the night sky. Seeing the moon and stars adds to the pleasure of being in bed.

However, being in bed from 7 pm to 8 am the next morning is a lot of time to be inactive. I don’t want to be bored so I try to use the time productively. I made my half of the room into an office workspace. It’s a peaceful sanctuary where I can slow down, relax and quiet my mind. A refuge where I can recharge my energy by having something absorbing, educational and meaningful to do – Write!

Writing is a skill I learned from being an academic, especially from the gruesome task of writing a 253-page doctoral dissertation. After that experience I promised myself, I would never write again. But when I ended up living in a nursing home, I became a long-term care advocate and accepted the responsibility of publishing pieces about concerning issues in these facilities.

Later, I was asked to write for the *Disability Issues* newsletter, which I feel is a privilege. I write about positive and negative experiences that I would not have if I wasn’t a person with a disability. Reflecting on and writing about my disability related experiences helps me to process them more fully; to make sense of them and have closure. I cannot do anything physical like cooking or swimming, but writing is something I can do independently. It is not affected by my physical limitations.

Writing gives me the opportunity to learn and grow intellectually. Reading and doing research for the topic I’m writing about supports my natural curiosity and my quest for new knowledge. I am an avid learner who is always seeking to know more. I am deeply engaged when reading books, professional journals, newspapers, and articles printed from the internet. This type of reading promotes deep thinking and provides me with ideas that are useful for other articles. While reading I take notes and place them into folders, organized by topic, to write about in a future publication.

Learning something new every day keeps my mind active and gives me positive energy.

Continuous learning not only promotes my intellectual stimulation and mental well-being, but using new ideas makes writing each piece a new adventure. Being a writer keeps me alert subconsciously. When I am out in the community, I am more sensitive to events that could be good subjects to write about.

As a wheelchair user, writing is beneficial because I can do it indoors when rain, cold or snow prevents me from going out. I can read and look for ideas, which keeps me actively engaged while living in a facility where there is little to do. Writing gives me the opportunity to share my ideas and experiences about being a person living with a disability. Publishing allows me to be part of a larger conversation with other people who have disabilities and, hopefully, give back to our community.

The facility where I live has a problematic resident computer and no printer, so I do my writing at the local public library. It’s a pleasant environment where I can go, weather permitting. The library is also a social place where I benefit by connecting with the staff I know and patrons I meet there. I am eager to spend time at the library and briefly get away from the endless frustrations created by institutional life. Working at the library allows me to thrive and survive in a positive environment within the community. I can't change my living circumstances, but I can compensate for them. I also feel it is important for the so-called able-bodied to see someone in an electric wheelchair using the same library services they are. The library also has a resource I greatly appreciate – a used book sale area where I can buy books for 50 cents or a dollar. I select and read some for ideas to use in future pieces.

I admit writing is hard work. It’s a challenge to write well, find original topics and, hopefully, write a piece others will find interesting. The writing process is long and involves narrowing the subject, crafting sentences and paragraphs, selecting words that best convey my thoughts, deciding what to keep or delete during the editing stage, and writing numerous drafts until I’m satisfied. These decisions not only take time but require thought.

Before I became disabled, I was able to go to an art studio for relaxation and create works on paper such as developing film and printing the images. I worked with watercolors, wood block prints and monoprints, all of which require being able to stand and walk. I confess, I now dream of becoming a literary artist by putting words on paper.

Writing has become part of me. A necessity. My daily life is rich and fulfilling because I am a writer. I am happy when I write. It is an activity that promotes more than my intellectual, mental, and social well-being. It keeps me alive.

*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.*

**Massachusetts Permanent Commission on the Status of Persons with Disabilities: Interview with State Representative Denise Garlick**

**By Sandy Alissa Novack**

As a member of the Disability Issues editorial board, I was recently offered the opportunity to write an article on the [Massachusetts Permanent Commission on the Status of Persons with Disabilities](https://www.mass.gov/orgs/permanent-commission-on-the-status-of-persons-with-disabilities). The Commission can and will be taking on a range of issues for the disability community. Currently, most of their work currently centers around the workplace because multiple issues can be addressed by addressing the employment of people with disabilities.

Typically, employment income and benefits enables someone to pay for housing, medical care, transportation, education, food, clothes, recreation and everything else.

According to the U.S. Bureau of Labor statistics, which is included in the Commission’s [2023 Annual Report](https://www.mass.gov/doc/mcspd-fy23-annual-report-w-photos/download), in 2022 21.3% of persons with a disability were employed compared to 65.4% for persons without a disability. In Massachusetts, the current unemployment rate for people with a disability is 13%, which is more than triple their non-disabled counterparts at 3.5%. Barriers to the employment of people with disabilities include inflexible workplace policies, stigma and employer bias, physically inaccessible buildings, and lack of adequate transportation access.

As the Commission’s report indicates, they are an independent state agency with the goal of advancing the cause of all people with disabilities in the state. There are [23 volunteer Commissioners and staff members](https://www.mass.gov/info-details/commissioners-staff-0), who represent a range of disability, age, race, gender identity, ethnicity, religion, and socio-economic backgrounds. They use their personal and professional experience to serve everyone with disabilities.

My initial interview was with the Commission's Executive Director, **Imene Bouziane Saidi**.

**Sandy Novack (SN)**: What inspires your passion for working in the disability field?

**Imene Bouziane Saidi (IS)**: My passion has deep roots in my personal and professional life. As a parent of three children with disabilities, I have firsthand understanding of the challenges and triumphs that come with advocating for their needs. This personal experience sparked my journey into the world of disability advocacy. Professionally, I began as an educational advocate, dedicating my efforts to assisting students and their families in navigating the often complex and daunting special education process. My role involved ensuring that each child received the support and accommodations they needed to thrive academically and socially. This work was deeply fulfilling and fueled my commitment to making a difference in the lives of children with disabilities.

Serving as the vice president of my local Special Education Parents Advisory Council (SEPAC), I worked with the school system to advocate for the needs, education, and safety of students with disabilities, promoting inclusive and accessible policies. My academic journey, including completing the LEND fellowship at UMass Chan Medical School, earning a Master of Social Impact Business Administration degree from Brandeis University. This advanced training provided me with a broader perspective on systemic issues affecting children and families. Combining these experiences, I have developed a holistic approach to disability advocacy and am committed to creating a more inclusive and supportive environment for individuals with disabilities and their families.

**SN**: What is one of your favorite parts of working in the disability field?

**IS**: Amplifying the voices of people with disabilities. I am dedicated to promoting meaningful inclusion and ensuring that their perspectives are heard and valued in all aspects of society. This role allows me to dig deeper into policies and practices that foster a more inclusive and supportive environment, making a tangible difference in the lives of individuals with disabilities.

Additionally, I am passionate about staying up to date with the latest advancements in assistive technologies. These innovations dramatically enhance the quality of life and independence for people with disabilities, and I am committed to leveraging these tools to their fullest potential. I also enjoy engaging with the public, so I encourage your readers to reach out to me with their interests and comments (Imene’s contact information is provided at the end of this article). Connecting with the community and hearing diverse viewpoints is both rewarding and essential to my work.

**SN**: I notice the Commission's 2023 annual report refers to younger people wanting jobs. What about the intersection of ableism and ageism around getting and keeping jobs?

**IS**: The intersection of ableism and ageism in the workplace is indeed a critical topic that affects many individuals. The Commission recognizes that age and disability can present unique challenges in obtaining and maintaining employment. We are committed to studying and addressing this issue.

**SN**: In your materials, you mention the Disability Equality Index (DEI). Can you tell readers more about that?

**IS**: It is a disability inclusion benchmarking tool for Fortune 1000 employers. Companies get scores on a scale of 0-100 with those scoring 80+ earning the distinction of “Best Places to Work for Disability Inclusion” in a particular year. Last year, [Becky Curran Kekula](https://www.mass.gov/doc/disability-index-dei-presentation/download), Senior Director, Disability Equality Index, presented at our disability employment subcommittee and shared best practices from [Getting Started on the Disability Journey](https://www.mass.gov/doc/getting-started-on-the-disability-inclusion-journey/download).

**SN**: Sometimes due to disability, the public may not be able to travel to the State House for public access to your meetings. Do you have meetings on Zoom?

**IS**: People can [sign up](https://lp.constantcontactpages.com/su/WWIIUNL) to receive email notification about upcoming meetings, which they can attend via Zoom. Additionally, all our sessions are recorded so people can view [past meetings](https://www.mass.gov/info-details/meetings-and-materials), as well as read meeting minutes. Every meeting is equipped with American Sign Language interpreters and Communication Access Real-Time Translation (CART) providers for captions. Ensuring accessibility for all participants is central to our mission, reflecting our commitment to inclusivity and making sure everyone has the opportunity to engage and participate fully in our discussions.

A week later, guided by the background information Imene provided, I was ready to interview the Chair of the Commission, [State Representative Denise Garlick](https://repgarlick.com/).

**Sandy Novack (SN):** Representative Garlick, it’s so nice to meet you! I’ll begin our interview by asking you the same first question I asked Imene, what inspires your passion for working in the disability field?

**Denise Garlick (DG):** Like many women, I wear many hats. One hat is being a mother. I have four children, now young adults. My second child was born with microcephaly and has global developmental delays. Early on, I learned about disabilities in a very close up and personal way.

My second hat is the role I had for decades as a registered nurse. I was the Health Care Supervisor in a Day Habilitation Program for several years. My work included individuals with moderate to severe disabilities who were medically fragile.

My third and current hat is, I am a legislator. In this role, I see the fragmented work of Massachusetts to meet the needs of citizens with disabilities. We need more unified approaches. I come to the work of the Commission able to relate to issues of disability from multiple perspectives.

**SN**: I find it interesting that the Commission is called “Permanent.”

**DG**: “Permanent” and “funded” are the two most important words for our existence. It is a commitment by the Legislature. It allows us to approach our work in an organized way and gives us the time needed to invest in setting and meeting our goals.

Having the right politics, the right people, and the right opportunity is essential for moving forward. [Representative Josh S. Cutler](https://www.repjoshcutler.com/about) took on employment issues and did meaningful work which is documented in the [WorkAbility Subcommittee Report](https://www.mass.gov/doc/workability-report/download). At the time, there was an incident about a person with a developmental disability and the interaction with local police. Police reforms were, and still are, an important issue. This is where we had the “right opportunity.” The Commission was established in [Chapter 3 Section 74](https://malegislature.gov/Laws/GeneralLaws/PartI/TitleI/Chapter3/Section74) of the Massachusetts General Laws by the 2020 law enforcement reform legislation, [An Act Relative to Justice, Equity, and Accountability in Law Enforcement in the Commonwealth](https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter253). It was a case of “find the train that's moving and legislators advocating for individuals with disabilities got on it.” That's how the Permanent Funded Commission on the Status of Persons with Disabilities came into existence in 2020.

**SN**: I like the image you created of the legislation train and how legislators jumped on the moving train to include the Commission into the police reform bill!

Now that we have the Commission in Massachusetts, how can readers get engaged with your work?

**DG**: On our [website](https://www.mass.gov/info-details/commissioners-staff-0), we have listed all the Commissioners with their role and areas of special interest. Readers can select one or two interest areas and reach out to the appropriate Commissioner to discuss ways to get involved. Readers can also [sign up](https://lp.constantcontactpages.com/su/WWIIUNL) to our email list to stay in touch and receive updates about the Commission.

**SN**: I see one Commissioner has a background in voting in the State. If someone is interested in getting out the vote of people with disabilities, are you suggesting they contact that Commissioner?

**DG**: Yes. We also have had some great presenters at our meetings, including someone from the Disability Equality Index. Soon, we will have a presentation by WorkAbility on SSDI and working with barriers to employment.

**SN**: In ten or so years, where would you like to see the Commission's impact?

**DG**: In the next ten years, I would like the societal stigma of having a disability to be reduced. People with disabilities should be valued for their contributions. They should be included in our school systems, workplaces, and recreational activities so we can understand and show that everyone belongs.

**SN**: Could this Commission be a model for other states?

**DG**: This kind of work is happening now in many parts of the country. The federal Department of Labor has also been in touch with the Massachusetts Permanent Commission.

The Commission recognizes that disabilities are not monolithic. Many disabilities are like planets with their distinct concerns and issues. The Commission is trying to build a galaxy, with all shared interests in the disability community. Everyone has the right to be seen, heard and become the choices they make for themselves.

To contact the Commission, please reach out to Imene Bouziane Saidi, Executive Director, at Imene.BouzianeSaidi@mass.gov or 617-413-5703.

Sandy Alissa Novack, MBA, MSW has been on the Disability Issues newsletter Editorial Board since 2005. She has written on emergency preparedness, housing, hospitals and universal access, and more.  She *is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**Adaptive Climbing Group:**

**Making Climbing Accessible for People of All (Dis)abilities**

**By Lou Lim**

The Adaptive Climbing Group (ACG) is a non-profit organization that provides affordable climbing experiences for individuals with disabilities, aiming to transform their perspectives. If you have a permanent disability that limits normal daily function either physically, mentally, or developmentally, the Adaptive Climbing Group considers you eligible to be an adaptive climber. The Massachusetts chapter of ACG was launched in August 2013 at Brooklyn Boulders Somerville, now known as Boson Bouldering Project since 2022. The community quickly grew and ACG Massachusetts now hosts regular indoor climbing, outdoor climbing, monthly youth sessions, and special events throughout the year.

One of ACG’s regulars, Danielle (69 years old), speaks to her experience as a climber with disabilities:

I have multiple sclerosis and have difficulty with balance and walking among other impairments. Climbing with ACG has been a blast. I love both the climbing and the social contact with other climbers and volunteers. Figuring out how to climb a new route is challenging but rewarding. There are no balance issues on the wall and being on a rope with a belay feels very safe. The wonderful volunteers are skilled at adjusting their belay to suit our particular climbing needs. Climbing is very hard for me due to my leg weakness. But the volunteers give me a very ‘tight’ belay which allows me to get off the ground! Lastly, it is a lot of fun talking with climbers who have other kinds of physical challenges and hearing about the amazing adjustments they have made in their lives!

**Volunteering**

ACG also wants to empower people who have a passion for caring for others to consider volunteering. At the Massachusetts chapter, we want to help to make our regular programming happen in a kind, compassionate, respectful, and fun fashion. Friends, family members, and aides are also welcome to join sessions to support or accompany adaptive climbers who participate in our programming.

One of our volunteers, Lea Cleary, has this to say about volunteering with ACG:

Volunteering with ACG has been an enriching, grounding, and rewarding experience for me so far.  I look forward to watching how each adaptive climber finds their own way up the wall.  I am impressed by their creative and unconventional beta!  I love working a climb with an adaptive climber because it forces me to think outside the box.  As I try to understand climbs in their perspective, adaptive climbers help me grow as a climber in ways that I never would have experienced on my own.

While I can get discouraged during my regular climbing thinking about the things I can’t do, like the reachy move I’m too short to get or the crux move that I’m not strong enough to latch, adaptive climbing is all about celebrating everything we CAN do!  My favorite part of the day is seeing the joy and sense of accomplishment on the face of a climber I just belayed, especially if it was the very first climb they have ever tried.  Volunteering reminds me that the most important thing in climbing is to have fun!

What really gets me coming back to ACG is the camaraderie and inclusive community.  For a couple of hours or so, climbers and volunteers all partake in the same struggle against the wall no matter our background, walk of life, or ability.  I feel lucky to be part of an organization that makes climbing so accessible and allows me to share a sport I love so much with climbers of all abilities!

**Youth Climbing**

We also host monthly sessions specifically for younger climbers at most of our participating locations. No prior experience is required! These events are open to parents, friends, and other family members. We offer youth climbing at our Massachusetts chapter to help cater to the needs of younger climbers - especially in regard to creating a quieter climbing environment to help those with sensitivity to noise to thrive.

**Outdoor Climbing**

ACG also arranges multiple outdoor climbing trips every year, catering to climbers of all ages and abilities on both rock and ice. These events are led by professional guide partners and are designed to be affordable and accessible to all. Common ways we have engaged with outdoor climbing for ACG include trips to Hammond Pond in Newton, MA, Acadia National Park in Bar Harbor, ME and the classic sport climbing crag of Rumney, in the White Mountain National Forest in NH.

**Competition Climbing**

As well, our organization provides sponsorship opportunities for competitive adaptive climbers nationwide through three levels. We offer various forms of assistance, including gear costs, training, competition registrations, and more, tailored to individual needs. ACG-MA was proud to send climber, Maria Cabral, to a recent paraclimbing competition held in Stoneham, MA in November 2023. Maria is a regular adaptive climber who has right hand limb difference at the ACG-MA chapter - here’s what she says about her experience:

Stoneham Slam was my first competition, and I didn't know what to expect when I first got to the gym. Seeing all these athletes that are regularly competing was a little bit overwhelming but then I saw that there were other climbers that the Stoneham Slam was their first competition as well. And that made me feel better about it. As the competition started, I started climbing and meeting the climbers, and I felt welcomed. Everyone was really nice; they cheered for other climbers and created a very pleasant atmosphere. All this helped me enjoy the comp and climb …encourage[ing] me to do it again!

With over 1000 participants annually, ACG is the largest national adaptive climbing program in the United States - recently opening chapters in both Tennessee and Hawaii. It offers climbing opportunities for people of all ages and abilities, including indoor, outdoor, ice, rock, and competition climbing, every day of the year, empowering them to explore their potential.

To learn more, visit [Adaptive Climbing Group in MA](https://www.adaptiveclimbinggroup.org/massachusetts)

*Lou Lim, LMHC, REAT is a licensed therapist and expressive arts therapist residing in Medford, MA. He is an active volunteer for Adaptive Climbing Group and deeply values the access of sports to people of all (dis)abilities. When not providing therapy or climbing, he enjoys playing Dungeons and Dragons as well as trying new food experiences in the local Boston food scene.*

**WALTER’s PLACE**

**Learning With and From People with Disabilities**

**by Joan Burrows**

It is sad for me to write my last article for this publication that reaches out and helps so many people with disabilities and teaches so many without disabilities.

Growing up in the 30's in New England, I did not see anyone using a wheelchair. Several years ago, I saw a film that reminded me that people with disabilities were in institutions! Their treatment was often inhumane, as pictures showed.

When I met Walter Kiver, a man with Muscular Dystrophy, in the 1980's at a day center it was a first for me. Walter used an electric wheelchair and other clients were using manual chairs. Most were eager to make friends, and so was I. I set up a music program for everyone. Everyone loved to sing except one woman who only danced to one or two songs. The disabilities faded as I got to know them. Their personalities, their likes and dislikes, their skills are clear memories that are dear to me. Rosy loved to set the table for lunch but needed help because she forgot where the utensils went so, she got upset. I invented a game that we played together. I placed a model of a sample place setting in the middle of the table so Rosy could follow it. Then, I set the table on one side and Rosy the other. Sometimes I made errors too, so we checked each other. Rob loved John Denver, so I brought my recordings into the center. Terry had a strong voice, so I asked him to help me read the morning news.

I was an intern for my Social Work Degree at the center. I remember so many of the people and it was my first connection with senior citizens and disabilities, which was a life changing and enhancing experience. From that start, I have worked to help people understand and be understood. I spent over twenty years living with a man I met there, Walter Kiver. He attended school and graduated. We bought a van, moved in together, and were married in our hearts. He was a very caring and loving person. I was very fortunate. Together, we started the Acton Commission on Disabilities and I still serve on the Commission.

Over many years, I have met many people in the disability community and have learned from all of them. I learned to look past the wheelchairs and canes, etc. and see the real person. I also learned how hard it is to be seen as different. The only differences I can see are, in many ways those with disabilities have more challenges, and they have learned more compassion than most people.

I now use a walker to get around and I try to remember all I have learned. I don't run upstairs anymore or drive a car. There are many other things I can no longer do or need help with, but I am still "me!" I greatly value my friends. I love chocolate. I love the birds and the flowers on my terrace. I love music, teaching children, and more.

I will greatly miss sharing thoughts and stories in the *Disability Issues* newsletter.

*Joan Burrows studied music in New York City and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.*

**A Rare Disease, and the Rare Gem of a Person Who Has It, Annahita Forghan**

**By Sandy Alissa Novack**

I recently interviewed Annahita Forghan of Brookline, MA on what it is like to have a rare medical syndrome.

**Sandy Novack (SN):** Annahita, please provide readers with an overview of what PHARC is.

**Annahita Forghan (AF):** A mutation on the ABHD12 gene causes this monster of a condition called PHARC, which stands for Polyneuropathy, Hearing loss, Ataxia, Retinitis pigmentosa, and Cataracts. It is a neurodegenerative condition that will continue to get worse. There is no treatment for it.

**SN:** How rare is PHARC and are there any support groups?

**AF:** There are less than 50 people in the world who have it, according to the *National Institute of Health* article, “[The Phenotypic Spectrum of Patients with PHARC Syndrome Due to Variants in ABHD12: An Ophthalmic Perspective](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8467809/).” It is considered an “ultra-rare syndrome” in the world of rare diseases.

I wish there was a support group or foundation to support people who have PHARC. The closest I have found with any overlap are Multiple Sclerosis groups and online groups, such as the National Organization for Rare Disorders.

**SN:** What is it like to deal with a disabling condition that so few people have?

**AF:** I wish I knew one person with it. My brother had it, but is no longer alive. We bonded over our struggles, some of which had to do with our hearing loss, but we never directly talked about it. I didn't see it as a weakness, in the ways my brother's body changed. Kids don't form ableist judgments without influence from others.

Now here I am with a constantly changing body and losing my identity bit by bit. There is no one with PHARC to ask, “When you lost the ability to hear music, compose it, and dance to it, what form of self-expression did you replace them with?”

The doctors at Mass. General Brigham have made a connection with only ONE other case of PHARC. I frequently reach out to medical specialists to ask if they can connect me with patients with this condition, but they only have medical literature to indicate that a few other people with PHARC exist.

**SN:** For our readers who may have rare conditions or know someone who does, what words of empathy and wisdom do you have about how to move forward in the world?

**AF:** As frustrating or scary as it can be to lose yourself through a degenerative condition, we really cannot know the future. Therefore, you can hope. Hope that there will be a way for you to do what you love in another way. Whatever happens, it’s important to find a supportive community who will accept you as you are. Lean on those supportive people to feel more positive about those who seem unable to accept you.

**SN:** Do you have a team of people helping you? What kind of support do you recommend others seek out?

**AF:** I have a great support system of people who give me more than I could ever return. These awesome humans have become my friends and role models. They have given me ground to spread awareness. As my disabilities progressed, I wasn't sure I would meet my lifetime partner. But then, I happened to meet him when he was volunteering just as I lost most of my ability to run. He told me he knew I was “the one” when he first saw me. I am deeply in love with this caring man. He reminds me all the time about how much I do for him, which is important when society often contributes to someone with visible disabilities feeling a little helpless and brainless. He doesn't just love me despite my different abilities, he loves me because of them. He actually sees them as cool, which encourages me to grow with my differences.

For most of my life, I didn't have anyone to guide me. My temporary friends couldn't understand what was happening, and I didn’t either. We need peers for validation. Many of the people who keep a distance do so out of ignorance or fear. I blamed myself when my eyes didn’t focus well, or when I limped, lost my balance, etc. I thought it was my fault for not trying harder. Desperate to understand, I went for genetic testing when I was 29, almost 15 years after severe depression from losing my brother who died by suicide. At the time, I thought I only had hearing loss. If I knew earlier about my rare syndrome, I think it would have helped. For example, I would have learned American Sign Language earlier in life.

**SN:** I am very sorry to hear your brother died by suicide because he had PHARC. Do you have suggestions about what might help people cope with rare conditions?

**AF:** The earlier you know about your condition, the sooner you can get support from others. People can change each other’s mindsets. Physicians and librarians can do a lot too, in terms of resources and knowledge. Then it's up to the patients to take risks and make connections with people in the community.

Something that seems bad to you, might not seem bad at all when someone shares a different point of view. When I first wore hearing aids in second grade, I was a vulnerable kid and was affected by anything people said. One very simple thing happened that gave me the confidence I needed for the rest of my days with using assistive devices. My classmate wanted to see my hearing aids, so I showed him, and he said, “Whoa! That's cool.” From then on, I was shameless about my hearing aids. My brother didn't have a similar experience. He rarely wore his hearing aids to school because he had to avoid being bullied. If you can't understand your difference, it is better to embrace it. Love it. Be strong.

**SN:** You are a strong advocate for yourself, and you persevere. What else has PHARC shown you about yourself?

**AF:** One of my weaknesses was to stand up for myself, which stemmed from being belittled and harassed constantly in my youth. It was much easier for me to advocate for others. I remember my brother's friends dragging him around on the floor of a basketball court. My brother was laughing, but I knew it was only because he wanted to look tough. We were kids; I was four years younger than him and his friends, but I walked up and told them to stop. I told them it looked like they were harassing my brother, and they should know better at their age. They stopped.

PHARC gave me a voice when I couldn't hide my own needs. I was in college and while sitting through hours of lectures, my the Bluetooth device often disconnected from my hearing aids. It was a waste of my time. How could I learn something that I couldn’t hear in the first place? I wasted more time trying to learn it afterwards, which took away from my study time. It was an unequal education and this mattered when it came to grades. I ended up needing to interrupt the professor whenever it disconnected. I hated drawing attention to myself, and my classmates gave me a hard time about it, telling me I didn't belong. It was so twisted, but the tension gave me the confidence I needed. By the time I graduated, I was desperate and that’s why I got my genes tested.

**SN:** What have we not talked about that you want readers to know?

**AF:** Two matters come to mind right. My experience of getting a cochlear implant was not at all like the YouTube videos many people have seen. It wasn't so wonderful, and I almost passed out. The process of relearning to hear is a frustrating and exhausting experience.

When I was younger, I loved the orchestra. I am happy to say, this past month I was invited to join an orchestra. It was a fabulous experience, but there were unexpected challenges. It was difficult to count the rest measures when the conductor wasn't showing the beat with his arms. When this happened, I had to watch the flautist next to me to know what it was time to come in, and when I did come in, I usually could not hear myself. My boyfriend tried to sign to me what the conductor said in between playing. We made up our own signs for “fortissimo,” “note,” “measure” and a few other music terms, realizing that a deaf person probably would not be using signs for those words when they can’t hear details in music. I am very excited to be playing in an orchestra again!

To read more about Annahita, an article about her running accomplishments was published in Dignity Alliance Massachusetts’s [The Dignity Digest](https://mcusercontent.com/de034eba49faa71f4a93eef9d/files/d28d8f3d-b2d4-3596-008f-bb36aabc1a32/DAM_Digest_No_185.01.pdf) on page 12 in the April 30, 2024 issue.

Sandy Alissa Novack, MBA, MSW has been on the Disability Issues newsletter Editorial Board since 2005. She has written on emergency preparedness, housing, hospitals and universal access, and more.  She *is on the Board of Directors of the Disability Policy Consortium and volunteers with the Boston Center for Independent Living.*

**The Importance of Certain Objects**

**By Penelope Ann Shaw**

When I became physically disabled from Guillain Barre Syndrome, it was a dramatic change. It changed which objects in my life were important.

An electric wheelchair which provides mobility since I cannot walk. A flat control panel – not a tilted one – allows me to push down on buttons since my shoulders don't work and I cannot push up. A bag for the back of my chair to put purchases in and where I keep ponchos in case of unexpected rain to prevent me from getting wet when I’m outside in my chair. I keep a small backpack on my lap, so I have access to things I need such as, my wallet, pens, scissors, a steno notebook with daily to-do lists, my address book, and, in the winter, arm warmers and gloves.

A floor lift so I can transfer from bed to my chair. An Invacare Divided Leg Sling because this brand positions me upright and comfortable. A hospital bed with an alternating air mattress to protect me from getting pressure sores. Since the mattress may need the amount of air adjusted, a small flashlight to provide light on the control panel. I have personal bedlinen, pillows and blankets, to make my room more home-like. I only use sheets from the facility.

As for clothes, I buy them with my disability in mind. Sweaters with zippers I can grasp, not with buttons because my fingers overlap, and I do not have fine motor skills. No skirts or dresses because the sling transferring me to my chair pulls these up too high. In winter, extra warm clothes to protect me from being directly exposed to cold air when I go outside. Most gloves do not stretch sufficiently to get my contracted hands into them so the couple pair I found which I can wear are precious personal belongings and hard to replace. I wear heavy socks year-round to avoid pain in my feet from the edge of the footbox of my chair. In the facility where I live, a few years ago, aides were putting my clothes on my roommate, so I bought a padlock for the door of my closet to prevent my clothes from getting lost. I keep the key on a wristband.

Because of my non-working shoulders and contracted hands, I use only metal silverware to eat because I cannot press down hard with plastic. If I want soup, I need to put it into small juice glasses so I can pick up with two hands and drink. I am not able to use a spoon for any food with thin liquids, such as cold cereal with milk. I no longer eat food cut into small pieces because the damaged muscles in my throat affect my ability to swallow. Once, while eating rice, some grains got into my lungs, and it was a code blue. I was transported to an emergency room at my local hospital. I am careful to avoid something similar occurring again.

Since my hands are contracted and my fingers overlap, I use scissors to cut open envelopes and packages. I also use them to clip my fingernails. An object I use daily is a traditional wooden cane with a black rubber grip on the end. With this cane, I can reach up to the buttons and use elevators independently. I also use the cane to knock on closed doors, to push away and pull towards me things on tables. I cannot use a smartphone because my hands do not open wide enough to grasp one. Being unable to correctly position my fingers with a disabled shoulder I would also make mistakes on a touch screen. Instead, I use a small flip phone that has a grip with a loop of parachute cord to put my arm through so I can't drop the phone with my bent hands.

Access to a computer with a printer is important to keep myself busy, engaged and happy in life. I research ideas and take notes for my writing. Because the resident computer in my facility doesn't work properly and doesn’t have a printer, I do my work at the local public library where I can get assistance when needed, including reaching books and scanning text into files.

I like to read and write and have nonfiction books where I capture ideas for my writing. I put notes with these ideas on legal paper into folders by topic. I use gel pens because with bad shoulders I cannot press down hard to use ballpoints. Reading books also benefits me when I am unable to go outside in bad weather; it gives me something to do indoors.

Organizers are important. I put belongings in them. On the windowsill in my room, I have bags for access to items I use daily such as office supplies, stickers that I like to put on steno pages, snacks, and Styrofoam cups with lids. I also have memorabilia, including pictures from childhood and artwork I was previously able to do. I have a newspaper clipping from a 1972 Dominican Republic newspaper which had an article about me as the new Director of an English language program in the capital. I have bags in my dresser drawers with items including extra chargers for my cell phone, hair bands, pens, and markers. In my closet there are duffle bags for off-season clothes. I documented my possessions and their locations in a small notebook to help the aides give me things I want since I am not physically able to get them myself.

I often think of objects I can no longer use now that I am disabled. Shoes and boots because I cannot walk. Shoulder bags because I cannot reach up to put them on or take them off. A car because I can no longer drive one. Kitchen appliances and utensils as well as cleaning supplies because I am unable to stand to cook or clean.

I have a different life now that I am disabled, and different objects are essential to leading a good life.

*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.*

**THE PCA CORNER**

**PCAs I Have Known**

**By Ray Glazier**

Credit: originally published in [*New Mobility*](https://newmobility.com/pcas-i-have-known/), July 1, 2000.

Bob arrived for his interview the week that three other people responding to my newspaper ad for a personal care attendant (PCA) had failed even to show up. I tried to keep the desperation out of my voice.

“So, Bob, what was your last job?”

“Well, I haven’t been working for a while. I was at Frostberg State for the last year, but I left without a degree.” As a once-upon-a-time temporary college dropout myself, I could relate to that. “I have some part-time day work in Boston and thought I could do PCA stuff for you mornings and evenings to help make ends meet.” He was in his 20s, prematurely losing his hair on top, clean, if shabbily dressed, and was exactly my height and build before I landed in this wheelchair and started putting on weight. By the end of the interview Bob had a second part-time job.

It turned out that Bob’s first part-time job was posing in the nude for art classes at the Museum School. “What if you get a hard-on?” asked Jason, my other PCA. “With 20 people staring at you and a draft in the room,” said Bob, “no way.” Jason looked dubious.

It was late fall, and Bob had almost no clothes, a problem even for a nude model. I gave him my pre-injury winter wardrobe, which fit him exactly. Bob was grateful and dedicated himself to becoming the Perfect PCA. He even learned to cook. Sometime during those first few weeks he owned up to having just been released from Frostberg State Hospital, not having dropped out of Frostberg State College. Bob was sent there by the courts for pursuing his avocation as a Peeping Tom. He was very forthright and honest in these revelations and was really doing very well for me. So why make waves?

As time went on, Bob’s accounting for the grocery money became sloppy and I realized that $40 or so per week was being siphoned off for marijuana purchases from the kids dealing from the basement apartment next door. But things were going so well with Bob PCA-wise that I decided not to make an issue of it. (And hadn’t I tried the neighbors’ merchandise once or twice myself?) Then my MasterCard statement came in the mail, and I spotted a blatantly bogus $80 mail-order charge that I could ill afford.

“I was desperate!” said Bob when confronted.

“You were that desperate for two ounces of anti-baldness potion?”

“It’s very important in my line of work to have a full head of hair.”

Bob was contrite and agreed to pay off the $80 in four weekly installments with the firm understanding that the police would be called immediately if anything else went missing. But after a week, Bob found the terms too onerous, quit his day job, and skipped town in his new wardrobe.

**The PCA Tango**
Bob and I were doing what I call the PCA Tango. I’ve seen the pattern repeated over and over, and so have my friends who are PCA consumers. Typically, both the PCA consumer and the PCA candidate are equally desperate and living pretty much hand-to-mouth. The consumer can’t find good help for love or money, and the candidate can’t get a mainline job because he or she has no green card, has just come out of a detox unit or has a criminal record. Yet at its best, the relationship between PCA and consumer is a healthy symbiosis in which each party contributes something to the other. At its worst, one party becomes virtually a hostage of the other. The only redemption in that case is the transitory nature of the relationship. PCAs just don’t last that long anyway.

At first, I figured I was just too difficult, expecting to go to bed before 2 a.m., get up on time to catch my paratransit ride to work, and be dressed in something more office-appropriate than sweat pants and sneakers. It seemed no PCA ever lasted more than a six-month hitch. Then a friend more experienced with PCAs than I told me the truth: “The half-life of a PCA is three months.” So I stopped beating myself up on the tenure issue, polished up my recruiting and interviewing skills, and learned to appreciate variety and change.

And, man, have I had my fill of both. The best that can be said for certain PCAs is that they beat the alternative–lying in bed all day watching soaps and waiting for a pressure sore.

Yet a good PCA is a true gift. Fred, my very first PCA, still tops my list. He was a college student from Iowa who signed on for the duration of my wife’s pregnancy because he wanted to share in the experience, Lamaze classes and all. He was so excited when the Big Moment came that he drove right past the downtown hospital, and we almost didn’t make it there on time. Nowadays Fred is delivering babies himself and stitching up stab wounds as an ER physician in a big-city hospital in the Midwest. He is one of the few doctors I still speak to.

Over the years I’ve preferred to have male PCAs, when I had a choice, which wasn’t always. While I confess to once having had adolescent fantasies of reclining in a hot tub while being bathed by nubile maidens, nothing in my pre-injury life prepared me for how it would actually feel to be assisted in the shower by a female PCA. And who wants anyone’s help with toileting unless it just can’t be avoided? But female PCAs can have the requisite detachment and physical strength, are initially less squeamish than guys, are often handier at dressing and sewing on missing buttons (sexist as that sounds), but can’t deal with neckties that aren’t clip-ons. Yet I know male PCAs working for women with disabilities who have become expert at makeup application and hairstyling, as well as strategic placement of clothing accessories.

Fred excepted, I’ve found aspiring members of the medical establishment–student nurses, medical students, budding therapists – attitudinally unsuited to PCA work because they are trained to objectify patients and distance themselves emotionally from those they treat. They work on people, not for and with us. But students by and large are good PCA candidates. They are in a temporarily needy status, prefer part-time work, don’t mind odd hours, and are young enough to be strong, flexible, learn quickly and adapt to change. Of course they’re also young enough to be fickle, insensitive, unresponsive, and unreliable. One must be prepared to make accommodations for heavy dates, exam periods and changes in class schedules.

**A PCA Rogues Gallery**
Mike was a computer whiz who’d been recruited by Harvard, so PCA work supplemented his scholarship nicely. He was agreeable and helpful, but on Thanksgiving Day, just before dinner guests arrived, he handed me a long list of accumulated grievances along with his resignation. It seems he’d especially resented helping me host a party the previous Halloween, and he was gone in a flash.

Frank was going to physical therapy school on the GI Bill and drawing a 50 percent disability benefit from the Veterans Administration because of a knee injury he’d incurred playing basketball off duty and a social disease he’d also picked up off duty. Frank was strong and agile, despite his disabilities, and I wondered what the VA might think of his PCA work and his physically demanding choice of profession.

And Frank wasn’t my only PCA with a disability. Roger was a preacher who’d had a psychotic break and been carried from the pulpit one Sunday by men in white coats. He happened to be a fantastic vegetarian cook, and I was sad the night he wandered off and simply never returned. Mark was a former high school athlete and ex-Marine coping well with recovery from alcoholism and taking heavy meds to control his bipolar disorder. He saw me through the breakup of my marriage, so I felt a loss when he quit abruptly. I learned later that he sensed he was on the verge of a psychiatric hospitalization and withdrew to spare me that tension.

Gwynne was a middle-aged British divorcée looking to extend her American holiday as a live-in PCA; she answered my ad at a time when I was, as usual, desperate. She was rather ditzy and did things like serve up a supper of beef liver that had been cooked all afternoon with a can of Veg-All thrown in the pot for variety. She did nothing to improve my low opinion of English cooking, and she assured me that everybody in England leaves the fridge door open throughout meal preparation. Gwynne liked to clomp around the house in lavender satin pumps with high heels and big pompoms, wearing a pink chenille bathrobe and with her hair in rollers. She actually handled transfers better than I expected, despite teetering on the high heels and mumbling incantations to levitate me out of bed. But I vividly recall the day Gwynne dressed me for work, and I discovered after a mad dash to the men’s room that she had put my undershorts on backwards. I’m sure it never occurred to her that this could be problematic.

One reason I kept Gwynne on was that she got along so well with Mickey, a physical therapy student moonlighting as a PCA. Between the two of them, they shared my regular morning and evening routines. They also shared each other’s wardrobes; Mickey liked to cross-dress on the weekends and was drawn to Gwynne’s more frilly outfits. That cozy arrangement ended the day I got a legal notice suspending my right to drive in the state of Maine because of an unpaid speeding ticket. I hadn’t driven in years anyway, and hadn’t been to Maine recently. But my extravagance of the moment was maintaining a Saab sedan in which I was transported to and from the office by my PCA. I learned that Mickey and his boyfriend had “borrowed” the Saab to go running nude on the beach in Maine one fine spring day and were nabbed for speeding as they raced back to Boston to pick me up after work. He didn’t have the sense–or maybe the funds–to pay the ticket, else I wouldn’t have been the wiser.

And then there was Rod. He’d been my PCA all during his senior year at a local university, then left to take a counseling job on campus. Months later he phoned to suggest that he accompany me to Bermuda, where I’d never been, for spring break; I was to pay half his expenses in exchange for on-site PCA services during the vacation. Shortly after we checked into our Bermuda hotel room, Rod ducked into the bathroom and emerged quite some time later wearing nothing but a big smile and an erection of porn-star proportions! This was day one of a week-long stay, so I had to think quickly. I looked up from the postcards I was writing, pushed my glasses up my nose, cleared my throat, and said, “Rod?”

“Yes,” he grinned.

“How do you spell Albuquerque?”

*Raymond E. Glazier, Ph.D. is a longtime MassHealth PCA consumer who has studied PCA issues for decades. Before retiring, he directed* the Center for the Advancement of Rehabilitation and Disability Services for Abt Associates, Inc., in Cambridge, Mass. Ray has published extensively on vocational rehabilitation and personal assistance services and *is currently founder and Principal of disAbility Research Associates in Belmont, MA.*

**The Seasons of the Year**

**By Penelope Ann Shaw**

I live in Massachusetts near the center of town where I live. I like to go to out into my neighborhood to visit the public library, the Town Hall Plaza, to shop and to eat lunch in a restaurant with friends.  As an individual who uses an electric wheelchair to travel about, the seasons of the year have a profound impact on the livability of the life I can lead in my community.

**Winter**

In winter months it can be freezing cold for me, especially since I am directly exposed to the elements in an electric wheelchair. There can also be snow and/or ice on the sidewalks. When snow and ice cover sidewalks I am unable to get where I'd like to go. Last winter I was stuck inside for several weeks as the sidewalks in my neighborhood were impassable. One year there was so much snow a neighbor-friend came over and used her wheelchair with a plow attachment to clear a path on the sidewalk so I could drive to where I was going. If sidewalks are blocked, I drive in the street with vehicles, making sure to hug the curb to be safe. Cold weather also draws more power from my batteries decreasing the range I can travel in my chair.

Going to the local library in winter I often must stop at a pharmacy to warm up and then continue my journey. I must be dressed for the season with layers of a sweater, winter jacket, hood, arm warmers and gloves. I wear heavy winter socks and place a blanket over my legs. When the weather is frigid with a strong wind, it is particularly chilling so, I often stay indoors and entertain myself by reading books, working on my writing, and talking to people. I remind myself that winter will not last forever and spring will follow.

**Spring**

Spring is the season of renewal. There are new leaves on the trees. Lawns are greener. I hear birds singing. There is more sun shining brightly. Bulbs become flowers. I especially like seeing lilacs and daisies. People spend more time outdoors. As I drive around, I see people out on their porches, often with flowerpots. In their backyards summer furniture is often already there. Wheelbarrows and gardening tools too.

I no longer need to dress in layers of winter clothes. My electric wheelchair has more driving range. I am not trapped inside the facility where I live because of a snowfall or subfreezing temperature. When it's warmer outside I can stop on the sidewalk and listen to the birds sing or look at squirrels. I occasionally stop and talk to people. Spring makes me optimistic. Summer is on the horizon and will soon come. Then, I will then be able to fully enjoy the out-of-doors.

**Summer**

Summer is my favorite season. I get dressed in comfortable lightweight clothes such as short sleeve t-shirts with lightweight cotton Capris. The temperature is warm so I can spend all day outdoors if I choose to. Instead of the heavy blanket I put on my legs in winter, I use a small towel to keep my legs warm and the backpack from sliding off my lap.

On Saturdays, if it isn’t raining, I go to our local farmers market, which is a real treat. Fresh fruit and vegetables. Strawberries picked at 5 am and available for sale at 10 am. As the season continues, tomatoes and corn on the cob arrive. The market also has vendors who sell homemade cheese, bread, and Middle Eastern food like Baklava.

Other reasons I like summer are, when it’s really hot, I can sit on a sidewalk in the shade of a tree and ponder life. If I run into someone I know we can stop and chat without getting cold. I especially like being able to watch our annual 4th of July parade from a sidewalk where floats and musicians pass by. My wheelchair is my seat. I don't have to bring a folding chair like some others do. When eating at a restaurant with friends, we can choose places that have outdoor seating with awnings that protect us from getting sunburned.

My town opens onto a conservation area with a pond. There is a boat launch for canoes and kayaks. No swimming which I could not do anyway because I'm paralyzed. There are hiking trails and a picnic area. I enjoy going there just to look and enjoy.

**Fall**

When I think of fall, I think with sadness of the end of summer. Fall is a time of change. The transition from bright summer days toward dark winter. It is harvesting time. Apples and apple cider are at the farmers market, and I know the outdoor market season will soon come to end. Fall also reminds me of when I was young as it meant a return to school after months of summer activities like going to overnight camp, swimming, canoeing, and sleeping outdoors at night.

The days are shorter in fall. Less daylight. The leaves on the trees do turn beautiful rich colors of yellow, orange, and red, each like a flower, before turning brown and falling off the trees. Nature begins its hibernation. The weather gets colder and there is more wind. It takes my aides more time to dress me because I am once again wearing layers of clothes. I think nostalgically of summer and the coming of winter with cold weather when I will need to plan indoor activities to keep myself occupied.

As a person with a physical disability each season affects me in different ways. These seasons determine not only when I can get outside in my wheelchair and what to wear to be comfortable, but also how long I can be outside and what I can do. Being disabled late in life at age 58, I am now more impacted by seasons than before when I could just get in my car and go wherever and whenever I wanted.

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**LOVE & INTIMACY CORNER**

**Goldie-Love, Three Realtors, and Disability Inclusion**

(With Thanks To Goldilocks and the Three Bears)

**By Ms. Love**

**Chapter One:** Once upon a time, Goldie-Love, a lovely young girl and a loving daughter, overheard her parents talking late one night when Goldie-Love got up from her bed during the night to get a glass of water.

“We need a larger home,” said her dad.

“We've been looking, Howard,” said her mom. “There is just nothing available that meets our family needs right now.”

“Right now? It's no longer an issue of 'right now,' Rosamond. We have been looking since Goldie-Love was born, and she will be turning six years old soon.”

“Now Howard, let's not stress ourselves more than we already are. Spring is here and many people will be moving out of their home. Surely, we will find an accessible home soon.”

Goldie-Love got so upset overhearing her parents talking in the kitchen, that she decided not to continue going to the kitchen for a glass of water. Instead, she went back to bed and quickly fell asleep because she knew what she would have to do in the morning.

**Chapter Two:** Before the first light of day, Goldie-Love removed what her mother called her “magical pajamas” that had dancing baby bears on them, and put on a wool sweater, a warm hat, and warm mittens. Then, she quietly put on her leg braces, got in her wheelchair decorated with pink stickers, rolled down the ramp, and out of the apartment building where they were renting a unit before her parents stirred.

She couldn't recall being up so early and outside on her own before, but she had a mission: she was going to find her family a new apartment, one that had true wheelchair accessibility. It would be more affordable, too, because she brought the allowance money she had saved to give to the new landlord.

At the end of the block was a big intersection. Goldie-Love forgot that she would have to cross streets. She was not allowed to cross streets on her own and it was too early for the school crossing guard to help her cross. Fortunately, a man delivering daily newspapers on a rickety bicycle was heading her way.

“Hi, little girl. What are you doing up so early in the morning?”

“Hi. My name is Goldie-Love and I am out looking for a new apartment for my family.”

“My name is Benjamin; you can call me Ben. I deliver newspapers and work at every job I can because I too need to get housing.”

“Do you have a disability, too?”

“I have a mental health issue. Do you know what that means?”

“No.”

“Well, in my case, it means I am often very sad and there are many types of jobs that I am not able to do. And *that* means it is hard to pay for housing.”

“Where do you live?”

“I live on the street; I am unhoused so I don’t have a home.”

“Do you want to live with me and my parents?”

“Where do you live now?” Goldie-Love pointed to the apartment building where her family lived. Ben asked, “Is the landlord evicting you?”

“What does that mean?”

“Maybe I should just ask why you have to find another apartment.”

“My wheelchair doesn't fit in our bathroom, and my mom can't lift me anymore because of her own disabilities. Mom and Dad have something called a ‘dudget’ and they can't afford a lot of apartments.

“I think you mean budget, Goldie-Love, not dudget. A budget is how much money you can spend on things. Often, things cost too much for a family’s budget. Listen, I have two more buildings to deliver newspapers to then, if you like, I can help you look for a new apartment.”

“Oh, I would like that. Thank you so much. Are you allowed to cross streets?”

“Yes, I am. You can cross the streets with me.”

**Chapter Three:** Ben explained to Goldie-Love that a realtor, someone whose job it is to rent apartments, could help them. They stopped at Realtors R U*s*. It was a huge building with lots of phones ringing off the hook. Benjamin told the receptionist that he and Goldie-Love were looking for a reasonably priced, accessible apartment to rent. “Uh-huh,” muttered the receptionist, and she paged a realtor, Mr. Smooth.

Mr. Smooth took Goldie-Love and Ben to look at two different apartments. At the first one, the street didn’t have a curb-cut, so Goldie-Love would not be able to roll herself to school or any place else. Benjamin told the realtor this would not do.

Then, Mr. Smooth took them to look at another apartment on a different street. This building was as large as Realtors R Us, but Ben wouldn't let Goldie-Love roll herself in because he told her it looked scuzzy. Goldie-Love started to ask what “scuzzy” meant, but Mr. Smooth interrupted. “Hey, this is what I have for people like you.”

“What d'ya mean people like us?” Ben asked.

“You know, this kid in a wheelchair, and you, well, you look like you have your own issues.”

“Goldie-Love, we can find a better realtor AND a better apartment building. Let's leave this guy.”

**Chapter Four:** Ben and Goldie-Love found a second realtor at Realty, Realty, Realty, who immediately asked how much money they had to spend on rent. Goldie-Love took her piggy bank out of her backpack and handed it to the realtor. My dad works hard, and I can add my piggy bank money to pay for rent.”

This realtor also showed Goldie-Love and Ben two apartments. The first apartment had steps leading into the building. Ben reminded the realtor that wheelchairs can't walk up stairs. Ben said this in a matter-of-fact tone and was not rude like the realtor, who kept insisting that it was only a ‘few stairs’ and since all little kids like to climb, surely, Goldie-Love could give it a try. Ben emphatically said, “No!”

The second apartment was on a street that had a curb cut and a flat entrance so Goldie-Love could roll into the building. Goldie-Love looked up at Ben and smiled. No one had smiled at Ben in a long time; it felt good.

As soon as they entered the lobby, Goldie-Love started coughing, hard. Ben saw her trying to reach behind her wheelchair and get into her backpack. He offered to help retrieve what she was looking for and place it on her lap. Goldie-Love gratefully accepted his help. Ben pulled out her inhaler and Goldi-Love expertly took a puff. She explained to Ben that she has asthma. Ben sniffed the air, looked at the realtor and said, “We need a smoke-free building.”

“This building has a no smoking policy but, it can be hard to enforce.”

“Not if the landlord doesn’t tolerate smoking,” said Ben. “Goldie-Love needs a smoke-free building.”

“Hold on there, Cowboy, let's look at the apartment itself.”

Ben looked at Goldie-Love who had stopped coughing when the smokers in the lobby left the building. Goldie-Love nodded her head, so Ben told the realtor that since they were already there, yes, they would like to see the unit.

While they went up the elevator, the realtor told Ben and Goldie-Love they would like this apartment; it was at the top of the building and would be very, very quiet. Except it wasn't on the top floor, and the family above the unit was very, very noisy. It sounded like a herd of buffalo was running over them. Goldi-Love was scared.

“That must just be the kids,” said the realtor. Then, adult footsteps were heard, and the adult dropped something heavy overhead that vibrated not only the apartment in which they were standing, but also Goldie-Love, Ben, and the realtor.

Ben and Goldie-Love looked at each other and simultaneously shook their heads no at the realtor. They would not be looking at the rest of the apartment or renting it.

**Chapter Five:** When they were back on the street, Ben apologized to Goldie-Love. “I guess I have a cloud over my head that is a jinx. By being with me, I am jinxing your hunt for an accessible apartment. I'm sorry.”

Goldie-Love reached out from her wheelchair to hold Ben's hand and smiled at him again. “I don't think you're jinxing anything. I wouldn't have gotten to see any apartments if you hadn't helped me. Thank you!”

And with those words, Ben felt re-invigorated. He told Goldie-Love he would have to leave in about an hour because he had a job flipping hamburgers at a nearby sandwich shop, but they still had time to approach one more realtor.

Realty company number three was a small business located in a small building. The only person inside was the realtor. She smiled as they approached, spoke directly to Goldi-Love, and came around from behind her desk to be closer to them.

“Oh, oh,” said Goldie-Love, all excited. “You use a wheelchair, too!”

“Yes, I do,” said the realtor who introduced herself as Melody. She asked Goldie-Love about the stickers on her wheelchair.

“My favorite color is pink,” explained Goldie-Love. My mom got me pink stickers and helped me decorate my whole wheelchair. Goldie-Love saw the realtors’ wheelchair was also decorated and asked, “Did your mom help you decorate your wheelchair too?”

“No, I decorated it myself. I bought fake pearls at a sewing store and glued them to my wheelchair. They bring sparkle to my day.”

“It is very pretty,” said Goldie-Love.

“Thank you,” said Melody. “What can I help you with today, Goldie-Love?”

“We are looking for an accessible apartment, so my parents don't have to be stressed about how my wheelchair fits – or doesn't fit – in our home.”

“I think I can help you with that. Are the two of you narrowing down the options, and then your parents will join us?”

Ben explained to Melody that Goldie-Love had set out on her own that morning. Her parents didn’t know she left. He was trying to help her but, unfortunately, finding accessible housing isn't easy at all.

“Yes, indeed,” said Melody, but the good news is, Ben and Goldie-Love had come to the right realtor. Melody had disabilities and worked with people to find the kind of housing that meets their needs. Melody suggested that Goldie-Love use her office phone to call her parents and invite them to come in at their convenience, so all four of them can talk about what they need and want for housing.

**Chapter Six:** In the days that followed, Goldie-Love's parents, Rosamond and Howard, met Ben. The three of them told Goldie-Love it was great that she had met a kindly man like Ben when she went on her mission to find housing for the family. However, for her own safety and everyone’s peace of mind, in the future Goldi-Love should always let her parents know before she leaves the house; they had been worried about her. They also had a conversation with Goldie-Love about being aware of strangers and reminded her about the precautions she and her classmates need to consider when they start going out of their homes on their own.

Rosamond and Howard invited Ben over for many home-cooked meals and they got to know each other. They discussed what Goldie-Love's family needed in housing and what Ben needed. Ben disclosed to them that he was a veteran and had PTSD from his service in the Army.

Melody showed Goldie-Love's family and Ben a few options for housing. Some had the accessibility that Goldie-Love and her mother needed; other units had a landlord who said they could make reasonable accommodations. One option involved renting a house instead of an apartment. However, the day after seeing the house, the owner changed his mind about renting it and decided to sell it instead. The owner asked if Goldie-Love’s family were interested in buying the house. Melody guided Rosamond and Howard on how to buy a house and what to consider, including explaining how to make the home accessible with town and other grants they may be eligible for. The house came with an accessory dwelling unit in the yard that the current owner's parents had lived in for a short while. Goldie-Love's family asked Ben if he wanted to live in this unit so they would be an integral part of each other’s lives. Ben enthusiastically agreed and they all lived happily ever after.

***The End***

**Epilogue:** Once upon a time, a little girl dreamed of better and accessible housing. Never underestimate the power of children, of helpful strangers, and of dreams. Most especially, never underestimate that you, as a person with disabilities, deserve decent housing that fits you “just right.”

Dear readers, I hope you like my inclusive fairytale. People with disabilities *can* make fairytales come true.  If your Ms. Love could wish you anything, it would be to wish that you bring passion to all you do – advocacy, love, and everything else.

The Love and Intimacy Corner welcomes questions from readers. Ms. Love will continue to read your emails and respond individually, so please send comments and questions to Ms. Love at DI.LoveandIntimacy@gmail.com.

Big reveal to longtime readers, Sandy Novack has been the author behind the Love and Intimacy column for the past ten years, writing under her pen name, Ms. Love.

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