DisABILITY Issues

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

Vol. XX ~ No. 3 ~ Spring 2013

TABLE OF CONTENTS

From the Editor ~ Marianne Gilliam
The PCA Corner: Rolling Back the Curtain - Life Before the PCA Program | Ray Glazier
Challenges | Confronted Getting My Rights Under the ADA | Penelope Ann Shaw
A Woman of Valor: Arlene Germain | Sandy Alissa Novack
Colleague | Confronted Getting My Rights Under the ADA | Penelope Ann Shaw
Ask Dr. Bob: Exercise is Safe | Robert Verdecchia
Laws & Embargo Where You Live Could Disability Clarity, Go for Grandeurness | Ms. Leni
Disability Education & Disability Liberation | Mary Grimley
Resources
Ready & Able: New Speaking Podcast Gives a Platform to Disability Community
Information Bonus
• Annual Adaptive Recreational Fair

From the Editor...

Dear Readers,

In this issue, there are multiple articles about disability advocacy from various perspectives. In the letter from the editor, I'll be to talk about the ADA and the ongoing efforts to make the anniversary spectacular during a whole month celebration with another. Advocacy is was excited to attend an open house for a new colocasing facility that will be opening in our community. Also, I'll be talking about a conference I attended with a "colleague" from Cerebral Palsy of Greater Kansas City and my family. I replied, "This is a wheelchair user, not wheelchair bound." I'm sure I'm not the first person with a disability who has had to correct my friend. Language is important. Today The Interrupter shares a letter she wrote.

My partners with disabilities, we often find ourselves educating those who are temporarily able-bodied, which is beneficial – up to a point. Sometimes, I'm tired of being the teacher. I want to be able to be a student in a safe environment with education, rather than expecting those with disabilities to be their educators. An abundance of misinformation is out there. Sometimes, it's difficult to find the correct language and address. In the Green Mile Series, I am involved with local organizations who are committed to advancing equity and inclusion for people with disabilities. Sometimes, I feel compelled to represent a disability community. Other times, I feel guilty, as educator, I am starting to point people to educational disability resources.

A long time member of one local organization recently asked me to write a disability-focused piece for their column because she said, "I don't know what to write about disability issues and I don't know the language in discussing disabilities." Apologetic, I couldn't help but think that after all these years, there is still reticence in having conversations about disability issues. Perhaps, I should be grateful. I am! I am for some disability conversations and asked her to write a first draft because, "as a non-disabled person, writing this piece is a learning experience for me." I'm hoping she will include accurate language and current disability-related "Lingo." Offered to review what she wrote and provide comments. My intention is to support her learning and to provide a conscious reminder of continuously being mindful on the expert situation.

I'm sure each of us have our favorite disability education resources. Here are two of mine: Nancy Mitchell's Disability Etiquette Series, Leslie, disability rights advocate, speaker, and writer. And an article by Stephen Hawking's daughter, Lucy Hawking, "Disability Etiquette: Ask Leslie – In the Medium Rare Series" by Steve Tarzia, published in Nonprofit Quarterly.

Marianne Gilliam, Editor

Marianne Gilliam has been the editor of "Disability Issues" since 2011. She was born with Spina Bifida and has been a wheelchair user since childhood. Married with two adult children, her background in sales & marketing and disability inclusion training. In May 2009, she was appointed by Governor Mike Pence to serve on the Indiana Developmental Disabilities Council.

PCA CORNER

Rolling Back the Curtain: Life Before the PCA Program

By Ray Glazier

More than one reader of this column has expressed an interest in the life of a Personal Care Assistant (PCA) before the Medicaid Waiver of Disability Issues in the changing experience of acquiring mobile disabilities. Tomorrow's Challenges, A Disability Issue', published in the Spring 2013 edition of DisAbility Issues, I will be talking about my own PCA experiences. In particular, what life was like before the PCA Program was in place to support people with disabilities.

When I was ordinarily injured in an auto crash at 20, I was very fortunate to three important requisites: (1) I had already completed my Vocational Rehabilitation Training, (2) I had a PCA who was a great job with an exciting startup company, and (3) I was already married to a lovely, loving college classmate. But at the time there was not much in the way of assistance for people like me. Fortunately, there was no PCA Program, so Carolyn, my independent Living, my Brainchild, was able to be my PCA. Yes, I said my PCA. Carolyn was a cup of a consummate charge, thanks to the tireless efforts of Carolyn, I was able to be independent and live a fulfilling life.

When I returned to the office after seven months of hospitalization, my employer employed a Home Health Care hospital worker to provide the help I needed to function in the high pressure consulting firm. Years later, I discovered that the cost was $75.00 per day, which was a big dealing working hours, paying from the regular PCA Program having wage, and letting them hang out in the vacant office now is mine.

My primary day-to-day concern was my wife, which turned out to be a great mistake. She gave up and left me after three years of struggle. I was a very independent person, I was a very independent person managing a household more than a person with full time job, and (3) The empty benefiting in an apartment was an invaluable asset in maintaining my independence. Yes, I was married, I was married to a very caregiver and not to have to hide my disabilities and appreciated the extra feel housing that I was able to offer. As a single guy, I have always been independent and I wanted to remain that way.

My friends in the business community were very supportive and I learned people who responded to my messages and they were responsive to my needs. I was able to hire a young college student Brandon Bell AKA Jeeves, who was a very conscientious and caring care of me and the apartment in addition to their nightly performance of his duties. Brandon was a great cook, and I was able to hire another freshman and trade in Harry and Chris, a sophomore friend of a fellow guys' friend. But the helders couple and the guy couldn were not available on weekends, so I was left with a gap. I was in a situation desolved incredibly stressed, alone and everyone moved out. A huff, a young friend came to my rescue and served a stint as caregiver. Unfortunately, he was a Jehovah's Witness, so I was left with a gap on Saturday and Sunday mornings and afternoons.

Eventually I found Sam and Sally, a jammed underpaid couple with an elderly, jaggy little Yorkie who thought he chose into the two story single family home I bought using funds from the auto accident settlement. Sally was a Jehovah's Witness and was willing to provide my bathroom (office) two days (Saturday and Sunday). Sam, I married with their heavy crew schedule, and Sally complained that Sam was a workaholic and was not home to help with the chores on the nearby commute and Sally, having grown up in a tiny town blessed by the Pennsylvania Railroad, I were unparalleled by train service. Sally was a PCA, and I was her ticket out of the small town. Sally was a great cook, I was able to have an ongoing relationship with her and her family.

The next couple was a Russian School nude model and his girlfriend. He said he had just left Russian Bride, the University. I was sent to assume. It turned out that he had just been released from Bridgewater State Hospital, and I was his first employer in Massachusetts. Sam was doing 28 for rap as the PCA and I was disappointed at the time, so... They Married Clark statement came to the mail, and I sprained a battery of the Massachusetts Department of Mental Health. Clark was a great lead the other contributing factor, I was thoroughly disappointed in the successful of self-battered pottery!!! "It's very important in my line of work to have a full head of hair."

About this time I learned of the Massachusetts PCA Program and my Vocational Rehabilitation Counselor, Ms. Ann Marie Sullivan, informed me I was insured that I was ineligible because I was not eligible for Medicaid. The Commonwealth's Medicaid program for the impoverished. This seemed to be a Catch-22 situation, but I was able to find a Medicaid Waiver created to address the needs that exceptional health insurance programs refused to cover PCA services needed by many workers with disabilities who were not eligible for Medicaid. Ann Marie was professional life saving in my career as I became the resident expert on Medicaid Buy-Into within the Health Policy group of the consulting organization I worked for.

The Pennsylvania Department of Public Welfare reached out to the company and to me in particular, for consulting help. Some Pennsylvania Senators had heard about the Buy-In Program and wanted a PCA program that was modeled on the state's state funded Attendant Care Program. Such a pretty state and federally funded program, the Pennsylvania Department of Public Welfare was looking for a PCA Program that would be cost effective. They had little hope that potential client was that these social consumers and their lawyers would be willing to accept a PCA Program. I was hired to help them with effort to design and implement the Pennsylvania Medicaid Waiver Attendant Care Program.

Day and other disability oriented research projects over the years required travel around the country. Sometimes I flew solo, making arrangements for my PCA to fly with me. Other times, I had my PCA drive when I got off the plane. Other times my home PCA or a close staff members from the company travelled with me in exchange for a daily cash honorarium.

I hope this summary of my PCA experiences sheds some light on how life was before the PCA Program. Independent living was and is well being for people with disability. Advocacy to maintain and enhance the program is essential. Let us all ask our lawyer and our legislators what we can do to help. Let us all ask our Congressional representatives what they can do to help.

To read more about Jury Nullerism, Disability Issues published a review of the movie, Nullification: An Unreasonable Defense of a Disability Activist in the Spring 2011 issue.

We Have a Right to be Safe

By Shirley Pacelay

We cannot solve a problem that we are not brave enough to talk about. The problem is this: People with disabilities experience sexual violence more often than people without disabilities 3 to 7 times more depending on the disability.

What is sexual violence?

Most people think that sexual violence is rape, but it is much more than rape. Sexual violence is any sexual contact or behavior that another person through coercion or force makes someone do against their will. Sexual violence is rape includes the forcing someone to listen to sexual comments, to look at sexual pictures or movies, to touch parts of different ways. Sexual violence includes forced or verbal threats and manipulation.

What can I do if I am a survivor?

If you are a person who has experienced sexual violence, please know that it is not your fault. It is not your fault. It is not your fault. Having difficulties because of this trauma, there is help available. Take the resources at the end of this article.

People with disabilities can be hard and part of the solution!

People with disabilities are smart and capable and strong! We are the experts in our own lives. We know what we need and we can access victim services. People with disabilities are leaders in the movement to end sexual violence against people with disabilities. We are a force of the movement to make the world a better place.

- Work on policies and procedures in disability agencies.
- Work on Sexual Violence Prevention.
- Speak at conferences about sexual violence.
- Make videos to train parents and staff and victim services.
- Speak on panels at Sexual Violence Prevention Trainings.
- Speak at "Take Back the Night" Events.
- Work in Volunteer at Rape Crisis Centers.
- Work in Victim Services Programs.
- Speak at Rape Crisis Centers.
- Speak at Victim Services Programs.
- Help a friend, who is being bullied, threatened, or touched.
- Tell your friend that it is not their fault.
- Tell your friend that it is not their fault.

I wonder, what you might want to do to help end sexual violence against people with disabilities?

Where you get help if you or a loved one is being (or has been) sexually assaulted:

Rape Crisis Centers offer free and confidential help. You can get their phone number from the Rape Crisis Center in your area. Rape Crisis Centers are victim services that are discussed above in continued. It is easy to see on line.

The DMHS (Pope House Inland Northwest network) is a National Sexual Assault Hotline that is confidential and available 24/7. Call **800-656-HOPE (4673)** to be connected with a trained staff member from a local rape crisis center nearest your location.

- Listing of sexual assault victim information for **Rape Crisis Centers in Massachusetts**

Survivor, Advocate and She is past-President and Board member of the Burn Survivors of New England, Dave Estrada JD, United Spinal Association as a peer mentor, board member, and former executive director of its Greater Boston chapter and a program manager at the Spaulding New England Regional Spinal Cord Injury Model System and the Exercise for Persons with Disabilities Program, and Juan Hererra-Escobar MD, MPH, Research Director in Long Term Outcomes in Trauma at Brigham & Women's Center for Surgery and Public Health.

In **episode 3**, Joseph Giacino PhD, Director Spaulding Rehabilitation Neuropsychology Service, Disorders of Consciousness Program, Nicole Godaire, CEO, Brain Injury Association of Massachusetts and Tracey Macarty, mother of TBI survivor, discuss clinician's ability to predict outcomes after moderate to severe brain injury. For the May 1st episode, Alan Jette, PT, PhD, MPH, FAPTA Professor Emeritus, Boston University, MGH Institute of Health Professions and Sarah Skeels, BS, MPH, Tufts University, were invited to discuss the development and use of a tool that measures function after spinal cord injury: the Spinal Cord Injury Functional Index / Assistive Technology (SCI-FI/AT).

To listen and subscribe to stay connected to the groundbreaking work coming out of Spaulding's research labs, available on Spotify, Apple Podcasts, Google Podcasts and iHeart! New episodes are released the first Monday of each month. The production is a collaboration amongst Spaulding's three Model System programs and the Rehabilitation Outcomes Center at Spaulding.

Follow us on **Spotify** **Apple Podcasts** **Google Podcasts** **iHeart**

Learn more
at **https://spauldingrehab.org/research/about/podcast**

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

INFO BRIEFS • INFO BRIEFS • INFO BRIEFS

Annual Adaptive Recreational Fair

The Massachusetts Department of Conservation and Recreation's Universal Access Program is hosting our Accessible Recreation Fair,
Saturday June 10th • 10am–3pm
Herter Park/Artesani Playground in Brighton.

Join us rain or shine for a free, fun-filled day celebrating accessible outdoor recreation in Massachusetts state parks! **Pre-registration is highly recommended, especially for use of equipment.** You can pre-register online, or by calling Universal Access at (857) 319-2168. Please pre-register to request an ASL interpreter or other accommodations. In case of severe weather, call (857) 319-2168 for a recording of the fair's status.

Family-friendly, accessible, and inclusive activities include cycling with an assortment of adaptive cycles, hiking and letterboxing with all-terrain wheelchairs and walkers, face painting, kite decorating, sidewalk chalking, golf and other equipment demonstrations, adaptive birding and fishing booths, bubble blowing and games, music, and more. Smokey Bear will be visiting the fair, too!

Come meet an array of regional adaptive recreation organizations and learn about accessible, adaptive, and inclusive recreation opportunities in the greater Boston area and beyond. Learn about adaptive equipment like hiking wheelchairs, beach wheelchairs, and adaptive bikes and trikes. Find out about upcoming adaptive summer programs like swimming, fishing, horseback riding, kayaking, exercise classes, nature activities, and hikes!

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

Editor: Marianne DiBlasi

Editorial Board:
Marybeth Barker • Joan Burrows • Raymond E. Glazier
Mary Grimley Mason • Sandy Alissa Novack

Contributing Writers:
Raymond E. Glazier • Mary Grimley Mason • Sandy Alissa Novack
Shirley Paceley • Penelope Ann Shaw • Tim Sullivan

Advisory Members:
Bill Henning • Ruth Kahn • Oswald Mondejar
J. Archer O'Reilly III

Graphic Design:
Louise Martling, Eleventh Hour Design
www.11th-hour-design.com

Mass General Brigham Liaison:
Colleen Moran

Mass General Brigham

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 **massgeneralbrigham.org**

The ***Disability Issues*** newsletter is a free and independent publication. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

To Subscribe: The ***Disability Issues*** newsletter is available without charge to anyone who finds it useful and interesting. To subscribe, visit Disability Visibility and enter your information in the Subscribe to Disability Issues form.

Share Tweet Forward

Copyright © 2023 Disability Issues. All rights reserved.
Feel free to reprint articles. When doing so, please credit Disability Issues (Vol., No. and Date).
For articles that appear under a byline or that will be altered in any way, please obtain permission from the editor. Any inclusion or exclusion of a particular entity, product or service in this newsletter does not constitute endorsement or opposition.

Our mailing address is:
Disability Issues C/O Public Affairs
Spaulding Rehabilitation Network
300 First Avenue
Charlestown, Massachusetts 02129

Want to change how you receive these emails?
You can update your preferences or unsubscribe from this list.

www.disabilityvisibility.com/resources/disability-issues