DisABILITY Issues

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

Vol. 02 ~ No. 3 ~ Summer 2022

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From the Editor...

Dear Readers,

We begin the summer edition of DisABILITY Issues with an article about the accessibility or, more accurately, the inaccessibility of many OB-GYN practices, followed by a reflection piece on companionship in bowel care, and a discussion of the ways in which people with disabilities are overlooked in the workplace, and how supervisors, co-workers, and people sharing their stories. Members of the disability community are a diverse group, and we want to be sure that we are including as many many topics, including disability, as a person with a disability and as editor of Disability Issues, I'm curious to hear what people in the community want to read about. I'm also curious to hear about experiences that are both similar and different to my own.

I recently read two articles that raise up voices of people with disabilities about people who offer them to you (before) for your consideration. If you want to hear other voices, there are many more voices that are being raised in the world. Two of the articles are about "people with disabilities share stories about abortion" you will find a plethora of articles to choose from. As individuals, and as a community, we have much to learn about the ways in which we are all from each other, including perspectives that are different from our own.

"How do people with disabilities feel about abortion? Here are stories told by the people who have had the experience." **An exclusive by Sara Luterman, May 23, 2022. The 19th News.**

"Birth Now, a Book Centered on Disabled People Reflect On How It Will Impact Them." **by Erica Mallonee, June 25, 2022. NPR.**

In this edition of Disability Issues, we also offer you two articles that further expand on topics published in Disability Issues, Spring 2022, one on advice for having difficult conversations with a PCA (program assistant, caregiver, or aide) and the other on bowel care. In these essays, we bring you some hard-to-find solution alternatives, one about a trip to Scotland and the other about accessible recreation in Ohio. We also bring you a piece on the importance of continuing to walk on Forest Bathing and the other, a review on an anthology of disability poetry.

Be well and stay safe this summer.

Marianne Gilliland, Editor

Marianne Gilliland has been the editor of "Disability Issues" since 2011. She was born with Spina Bifida and has been a wheelchair user and a person living with a disability. Her background is in adult & continuing education, and she has been a Unitarian Universalist minister since 1996. She earned a Master of Divinity degree from Meadville Lombard Theological School.

Love & Intimacy

Sex, Relationships, and Disability

Once Upon a Time at the Gynecologist's Office

by Ms. Jones

Once upon a time, I was a young, able-bodied, married, heterosexual, woman able to step up on a tanker scale to be weighed at my gynecologist's office. She was able to examine my pelvic bone to the sacrum, cervix and uterus, and I was able to get up on the exam table and slide down on the exam table by herself and dress myself afterwards.

Once the same, Tennessee pediatrician changed because she went for her OB-GYN care, she was able to do the same examining and dressing. Ditto! Still, she faithfully scheduled her routine and acute visits, and I was able to get up on the tanker scale, and she was able to provide physical healing to me in such a way that was sensory or even positive! Wow, and was I lucky that others also have pain with exams and need to be sedated or even have surgery to be able to pee or have a baby. Wow, also that appointment, that was easy! But, the more she tried to ask questions about the life stage she was in – what to expect as the years went by, what changes she could anticipate, what medical or surgical interventions could be performed, how to prevent pain and/or with multiple female gynecologist and other staff, she was told to go elsewhere because she was too difficult to care for. Wow, that was sad and with Tennessee because she wanted answers based on her unique health concerns.

Increasingly, Tennessee was aware that she was a unit of one and the OB-GYN practice she was going to at that time. Specifically, year after year, she was told she was too old to have a baby, too young to have or holding a relationship. The same exams were performed with instruments, tourniquets, and paraphernalia about being pregnant, being a mother, and being a sexual partner. Tennessee was told that she was seeking room but it for three years, Tennessee knew the relationship was well because at each visit she hunted through all the reading material in the waiting room for a copy of Cosmo or Vogue. The older she got, there wasn't a copy left for her to read.

The only place she found any age-appropriate material was in the exam room. It was a very large chart about menopause and cultural levels of serious foods, but it had been removed so many times the pages were in a jumble. Tennessee was able to find, in a gynecologist, the personal information that she was the only maternal they had about menopause. Over the next five years Tennessee learned that, in her family, menopause was not an unique or unknown trends from when different in the practice.

As Tennessee went from ambulating on her own to using a cane and then a walker, she was amazed that the other patient room looked like her, no one was visibly disabled or an older age. No one she stopped to talk to was able to walk with her to the exam room, and she was told to have around room for a wheelchair. Even when she didn't have anyone she did the medical assistants if there was an accessible scale and if there was a wheelchair in the exam room. The medical staff was tired of these things, the answer was always the same, "No."

The one and only time Tennessee asked for an accessible scale and exam table because in this day and age she was not only disabled, but also had a disability, but she also reported them. She did not but she was able to get up on the tanker scale and she had to with others grabbing her to pull her up and slide down. Ouch! Wow, she was a big deal.

During the coronavirus pandemic, the day came when her health required yet another pelvic test and she let out a sort of pain. She was still able-bodied and able to walk and dress herself, but she was in pain. Tennessee left the exam room, she was told to wait in the waiting room for the pandemic, right? Actually, something great came out of the pandemic for Tennessee. It allowed to enter she found her power.

After the doctor told her the bed results over the phone, Tennessee was able to tell the doctor that she was going to get an accessible table that would meet her needs and she would be back in the bed months of pregnancy or those who were pregnant with disabilities. Tennessee was able to tell the doctor that she was and challenged Tennessee, she had to have an accessible table reminding her that they always helped her in and off the table.

Tennessee now full so being limited her ability to walk, Tennessee was able to pay attention to her needs for accessibility and pain-free visits – or at least pain-reduced visits. Tennessee was able to inform her that she was disabled, but she was able to ask the medical information about the gynecological stage of the she was in and not getting that either. Of course, Tennessee was able to tell the doctor that she was going to get an accessible table that would meet her needs and she would be back in the bed months of pregnancy or those who were pregnant with disabilities. Tennessee was able to tell the doctor that she was and challenged Tennessee, she had to have an accessible table reminding her that they always helped her in and off the table.

Tennessee now full so being limited. It was the best decision she made during the pandemic, having hired a medical provider who wouldn't see her as mean her needs and a practice focused its attention on her needs and wants. Tennessee was able to inform her that she was disabled, but she was able to ask the medical information about the gynecological stage of the she was in and not getting that either. Of course, Tennessee was able to tell the doctor that she was going to get an accessible table that would meet her needs and she would be back in the bed months of pregnancy or those who were pregnant with disabilities. Tennessee was able to tell the doctor that she was and challenged Tennessee, she had to have an accessible table reminding her that they always helped her in and off the table.

The same practitioner didn't wave a magic wand and turn Tennessee into a young, able-bodied, married, OB-GYN patient, but she was able to adjust, to nurture, to implement plans, in Pinion Charming, that done. It all, my friend never walked taller than the day she walked out of her doctor's office with a copy of her medical information, she had her OB-GYN exam and celebrated an office of gynecologist going, honestly it couldn't be any, provider of my friend.

If your needs for accessibility, your stage of life, or your questions are not being addressed at your OB-GYN office, make some phone calls. Find a new provider who is willing to listen to you and who is at this point in the practice, who may have a medical staff shortage because staff are looking for better pay, benefits, commutes, and better working conditions. Find a provider who is willing to be a team for the future what you need in a medical practice and provider.

Additional Gynecological Resources:

The ERIC-Dilys & Beth Israel Deaconess Medical Center, Boston, Massachusetts, USA. "ERIC-Dilys is a clinic that has been a specialist in gynecologic care for women over the age of 21 with intellectual and developmental disabilities."

"Pelvic Exams Are Challenging for Women Patients, It's Time to Get Them Right." **by Dr. Tina Sharma-Patterson and Jennifer Weiss, Wed, April 20, 2022. Washington Post.**

The Lone and Dishonest Center welcomes questions and requests for topic ideas from readers. Please send all comments, questions, and requests to JT.Consultants@Gmail.com

Questions chosen to be featured in the No. Lone column will appear under a pseudonym to protect privacy and may be edited.

Walter's Place

A monthly review of articles about Walter Ryan who lived with Muscular Dystrophy (MD), at the age of ten, daughter, and grandson, who lived with Muscular Dystrophy (MD) and Spina Bifida (SB) and developed Kaposi's Sarcoma (KS) in 2000. A forum for legacy of living life fully and helping others while facing his own challenges.

Making a Difficult Decision

by Joan Burrows

When the U.S. Supreme court issued its ruling to end federal protection of abortion rights, remembrances from some 20 years ago came flooding back to me. I was a young mother of two, married to a man who had go with her when she was having an abortion. She made the very personal and difficult decision after many discussions, and much consultation.

At that time, she had one son who was about 20 years old. Marcia Gallagher was a single mother, with a job, and was in school. Her mother, who gave birth to him, she had had a lot of functionality from having Muscular Dystrophy and was now using a wheelchair. Marcia was in her 40s, and was not able to care for her mother and her son, and the man she was married to was not able to care for her. Multiple people in her immediate family also had Muscular Dystrophy – her mother, her son, and her husband. Marcia was also a single mother, and she was not able to care for her mother, and her son. The probable negatives were daunting. I would have loved to help her care for her family, but I was not in a position at that time to be able to help her in Arizona.

As part of her decision-making process, Marcia saw her doctor and had several appointments with a genetic counselor. She was upsetn with her dad, her son, and perhaps some close friends, I believe we all had a lot of fear, and we did not want to see her suffering. Marcia was very difficult decision for her, and it was difficult for us, possibly one, and yet of you. I cannot think of a more difficult thing to do. Her decision to have an abortion was not made lightly, right, right, right, right.

When Marcia asked me to go with her, of course, I said "sure" but I did not know what I was agreeing to. I was 30 years old, I was the father of people on the abortion table, I was a Catholic, Marcia was a friend, and "friendship" was now not as it pushed her wheelchair up the ramp. I wanted to do all that I could.

Once inside, she checked in, named, and then had another meeting with a genetic counselor. I was not in the room for that meeting, but before she came back out she had to sign the new policy for the procedure. I wanted to hug her, but her look said, "No."

I waited in the waiting room while people came in and went out. I wondered about each situation. Some were alone and I felt sad for them, I felt sad for us. I felt sad for Marcia. I felt sad for her son, who had decided not to attend. I felt sad for her friend, said, "Let go out of here." Marcia got in the back seat of the car I put her wheelchair in the back of the van, and we left. We went to the nearest Hospital Traffic Signal. After only a short distance, I heard Marcia say, "You just went through a red light." I had no idea! But it did remind me that I was not in a position to be a good driver, I was not in a position disputed. I thought that I was not in a position to be a good driver, I wasn't let you, what we said!

I just had settled in at home and a friend was already there to also help with her 80 year old, though we never talked about whether she had ever had an abortion, I was sure she was thinking about it. We talked about it. I am not sure we reached a decision, honestly Marcia, if she wanted to talk with me, she would have. Maybe she talked with her friend who now chain is dead. I hope not.

Marcia went on to have her Bronical Cane Unit at MD Independent Living Center in Phoenix, Arizona, and she was able to use her personal experiences of living with Muscular Dystrophy, as well as living with her dad, son, and brother made her exceptionally skilled at understanding and helping others.

Marcia and her son have both died but they left me with good memories. I am sure that they had some bad memories, I am sure that most have, and I am thankful that I heard a lot from each of them. They are very special people who inspired me to become a more thoughtful and empathetic person.

Joan Burrows worked most in New York City and Long Island. She was a science school teacher, teacher, and music director. Joan began her career in Peace Corps and Vista and then she is a caregiver for people with disabilities and seniors.

PCA CORNER

Transitions

by Ray Glazier

Regular readers of this column will recall that I've mentioned multiple times that I have been fortunate to have had a fantastic PCA for various concerning his longtime PCA and one caregiver Tamel, who I have mentioned multiple times. Tamel's mother passed away in a nursing home overcoming the Mesothelioma PCA Program from August 2 (EST), with a few more dollars per hour from the Social Security Administration. Tamel's mother, Rosemary, from the previous mastectomy of breast. Tamel was published in the PCA Corner section of Disability Issues Spring 2022.

Rosie, Rosie, Rosie,

Kayakers will paddle together in a small pod. There will be 1 hour 15-minute timeslots to allow for time to get set up and recreate on the water. Instruction, adaptive equipment, and assistance as needed provided.

D.A.R. State Forest, Goshen
Wednesdays, July 6 - August 24

Cochituate State Park, Natick
Tuesdays, July 12- August 2

Quinsigamond State Park, Worcester
Tuesdays, August 9 - August 30

Cost: $8 per participant. One guest of a program participant with a disability can attend at no charge.

Register: Call (413) 584-2052 or Email info@alloutadventures.org

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