The Value of a Disabled Woman

KIM OWENS
Disclaimer

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EDITOR'S NOTE

Love is acceptance and in recognition of LGBTQ Pride Month our team at CAPTIVATING! felt this quote by renowned author, James Baldwin was appropriate:

"Somebody, your father or mine, should have told us that not many people have ever died of love. But multitudes have perished, and are perishing every hour--and in the oddest places!--for the lack of it."

Envisioning a world where all people of all abilities can embrace and empower one another begins with our team who understands and respects individuality. Our team is unique because of its makeup as we are a diverse group of individuals who share a common vision of creating a more inclusive world. Sadly, on June 5th we lost one of our own, Carla Anne Ernst. What made Carla an outstanding person was her light and positivity. She was a remarkable person who will be greatly missed.

As co-founders of CAPTIVATING! Chelsea and I are constantly amazed at the serendipitous nature of how we have evolved. From how she and I met, to envisioning a project neither of us knew how we’d accomplish, to the remarkable people placed in our path. People like our passionate team, captivating guests, and you, our readers and followers who motivate us. All of these things further reaffirm that we are on the right path which makes the announcement of an award from the Texas Rehabilitation Association so much more exciting! This was totally unexpected and so welcomed that we will share the details about it in the next section.

While there are fewer awareness days in June in this edition of CAPTIVATING! we are pleased to highlight a couple of lesser-known topics about clubfoot and one woman’s personal journey with PTSD.

- LGBTQ Pride Month
- 3rd - World Clubfoot Day
- 6th - Isacra Day
- 13th - International Albinism Awareness Day
- 17th-23rd Chromosome Disorder Awareness Week
- 18th Autistic Pride Day
- 27th PTSD Awareness Day

Love is the driving force behind CAPTIVATING! and connecting and enlightening people of all abilities is our mission.

As always we hope you enjoy this issue of CAPTIVATING! Magazine. We invite you to submit questions, articles, and ideas to editor@captivatingmagazine.com or through our website at www.captivatingmagazine.com

CAPTIVATING! "The power and possibilities of inclusion are limitless"
ANNOUNCEMENT
"I am writing to inform you that you have been chosen to receive a Texas Rehabilitation Association 2019 Award for your efforts in the representation of people with disabilities in journalism." –Texas Rehabilitation Association (TRA)

How exciting it is to be recognized for simply doing what you love and believe in? Before Chelsea and I had a project name, website or team we had an idea. The idea was to create a fully accessible collaborative publication platform but we weren’t sure where to begin. All we knew was we wanted to provide a space for people of all abilities to collaborate, create, and publish professional digital publications. Since neither of us have the technical know-how to develop what we envision, we began with what we could do—enter CAPTIVATING!

At the outset, Chelsea and I knew we wanted to change the perception of disabilities and the people who are living and thriving with them. We wanted to create opportunities beginning with an inclusive digital magazine that embraces disabilities with a focus on abilities. In addition, we also felt it was equally important to connect and enlighten people of all abilities. CAPTIVATING!’s inclusive digital magazine was the answer. It is for all—everyone.

We have team members as well as contributors who do not have disabilities but they share our passion for positive change. Several examples are Chelsea, the staff of the ALS Association of Texas, Stacy Flynn of Serenity Physical Therapy Education & Consulting, and John Ficca of Hands On Education.

Chelsea, me, and our team are passionate about bringing more understanding, compassion, and inclusion to our communities, it’s who we are. Being honored with a TRA 2019 Award for our efforts in the representation of people with disabilities in journalism is HUGE!

The 2019 TRA Annual Conference “Navigating the Rivers of Change” will be held in San Antonio, Texas from July 17-19. All honorees will be recognized at a luncheon on Thursday, July 18 at the Drury Plaza Hotel.

As President of the Houston Area Rehabilitation Association, Chelsea wouldn’t accept the award unless I was included as CAPTIVATING! co-founder. And
guess what? The TRA agreed and are recognizing me as well, how cool is that?

Receiving an award for what we do to better the lives of people of all abilities is such an honor and we are truly grateful and humbled by it. We couldn’t do any of this without our phenomenal team who shares our passion. All of us believe, inclusion is everything.

For the past seven months everyone at CAPTIVATING! has spent many volunteer hours working to promote the abilities of the disabled community. Because we strongly believe in the value of people with disabilities, we provide our time, talents, and content free of charge. We do this for the betterment of all people and to get our message out to the world.

While this section is typically the question and answer portion for Chelsea and I, we need to turn the tables. We have a question for you...

Will you help us to attend the 2019 TRA Annual Conference in-person to collect our magazine’s first award on behalf of our team?

We are requesting sponsorships through a Go Fund Me called “CAPTIVATING! Inclusive Magazine Wins Award.” Our goal of $1,500 will help pay for our registration, travel, hotel, and parking.

Being able to represent our whole team by giving a speech and sharing in-person the importance of our mission will help us strengthen and grow the magazine. Acquiring valuable resources at the conference as well as networking with other rehabilitation professionals will help us to advance our mission. The timing couldn’t be better as we begin to enter the second half of our first year of publication.

When we began this project, we believed we could change the world by connecting and enlightening people of all abilities. With this award, it has proven to us that we are making a positive difference and important impact. So, if you have been looking for an opportunity to become part of something bigger than yourself, we would love for you to become part of team #WeRCaptivating.

Our big question and our big ask for this month is will you please help support our mission with a generous donation? You may do so at our GoFundMe account at http://bit.ly/CAPTIVATING If you are unable to make a financial contribution, please share this link and this month’s issue on your social media platforms. Share far and wide with friends, family, and people in your lives that can benefit from our content.

As always, we appreciate you reading our magazine and hope that we have added value to your lives through our stories.

We wanted to create opportunities beginning with an inclusive digital magazine that embraces disabilities with a focus on abilities. In addition, we also felt it was equally important to connect and enlighten people of all abilities. CAPTIVATING!’s inclusive digital magazine was the answer. It is for all—everyone.
The Value of a Disabled Woman

“What do you do for a living?” she asked just as the rock band’s drummer, Kai, began counting off “...one, two, three, four!” Thankfully the music was so loud that I didn’t feel pressured to answer immediately as we tuned-in to the music and devoured our pizza.

By Kim Owens

Since moving to a small town I have rarely been asked this “big city” question. “Where do you go to church?” and “Who’s your kin?” seem to be our town’s version of “What do you do for a living?”

In my late 20’s I could easily and proudly respond, “I’m a global marketing director in the internet industry.” In my mid-30’s, with 2 young boys, I loved to tell the story of how I chose a kinder, gentler path and had become a Neuromuscular Therapist who owned my own massage studio.

The week that I turned 40 the answers became more complex and murky. I awoke to find that it hurt to bend my fingers. I thought maybe I was working too much so I cut back a bit. A short time later I began to have trouble swallowing and was hit with unbearable fatigue and shortness of breath. My legs felt like lead weights and my previously strong “massage therapist” arms were so weak that it became difficult to drive. My family doctor was puzzled and after running some tests found systemic scleroderma antibodies – an indicator of rare disease with no known cure.

I was so sick that I had to hire someone to take over my practice, then as time passed and the illness lingered, I closed my business completely. I tried working part-time for my church but eventually, even that was too much. I called it quits when after getting ready, and driving to work, I found myself sitting in the car sobbing – too sick to go in and too exhausted to drive home.

We’ve learned so much, grown so much, and overcome so much adversity – but, what do I actually do for a living?
cope with all the changes in our lives.

I’m 50 now, and about 4 years ago I found a great doctor who is a good listener, compassionate and smart. He’s currently treating me for morphea (a localized form of scleroderma), undifferentiated connective tissue disease, and psoriatic arthritis. He’s changed my treatment plan several times in order to stay on top of progression and he’s improved my quality of life immensely.

Kai is 16 and legally blind with about 5 degrees of vision. He’s a junior in a mainstream public high school taking honors and AP courses with Braille materials. Kai is earning straight A’s, drumming in 3 rock bands and has a wonderful group of friends. He walks with a mobility cane and is in the process of getting a guide dog. He’s become a strong advocate for himself and has become a voice for inclusion in the blindness community since becoming the world’s first blind, sponsored skimboarder. My oldest son is a motivated, happy Geology student living about 3 hours from home and traveling around the US conducting field research. And, my husband of 22 years continues to be my go-to-guy. The adversity we’ve faced as a family has drawn us closer together. We’ve learned so much, grown so much, and overcome so much adversity – but, what do I actually do for a living?

Then I asked: “What do you value?”

About the Author:
You can find Kim Owens on Instagram at www.instagram.com/navigatingblindness or on the web at www.navigatingblindness.com. Kim is passionate about connecting with other parents of children who are blind and visually impaired and believes that we are stronger when navigating blindness, together.

My family of origin valued hard work and financial success and I have an impeccable work ethic so being unable to work due to illness was devastating. The financial stress of losing my income, plus big medical bills, was taking a huge toll on me and my husband. After 3 years out of work, 2 disability denials and 1 hearing in front of a disability judge, I was finally awarded disability benefits. The money relieved our financial burden, but the process had been difficult requiring many doctors’ visits, copious amounts of documentation, meetings with attorneys and stress. When I deposited my first SSDI check reality set in: I was seriously ill -- and everyone, including the judge, agreed. I felt a strange mix of validation and relief combined with sadness and grief as I considered life “without purpose.” However, I didn’t have time for a full-blown existential crisis because, in addition to feeling like hell, the unimaginable happened: my youngest son, Kai, began to go blind! At the age of 10, he was unexpectedly diagnosed with Retinitis Pigmentosa (RP), a degenerative retinal disease with no treatment and no known cure.

Kai was losing vision aggressively, so he needed to learn Braille, how to use assistive technology and how to navigate with a white mobility cane. In a matter of just a few years I went from being gainfully employed earning a comfortable income to being chronically ill, disabled and advocating for my son’s mainstream education and blindness services. We were overwhelmed and began both family and individual therapy to grieve our losses and learn how to

Images: Cover - Attractive middle-aged couple Kim & Chris are smiling. Chris is bald and wearing dark frame glasses. Kim sports a sharp silver cropped haircut. Pg 8 the Owens family (Cash, Kim, Chris & Kai) standing side-by-side with their arms around each other. They are dressed for a beach day and they are smiling.
AWARENESS
ARE YOU READY TO WEATHER THE STORM?

BY STACY FLYNN

The 2019 Atlantic hurricane season started June 1. Are you ready for what this could mean? You often hear warnings on the news about being prepared but have you really thought about what it would take for you to be ready and took inventory to be sure you are?

First you have to understand what they are talking about when they talk about hurricanes so here is a quick vocabulary lesson on hurricanes:

**Hurricane warning:** hurricane conditions expected somewhere within the specified area, issued 36 hours in advance of the anticipated onset of tropical-storm-force winds to allow for important preparation. During a hurricane warning, complete storm preparations and immediately leave the threatened area if directed by local officials.

**Hurricane watch:** hurricane conditions are possible within the specified area, issued 48 hours

The assessment will help you determine what things you many need during a disaster.

“...”
in advance of the anticipated onset of tropical-storm-force winds in an area. During a hurricane watch, prepare your home and review your plan for evacuation in case a hurricane or tropical storm warning is issued. Listen closely to instructions from local officials.

**Hurricane Categories:**
Cat 1 - 74-95 mph (119-153 km/h)
Cat 2 - 96-110 mph (154-177 km/h)
Cat 3 - 111-129 mph (178-208 km/h)
Cat 4 - 130-156 mph (209-251 km/h)
Cat 5 - >=157 mph (>=252 km/h)

*Note that hurricanes are rated only by wind speed inside the storm which tells you nothing about how fast the storm is moving (how long it will be in your area) or how much rain will fall. A category 2 storm can still cause a lot of damage by causing flooding.*

You often hear things on the news such as making sure you have bottled water and be sure your gas tank never gets under half full during the season for safety. This is good advice but is it enough? When you have a disability, you have to be extra prepared for a disaster. This article is going to give you some ideas on ways to be prepared and safe!

**GENERAL PREPARATION**
To be prepared you should keep a list of emergency numbers for your area. You also need to create a personal support network to have a plan for who can help you to prepare for a disaster and/or assist you during a disaster. You also need to complete a personal assessment. The assessment will help you determine what things you may need during a disaster. There are many things to consider:

**Personal care needs:** Do you have any specials needs that will need to be addressed during a disaster? Do you need to evacuate to a wheelchair accessible shelter? Remember that just because the building entrance is accessible does not mean they will have an accessible shower or other areas so call ahead to be sure they can address your needs. (By law a shelter should be accessible meaning they should have ramps for those with mobility issues and an interpreter for the hearing impaired however you should still verify a shelter is able to meet your needs and not assume it will.) Will you have to go somewhere you can still get dialysis or other regular medical care? These are things you need to plan ahead to ensure you get what you need. Talk with your health care team about a plan for continuing care if you have to evacuate before a storm and you are unable to reach them.

**CREATE A PERSONAL SUPPORT NETWORK**
A personal support network is the group of people who have agreed to help you prepare for a disaster and/or help you during a disaster. These people can be friends, family, neighbors, co-workers or city employees. Examples of ways they can help you are by providing assistance preparing your home before the storm, assisting you in putting together your disaster supply kit, giving you transportation or shelter. It is important that you communicate with your network and that they know what your plans are, including who else is helping you to avoid confusion should a disaster occur. Have a call list of your support network and share it with everyone.

**DO A PERSONAL ASSESSMENT**
This will help you determine what needs you may have during a disaster. There are many things to consider:

**Electricity-dependent equipment:** Do you have anything that you use you must plugin such as a computerized prosthesis or powered wheelchair? Is this something you can do without if you lose power for days or weeks? If not, do you have a generator you can use to charge it? If not, you may need to evacuate if there is a risk of losing power, even if you are not in an area told to evacuate. Remember to pack back up chargers if you leave and to bring car chargers for devices if you have them. This can include medications that require refrigeration. If you lose power you will need a generator or cooler with ice for your medication. If power loss lasts for days it can be difficult to get more ice so you need to consider this when you are deciding if you should evacuate or shelter in place.
Transportation issues: Do you have a trustworthy plan to leave if needed that is accessible to you? Have a plan in place before you need it.

Possible debris: Are you aware of things in your yard and surrounding yards that will become debris? Do you have someone who can help you clean debris if needed to keep your yard accessible?

Utilities (water): Be sure you know how to turn off your gas, electric and water if needed at the main switches or valves. Share this information with your personal support network. Keep any tools you will need near gas and water shut off valves. Turn off utilities only if you suspect lines are damaged, you expect a leak or local officials have instructed you to.

Pets: If you have a pet, do you have a plan for them? Do you know if the shelter you will evacuate to will allow you to bring your pet or will you have to leave your pet behind? Many shelters do not allow animals except service animals but it is becoming more common for shelters to accept animals. If you are able to take your pet, be sure to take records of their vaccinations and enough food and water for them. Almost all shelters will require vaccination records. If you must leave your pet, you will not be able to return for him or her. It may be days or weeks before you return. Planning ahead to know a shelter that will accept pets or find someone in your personal support network who will allow you to stay with them with your pet will help avoid having to leave your pet behind.

Records: Keep vital records and documents in a safe deposit box or other safe location. Share this location with your personal support network.

Home inventory list: Make a list of all your valuable items in the home with serial numbers if possible. Take photos if you can. Keep the list and photos in a safe deposit box or another location not in the home. If a disaster does come, you can use this list to identify what items you have lost.

Have an Evacuation Plan

It is important that you have a plan for how you will evacuate BEFORE you have to evacuate.

If you need help evacuating, plan to evacuate early. If you wait until the last minute you may have issues being able to leave. If you will need assistance evacuating and do not have someone in your personal support network who can help, contact the department in your city in charge of disaster planning. Most cities have a plan to help those who need it. If you have done your personal assessment you will know if you need a special vehicle or need to evacuate to a shelter with specific things (wheelchair accessible or near dialysis center). Be sure if you evacuate that you take your medications and your medication list in case you are unable to return and need refills.

NOT IN THE PATH OF THE STORM?

It is certainly easier when you are not in the path of the storm but that does not mean that you will not be affected. Storms often affect the transportation of supplies. Be sure you have at least one week’s worth of medications and medical supplies in case there is a shortage. If you have any special dietary needs, be sure you have a week or more of the foods you need as grocery supplies will likely be low while supplies are directed to areas hit by the storm.

We cannot stop mother nature but we can plan and be prepared to weather the storm. For more information about what you can do, check out these websites:

https://www.ready.gov/hurricanes

Image Descriptions: Pg. XX Wind blown palm trees and choppy ocean as a hurricane comes ashore. Pg. XX satellite image of a hurricane making landfall.
LORD BYRON: Famous Romantic Poet and an Important Person for Disability History

BY: REV. REBECCA L. HOLLAND

As a person with low vision and a love of the written word, I am always on a lookout for writers with disabilities. I am also a huge fan of poetry. In today’s world, when people walk into a bookstore, they are usually searching for a novel, magazine, or other work of prose. But there was a time when a poet with a disability dominated the literary landscape. His name was Lord Byron and in many ways, he helped to define the age of romanticism. His verses remain some of the most beautiful and the most passionate that the western literary world has ever seen.

“Mad, bad, and dangerous to know.”

Lord Byron (January 22, 1788 - April 19, 1824) was one of the greatest poets of the romantic age. In many ways, Lord Byron was like a modern day rock star. He became renowned for his good looks, scandalous love affairs, and wild ways of living.

Byron’s true life story reads like a novel. His father was a sea captain known as “Mad Jack,” and his mother was Katherine Gordon, a Scottish heiress. At the age of ten, Byron inherited his title from a distant relative known as William “the Wicked,” Lord Byron.

Even from a young age, Byron was a colorful character. While he was still a college student at Cambridge, he kept a dancing bear for a pet. He was described by one jilted lover as “mad, bad, and dangerous to know.” He loved to travel, enjoyed fine foods, had a heart for animals, and even swam the Hellespont.

His life also ended like a novel. Inspired by the cause of the Greek people fighting for their independence, he set off for Greece and joined the people in their battle for freedom. Although he was not killed in battle and instead died from a sickness he contracted, he is still revered in Greece as a national hero.

Today, most people tend to curl up with a novel instead of a book of verse, but during his time, Byron’s works could be compared to blockbuster hits. The reading public, especially the ladies, were enamored with this brooding and handsome hero. Even so, Byron still had
his detractors. Another famous poet, Keats, made the derogatory statement that Byron was, “a hectorer in proud verse ("Stuff You Missed in History Class").”

Despite the criticisms that were leveled at Byron’s work during his time, his poetry has endured. He is most famous for his semi-autobiographical poem Childe Harold’s Pilgrimage (1812-1818), his satirical poem Don Juan (1819-1824), and his many passionate love poems.

**Byron’s Disability**

As a person with a visual impairment, I know that people are more than their disability. However, I am also a writer, and as such, I know that everything I write and every sermon I preach is filtered through my own unique view of the world. No one can be truly objective. We all view life through a unique lens that is shaped by our own unique experiences.

Byron was born with a clubfoot. Clubfoot is a congenital development that occurs when a person is born with their foot twisted inwards, which causes the person to walk with a limp or uneven gait. There are different levels of severity for clubfoot. According to the American Academy of Orthopedic Surgeons, “in clubfoot, the tendons that connect the leg muscles to the foot bones are short and tight, causing the foot to twist inward. “ Although Byron blamed his mother for his clubfoot because she wore a corset during her pregnancy, the actual cause of clubfoot remains unknown.

Sometimes clubfoot requires surgery in order to be corrected, but “most cases of clubfoot are successfully treated with nonsurgical methods that may include a combination of stretching, casting, and bracing (ibid).”

Byron wore special boots which he had made especially in order to hide his club foot and to provide support. Although we know that Byron walked with a limp, he still participated in sports such as boxing, swimming, and horseback riding. Sadly, we are told that Byron’s first heartbreak occurred during his school years when he overheard the object of his affections mocking him because of the way he walked (“Stuff You Missed in History Class”).

**Byron’s Enduring Legacy**

I cannot help but wonder how Byron’s disability impacted his own view of himself and his writing. Did he feel the same pressure to be exceptional that many people with disabilities face today? Was he goaded on to greatness by the snickers and mocking looks of his peers? Or, if we could ask him, would he simply say that his poetry and his art was beyond the reach of such human worries and concerns? Furthermore, how many of the stories surrounding Byron’s alleged “wickedness,” are fact and which ones are fiction? Sadly, we may never know.

Byron was also not without his faults. During his lifetime, he may have engaged in a romantic relationship with his half-sister as well as committed acts of violence against women. Because his personal memoirs were destroyed after his death, it can be hard to separate the truth from fiction.

As tantalizing as these questions are to consider, we may never know the answers in their entirety. We are left to wonder about the real Lord Byron. Who was he really? Perhaps, in the end, his poetry simply speaks for itself.

**She Walks in Beauty**

By: Lord Byron

She walks in beauty, like the night
Of cloudless climes and starry skies;
And all that’s best of dark and bright
Meet in her aspect and her eyes;
Thus mellowed to that tender light
Which heaven to gaudy day denies.

One shade the more, one ray the less,
Had half impaired the nameless grace
Which waves in every raven tress,
Or softly lightens o’er her face;
Where thoughts serenely sweet express,
How pure, how dear their dwelling-place.

And on that cheek, and o’er that brow,
So soft, so calm, yet eloquent,
The smiles that win, the tints that glow,
But tell of days in goodness spent,
A mind at peace with all below,
A heart whose love is innocent!

**Sources Referenced:**

“Stuff You Missed in History Class Classics: How Lord Byron Worked.”

“Clubfoot,” from the American Academy of Orthopedic Surgeons.
Adjusting To Disability Can Be Equally Tough On Friends & Family

After pouring myself a glass of water I set it down on the table and went to go grab my lunch which was in the kitchen. I came back to the table and realized I can’t see where the glass is. So I slowly put my hand out scanning the table until I felt the glass but before I did a family member points to tell me where it is. While I know where the glass is, in general, I think to myself “I can find it on my own actually. I didn’t really need the help”.

Everyone’s disability journey is different. Some were born with their disability while others had it happen later on in life. Some folks learned new skills to adapt to their disability while others learned what they know as children and it’s what’s always been familiar for them.

When it comes to friends and family however things may be difficult. For someone who acquired their disability later in life their family will likely be making changes alongside them to help each other adjust and adapt. For someone who was born with a disability, however, the family will still be making those changes but in this case, they may prove more challenging since it’s a near immediate adjustment compounded with the regular responsibilities of a caregiver.

Family and friends can find the adjustment period stressful and frustrating because this may be the first time that they’ve had to interact with someone who is disabled on a day-to-day basis. The only examples of disabled people for them might only be a random person they passed by on the street or saw while driving to the grocery store or work. Or what they’ve seen or read about in the media.

The idea that disabled people are helpless and in constant need of assistance can be a strong one especially when there are family and friends involved. A lot of times they want to help and even “protect”. They do this with good intentions but at the same time fail to realize that all of us whether disabled, or not, have to live out our lives and that friends and family aren’t going to be there to help all the time. In many ways, it stalls the progress of the person who wants their independence.

This idea of helplessness can also lead to isolation especially from friends because they may not know how to interact or adapt to the new life of the person with the disability. If the disabled friend can’t go places to hang out like they used to they may end up getting left behind for many activities which are unfortunate and unfair.

Asking questions can probably solve many issues. Maybe your friend or family member is a wheelchair user and they want to go hang out or go to a party with everyone else. Perhaps all they’re wanting is just a few accommodations. No one will know unless something is asked.

Just like in any relationship communication is key and for a friend or family member trying to better understand it’s best to ask rather than assume. The better a loved one understands the situation the better they’ll be able to address certain problems whenever they arise.

The road to adapting and accepting our disabilities isn’t necessarily a smooth one and there will be days where despite the progress being made we may feel down and wishing things were different. For family, this is difficult because one may feel powerless to say or do much.

Everyone’s disability journey is different.
On those occasions, I think letting the disabled individual have their moment is okay. We all have our bad days and sometimes trying to cheer someone up can inadvertently make things worse making it seem like you’re not understanding the problem even more.

Another reason for wanting to protect and take care can be because friends and family aren’t there when you’re going through the adaptive phase. Because of this, they aren’t aware of the skills you’re picking up. A good example I could give is a visually impaired person who is learning to use a cane to travel. While the person receiving the lessons will start to feel like they’re reclaiming their independence, their friends and family aren’t around to notice this so they may think the person is still not capable of going out on their own.

The idea of independent travel like taking public transit may sound terrifying to friends and family. This fear can likely leave the person with the disability with their back against the wall as they try to convince others that they can take public transit. However friends and family still have safety concerns.

In scenarios like public transit, I think communication is good here too. This time however the disabled individual needs to let those close to them know that they’re adapting by learning new skills. Demonstrating those skills and explaining how they are adapting will help friends and family familiarize themselves as well. Remember, it’s not just you who’s learning about things and adapting but also everyone else.

I get it. It can be frustrating and annoying to be asked for help or assistance especially for a task that you already know how to do. Family and friends don’t understand why we sometimes get upset or frustrated because all they wanted to do was to try to help and make things a little easier. I think there can be a solution of sorts to this—not just for the person with the disability—but also for the friends and family of that person.

The idea that disabled people are helpless and in constant need of assistance can be a strong one especially when there are family and friends involved.

To the friends and family of the disabled individual: Do not automatically assume the disabled person is incapable of doing much. They’re trying to show that they still have independence. If they happen to do things a bit slower or maybe in a way that may not look right to you realize that most likely they’ve come up with a system to help them do that task(s). If they do however look like they’re struggling with something ask before assuming they need help. Sometimes they might and sometimes they won’t. While you may never fully understand their situation do what you can to understand where they’re coming from.

Then there are times where the family or group of friends are so accustomed to the disability or to the individual themselves that they may even forget about it or might forget that you have a bit of trouble doing things the way they do.

I think the best way to help battle misconceptions about disability amongst friends and family is for both sides to have a mutual understanding and meet somewhere in the middle. It might not solve everything but at the same time would lessen the disagreements and confusion.
TRIGGER WARNING

THIS ARTICLE OR SECTION, CONTAINS INFORMATION ABOUT SEXUAL ASSAULT AND/OR VIOLENCE WHICH MAY BE TRIGGERING TO SURVIVORS.
MY LIFE AS AN EMOTIONAL MESS

BY: KATHLEEN GEMMELL

College bound, I planned on becoming a veterinarian.

Raised in a wealthy town, I was blessed to have horses that I show jumped. Little did I know that passion would forever change my course.

You see, I was nine and there was this man...

I began having panic attacks at the university. Imagine that your booted foot is stuck in a railroad tie. As the train approaches, you feel nauseous, light-headed, and your heart beats go wild. You may wet yourself or feel as if you’re dying.

Now, imagine please, that you aren’t in jeopardy. You may be at the store or driving to the post office. All of these symptoms arise out of the blue.

Welcome to the world of panic.

What did I do to avoid these attacks? I began to narrow my world by avoiding any place I had one. Within a month or two I was a prisoner of my own accord.

Welcome to the world of agoraphobia.

My parents schlepped me to every renowned physician in the northeast. “She has a chemical imbalance,” they likely stated. “We will put her on psychotropic medications.” Decades ago, med choices were few; Lithium, Thorazine, and Valium were popular. I spent my days in my room, walking into walls when I had to use the bathroom.

The attacks continued regardless, and my psyche was compounded by a “fear of fear.” My docs moved onto the MAOI (mono oxidase inhibitors) antidepressants and I felt as if I was a zombie who could not tell you of time or place.

I slowly began to experience O.C.D. (Obsessive Compulsive Disorder) rituals. Showering took at least an hour. Wash hair eleven times.
Wash face twelve times and so on. If I make an error with my counting, I’d have to start over from the beginning.

My fear of germs was part of my O.C.D. Silverware fresh from the dishwasher was cleaned again using antibacterial soap. You get the idea, I’m sure.

**Welcome to the world of O.C.D.**

*You see, I was nine and there was this man...*

Eventually, my parents acquiesced and had me see a psychiatrist. New daily medications, and a foreign language were had twice a week. “Transference, pathological, and familial dysfunction,” became a norm in my vocabulary.

My secret remained encased in stone. I feared he’d return. I feared I was bad and filthy. I feared my father would wind up in jail after killing him. Oh, that lists of worries was lengthy and grew by the years.

One fine day, I decided to get drunk, and drunk I stayed.

**Welcome to the world of alcoholism.**

I attended AA (Alcoholics Anonymous) meetings each day for a year or so. I made some welcomed friends and was finally out of my jail. Therapy, meds, and AA were my life as I hit forty years of age.

Yes, I tried suicide several times. I’ll admit they were half-baked attempts to gain attention. I was increasingly desperate for that attention, for a solution.

I was hospitalized twice in a prestigious institution. (In 1998, health insurance allowed me to stay for lengthy periods of time. Now you are lucky if you get care for a week.)

Today, as a sexagenarian, I have revealed my secret. My garden has been pruned of weeds and has been professionally landscaped. My work as a writer is cathartic and I also spend time as an animal welfare proponent. I feel a need to give a voice to the voiceless. The irony there hasn’t been lost on me.

I’m sure that man is dead. My father and mother are gone as well. Perhaps that is why I felt safe to speak out. “He” was a temporary riding instructor when my trainer was recovering from a nasty fall.

I am sober and less anxious. Although you could eat off my floor, my compulsions are muted.

I am content.

*You see, I was nine and there was this man...*

Kathleen is now teaching a writing course and publishes frequently.

**Image Descriptions:** Pg XX is a black & white photo of a young woman sitting on an indoor window ledge with knees propped up and arms crossed. She is staring out the window. Pg XX is a black & white photo of a smiling mature woman with long white hair seated outdoors appearing very relaxed.
THE BLIND SPOT
Ready for a Disaster? Why, CERTainly!

BY RON GRAHAM

It is the beginning of June, and that means it is also the beginning of the Atlantic hurricane season. Hurricanes mean so much to those who have any experience with them. There are the tropical and gale force winds, the relentless rains, and seemingly endless flooding, not to mention potential tornadoes that may develop. With this in mind, I would like to submit the following for your consideration.

When a natural disaster hits, who will you rely on? What about your neighbors? Who is going to help out until the police, fire department, or EMTs arrive?

Early in 2018, my friend Dan Stinson approached me and asked me those very questions. We live in Houston, Texas and deal with hurricanes, tropical storms/depressions, and some heavy spring rainfalls with some regularity. At this time, we were still recovering from the effects and devastation of Hurricane Harvey, so these were very valid and legitimate questions that I believe any of us who had lived through Harvey could relate to.

Dan is actively involved in the grass-roots volunteer force called Community Emergency Response Team, or CERT, as its more easily referred to. He had previously explained to me what all CERT has trained him to do. CERT is a nationwide, but community-based program sponsored by FEMA.
They train volunteers to get out and help the first responders when natural disasters occur.

The Idea is Born

He then proposed an idea to me as one of the leaders in the Houston visually impaired community. “Would there be any interest among the blind in being a part of a CERT team?” He explained the various training modules in the basic CERT training class, and added that he knew Liz Shuler, the area trainer, who was also specifically trained to teach this class to people with disabilities. He said he had mentioned this idea to her, and she was very enthused and eager to do this if there was interest within the blindness community.

And, with this, we began an interesting and rewarding project. I made contact with the other group leaders in the visually impaired community from across Houston, querying for interest. Liz said we would also allow sighted participants as part of the group, but only after all the visually impaired participants were in, and even then, they could not make up more than half the class. And, after a good response was received, Dan went to work locating a facility that was central to all and served by MetroLift, the city’s para-transit system.

Houston, We Have Lift-off

Our class culminated in a total of 18 students, 4 of whom were sighted; the majority of the other 14 were totally blind. In July and August 2018, we regularly met at the city’s Metropolitan Multi-Service Center to attend the weekly 2-3-hour class for an 8-week period. We were trained in the FEMA mandated modules which included disaster medical training, fire safety, light search and rescue, psychological aspects of disasters and others. Liz was the lead teacher in the class, but she was regularly aided in her teaching by fellow CERTs Arlene and Joyce, as well as Captain Ponce, a 31-year veteran of the Houston Fire Department.

What we developed most of all in this period was to understand the importance of communication and teamwork in achieving our goals.

The training was free of charge, as was all materials we were issued. Each of us received a standard CERT backpack full of the basic supplies. These basics included our official CERT vest, helmet, goggles, flashlight, multi-purpose tool, and various basic medical supplies.

One of the most positive aspects of this training was that Liz was determined to make it hands-on. She said she was aware of one other CERT training class for the blind but that one had used computer simulations and she didn’t think that was effective training. She was steadily thinking through how to best teach us how to do various tasks in a safe manner. This was reflected in the time and effort she put forth in fire suppression, where we worked in teams, just as any other CERT team would do, and approached a fire with a fire extinguisher. One sighted member was partnered with a blind team member. In a coordinated effort, they approached the live fire, sprayed it with the extinguisher, and then extracted themselves safely from the scene as any other CERT team would do. Liz’ detailed attention to planning was also particularly evident on the larger group activities such as gang planking, evidence collection and identification, light search and rescue, and transportation of the injured.

Our final class was a series of stations where we were drilled on the various skills we had learned in our previous classes. It was a great experience for all of us. We all received certificates signed by the mayor of Houston.

While we learned many new skills and built confidence in our achievements, what we developed most of all in this period was to understand the importance of communication and teamwork in achieving our goals. No matter what task we undertook, these two things were core to our success. We do things in pairs or as a whole.
team, and the only way to complete our tasks was with clear and proper communication, and to work as a single, unified team. The CERTs who graduated in this class were: Eva Bergara, Ava Carruth, Kellie Dewveall, Karen Eitel, Stacie Gallegos, Suva Gomes, Ron Graham, Kenda Greer, Clarice Henry, Victoria Hillard, Cindy Holifield, Leslie Lang, Louis Maher, Jamal Mahmoud, Laura Mulraney, Chelsea Nguyen, Shaquita Rivers, and Donna Whitesides.

That's Done, What's Next?

Now that we were certified, we faced the situation of wondering what we can do with this training. Normally, a CERT team is based in a particular geographic area and gets together regularly to drill and practice on the areas they've been trained on. However, since our group was different in that we were drawn together by our similarity of being blind, or somebody who works with the blind, we were spread out in a wide array of areas across Houston. Also, with most of us being blind and unable to drive, it isn't easy to meet in a central location, this left us facing a unique and challenging situation.

First and foremost, what this training has done is taught us how to prepare and respond in the event of a disaster in our own neighbourhood. We will be able to fend for ourselves and our families when the next situation presents itself. It also instilled a desire within each of us to share this message. We are able to talk to our friends and neighbors, to pass along what we know, and, hopefully, inspire them to get certified as a CERT themselves.

This is Texas, so we Rodeo

Throughout our training, we had been hearing about this thing called CERT rodeo. No, it is not like traditional Western rodeos with horses and cattle, but this is nonetheless a very competitive, skills-based event. We were told that the annual Houston CERT Rodeo would be on Feb. 9, 2019 and were encouraged to think about competing as a team.

First, we had to figure out who all was interested in doing this as a team, and who was going to be available. Not everybody from our training class was able to do this. We had to practice and prepare, so this took some extra planning and meeting for training sessions. We met back at the same Metropolitan Multi-Service Center where we had trained. We were again trained by Liz, Joyce, and Arlene.

Then we had to have a name. And, even though we had one guide dog on the team with us, we chose the tongue in cheek, but appropriate name, Team Cane and Able.

The Rodeo was held at the Harris County Fire and Sheriff's Training Academy. I was selected as team captain and incident commander. Arlene was assigned to our team and was my right hand in all activities.

Because it was February in Texas, it was cold out, and we felt it throughout the day. Temperatures were in the 40s with a bitter, north wind that made its presence felt on any exposed skin. But this was like anything else we prepare for and had dressed in layers.

We had a team of 12 people, seven of whom were totally or legally blind, and one of them was on a motorized scooter. On display throughout the day was the working definition of teamwork and communication. There were 12 different people, each working independently but as part of a larger and cohesive group to accomplish tasks. There were 10 stations and we were able to fully participate in 8 of them. The other two were not in our skillset and not safe for us to undertake, so as the Incident Commander, I deemed it unsafe to enter the activity. In CERT, team safety is stressed as the first priority in all we do, so we get credit for assessing the situation as such.

There were some activities, like triage and medical treatment, that were strengths, due to the training we have undertaken. Even gang-planking, which is a coordinated team activity with four team members walking atop parallel two-by-fours with rope handles, lifting the planks in a syncopated motion and walking for a distance of 20 feet, turning around, and returning to your starting point, was something we had practiced and a strength for us.

We also had our plan of action on approaching fire suppression, working to the strengths of the team. We took on some new challenges that we had practiced briefly, like hazmat identification, and our confidence was high on it.

Our team was pumped up and even ready to take on some things that might not have seemed like the best task to
undertake, because it was nothing we had trained for, forming a line search for evidence identification. There was no danger for the team to attempt this, so we eagerly took this on and identified all 50 of the washers which had been laid out in the field. Yes, it took sighted members to spot the washers, and the team member closest would retrieve the washer, as we were lined up in a long line and moved forward one step at a time. It was a total group effort to accomplish this, but that is what CERT is about, the strength of the team. Some of the other teams, all of which had fully sighted members did not score as well as we did on this task, and this was the first time we had attempted it.

Several times during the day, we were complemented for delivering one of the best times or highest scores on various events, the evaluator’s pride in our accomplishment being clear in their praise. One of them even commented that he would not like to run into us in a dark alley, because we’d have an even greater advantage! Each event had a possible score of 100 points, and there was an optional Amazing Race game that could earn an additional 100 points. We hit the ground running on that optional game, beginning at 12:40, racing to meet the 1 PM deadline. Like everything else, we approached it as a team, and nailed the full 100 points!

At the end of the day, the highest score was 1030, and the lowest was 950. Team Cane and Able scored 1020, the second highest score of the day!

Initially, I’m certain that we raised some eyebrows and caused some heads to shake as we began to take on the day, but, as the day went on and we held our own, I feel confident that we earned the respect of everybody involved.

CERT Rodeo was a great confidence booster for our team, and the lessons we learned during the course of the day only added to our depth of knowledge we had already acquired. We now know the kinds of events that take place at the rodeo and can work to further expand our expertise. We have also laid the groundwork to begin training for Tower Search and Rescue, one of the events we didn’t participate in, so that, at future rodeos, we can be fully engaged and can accomplish this task safely. I have some ideas and believe that we can safely train on both of the events we passed on at this rodeo, so that at future rodeos, we can accomplish them both safely and successfully.

Resources: If you are interested in locating a CERT team near you, or to get trained as a CERT, here’s the web site to do that. https://www.ready.gov/community-emergency-response-team

Image Descriptions: Pg 19
Header image is a group photo of CERT team Cane and Able which consisted of 12 people, seven of whom were totally or legally blind, and one of them was on a motorized scooter. The second image is a closeup of the Harris County Cytisine Corps CERT Rodeo 2019 Badge. Pg 22 a photo of a fire extinguisher.
Hi, it’s your friendly health and fitness friend! While I normally focus on physical health, I’m going a slightly different route in this article.

Let’s talk about mental health and disabilities. Mental health is becoming a mainstream topic and I believe wholeheartedly that it is something every human, especially those differently abled, need to discuss.

Speaking from my own walk with sight loss, I know my mental health suffered after my diagnosis. The doctors don’t discuss how your individuality will be affected. They don’t discuss how angry you’ll feel, or how the depression can swallow you whole. And they most certainly don’t discuss ways to handle life after diagnosis.

Here is where I come in. Here is what every doctor should tell you but won’t:

- You’ll be angry
- You’ll cry
- You’ll deny the prognosis
- You’ll sleep away the feelings

Here’s what you can do to handle your diagnosis:

- Feel all of your feelings. Work through them, it’s hard and takes time, but do it.
- Find a hobby. No matter if its people watching at the mall, or baking, or shopping, find something that brings you joy.
- Be active. Moving your body improves mood with the help of endorphins. You will regain a sense of control over a life that can seem out of control.

And lastly,

- Find a source of support. Whether it’s a Facebook group, a local chapter of a disability group, or even a therapist, it will help you feel less alone.

Every human being has struggles, it’s a fact of life. However, the better equipped we are to handle those struggles, the healthier we will be, body, mind, and spirit.
Adaptive Recreation for People with Disabilities

BY MICHELLE BLUNT

The Verne Cox Multipurpose Recreation Center is a facility specifically dedicated to recreational activities, programs, and events for youth and adults with disabilities. The mission of the Verne Cox Center is to provide affordable recreation programming, innovative therapeutic recreation services, and an outlet to promote healthy use of leisure time for people with disabilities.

The center is staffed with two full-time staff (two of which are Recreation Therapists) and four year-round part-time staff. With a wide variety of programs year-round, the Verne Cox Multipurpose Recreation Center serves persons ages 5 to 95 years of age with any type of physical and/or intellectual disability. The building is equipped with a fully functional kitchen, gymnasium, pool, shower/locker room facilities, two accessible softball fields, two activity rooms, a weight room, and an accessible playground.

The center is funded by the City of Pasadena allowing for year-round programming that is low-cost to free programming for citizens of Pasadena and those in surrounding communities. During the school year calendar, we offer an Afterschool program, day time programming, community outing trips, fitness program, and wheelchair practices, leagues, and tournaments. In the summer, we offer four summer camps and a workshop (art & dance).

The Verne Cox Center is a special place because it is unique to its kind. It is free to become a member of the center and 95% of the programs are free of charge to the participant/family.
During the day, the building is open and individuals with disabilities can come and go as they please. The center staff run three programs a day preceding the Afterschool program.

Types of programs that are run during the day could be: science class, Zumba, art classes, trips to restaurants/libraries/book stores, volunteer programs, a fashion/talent show, choir and theatre programs, and various other engagement programs. We hold monthly adult dances, monthly resources presentations as well as a Sensory Saturday program for kids with autism. We also take an annual overnight trip to Camp For All in Burton, Texas. The goal for these day programs is for individuals with disabilities to be able to maintain their quality of life through socialization, fitness and community integration!

The center provides a wide variety of inclusive wheelchair sports programming. This means that the center holds wheelchair sports practices, and has sports wheelchairs to loan, meaning that people with and without disabilities can recreate together! In September, we host a long-standing wheelchair basketball tournament called “The Shootout”. This tournament has been running annually for over 25 years and has brought in teams from all over the world during its time. The tournament takes place during the Labor Day weekend.
Over Memorial Day weekend, we host a wheelchair softball tournament, using both fields at the Verne Cox Center. In the fall months, we hold a six-week wheelchair football league on Thursday nights with a playoff Saturday in November. These tournaments are open to the public to attend, we also encourage spectators!

Recently, the center has partnered with TIRR Memorial Hermann for an adult traveling wheelchair softball team. This team kicks off their season at the Memorial Day tournament and practices weekly during the summer months. This team travels to other local wheelchair softball tournaments preparing for the National Wheelchair Softball Tournament in August. We are extremely thankful for TIRR who is a great partner and really values the need for recreation. Keep an eye out for us - "THE TIRR MEMORIAL HERMANN HOTWHEELS" wheelchair softball team :)

The Verne Cox Center is a special place to be and we are so thankful that the City of Pasadena sees that value in providing this one of a kind resource for its citizens!

Feel free to contact me by email at: mblunt@pasadenatx.gov or by phone at: 281.487.1755

Follow us!!

Facebook: Verne Cox Multipurpose Recreation Center
Instagram: @vcmrc_pasadena

"The Verne Cox Multipurpose Recreation Center provides affordable recreation programming, innovative therapeutic recreation services and an outlet to promote healthy use of leisure time for people with disabilities."
ARTS & INCLUSION
This month I would like to share with you the creative process of one of the 5 commissions I’ve completed over the past 6 months.

I was commissioned by a professor of ophthalmology in Ireland to create a piece of work that depicted an eye. He had already shown a lot of interest in a piece called “Sight”, this piece was part of my Blind A Sixth Sense exhibition last year. As this piece was already owned by a client I offered to create something that was reminiscent of the work. Sight was the only one out of that collection that I just couldn’t connect with, I believe that is because I have no connection to my physical vision anymore. I no longer hold on to the residual vision as if my life depended on it.

My self-development has taken me on a journey of accepting my blindness and indeed I see it as a gift. The sight I now have goes beyond vision, I see through my heart and my mind, this truly gives me more vision than...
any functioning eyes could ever see. With this in mind, I took a very different stance with the piece I wanted to create for my new Irish client. He is an extremely well-respected professor in his field who also has a very good understanding of mindfulness. He works a lot with the wonderful Fighting Blindness organisation, one of the leading Irish sight loss support charities. He believes that although research is vital for the future of those with sight loss, he also is an advocate of the importance of supporting those with sight loss in the now, giving people a space for understanding and working through the psychological impact of sight loss. One of the more holistic approaches to this is mindfulness. For me, this has been something that has been a vital tool with my own journey of sight loss. Due to this understanding, I wanted to create a piece that would represent a more wellbeing approach to sight loss, as I knew this would resonate with him.

I began creating this piece after a very timely break out of the studio. Since I had created 3 commissions back to back from November, I was beginning to run out of steam so decided to take February off. This gave me time to recharge and reconnect with my spirit and find my centre once more. I practised daily mindfulness and meditation, as well as touched base with my holistic counsellor. I also was able to continue writing my book which is another creative outlet and project that I am very much enjoying.

Once I felt ready and recharged I went back into my studio to begin work on the piece “Mind’s Eye”, the name of this sculpture came to me whilst meditating, it is unusual for me to have a name for a piece before creating it. I decided what I wanted to portray differently from the previous Sight piece. I had a very defined idea of the fluidity of the piece, where Sight’s form felt too sharp and spiky, I wanted to show a softer line and curvaceous form. Sight was created from Tulipwood which is a light wood that has a lot of grain colour. I wanted Mind’s Eye to be made from Sapele wood, a very dark rich, almost redwood.

After working on a few initial designs I settled on a sketch that depicted everything I wanted to say and then set about creating it. The first stage was to draw with white chalk the outline of the piece onto the wood. I have to use a high contrast method to do this if I’m using a dark wood I draw bold lines in white chalk, if I’m using a light wood, I use bold black charcoal lines. This is just one of many adaptive ways I can continue working.
Then the outline was cut out and mounted into the vice. I then had the task of completely hollowing out the large piercing in the centre. I used a hole cutting drill to create an initial hole, the rest was carved out by using a large gouge chisel and mallet. Once this had been carved out enough I then set about shaping the inner and outer lines of the eye, one of my favourite parts was creating the eyelashes, unlike Sight, Minds Eyes eyelashes were created as indentations, this gave a much softer, more fluid form where there were no breaks of line.

The back of the eye had to be carved into a convex shape whilst the front of the eye swooped inward in a concave manner, this formed a much more 3-dimensional piece. The shaping of the overall eye was very much more like an animals eye, perhaps a cat’s eye or an eagle’s. The work was then smoothed out by using such tools as spokeshaves, surf forms, and files. After this, the sanding stage begun, initially starting with a very heavy grade of sandpaper and then working my way through the grades until I reached a very fine grade of paper.

The similarity between Sight and Mind’s Eye is how I portrayed the pupil, I suspended the chakra stone for the third eye, this chakra has such significance to how I view my own blindness, to see through one’s mind and heart, allowing the spirit, the soul to give you limitless vision beyond the physical. I created a wooden ring in which I inset the chakra stone and then suspended it in the centre of the piercing of the eye. This is always done by using a very thin nylon wire, very similar to fishing wire, just thinner, this is hard to see at a distance and creates the illusion of something being suspended. It is one of my favourite things to do within my work and indeed has become a very recognisable feature for a Victoria Claire sculpture. The last stage was to create a base to display the eye. I made a round oak base with a nice shapely stand coming from the centre of the circular base, everything about this piece of work I wanted to be curvaceous and flowing, even the base. Once all the elements were fixed together I then used a spray high gloss lacquer to give a highly polished finish, this is also a very durable way of treating the wood.

I had the pleasure of personally handing over Mind’s Eye in May to my client, Dr. David Keegan whilst speaking at the Fighting Blindness AGM. In fact, that truly was a time of handing over sculpture as I created a piece for the organisation and also a piece as a retirement gift to their head of counselling. All pieces were so gratefully received and Mind’s Eye was extremely admired, my client was over the moon with it and completely understood what the piece stood for.

As an artist I have the greatest honour of being able to have my work owned and proudly displayed all over the world but the best part of sharing my creativity with others is to portray my personal journey through my sight loss and have the privilege to touch many people on an emotional level, this is a blessing which humbles me every time.

To find the organisation Fighting Blindness: www.fightingblindness.ie

For any enquiries for sculpture commissions please visit: www.victoriaclairesculpture.com

To learn more about Victoria Claire and her work involvements, please visit: www.victoriaclaire-beyondvision.com
Alice Wong's Disability Podcast

In having a phone conversation with Stephanae McCoy, one of the founding editors of “CAPTIVATING!” Magazine, we felt we had such an animated discussion on disability that our phone conversation should be a podcast. This inspired me to look into disability-related podcasts.

It appears that the BBC, the public broadcasting network in Britain, has the largest lineup of disability-related podcasts. How amazing that the British people have such a supportive network to engage with.

I started searching for independent podcasts and came across a few. I would like to focus on one in particular hosted by the fabulous Alice Wong called “Disability Visibility.” I thought this was a perfect match as “CAPTIVATING! Magazine” is all about raising the visibility of people with disabilities.

Alice Wong is a self-proclaimed San Francisco night owl. She conducts conversations about politics, culture, and media. One of my favorite episodes was about Young Adult Literature or as it is often abbreviated, “YA”. The YA genre of literature is of great interest to me as a teacher of young adults. Wong’s guest makes so many excellent points why YA literature is so very relevant and diverse. The Dutch writer Marieke Nijkamp was a lively and informative guest. She is an award-winning author and a general authority on YA novels and disability.

One review in the “Disability Visibility” comment section said: “While listening to this podcast, I find myself nodding my head and at times taking deep breaths because someone has spoken a truth I hadn’t heard before and didn’t know could exist. I’m thankful for this podcast and the opportunity to hear, to listen, and to learn.” I myself would say I hold the same level of gratitude. Another comment said that “Disability Visibility” “presents a wide coverage of issues faced by people with disabilities, but illustrates well the intersectionality between disability rights and justice and that of people of colour, LGBTQ, and other marginalized groups. Good diversity of guests sharing experienced, thoughts on issues.”

Alice Wong seems to be able to bring the best out in people and does her research on them. Her guests are as diverse as her topics. Alice Wong has a lively Twitter feed and is about to publish an anthology of first-person essays on the disabled experience in 2020, in time to celebrate the thirtieth anniversary of the ADA. Her blog and Twitter account also offer a meaty mix of content. I have a 45-minute commute and have enjoyed Ms. Wong’s good company with her podcast. I recommend you download a couple of episodes of “Disability Visibility” and find one of Alice Wong’s guests to connect with.

I want to hear from you and want to know what podcasts you listen to about disability issues. I want to know about your own podcast. Or what kind of other projects you are working on. Do you have a blog? Do you have an art show coming up? Please send me an email and tell me. I have tried to make this column quite mainstream so that what I review can be accessed by many people. I also want to know what media you produce. Is there a film you think I should see? Do you have a “zine”? Do you play in a band? Do you have recordings? Do you have a favorite musician with a disability? Have you read any good books about disability you’d like other people to know about? How about movies, plays or shows? Tell us about what you like and why it’s worthy of a review. We would love to hear from you in our comment section.

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Sometimes I have wrong ideas about countries or cities I have never visited. In my mind, South Finland was a cold and grey place and Helsinki was a small, serious and boring city. While I was visiting I realized Helsinki is not grey at all, in fact, it has a pretty diverse architecture. It is also a very alive city with good ambiance and nice nightlife. During the night I went out and Helsinki is not so dark as other northern cities, light makes everything easier for my eyes.

During my two weeks there, I met some Finnish people to who I asked about how it’s life in Finland. My impression is the country really cares about its people. They have good education, good social services system and people were very open to answer my questions and show me around Turku city while telling the story of different buildings. After my experience, South of Finland is not grey, not boring, it is a place to enjoy, to discover and to forget about the crowds.

Images (clockwise from left to right): Helsinki Cathedral - Wandering around Helsinki, I visited two cathedrals. Helsinki Cathedral (in Finnish Helsingin Tuomiokirkko) is a Lutheran Cathedral and one of the most popular tourist sights in the city. With a green dome and white walls, this building is placed in the Senate Square, where there is also a statue of Emperor Alexander II, Grand Duke of Finland. The second cathedral is the Uspenski Cathedral, the largest Orthodox church in Western Europe. The entrance is free of charge. One is an exterior photo and one an interior wedding photo.
During my time in Finland, I also had the pleasure to discover Turku and its surroundings. The Turku Archipelago is one of the most prolific in the world with a total of some 20,000 islands and skerries. Inhabited islands in the Turku Archipelago can be reached by inter-island ferries. My friend and I did a tour by car using also those ferries. Something to highlight about the tour is the feeling of freedom that fulfills me being surrounded by nature, with almost no buildings and just a few people in the area. It was a healthy disconnection from the world.

Christmas trees: One of the funniest moments of my visit was when I saw a Christmas shop. I love those shops with all sort of Christmas decorations and this one was very big. I am from Spain and we do not really have those shops here. Another experience that shocked me was seeing a forest full of ‘Christmas trees’, now I understand when some of my friends from the North of Europe get excited when they see Palm trees in Spain.
Photo de Suomenlinna - My friend Mikko brought me to Suomenlinna which is a sea fortress built on six islands declared by UNESCO as a World Heritage site. This cultural treasure with almost 300 years of history is now home of approximately 800 residents and a place to visit for tourists. Suomenlinna is accessible only by water, you can take a ferry from the Market Square. In the webpage, you can find more information including information about accessibility.

Panoramic view from the ferry. Blue skies with puffy white clouds in the distance. Tree lined hills can also be seen afar.

Views from a wooded trail and a lake.

Lake in Finland surrounded by trees on both sides.

Photo nature - Another day I did a trail with my friend. It seems to be a usual practice, at least during summer time. I found out the trails are not accessible at all. We walked on a narrow path made of wood were only one person at the time fits. Accessibility in nature is complicated to find.

Wooden path on a trail.
CLOSING REMARKS

Chelsea & Stephanae

We began June’s edition of CAPTIVATING! by stating that love is acceptance. Acceptance begins with understanding that can lead to embracing that which we didn’t previously comprehend.

Human beings are extremely complex with copious amounts of backgrounds and characteristics that make each of us unique individuals. With over 7 billion people on the planet it’s extremely unlikely we will ever get to know everyone let alone embrace all those that we do know. Even so, the very least we can do is to respect one another and recognize that we are different and this okay.

CAPTIVATING! is driven by love and connecting and enlightening people of all abilities is our mission. We want to end this edition with the opening quote by James Baldwin.

"Somebody, your father or mine, should have told us that not many people have ever died of love. But multitudes have perished, and are perishing every hour--and in the oddest places!--for the lack of it." –James Baldwin

As always we hope you enjoy this issue of CAPTIVATING! Magazine. We invite you to submit questions, articles, and ideas to editor@captivatingmagazine.com or through our website at www.captivatingmagazine.com.

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