Spring 2023

mélange

Accessibility for All

20-year old self-taught artist

ANIS JERBI

He found solace in art and it quickly became his passion

From struggle

TO OPPORTUNITY

Christine Staple Ebanks finds inspiration in unexpected places

Talking with

Tara Llanes

Adaptive Athlete and Entrepreneur

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May	Mobiity Awareness Month (U.S.)
May 18	Global Accessibility Awareness Day
May 30	World Multiple Sclerosis Awareness Day
June	Alzheimer's and Brain Awareness Month
June 19	World Sickle Cell Day
July 26	Americans with Disabilities Act Anniversary

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Welcome
TO ACCESSIBILITY
FOR EVERYONE

Editor's Note

Fred J. Maahs, Jr.

Greetings!

. . . and happy spring! Welcome to our April issue of Melange, Accessibility for All magazine.

My editor's note will start on somber and solemn note. All of us in the disability community are probably already aware that we lost a very dear friend, family member, mentor, disability rights advocate, and frankly, a disability rights treasure this past March: Judith Heumann. I knew Judy, as many of us did, for quite a long time. Even if you were new to the disability community, chances are you were somehow touched by her directly or indirectly. That's just how it was with Judy. She was well-known and highly regarded the world over. No matter where I've traveled in the world, someone always knew her name and what she did for the disability community. I had the pleasure of serving with Judy on the National Board of Directors for the American Association of People with Disabilities, numerous panel discussions, and I even shared an interview with her in the very first issue of Melange, Accessibility for All magazine – October, 2020.

There's nothing I can say or write about Judy that hasn't already been conveyed about her. Well, maybe one thing. Judy was a fighter, and you were always going to lose if you dared to take her on. I never had to. We were always on the sane side and fought the same fights. I still do, in her honor. I will not give up my fight to ensure that all people, regardless of ability, have the same access and the same rights as everyone else. It's Judy's legacy. None of us would have the rights as people with disabilities that we do had Judy not stood up for all of us. So, I ask each of you to honor Judy by never giving up and to always advocate for your rights. Disability rights are civil rights! Never forget that.

To further honor Judy, we will continue to bring you stories from around the world about people, places, innovative technology and companies that each make a difference in the lives of people with disabilities around the world.

And, don't forget our latest magazine, Melange Accessible Journeys. In this Melange digital magazine, we share stories from all around the world about accessible travel destinations written and experienced by people with disabilities. In each issue of Melange Accessible Journeys, you will find personal, firsthand accounts of what each traveler experienced during their journey. It is a resource for anyone of any ability who wants to take an accessible journey. In the summer issue, I'll be sharing my recent visit to Portugal, so keep an eye out for it.

Keep using your voice and sharing your stories with us. We will continue to make it all real, all relevant, and we certainly appreciate your thoughts. Let us know if you have a product you want us to write about. Invite us to visit your city, country, resort or place of interest so we can write about it and share it with our audience.

You can reach me at fmaahs@readmelange.com.

Thank you for reading.

Warm regards,

Fred J Maahs Jr

@FredMaahs - Twitter

Fred J. Maahs, Jr. is an internationally-renown disability and civil rights champion who believes in and advocates for the rights and access for all! A recognized leader and former corporate executive, he's also an International Keynote speaker, collaborator, and an international accessibility travel expert.

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We try to present information that is current and accurate, but errors can occur. If you've found an error in the magazine, please **email:** Fred Maahs, Jr. fmaahs@readmelange.com

Canada

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Peggy's Cove accessible viewing path

Putting people first: creating accessible tourist attractions in Canada

By Katie Kirker, Rick Hansen Foundation

Canada is home to many world-renowned tourist attractions which helped draw 22.1 million visitors to our country in 2019. Yet with 1 in 5 Canadians, and over 1 billion people worldwide identifying as having a disability, ensuring these tourist destinations are accessible is essential to allowing everyone to participate fully in these experiences.

At this year's Accessibility Professional Network conference, #APN2023: Building Together presented by Royal Bank of Canada, representatives of tourist destinations came together to discuss the need of ensuring our tourist attractions are accessible. The panelists included: Peter George, Chief Operating Officer at CN Tower; Omer Dagan, Business Development Sr. Analyst of Whistler Blackcomb; and Matt Neville, Principal Planner at Build Nova Scotia. The panelists discussed how putting people first creates greater inclusion at their three destinations across Canada.

Whistler- Blackcomb

One of Whistler-Blackcomb's values is inclusiveness. "It is why we are prioritizing opportunities for everyone to experience these incredible environments," Dagan said.

There are challenges involved in creating accessible experiences on a mountain landscape, but they have not let that stop them. Whistler-Blackcomb has seen success in one area in particular: adaptive mountain biking. Whistler-Blackcomb is home to the first bike park with lift access and hosts the largest bike festival in the world. Ensuring everyone has access to the sport is important to Whistler-Blackcomb. One way to improve access of the trails was to think about how those on an adaptive bike use the environment. Through continuous consultation with the community, advocates and

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businesses, Whistler-Blackcomb incorporated the Kootenay Adaptive Mountain Biking Trail Standards to many of their trails.

"The detailed and well thought out standards allowed us to understand things like the minimum size for a bridge or wooden structure, best practices for lift loading and extraction," Dagan said, adding, "We added signage to create a reference point for adaptive bike users." This understanding of why people come to Whistler helps guide how to begin making more and more mountain activities inclusive for all.

CN Tower

"People have to come first," George said, emphasizing this statement throughout his presentation on the journey of creating an accessible CN Tower. He added, "The CN tower is more than an attraction; it is Canada's celebration destination. We want it to be inclusive for everyone to come and have a great time."

The CN Tower, built 50 years ago, is one of the most iconic attractions in Canada and hosts 1.5 million visitors per year. In 2022, the CN Tower achieved Rick Hansen Foundation Accessibility CertificationTM (RHFAC) Gold in recognition of its efforts to create an accessible space for all to enjoy.

Their journey began in 2017 with their first RHFAC rating. George learned they had a long way to go to become accessible. But after working with an accessibility consultant to implement the learnings from their rating, they have made enormous progress, and are continuing to make large upgrades to the space to ensure everyone has access to all that the building has to offer.

"We have to work every day to eliminate barriers for all, from top to bottom," George said, adding, "The most important thing we did was weave accessibility right into the fabric of our organization."

Peggy's Cove

Built in 1915, Peggy's Cove Lighthouse stands tall against a village of 35 that welcomes nearly 750,000 visitors annually. The lighthouse itself is a popular tourist destination in Nova Scotia. When the opportunity arose years ago to upgrade the old site, Neville explained that Build Nova Scotia had one objective: improve the visitor experience. "It is an iconic landmark that so many visitors interact with every year," Neville said, adding, "The problem was, it wasn't a place for everyone. Not even close."

Neville credits their consultation efforts for much of the success of the project. In 2022, Peggy's Cove Lighthouse achieved Gold certification through RHFAC. "We worked with allies, those with lived experience, experts, those who were most affected. It was a constant dynamic process," Neville said.

Rick experiencing CN Tower's accessible skywalk

Neville explained that the team would get input, then "try to achieve as much as they possibly could to make it a little bit better," before inviting people back to take another look. This iterative process of continuously collecting feedback from those with lived experience helped put users first and try and make the space as accessible as possible and immerse everyone in the beautiful environment.

From the snowy peaks of Whistler Mountain to the urban cityscape of Toronto, to the rocky shores of Peggy's Cove, Canada's most accessible tourist destinations have one thing in common: putting people first.

If you are interested in learning more about how to make the built environment more physically accessible, visit RickHansen.com/RHFAC

I felt like the first wheelchair user in the Caribbean

A Caribbean cruise and best places in Miami

By Werner Rosenberger

For the first time, I traveled with my wife and my two children (8 and 12 years) over the Christmas holidays to a warmer area, while the winter in Austria is very cold. We wanted to enjoy the warmth and took a Caribbean cruise on MSC Seascape, followed by a lovely few days in the City of Miami, Florida.

We already knew this ship and it is ideal for people in wheelchairs. The new ship of the MSC Shipping Company is very barrier-free and well designed for my needs. Only a few electric door openers are missing, but there is always a helping hand nearby. We can recommend the yacht club, a ship-in-ship concept. The price is higher, but the service is much better, and the rooms are amazing and big enough for wheelchairs. Our destinations of the trip were the Bahamas, Puerto Rico and the Dominican Republic. In our opinion not many wheelchair users had explored the islands of the northern Caribbean before. We didn't see any wheelchair users during our trip. MSC also did not offer any special excursions for the disabled people in the Caribbean. However, the first stop on the trip, the private island of MSC, Ocean Cay, is very wheelchair accessible. All roads on the island are paved. I could have gone swimming in the sea if the weather had been better that day.

In Puerto Plata we took a taxi and explored the city and the hinterland on our own. In Puerto Rico we wanted to explore the capital San Juan by foot, but due to the bad sidewalks and the steep inclines, we stopped our plan and visited the barrier-free fortress Castillo de San Felipe del Morro—a UNESCO World Heritage Site. Getting money was a bit difficult. We did not find an ATM on both islands that could have been reached without steps. In Nassau, Bahamas we took a taxi again and visited a beach and enjoyed the Caribbean flair.

After a week at sea, we stayed in Miami for a few more days. We stayed in a great Airbnb downtown. This was fairly well accessible, but the rooms either had a bathtub or a higher step into the shower.

We had a rental car and visited different districts like Midtown, Coral Gables, Coconut Grove, Little Havana and Key Biscayne. Although there are disabled parking spaces throughout the city, we did not find any vacant disabled parking space in five days. Wynwood is highly recommended for art and design lovers. The world-famous graffiti

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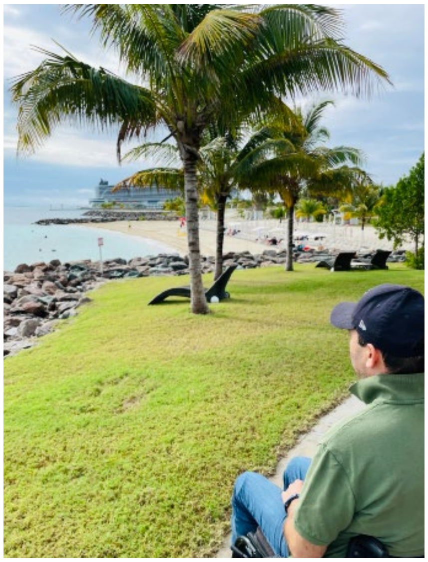
are designed by international artists.

Miami Beach is not wheelchair accessible. Miami Beach is over 10 miles long, you have to pay between $3 and $10 an hour to park your car, but there is no wheelchair access to the ocean. There are only two places where you can rent beach chairs for wheelchair users, but no guide will help you into the water. Manual chairs require the assistance of another person, but my wife wasn't strong enough to help me on the sand. You can rent an electric beach chair to go by yourself on the beach without assistance, but there is only one and it was broken. So, I couldn't go into the ocean, and I didn't see my children playing in the water, because all barrier-free paths end at the beginning of the beach. John Morris, founder of Wheelchair Travel, also talks about this in his blog.

The Everglades are very easy to get to by car. Of course, the national park and the alligators could not be missing in our trip. We also spent a day in Fort Lauderdale and looked for the luxury villas and yachts. The city is best explored by the water. The well-known water taxi was unfortunately not possible for me, but www.junglequeen.com was barrier-free. Then we drove to Hollywood Beach, but there was the same problem for me on the beach as in Miami.

"I travel a lot and have been dependent on a wheelchair for a long time and actually thought that Miami would be optimally handicapped-friendly, but I was taught otherwise. That spoiled the holiday mood a bit. However, the warmth did me good and it was an unforgettable journey for us." ~ *Werner Rosenberger, Austria*



Instead of seeing obstacles as something to avoid or overcome, I began to view them as chances for growth and new possibilities.

From struggle to opportunity

How reframing your mindset can transform your life

By Christine Staple Ebanks

Have you ever found inspiration in unexpected places? I know I certainly have. Sometimes, it's in the midst of the struggles we face that we discover our inner strength, resilience and determination. During these tough times, we learn to see things from a different perspective, find creative solutions to our problems and appreciate the small blessings in life.

I will never forget when my fourth child was diagnosed with a congenital diaphragmatic hernia while I was still pregnant. It was overwhelming, and fear and uncertainty filled me. Looking back, however, I find inspiration in the strength and resilience my family discovered during that challenging time. When my baby was born, the experience was intense and traumatic, but the support of our loved ones helped us find hope and comfort.

At nine months old, we received another diagnosis—cerebral palsy. I struggled with guilt, fear and uncertainty about my identity as a parent and a person for years. The diagnosis was difficult to pronounce and understand, and I felt lost. But with time, I learned to lean on my support system and embrace the journey ahead with compassion and strength.

It wasn't until my son was two and a half years old that I had a turning point that helped me see problems as opportunities. Instead of seeing obstacles as something to avoid or overcome, I began to view them as chances for growth and new possibilities. By reframing my mindset, I discovered new solutions and transformed my life.
I realized that every problem presents an opportunity to learn, adapt and make positive changes. I also found companions who had been through similar experiences, which made me feel less alone on my journey. Ultimately, I learned to see my journey as a gift and regained control of my life.

From my experiences, I want to share three lessons that helped me along the way.

Lesson #1 – Reframe your mindset

When faced with challenges, it's important to remember that you can change your situation. One way to do this is by shifting your mindset. We can develop greater resilience, creativity and problem-solving skills by focusing on opportunities for growth and joy in every struggle. This mindset can also help us find greater meaning and purpose. Some questions we can ask ourselves are: How can reframing our mindset help us find meaning and purpose in our lives? How can we identify our values and passions and

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use them to create a more fulfilling life? Overall, shifting our mindset to focus on opportunities for growth and joy within every struggle can lead to a more positive and fulfilling life, and help us find meaning and purpose in the challenge.

Lesson #2 – Cultivate gratitude

It's important to regularly reflect on the positives in your life and practice gratitude. When we live in gratitude, we tend to be more positive, happier and more content with our lives. It helps us to find meaning in our experiences, to be more compassionate and empathetic towards others and to cultivate stronger relationships. Living in gratitude can transform our mental, emotional and physical well-being. One tip for cultivating a grateful attitude, even amid difficulty, is to keep a gratitude journal. By writing down things you are grateful for, even the small stuff, you can help yourself focus on the positive aspects of your life. Write down at least three things you are thankful for each day.

Lesson #3 – Ask for help

This lesson emphasizes the importance of seeking help when facing challenges. It's not something to be ashamed of and doing so can give us the support and resources we need to improve our situation. No matter how difficult a problem may seem, there is often a solution, and asking for help can help us find it. Additionally, seeking help can make us feel less isolated in our struggles, and talking to someone who has gone through a similar experience can help us feel understood and supported.

Finding inspiration in difficult situations is not always easy, but it can have numerous benefits. Doing so can help you build resilience, creativity, perspective and empathy. By looking for sources of inspiration amid your struggles, you can find the strength and motivation to overcome your challenges and emerge stronger on the other side. Additionally, finding inspiration in difficult situations may lead to growth and new personal and professional opportunities.


Nathan Ebanks

I would love to hear from you.

Please send me an email: raisingspecialneeds@gmail.com.

Also, connect with me on social media: @raisingspecialneeds.

Until next time.

Christine Staple Ebanks is an experienced special needs parent advocate, researcher and educator who is deeply committed to domestic and international disability advocacy. With her strong passion and drive, Christine founded the Nathan Ebanks Foundation (Jamaica) and Raising Special Needs Inc. (U.S.) to help families and communities create more inclusive and supportive environments for children with disabilities. Through her engaging writing, inspiring speaking, and insightful consulting, Christine has worked closely with parents, governments and professionals across various human service settings in Jamaica and Dominica to ensure that every child with a disability has the opportunity to thrive. She holds a Master of Science in Human Services specializing in leadership and organizational management from Capella University.

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PURPLELENS

the future of web accessibility

OUR MISSION

We seek to improve the community of disabled people with their day-to-day basic tasks. We help institutes and governments around the world, and civilian businesses, achieve this goal by providing them with assistive technology solutions that really help navigate the digital and online world. Today it is possible with Purple Lens' assistive technology solutions to present an opportunity for small-medium businesses (SMBs) with existing websites to be accessible in a user-friendly way.

Today's accessibility products, services and implementation fall into extremes:

- Artificial vs. human intelligence
- Fully automated vs. hand-coded from scratch
- Easy vs. complicated implementation
- Cookie-cutter vs. custom
- Fast vs. time-intensive
- Expensive vs. more expensive

Additionally, the real-world user experiences, and levels of compliance delivered often don't live up to the promises implied.

Purple Lens occupies the unclaimed middle ground between these extremes. How? We offer the best of both worlds: a high-tech solution with a human touch.

Our semi-automated and guided do-it-yourself system is effective, flexible and affordable. It addresses the challenges small and medium-sized businesses face. As they work to grow an online footprint, SMBs may not have the resources (or desire) to:

- Have a team of specialized developers and accessibility experts on call
- Rebuild website properties from the ground up to achieve accessibility standards, and/or
- Maintain accessibility standards on a sitewide basis, over time

But our ultimate advantage may be our positive impact on site owners' revenue. Purple Lens makes it possible for site visitors with disabilities to successfully research, browse and complete inquiries and purchases — instead of abandoning sites in frustration.

Purple Lens is a mature platform and the result of three years of self-financed development. We serve:

THE COMMUNITY – We aim to achieve maximum usability for end users, the community, by providing a friendly and equal way to navigate the website.

WEB DEVELOPERS – We provide developers (website builders) and professional web accessibility consultants with development tools (accessibility builders) to ensure 100% accessibility.

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WEBSITE OWNERS – We offer affordable assistive technology solutions to website owners, thus removing cost barriers.

REGULATION – We always stay up to date so the solutions we provide adhere to WCAG and regulation guidelines.

We realize the inverse relationship between fancy sites and the interaction of users with different abilities. A seeing user is likely to click away from a straightforward site format, taking his business to a site that appears more enticing, while a blind user needs the site to lack fancy windows, colors, fonts, drop-down menus, pop-ups, etc. in order to operate the site. For this reason, we created options for any user to choose if and how he wants to employ our assistive technology.

When establishing full equity, we must provide options for people to choose what is best for their needs. This development, led by our fully blind head QA software engineer, was based on the feedback of the blind community because we know the best way to serve people is to ask what they need, rather than guess.

Further, we are unlike other overlay companies because we empower a human following our DIY plan to fine-tune the fit of the overlay to each website for optimal user accommodation.

PURPLE LENS OFFERS:

1. The ability to change preferences in the way the site looks

2. The ability to alter the entire site structure

This way, we are not failing any user with specific needs, but rather, offering autonomy for him to choose how he relies on us.

With Purple Lens, 80% of the client site will be automatically more user friendly, yet 20% of the site must be fixed with human awareness and make respective touch-ups to the system. We assist our clients to complete this step when they follow our DIY program to fine-tune our assistive technology with their website. Our troubleshooting scanner will reveal areas that may experience glitches. Re-integrating and simple coding steps will fix any errors.

Should a website owner need assistance, we have a hub of international web developers called Purple Zone, who are already experts in Purple Lens.

We are living in a world that is very progressive and advanced with technology and innovation, yet the web accessibility industry still has a long way to go. We decided that we, at Purple Lens, will set the standard of a more accessible world for everyone; we decided to be the most effective, affordable and productive solution for our clients and users.

Our dream is that web accessibility does not need to be something that is punishable according to laws or legislations. We want Purple Lens to help pave the way for accessibility becoming the norm that is a standardized expectation by all.

Whether you're the website owner, web developer or the end-user, Purple Lens' packages and tools are able to fit to website styles, product types and target audiences.

We fight hard to fulfill our mission statement. Equality is important, but inclusivity is essential.

WWW.PURPLE-LENS.COM

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Breaking barriers

Anis Jerbi is making his mark on the world stage

By Yuki Muraille

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Meet Anis Jerbi - a young, 20-year-old man from a small suburb in south Tunisia. Anis was born with osteogenesis imperfecta (OI), commonly known as brittle bone disease. Brittle bone disease is a genetic disorder that affects the bones, causing them to be fragile and easily broken. This debilitating condition impacts his ability to walk and he is mostly wheelchair-bound. From a very young age, he knew that his life would be different from other kids his age. He couldn't play sports or do other physical activities, but he was determined not to let his disability define him.

Anis' story is one of resilience and triumph. Despite the challenges that often accompany disabilities, he has been fortunate enough to have had a positive school experience. With a supportive family by his side, Anis navigated his way through elementary and high school with grace and dignity. He has, luckily, never been the victim of bullying, and has always felt respected and valued by those around him.

From the tender age of 13, Anis found solace in art and it quickly became his passion. He would spend hours creating intricate sketches and paintings, losing himself in the process. As he grew older, his love for art only grew stronger. He knew that he wanted to become an artist and create beautiful works of art that would inspire others.

Ana de Armas

Despite his disability, Anis was determined to pursue his dream. He worked hard, honing his skills and perfecting his craft. He is self-taught, learning from watching tutorial videos on YouTube. Anis started practicing every day, drawing everything from landscapes, to birds to still life. He found that creating art was a form of therapy and a way to express himself creatively. He would spend hours lost in his own world, sketching and shading, experimenting with different techniques and mediums, using mainly graphite and oil-based materials.

In his teenage years, Anis began to explore new forms of art, including portrait drawing. He found that

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he had a special talent for capturing the likeness and personality of his subjects. Anis started taking commissions from friends and family, and his reputation as a portrait artist soon spread. His portrait of U.S. politician, Alexandria Ocasio-Cortez, has achieved widespread notoriety. The painting of Ms. Ocasio-Cortez was actually his very first portrait, which he did when he was just 16 years old. Most recently, the Worcester County Orchestra, in Massachusetts, has commissioned him to create a piece that will be auctioned to raise money for charity.

Anis' art soon gained a huge following on social media, he began to receive positive feedback from people all over the world and his work was met with critical acclaim. His Instagram account has over 100,000 followers. Since he was 15, he has painted portraits of dozens of famous people including, Taylor Swift, Justice Ketanji Brown Jackson and Emilia Clarke.

Before making his decision to pursue his dream as an artist, Anis was contemplating studying political sciences. He is an astute observer of world politics, especially in the U.S., with a particular focus on the actions and legal troubles of former president Donald Trump. He avidly follows the latest news stories and analyses, staying up to date on the various criminal indictments and controversies surrounding the former president and his associates. Anis is not only interested in the legal aspects of these cases but also has a critical eye for the political and ethical implications of the actions of those in power. He is an active participant in discussions and debates surrounding these topics and is constantly seeking out new information to deepen his understanding of this complex and ever-evolving political landscape.

However, Anis is leaving the political field behind and focusing on his art. He enrolled

US politician, Alexandria Ocasio-Cortez

Beethoven

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Rosanna Arquette

at the Fine Arts Academy in Verona, Italy, and will begin his studies in art this September. He has a dream to be a world-famous artist and have his artwork displayed in art galleries around the world.

Anis' story is a testament to the power of determination and perseverance. Despite facing numerous challenges, he refused to let his disability hold him back. Instead, he uses it as motivation to pursue his passion and make a difference in the world. His art is a reflection of his indomitable spirit and his unwavering belief in himself.
If Anis can overcome his obstacles and

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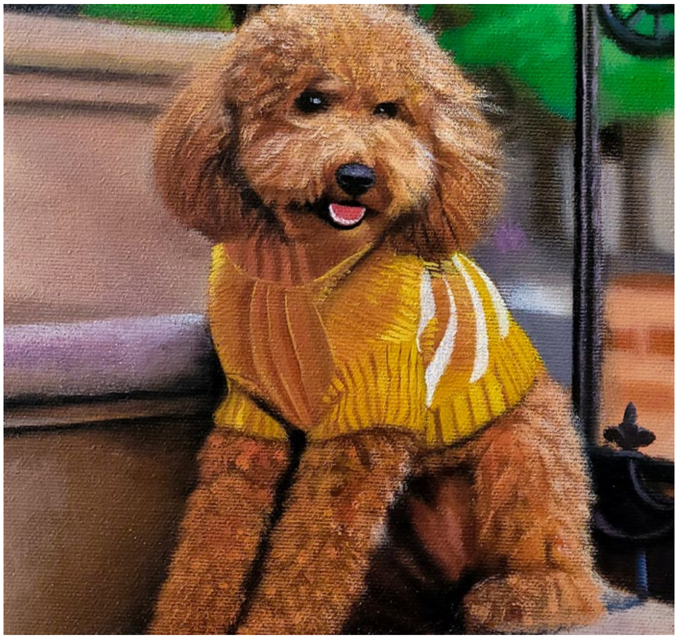
achieve his dreams, then so can you. No matter what challenges you face in life, always remember that you have the power to overcome them. Believe in yourself, work hard, and never give up on your dreams. Who knows? You might just end up inspiring others, just like Anis did.

Find out more about Anis, his artwork and how to commission art on his website: www.anisjerbi.com. Follow him on Instagram and support him on [Patreon](#).

Billie Ellish

Kathy Griffin @kathygriffin · 29m

Thank you so much @ArtistAJ17 for this amazing drawing. You are so talented! I did my best to recreate the facial expression. ❤



Rep. Eric Swalwell @RepSw... · 7h

Amazing piece of art. But who did @ArtistAJ17 depict? Me or Nelson? Thanks, Anis for this beautiful drawing.

[redacted]

19/04/2023

Sydney Sweeney

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A tale of two destinations

By Fred Maahs, Jr


The Royalton Antigua pool area


Fred Maahs, Jr.


JW Marriott Marquis Dubai pool area

I want to start by saying that I am a loyal Marriot guest. For more than 20 years, I have chosen Marriott properties based on the level of accessibility I have come to expect. I am a Lifetime Titanium Rewards member. There are other brands, such as Hilton, that I also choose when a Marriott property is not available. I just want to get that out of the way before I finish the rest of this story. For the past two years, I have been working with a group of disability rights and accessibility experts located throughout Central and South America as well as the Caribbean to plan and host the Fifth Continental CBR CBID Congress of the Americas and the Caribbean. It was held this past November on the island of Antigua at the beautiful resort, The Royalton, a Marriott property. We selected this property because of its location and overall accessibility. As with most large events, a sizeable sum was paid to host the more than one hundred attendees for the Congress. Many attendees came from other islands and countries. Some were invited guests from Antigua who were able to hear and witness the progress being made on behalf of people with disabilities.

The property is all-inclusive. My reservations were booked at least a month in advance. But when I checked in, I was told they did not have an accessible room for me and the two that they had were already taken. I politely told them I booked an accessible room, had the guarantee, and showed them my reservation confirmation printout. They insisted that they did not have any accessible rooms available, and I told them that I was not leaving the desk until they could give me the room I reserved which, by the way, cost over $500 per night! The front desk associate left, came back 10 minutes later and said my room was ready. Now I am not sure how they magically went from "no accessible room available" to "your room is ready," but I had my room. Or so I thought.

The first room they took me to was NOT an accessible or adapted room. I told them this would not work as I could not even get my wheelchair

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through the bathroom door. After about 30 minutes, they showed me another room. It WAS an accessible room with some exceptions. The configuration of the door and small hallway was difficult to navigate with a wheelchair and nearly impossible to open without putting lots of pressure on the door. I'm pretty strong so I don't know how anyone could easily open the door. The sink in the bathroom did not have enough clearance to position my knees underneath so I had to sit sideways to use it. The shower area was quite small. The bed was an appropriate height. There was an accessible large balcony that overlooked the lawn and a lagoon. At night, it was quite noisy from music being played in the outdoor lobby area and noisy neighbors. The beach area was about three hundred yards away from the main hotel building. There were no lifts for the pools and no beach mats to traverse the sand, but they did have a beach wheelchair. I did not use it and I do not know if the staff was trained to assist anyone who wanted to use it. There were sidewalks throughout the property that were easily navigable with a wheelchair. The only place I saw Braille was in the elevators. There were no assistive devices for people who are deaf or hard of hearing. And I did not see any quiet rooms for those who needed them.

A couple of hours later, a friend, Anthony Mills, who is a disability leader on the island of Nevis and a paraplegic who uses a wheelchair, tried to check into his reserved accessible room. He was told by the front desk clerk that his room was being used by someone


The Royalton Antigua - accessible room


The Royalton Antigua - accessible bathroom


The Royalton Antigua covered pathway between buildings


Fred and Anthony Mills

who did not have a disability and that they would try to locate them and ask them to move to another room. In the meantime, he was given a non-accessible room to freshen up in and rest. He went back to the desk a few hours later for an update. He was told that they had not located the guests and that he would need to check again the next day. The room he was using was not accessible. There was no space to get into the shower and not enough room to safely transfer to the toilet. UNSAFE! He returned the next morning and was told he would have to wait until the guests checked out the following night to get his accessible room! This is unacceptable and maybe even discrimination.

Here are my biggest issues with this property other than the game played during check-in and how Anthony was treated. Each night after our meetings, a group of about ten of us would try to get seated between 6:00 and 6:30 pm at one of the many restaurants on the property. We were consistently told that all of the tables were reserved, but hardly anyone was seated at tables. When we asked to make reservations, we were told that unless we were a Diamond Guest, we could not. So, how could all of the tables be reserved and not available every night while other people were walking up and getting seated? Many nights we could not get seated until after 8:00 pm. Sadly, what happened during our meetings for the Congress was more significant than any of the other issues experienced during our stay at The Royalton. Remember, a hefty sum was paid for meeting space, A/V equipment, and food for morning tea breaks and lunch. The Congress was a global meeting on accessibility and disability rights and services for people with disabilities. On day two of the Congress, one of our leaders took the podium and spoke to everyone in the room. He stated that he had been informed by management that, "some of our people have been taking too much food during the tea break or lunch." Wait, what?? Yes, management said that the employees at the food tables witnessed a few people taking an extra bottle of water or piece of fruit! Keep in mind that the food was already paid for, the people who were being singled out were local people with disabilities who were invited to attend, and THERE WAS ALWAYS PLENTY OF FOOD LEFT OVER! This announcement broke my heart and infuriated me. Antigua is not a rich island. The people who took water or a piece of fruit very likely were giving those food items to a family member who did not have enough to eat or drink at home. But seriously, is this the way guests are treated at an ALL-INCLUSIVE resort? The management should be ashamed of themselves for this kind of behavior!

Oh, and on a very insignificant note, not once was I greeted or thanked for being a Lifetime Titanium Rewards Member as is customary at every Marriott property. Nor did I receive an itemized printout of my charges when I checked out, even after asking.

Now, take all of that and compare that experience to a business trip I took two weeks later to Dubai. I was asked by His Highness Sheikh Ahmed Bin Saeed Al Maktoum, President of the Dubai Civil Aviation Authority, Chairman of Dubai Airports, Chairman and Chief Executive of Emirates Airline and Group, and his team to speak during the Dubai Accessible Tourism International Summit about accessible tourism for people with disabilities. Representatives from the Dubai government made arrangements for me to stay at the JW Marriott Marquis Dubai. When I arrived at the hotel, I was greeted by an entire team of managers, including "Captain" Yusef, a bellman who made sure that I had water and transportation each day, Mr. Hasham Alhaj, the Director of Loss Prevention and Government Relations, and Mr. Sajan Pallipurath, the Director of Rooms. They spent about 15 minutes with me after I checked in to explain the property and its amenities. What a wonderful way to be welcomed!

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Fred and Captain Yusef

Accessible bathroom

The property is a huge, two-tower, modern, elegant, and mostly accessible structure located on the Dubai River. Within 24 hours, each staff member I encountered at the pool, in a restaurant, in the lobby, you name it, greeted me with, "Hello, Mr. Fred. How is your day? Is there anything I can do for you? And thank you for being a Lifetime Titanium Rewards Member." WOW! Seriously, this was so nice. Admittedly, I do not like a lot of fuss wherever I go, but this was such a refreshing atmosphere to stay in during my fourth business trip to Dubai. The hotel was very accessible for people with mobility, sight and hearing disabilities. I spoke with the manager about considering a lift for the pool as they are planning to update the hotel, a bit surprising given its new look and feel. I also spoke with him about my experience in Antigua and he offered to provide training to management at The Royalton. I would like to return to this Marriott property again and experience the updates and enhancements made. The staff was friendly, helpful, and willing to take the time to learn what could be done to make future guests stays even more enjoyable. I hope that anyone reading this article sees it as a learning moment for the management and staff at The Royalton in Antigua. When I spoke with a Royalton manager about the treatment of people with disabilities and the ridiculous comments made about the food, I offered my consulting services to help train the staff and management about working and communicating with people with disabilities. As of this writing, no one has contacted me to take me up on that offer or to apologize for what happened.

Accessible bedroom

Dubai River

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Renee Bruns climbs to new heights, sets new records

American Renee Bruns tells us how she set a Guinness World Record for the most countries visited by a person in a wheelchair in a year.

AfA: Tell us a bit about yourself and what brought you to where you are today.

Renee: I was born with an undiagnosed skeletal disorder and started using a wheelchair full-time at the age of seven. Because of my disability, I started traveling around the country to see specialists when I was a young girl. Seeing different parts of the U. S. sparked an interest in traveling and when I was in the third grade, I expressed to my mom that I hoped to see all 50 states someday. We started taking family vacations each summer and would visit new states each year. By the time I was 16, my family and I had been to all 50 states.

In my early 20s, I started traveling internationally and quickly made it my goal to see all 195 U.N. member nations. In May 2022, I left my executive role at a Fortune 500 insurance agency to spend one year traveling full-time. I am coming up on my one-year anniversary and finishing my sabbatical year. At this point, I've been to 117 countries and all 7 continents (plus the 50 states). I'm not done traveling and still hope to get to all 195 countries, but I will be slowing it down a bit so I can launch the next chapter of my life.

AfA: Congratulations on winning a Guinness World Record for the most countries visited in one year by a person in a wheelchair. What was this experience like and what has it taught you about yourself and your life goals?

Renee: When I set out to see the world in May 2022, my ultimate goal was not necessarily the Guinness World Record. I really wanted to experience the people around the world and gain a better understanding of how we are all connected. A few weeks before I left, I sent a very casual inquiry to Guinness to see if they had any sort of a record I could break, knowing that it was unlikely that there were many disabled travelers doing what I was doing. We exchanged a few messages and the record I recently received was what we settled on: most countries traveled to in one year with a wheelchair. I had a bucket list and on it was, get a Guinness World Record. It's always been a very broad statement with no specific details on what the record would be, when I would get it, or how I would begin it. For me, receiving the record was one of the most monumental moments in my life. While it was a personal

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achievement, in many ways it gave me the chance to prove to others with limitations and challenges that outlandish goals are possible. There were many times in the past year that I told myself, "Stay the course. Do not give up." Even when I was feeling defeated or struggling, I kept powering through. I know now that I can do anything I put my mind to, and with hard work and dedication, the rewards at the end of that often-difficult journey are more impactful than I could have ever imagined.


China, Great Wall, November 2017


North Macedonia, June 2022

AfA: Your professional career began as an insurance executive. What encouraged you to leave your position for a year-long sabbatical to travel the world? What was your goal? What advice do you have for others thinking of doing this?

Renee: I had always wanted to take a year off work to travel the world. I had been saving for a trip like this for many, many years. We were coming out of a pandemic, and I was feeling very burnt out. I knew my performance at work would start to suffer soon and I knew I needed a change. I talked with my loved ones at length, and we decided this was the year for me to travel and redefine my future. While they did not travel with me, my family and friends were incredibly supportive and would meet me for a week or two along the way. My goal for the sabbatical was, of course, to travel and experience the world. But more importantly, I wanted time to reevaluate what the rest of my life and my career would look like. I was also struggling with my own inner demons and the struggles that come with living as a disabled woman. I needed to see that there were people in this world who could look past my wheelchair.

Once I got out into the world, completely alone, I found

Antarctica, November 2022

some of the most amazing human beings that I've ever met. My views of humanity have been refreshed and I am so much more confident with my disability, my future career, and who I am as a person. My advice for anyone who is considering this is to put together a plan to do it. That can include everything from planning financially to discussing it with your family and friends, to working with your employer (if they are open to you taking time off), to thinking about places that are accessible and what needs you will have in those places. Every step of the way will be incredibly scary—you can't escape that—but let yourself feel the fear and fight through it. We all deserve to have a better understanding of who we are so we can truly live our lives authentically. Society has a way of expressing what is and isn't acceptable, and as someone with a disability, it is

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Utah, USA, August 2019 with my siblings

Atlanta, USA, March 2020

even more uncommon to live this lifestyle. I am a big believer in making impossible dreams a reality. We all deserve to follow our passions.

AfA: You have experienced some amazing adventures during your travels. Of them, what is your most proud accomplishment to date?

Renee: One of my most favorite travel memories is when I visited Machu Picchu, Peru. It's absolutely not accessible and I knew it would be difficult physically and emotionally. I often get so frustrated when I cannot see landmarks and monuments, or sometimes even use restrooms in other countries, that I break down in tears full of anger and sadness. I knew this was a possibility when I went to Peru. My sister, Julie, and life partner, Tony, were traveling with me and they were more determined than me that we would all get to see Machu Picchu. For much of the tour, my sister carried me on her back. The entire staff at the site smiled and encouraged us to keep going, to see all the sites that we could. It was a beautiful place but more than anything, it was empowering to know that with the right people and the right mindset, we can do anything.

AfA: Of all the countries, locales and venues you experienced, what place would you recommend as a must-see for other travelers with disabilities?

Renee: The Nordic countries in Europe (Norway, Sweden, Denmark and Finland) are incredibly accessible and welcoming of disabled travelers. They are beautiful countries with amazing people and some fun culture too. I encourage just exploring the different cities on your own, stopping at museums, local restaurants, pubs, and chatting with the people. That is my favorite way to travel—meeting local people and wandering around aimlessly.

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Kyrgyzstan, July 2022

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AfA: What's next for you?

Renee: I am in the midst of launching a coaching and consulting business to help others aspire to follow their dreams and live authentically. There is a lot of work to be done in the disability travel space as well and I will continue to be an advocate for all things in this arena. More can be found on my webpage at reneebruns.net as I start to build out this new chapter in my life.

AfA: What advice would you give to your younger self?

Renee: Every single dream you have is achievable. So many people are going to tell you that it's not possible and you need to ignore those people. Only you can know what is possible for you.

AfA: What message would you like to share with the world about the importance of inclusivity and the power of blogging to unite people?

Renee: I'm a big believer that we all have a powerful story to be shared. I know that everyone has their struggles. Many of my struggles (like so many others) are visibly shared with the world, but there are others who are struggling with invisible disabilities too. For me, writing my experiences in words has allowed me to express a part of me that is more difficult to share vocally. I hope that my story and my words resonate with my readers, and I encourage everyone who wants to share their story to do so. The community that comes from story sharing is a wonderful place, and the self-discovery that comes from writing is so different from any other form of self-discovery. I also believe that sharing deeper parts of our experiences as disabled people allows others to see into a part of our world that isn't available by interacting in person.

http:// Snippets from the www

Improving vision and quality of life of individuals with intellectual disabilities

People with intellectual disabilities are seeing the world a little clearer thanks to a partnership with Special Olympics. Read the full article.

France has violated the rights of people with disabilities, rules Council of Europe

An international organization has ruled that France violated the European Social Charter by failing to guarantee the rights of people with disabilities. Read the full article.

Home loans for disabled buyers are widely available

The dream of owning your own home is possible, even on disability income. There are many government-backed loans and programs available to help. Read the full article.

Ironman creates new modified athlete divisions and rule alignment

The global IRONMAN competition is boosting inclusivity with new and modified divisions for people who are physically challenged or have an intellectual disability. Read the full article.

What Is the economic impact of hiring autistic, neurodivergent and disabled talent? Here's what you should know.

Want to increase productivity, problem-solving and innovation at your workplace? Hiring people with disabilities could be the answer. Read the full article.

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How AI tools Like ChatGPT can combat ADHD paralysis

AI tools are doing more than creating realistic images or conversations. For some people with ADHD, artificial intelligence is helping them stay focused. Read the full article.

With a little tickle, a new technology gives hope to stroke patients with paralysis

A procedure used to treat chronic pain is showing promise in helping some stroke patients regain use of their arms and hands. Read the full article.

This stabilizing beauty device is a game-changer for people with limited mobility

A cosmetics giant is developing a device to help people with limited mobility apply their own makeup. Read the full article.

It's 2023 and venues still don't understand how to be accessible for disabled people

The results of a survey out of Great Britain show that many venues lack an understanding of what accessibility truly means. Read the full article.

Molly Burke says you shouldn't wait to become disabled to care about accessibility

A social media influencer who lost her sight as a teenager is on a mission to change the way people view disabilities. Read the full article.

Parents of deaf children often miss out on key support from the Deaf community

By Pamela Renee Conley

An increasing number of deaf and hard-of-hearing kids in the U.S. are receiving cochlear implants – electrical conductors surgically inserted into the inner ear to stimulate the nerve responsible for hearing.

Fewer than 30,000 U.S. children had received cochlear implants by 2010, while an estimated 65,000 children had them by 2019. This is due to continuously improving medical and technological advances in cochlear implantation that make it cheaper and less painful to hear better than they would with other types of devices.

Yet most kids with cochlear implants still need significant help learning to understand and produce spoken language, much less learn material taught in lessons primarily meant for students who can hear. And they often struggle to fit in with peers who were born hearing, sometimes only finding a community that truly understands their life's journeys upon reaching adulthood and connecting with other people who were born deaf or hard of hearing.

When parents choose to get

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their child a cochlear implant, they are no doubt making the best choices they can with the information and understanding they have about growing up and living in a world where most people can hear.

But too often they miss out on key support for themselves, and for their kids, from the Deaf community, which I am a part of – as the deaf mother of a deaf son – and which I study professionally. People who are deaf or hard-of-hearing, and those with average hearing all use sign language – the most common of which in the U.S. is American Sign Language – to fully understand and express themselves in ways that go beyond speech, and help each other navigate the challenges presented in a hearing world.

Key materials leave out vital information

According to the U.S. Food and Drug Administration, some of the benefits of having a cochlear implant include being able to understand speech without lip reading, making telephone calls, watching TV and enjoying music.

Many professional websites maintained by hearing implant specialists boast that deaf and hard-of-hearing children can be successfully trained to speak and hear for full integration in their communities.

But these sources leave out key information, such as the common need for assistance in school even after getting a cochlear implant. Their primary focus, as with many consultations with hearing specialists, audiologists and speech therapists, is on helping deaf and hard-of-hearing children learn to listen and speak.

These efforts downplay or ignore the idea that there are other ways deaf and hard-of-hearing people can communicate, without hardship or difficulty. For instance, on the U.S. Centers for Disease Control and Prevention website section about screening for congenital deafness, the emphasis is on providing deaf and hard-of-hearing children early intervention services to avoid delays in learning to speak. Information on American Sign Language is reached only by clicking to another page and reading through a bullet list of technical jargon like "auditory-oral" and "cued speech."

A history of oppression

Over decades, even centuries, the Deaf community in the U.S. and around the world has been ignored, and even repressed, by mainstream hearing society.

As far back as the 19th century, educators of deaf people, such as telephone inventor Alexander Graham Bell, have tended to believe that speaking and listening are critical to functioning in the broader society. As a result, they have discouraged children from learning to sign, even though research shows that if kids can communicate effectively without speaking, they'll be more interested in learning speech.

This resulted in the methods used to teach generations of deaf Americans, including me, at schools for the deaf. I was not allowed to use American Sign Language in the classroom, but rather what was called the "Rochester Method," a combination of speech and fingerspelling.

Attendance at these schools, which are mostly residential, has been declining since the 1975 passage of the first federal law requiring public school systems to offer a range of education options for students with different medical or physical conditions, including hearing loss. One option was placement in mainstream schools with aides for assistance.

But public schools aren't always good at supporting deaf and hard-of-hearing students, who often struggle to follow along and fit in at school, including classrooms, hallways, cafeterias and recreational spaces – all of which can be very noisy, making it hard to distinguish one person's voice from another.

Little attention paid

All this history helps explain why there is so little research about the Deaf community, and why officials and families often don't know much about it.

There is no recent census data or systematic research on the use of American Sign Language. The best figure I've ever found was published in 2004, when the University of Iowa's Department of Speech Pathology and Audiology estimated that between 250,000 and 500,000 people in the U.S. – both deaf and hearing – used American Sign Language.

In my personal and professional experience, this group – the Deaf community – is made up of people who are well equipped to support the mental, emotional and social health of deaf and hard-of-hearing children and their families. They participate fully in society, holding a wide range of jobs unhindered by the limits on their hearing. And they have come to understand the role of deafness in their own identities and lives. The HeART of Deaf Culture website offers a selection of creative works that present profound insight for Deaf identity affirmation.

Yet deaf children who are taught to speak often struggle with language delays through childhood and into adulthood. Teaching them to sign, however, can help them fully express their thoughts, feelings and ideas, and find acceptance and connection with others with similar experiences. I believe these children deserve to be taught to sign, to celebrate their deaf identity.

And many parents of deaf children want more help from the Deaf community than they are able to find. A 2018 survey found that just 27% of hearing families with a deaf child were connected with deaf adults to help support their child.

One parent told the surveyors: "I wish we could have a deaf mentor or at least access to a program. I really would like to have a deaf person weekly in our home teaching us." And 8% of parents of deaf children reported wanting access to instruction in American Sign Language.

But there are not enough sign-fluent professionals available to meet that need.

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As parents make their decisions about how best to support their deaf and hard-of-hearing children, they will definitely encounter a large number of medical experts, speech therapists and other professionals who want to help their kids function in a world that places a lot of emphasis on hearing. But they should know there is another community available, too, standing ready to help their deaf and hard-of-hearing kids, with or without cochlear implants, gain deeper understanding of themselves and more fully develop their limitless human potential.

This article was originally published in The Conversation. Read the original article.

> **Over decades, even centuries, the Deaf community in the U.S. and around the world has been ignored, and even repressed, by mainstream hearing society.**
>
> \- Pamela Renee Conley

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Profoundly disabled Kiwi kid leads the world

Introducing Changing Places, New Zealand

By Shana Jones

Hamilton, New Zealand, 2017. Jenn Hooper, mother of two boys and Charley, a profoundly disabled 17-year-old-girl. A precious life worthy of the dignity so often taken for granted. A fierce determination to defy "acceptable" for an invisible sector of society.

It all started with a "twig":

When we realized how severe Charley was going to be, we realized that as soon as she was too big to lift without a hoist, she'd be housebound. We're a family package, so that meant we'd all be housebound. We wanted more for her - and for us.

Suddenly one day, something kind of "twigged". I kept finding myself saying, 'The world isn't set up for this level of disability'… And I thought, 'Well, actually, why isn't it? Let's change that'.

So, I started developing a room.

[So started Changing Places New Zealand, a charity that designs customized public restroom facilities for people whose high and complex care needs cannot be met by standard accessible accommodations. These facilities provide clean, dignified, and secure spaces in which the needs can be met. There are currently five rooms across the country with another five to be completed this year.]

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What does a Changing Places New Zealand room look like and what sets it apart?

Jenn: Changing Places in New Zealand differs from others worldwide [in Australia and the U.K.] because our rooms are designed by somebody who uses them. I use these rooms. I've checked my designs with hundreds of other people who need these rooms. I'm probably the only subject matter expert in the design of these rooms, from a user point of view worldwide.

The standards include: $12m^2$ (minimum) with a wall- or ceiling-mounted hoist, height-adjustable change table, privacy screen and a toilet set away from the wall.

We also put artwork in all our rooms to avoid that clinical feel. The layout gives users the function needed to perform the care. The artwork says they're genuinely cared about.

Access to our rooms is restricted to registered users to keep out people that don't need them or who might damage [the rooms] or themselves.

Who benefits from these rooms? Why?

Jenn: *The people needing the care:* They get to leave their houses and participate in activities and outings like everyone else.

The carer: Specialized equipment

with adjustable height, everything within easy reach and a privacy screen around the toilet. These are the first rooms to consider the carer's needs as well.

Asset owners: If there are three shopping malls and only one has a Changing Places room, people like me are going to shop there and be able to stay longer.

How do you measure the impact of your fully accessible public bathrooms?

Jenn: If a room has been used three times in a month, that's a win. That's three times that somebody like me, with someone like Charley, was able to care for them in a safe and dignified way.

How do I measure the success? By being safe in the knowledge that Changing Places gives those that need these rooms the confidence to leave their houses. Even if they don't use the room, they know they can.

How can people support Changing Places?

Jenn: Share our Facebook page and website and invite us to [give] speeches to community groups. Suggest that we present to accessibility advisors, local government, businesses or at conferences. Help us not be quite so invisible. Or donate money, as we are not government funded like elsewhere in the world.

How do you envision the future of your charity and the role it will play in improving the lives of people with disabilities?

Jenn: Our aim is to have Changing Places bathrooms within ten minutes' drive of each other across the country. This would give everyone real equity and freedom to participate in communities.

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We’d like to change the culture of 'better than nothing' to 'nothing better'. Minorities have almost been groomed into having to feel grateful for any little bone they've been thrown. These rooms are my way of changing that culture. If I can do that here, maybe it can help inspire change for other minorities.

Hamilton, New Zealand, 2023. Jenn Hooper, mother of two boys and Charley. A precious inspiration who, “is changing more lives than anyone I know and showing the world that you don’t have to accept what somebody else says is good enough for you.”

It started with a “twig”, but Charley’s story continues to impact lives and inspire change. “I didn’t want her to end up as only this preventable tragedy. I didn’t want her story to end like that. And now it won’t.”

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A librarian recommends 5 fun fiction books for kids and teens featuring disabled characters

By Rebecca Weber

Disability representation is slowly increasing in books geared toward children and teens.

In 2019 the Cooperative Children's Book Center at the University of Wisconsin-Madison – a library that allows teachers, librarians and researchers to view books before deciding which ones to buy – found that only 3.4% of books it received from publishers included a character with a disability.

The CCBC website recently added a diversity statistics book search with categories for physical, cognitive and psychiatric disabilities or conditions. In 2022, the center received 165 books that included a character with a disability, up from 126 in 2019.

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As an academic librarian who also has a disability, I'm happy to recommend the following five children's books that treat disability as a part of life and living.

(1). **Maria Gianferrari** (author), **Patrice Barton** (illustrator), **"Hello Goodbye Dog"** (2017)

Moose loves her girl Zara – and she hates saying goodbye. When Zara goes to school, Moose wants to go too and keeps showing up, even though dogs aren't allowed. What will Zara, her parents, the principal, her teacher and the other kids in Zara's class do?

This fun picture book is perfect for preschoolers and kindergartners. While Zara uses a wheelchair, her disability isn't the focus of the story. Readers will have fun seeing what Moose is up to this time and learn that sometimes dogs can go to school.

(2). **Kelly Fritsch, Anne McGuire, Eduardo Trejos, "We Move Together"** (2021)

All bodies are different – whether disabled or nondisabled – and everyone matters. These are the themes of this easy reader. With its vibrant illustrations, simple text and portrayals of a wide variety of people, "We Move Together" is a great introduction to the concepts of community, disability and accessibility for readers in kindergarten through second grade, while older readers can learn more about accessibility and disability rights in the glossary.

(3). **Darren Lebeuf, Ashley Barron, "My City Speaks"** (2021)

A girl who is blind and her dad explore the city and its sounds. They wait at a crosswalk, play in the park, take a bus, avoid a rainstorm and eat ice cream. Words and pictures help the reader feel the rhythms of the city. Readers in preschool through second grade will enjoy this story because of its colorful illustrations and rhythmic text.

(4). **Ali Stroker, Stacy Davidowitz, "The Chance to Fly"** (2021)

Nat Beacon is the new girl in school with a talent for wheelchair racing, but when the 13-year-old gets the chance to audition for a summer production of the musical "Wicked," she knows the theater is where she belongs. How does she tell her parents?

This novel for readers in fifth, sixth and seventh grades explores themes of independence, friendship and first love.

(5). **Melissa See, "You, Me, and Our Heartstrings"** (2022)

Daisy and Noah are two of the best musicians in their high school orchestra and dream of attending Juilliard, the prestigious performing arts school in New York City. When their performance of an original piece goes viral, they have to deal with the world's interpretation of them and their relationship.

This rom-com of a novel combines disability representation with themes of friendship and romance. Great for readers in grades nine to 12.

For more books featuring characters with disabilities, check out the American Library Association's Schneider Family Book Award. For a wide variety of diverse titles, see We Need Diverse Books.

This article was originally published in The Conversation. *Read the* original article

In the know

with Angela Lynn

Deaf etiquette

How much etiquette do we need to respect and understand each other without offending or patronizing others? Etiquette is essential to fostering mutual respect and understanding while avoiding any sense of superiority or condescension. "Etiquette is the art of seeing others and respecting them", as described by Chinese philosopher Yixing Zhang. Etiquette can be fun or challenging when it comes to cultural differences. Interacting with an unfamiliar culture can be challenging, especially when it comes to etiquette in general.

As a world-traveler, I have a lot of experience in this area. The first one happened in Malaysia. Being American, I am accustomed to eating with both of my hands. However, during my first night in Kuala Lumpur with my Malaysian Deaf host family, I quickly learned that eating with two hands was not the norm around the world. As I sat on the floor eating dinner, my host family looked at me strangely. I soon realized that everyone held their food in one hand. The other hand was exclusively for bathroom use. It was then that I learned about Malaysian dining etiquette.

During my visit there, I discovered many aspects of Malaysian etiquette beyond dining, and I realized that American and Malaysian cultures differ significantly regarding customs and traditions. It was an eye-opening experience that taught me the importance of being aware of and respecting cultural differences.

My experience with my Deaf host family, taught me that etiquette is an essential aspect of communication and cultural understanding. It is crucial to be aware of and respect the customs and traditions of the people we interact with, especially when we are in an unfamiliar culture. By doing so, we can bridge cultural gaps and build meaningful connections with people from different backgrounds.

In this article we will explore the meaning of proper communication etiquette

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and how to approach and use it effectively. The question is this, how can we communicate effectively with people from different cultures while respecting their communication etiquette? From experience and research, it appears to me that the best way to display proper etiquette is to be patient and allow other persons time to process information. This is especially true when communicating with the Deaf, Hard of Hearing, and Deaf Blind People.

With that in mind, it is important to be mindful of the time it may take to communicate effectively. For example, a simple question that takes a hearing person a few seconds to express and comprehend, may take a Deaf person several minutes to receive, understand and respond to the statement or question. Why? Before they can respond several things must occur:

1. The receiver must wait for the speaker to complete their statement.

2. If they are lipreading without the assistance of an interpreter, they have to make sure they understand what was said.

- Did the speaker say, "fifteen or fifty" or did they say, "six or sex"?
- Take a second to look at yourself in the mirror and say those words (six and sex). If you really want to challenge yourself, try this: fore, for and four. Without sound, six and sex look very similar with mouth/lip formation.

3. If the hearer is relying on an interpreter, once the statement is made, or question asked, the interpreter digests the information and then relays it to the Deaf person.

- The receiver must wait to hear the whole sentence before they can reply.
- Once all of the information is received, the Deaf person can then reply to the statement or question.

Deaf community: Don't assume that all Deaf people use sign language or lipreading:

- Be respectful and treat them as equals with proper accommodation, if needed.
- Face them directly and maintain eye contact.
- Speak clearly and at a normal pace and avoid shouting or relying on the interpreter. Use visual aids or gestures if needed.
- To respect their communication preferences, ask if they need an interpreter or if they prefer written notes/papers, etc.
- When in a group, make sure everyone is included in the conversation.

Hard of Hearing community: Don't assume that all Hard of Hearing people have the same hearing and speech abilities.

- Speak clearly and face the person directly, not the interpreter.
- Reduce background noise or move to a quieter location.
- Don't shout or overemphasize words because it can distort speech and lipreading ability.
- Avoid covering your mouth or speaking while chewing.
- Use visual aids such as gestures or written notes if necessary.

Deafblind community: Don't assume that all DeafBlind people have the same hearing and vision loss. There are different degrees of hearing and vision loss:

- Use a gentle touch to get their attention, but never startle them. Always identify yourself when you approach them, even if you have met before.

- Use clear, simple language when communicating or body gesturing (tactile communication) and speak directly to them. If they use a communication device or an interpreter, address them and not the interpreter or device.
- When communicating through touch, use gentle touches on the arm or hand, and give clear and concise messages.
- Use descriptive language to explain visual information, such as the layout of a room or the appearance of a person.
- Use a reliable form of communication, such as email or text, to communicate important information in advance.

Hearing community: Don't assume that all Hearing people understand the etiquette of their own culture.

- Use clear and audible speech when communicating with others and face them directly to facilitate lip-reading.
- Avoid interrupting or talking over others and show active listening by using appropriate nonverbal cues.
- Be aware of your surroundings and adjust your behavior accordingly, such as lowering your voice in quiet places.
- Be respectful of others' personal space and avoid touching without permission.
- Show respect for others' beliefs and cultural practices, even if they differ from your own.

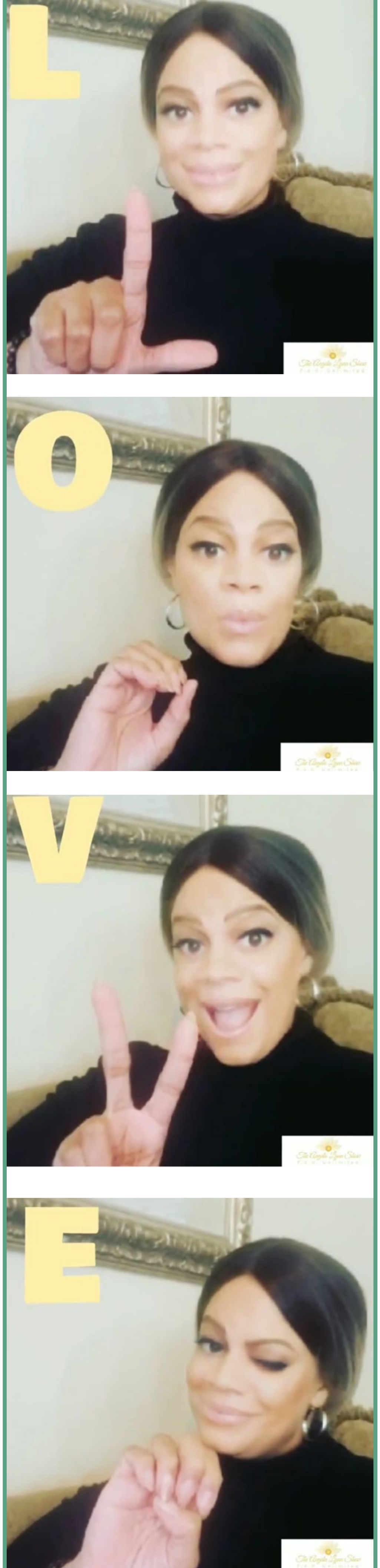
Additionally, it is important to remember that communication is a two-way street. Both parties should make an effort to understand and accommodate each other's needs.

By practicing good communication etiquette, we can build stronger relationships and foster a more harmonious and inclusive community.

If you would like to learn more about the Deaf Culture and Community, please do not hesitate to contact me at:

angelalynn@
theangelalynnshow.com

Angela Lynn



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Understanding some of the top things Deaf Individuals find offensive

Assuming all deaf people read lips

Not all deaf people can lip read and it's important to not make assumptions about their communication abilities.

Speaking loudly or slowly

Deaf people are not hard of hearing, and speaking loudly or slowly does not help them understand better.

Not providing closed captioning

Closed captioning is crucial for deaf individuals to access audiovisual content and it's important for businesses and event organizers to provide this accommodation.

Interrupting a deaf person's sign language interpreter

Interrupting a sign language interpreter can be disruptive and prevent the deaf person from fully participating in a conversation or event.

Not making public spaces accessible

Deaf people have the right to access public spaces and events, and it's important for these spaces to have appropriate accommodations such as sign language interpreters and accessible technology.

Using gestures instead of sign language

Gestures are not a universal form of communication and can be confusing for deaf individuals who use sign language.

Not accommodating deaf children in the classroom

Deaf children have the right to a full education and it's important for schools to provide appropriate accommodations such as sign language interpreters and assistive technology.

Refusing to learn sign language

Refusing to learn sign language shows a lack of respect for deaf individuals and their culture.

Using stereotypes or making fun of deaf people

Deaf people, like all individuals, deserve to be treated with respect and dignity. Using stereotypes or making fun of deaf people is harmful and offensive

> **I think the biggest misconception is that people think deaf people are not able to do things.**
>
> - Nyle DiMarco

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TravelAbility partners with nation's # 1 Hospitality Management College to change the way travelers with a disability will be treated in the future

TravelAbility is delighted to announce a partnership with the Rosen College of Hospitality Management, which is part of the University of Central Florida, to develop TravelAbility: Filling the Accessibility Gap in Hospitality. This self-paced learning module will be part of the college's experiential education program that is a requirement of graduation for all 3000 students.

"Perhaps more than any of the other projects we developed over the past four years," said Jake Steinman, Founder and CEO of TravelAbility. "This collaboration has the potential to make the most impact as it will infuse a new generation of hospitality supervisors and general managers with the awareness and empathy necessary to not only change the way people with disabilities are perceived, but also how they are treated."

"All 3,000 plus students at the Rosen College of Hospitality Management are introduced to the wider societal challenges that impact our industry through their courses, our incredible Internship program, and the opportunities to engage through their P.R.E.P. activities," commented Alan Fyall, Associate Dean of Academic Affairs, Rosen College of Hospitality. He added, "Our partnership with TravelAbility represents an important milestone as the travel industry awakens to the significance of travelers with a disability and the steps required to both welcome and accommodate them in a seamless manner."

TravelAbility will be contributing its expertise as well as content from The Accessibility Playbook, a copyrighted compendium of business cases, tips, products, innovations and 99 videos from prior conferences and events. The Rosen College of Hospitality Management was rated the #1 academic level tourism program in the U.S. and #2 in the world.

What is the Accessibility Gap?

Every disability has a spectrum. The Americans with Disability Act (ADA) was written for the median. That means that even if hotels, attractions and restaurants are fully compliant, they still work for only 50% of the people. The Accessibility Gap can be addressed by gathering and showcasing information online, providing training about accessibility needs and providing adaptive technology and innovations.

The course will begin with the spring semester and allow the next generation of travel industry executives, meeting planners and event managers to learn how to be welcoming to all guests.

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Talking with Tara Llanes

Tara enjoyed a successful professional mountain bike career as a five-time U.S. National Champion, an X-Games gold medalist, and multiple World Championship medalist before a bad crash. She went on to a successful professional career in adaptive cycling, tennis and basketball. She recently opened up to Accessibility for All.

AfA: Tell us a little about yourself and what brought you to where you are today.

Tara: I grew up in Orange County, California and had a pretty great childhood. I was raised by a single mom who kept me busy by putting me in all the sports. I ran track, rode horses, played softball, basketball and raced BMX and mountain bikes. Once I got to high school, I narrowed it down to basketball and our team went on to win multiple league and state championships. Then in my junior year of high school we won a National Championship. I didn't play my senior year and instead put my focus into racing mountain bikes. I moved to Colorado and wanted to make it as a pro.

After a successful professional mountain bike career as a five-time U.S. National Champion, an X-Games gold medalist, and multiple World Championship medalist, I had a bad crash. On Sept. 1st, 2007, the crash in Vail, Colorado led to a broken neck and back. I went through a few years of physio and, while still recovering, I ran into a former girlfriend. We started seeing each other again and eventually got married. I moved to Canada where she was really the only person I knew. It was a

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very difficult transition for me especially still being so new to spinal cord injury. I had just started to meet friends in the SCI community in Southern California when I decided to move to Canada. In retrospect I should have taken more time to work through some things, but hindsight is 20/20. In the end things didn't work out with my ex-wife, but we remain very close. I have since met my current girlfriend and we've been together for the past two and a half years. I look forward to many more with her.

It took many years for me to have a sense of identity again after my crash and to feel confident with who I was as a person. During those first five or so years of living in Vancouver, I didn't play or compete in any sport. It was the longest I'd ever gone in my entire life of not competing. It wasn't until I started to play wheelchair tennis that I started to feel like me again. I played tennis full time for about five years and ended up winning a singles and doubles Canadian Championship. From there I had started playing a bit of basketball. I didn't realize how much I missed playing on a team. I trained hard and tried out for the National team in 2018 and made the team. Ever since then I've played for the National team and was part of the 2019 ParaPan Am and the 2022 Commonwealth gold medal teams and went to my first Paralympics in Tokyo.

When I was in the hospital after my crash, my mom used to always tell me that things happen for a reason. I never believed her until years and years later. It wasn't until I started playing tennis and then basketball that I really got it. This is exactly where I'm supposed to be. This injury has taught me patience and more patience. It's opened opportunities for me that I never thought I'd have, and I want to take it all in. I'm not

scared anymore of the what ifs in life. It's taught me to embrace them and know that it's all for a reason.

AfA: Congratulations on being part of the Paralympic Games in Tokyo in August. When did you first decide to become a Paralympic athlete?

Tara: I probably wanted to be a Paralympian from the first time I picked up a tennis racket. I'd heard of the Paralympics before that but never thought much about it. I did compete for the U.S. in handcycling after I was hurt but even then, I never considered the Paralympics. It wasn't until I moved to Canada and started playing tennis. I don't know why I necessarily thought that, because I wasn't great at tennis, but I kept working at it and was making progress. It wasn't until I started playing basketball though that I thought it was a very viable thing.

AfA: What is life as a Paralympic athlete like? Can you walk us through a typical day of training leading up to the Paralympic Games? Are there any significant moments or achievements that stand out in your mind?

Tara: We train hard for about ten months out of the year, depending on where we live and how many majors we have that year. Things for me have changed a bit, being that I'm a more experienced athlete. Currently I'm training for Paris 2024, which is the next Paralympics and I need to be aware of my longevity. Instead of being on court five to six days a week like I was prior to Tokyo I am now on court three to four days a week with three lifts per week. On the days I'm not on court I try to do more body work and watch game film. I'm still learning but it doesn't take a toll on my body. We as a team have done some amazing things but I'd say the ones that stand out in my mind are the ones where we are playing as one. Even in those moments where we're losing, I always walk away feeling great inside and proud when we're playing as a team.

AfA: Besides wheelchair basketball, what other adaptive sports do you enjoy?

Tara: I really do have fun playing tennis and it's come up a lot lately, which makes me want to get back on court. I also enjoy riding my adaptive mountain bike. I've been sit-skiing but haven't done it for a few seasons because I didn't want to get hurt before Tokyo.

AfA: Tell us about why and how your company, Tara Llanes Industries came to be.

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Tara: I started my company in 2014, when adaptive mountain biking was still in its infancy stages. I'd moved to Vancouver in late 2009 and had been here for a few years when a couple friends wanted to get me back on the mountain. They contacted a company in Poland called Sport-On that made some of the most technically advanced adaptive mountain bikes on the market. I'd had my bike for about a year and any time I was on the trails people would ask me about it and say that they had a friend or knew someone that would love to ride one. I got in touch with the owner and let him know there was a real need for adaptive mountain bikes like this in Canada and that I'd love to start selling them here. It turned out that I'd met the Canadian rep when I was still living in California because he was living in the state as well. I was able to get the blessing of the rep to take over all of Canada. At that point I had to figure out how to run a business!

I had no idea how to run a sales business. I learned a lot from my ex who had been the B.C. sales rep for Shimano for quite some time. It was A LOT of trial and error. From the beginning, though, I always believed that so much of it was about working with adaptive organizations. There are many reasons for that but soon after I started working with Whistler Adaptive and it's been a great partnership. It's now 2023 and adaptive mountain biking has grown a ton and I don't see it stopping any time soon.

AfA: How does it feel knowing you are an inspiration and mentor to other wheelchair users?

Tara: I prefer to use the word

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mentor rather than inspiration. To me inspiration is an overused word in our community. I have gone through massive swings of identity, worth, confidence and ability since getting hurt. I don't claim to be a mentor either. I'm just doing the best I can and what feels right. Over these past 16 years in a chair, I've watched others lead a life of happiness while I struggled daily and a lot of times, hourly. It's taken so many years of fighting to get back who I was and to truly lead a life of laughter and love and that's all you want for people. I'm thankful for each day that I get to learn, create memories, travel, love deeply and laugh ridiculously hard.

AfA: What is your proudest accomplishment to date?

Tara: You might be looking for a sport-related answer to this question, but for me it might just be moving to Canada with no real support system other than my ex. I had all my friends from before my injury, my mom, my family, and had just started to cultivate a great support crew of friends in the disabled community and then I moved. I think having those friends in the disabled community was almost the most important because they were the first group of people back at home that I could talk to about anything and everything and I knew they KNEW exactly what I was going through. I needed that the most right in that moment. In the end and after a lot of difficult years I was able to find myself all over again here in the Great White North.

AfA: What can we expect to see from you in the next year?

Tara: In 2023, we have two majors—which isn't normal. We usually only have one major. A major is either a World Championships, ParaPan Am Games or Paralympics. Because Tokyo 2020 was pushed to 2021 we now have two majors in one year. The World Championships in Dubai in June determine how many spots a zone will get in the Paralympics. A zone is the Americas, Europe, Africa and Asia/Oceania. So, you want your zone to place well at Worlds.

The second major we have are the ParaPan Ams in November in Chile. This is big; the top two teams that place at this event go to the Paralympics. If you place third, you don't go. It's a big year for us with a lot of travel so I'll either be on a plane, training or at home sleeping. Lol.

AfA: What advice would you give to your younger self?

Tara: To enjoy every moment. Enjoy the little things you get to do with your teammates. Enjoy the wins, the losses and the ridiculous moments in between—because you don't get those back. I have a much better understanding of that now, but it's taken me a long time to appreciate them. It's hard when you have a goal in front of you and that is all you see. Sometimes that hinders you from seeing the present. I'm thankful now that I focus on the present.

AfA: What message would you like to share with the world about the importance of inclusivity and the power of sports to unite people?

Tara: I believe wheelchair basketball to be the most inclusive para sport out of any para sport. The reason for that is because we allow minimally disabled people to play. What that means is that people that have knee, hip or ankle injuries that deem them unable to play stand-up basketball to be classifiable. If they are classified in our sport they can play at the national level. These are players that would have most likely never found wheelchair basketball. They are players that can walk but can't play able-bodied sport. We as everyday wheelchair users and amputees get to show them what our everyday looks like. It's a second hand look at the struggles of everyday life and travel. What better way to spread that word?!

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Tara Llanes Industries
www.tarallanesindustries.com

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Under-diagnosed and under-treated, girls with ADHD face distinct risks

By Rodrigo Pérez Ortega

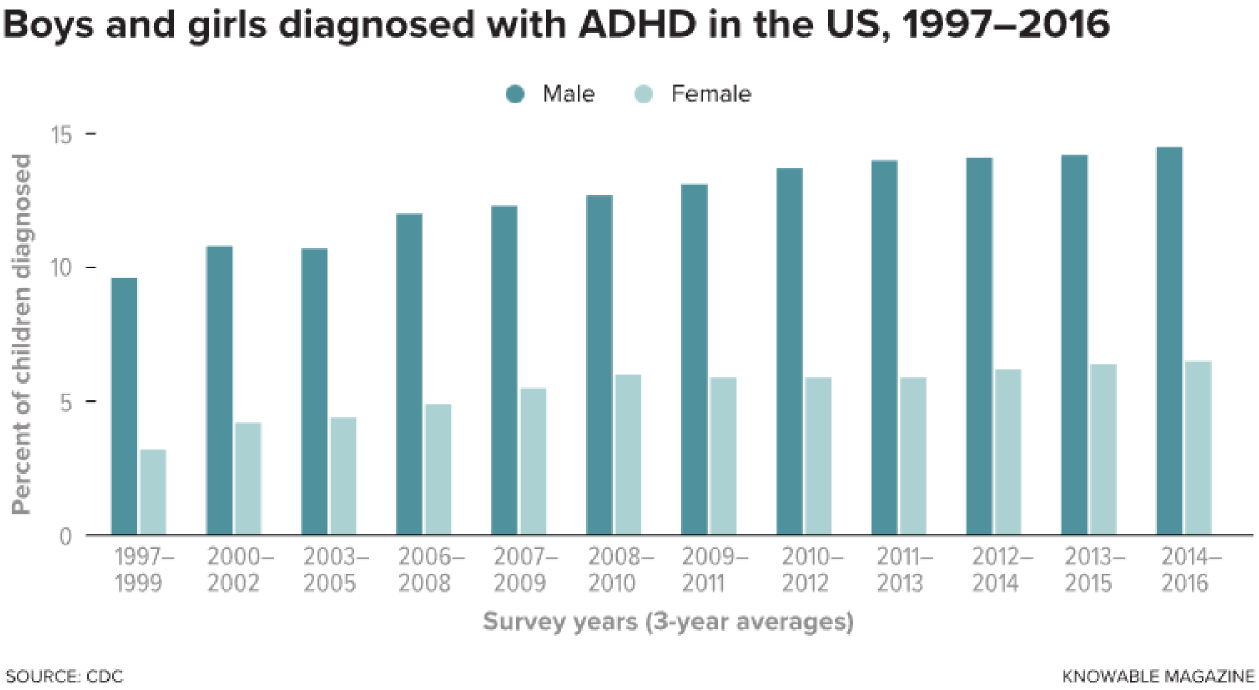
It took a long time to figure out how attention deficit/hyperactivity disorder presents in girls and women and the problems it can create. A pioneering study helped change that, but the condition is still often missed.

Anxiety. Depression. School failure. Self-harm. Unemployment. Unplanned pregnancies. Even an increased risk of early death.

The risks and toll of suffering that can come with having attention deficit/hyperactivity disorder, or ADHD, is huge, counted annually in billions of dollars in lost productivity and health care spending and in untold frustration and failure.

Yet despite more than a century of research and thousands of published studies, ADHD — marked by distraction, forgetfulness and impulsivity — remains largely misunderstood by the public. This is especially true when it comes to girls and women.

Over the past few decades, pediatricians, teachers and parents have gotten a lot better at spotting ADHD in girls. In the 1990s, scientists believed it was as much as nine times as common in boys, and very few girls were diagnosed. Today's diagnosis rate has narrowed to 2.5 boys to every girl.



The diagnosis of ADHD in the United States has surged in recent years, though current numbers are probably higher than its true prevalence. Estimates suggest that worldwide, 5 to 7 percent of youth have ADHD. The higher rates of diagnosis in the United States are probably due to several factors, including shifts in educational policies that emphasize student test scores and changes in medical benefits coverage.

Still, an old problem persists. Whereas many boys with ADHD are normally more physically restless and impulsive, traits clinicians refer to as "hyperactive," many girls with the disorder may be more introverted, dreamier and distracted — or in clinical jargon, "inattentive." In part due to these subtler symptoms, experts suspect that many girls with ADHD are still escaping notice — and missing out on treatment.

"Who gets noticed as having ADHD?" asks Stephen Hinshaw, a psychologist at the University of California, Berkeley, and a leading researcher on ADHD in girls. "You get referred if you're noticeable, if you're disrupting others. More boys than girls have aggression problems, have impulsivity problems. So girls with inattentive problems are not thought to have ADHD." Instead, he says, educators and others assume the problem is anxiety or troubles at home.

Hinshaw began studying girls with ADHD in 1997, in a federally funded project that became known as the Berkeley Girls with ADHD Longitudinal Study (B-GALS). As he and fellow researchers followed their subjects into womanhood, they found that girls with ADHD have many of the same problems as boys with the disorder, and some extra ones.

Escaping notice is just one of girls' special burdens. Girls and women, in general, engage in more "internalizing" behavior than boys, Hinshaw says, meaning they tend to take their problems out on themselves rather than others. Compared with boys who have the disorder, as well as with girls without it, girls with ADHD suffer more anxiety and depression.

PRODUCED BY HUNNIMEDIA FOR KNOWABLE MAGAZINE

Another key longitudinal study on girls, led by Harvard psychiatrist and scientist Joseph Biederman, has found that major depression in teen girls with ADHD is more than twice as common as in girls without the disorder.

The studies show that, as a group, girls with ADHD are also far more prone than boys with ADHD or other girls to self-harm, including cutting and burning themselves, and to suicide attempts. Moreover, whereas teenage boys with ADHD are more likely than girls with the disorder to abuse illegal drugs, the girls face a higher risk of becoming involved with violent partners.

Another major problem for girls with ADHD is risky sexual behavior that leads to strikingly high rates of unplanned pregnancies. Research has shown rates of more than 40 percent, versus 10 percent for young women without ADHD. In the most recent B-GALS update, published in 2019, Hinshaw and UC Berkeley psychologist Elizabeth Owens linked unplanned pregnancies to lower academic achievement earlier in life.

"Girls and women definitely blame themselves more on a daily basis," says Ellen Littman, a clinical psychologist in Mount Kisco, New York, who writes and speaks frequently about girls and women with ADHD. "If boys do badly on a test, they might say, 'What a stupid test,' while girls tend to say, 'I'm an idiot.' Girls have shame about feeling different, confused and overwhelmed, but they're often very good at hiding it."

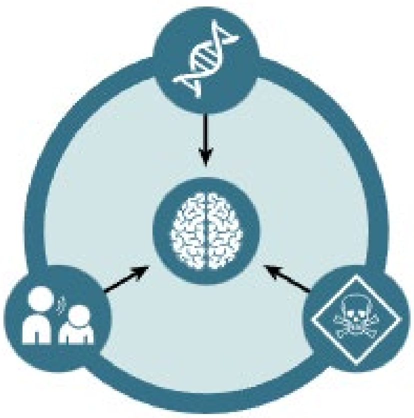
Attention control

ADHD is conservatively estimated to affect more than 6 million US children and 10 million adults. Most with the disorder have normal intelligence — although ADHD has been associated with slightly lowered IQ scores, Hinshaw thinks this is related to the way IQ is evaluated. Some with ADHD have super-high IQ scores, he says.

Many with ADHD describe an ability to focus intensely when interested, and value their creativity. (The research on creativity, Hinshaw says, is mixed, leaving open the questions of whether ADHD

Many factors influence ADHD development

ADHD has a strong heritable component and biological and environmental factors can exacerbate and propel its course



INHERITED GENETIC VULNERABILITY
- Inattentive, unfocused, impulsive behavior patterns

BIOLOGICALLY MEDIATED RISK FACTORS
- Low birth weight
- Prenatal exposure to toxins, such as alcohol
- Childhood exposure to toxic chemicals such as lead, pesticides and phthalates

PSYCHOSOCIAL RISK FACTORS
- Difficult parent–child interactions
- Unhealthy peer relationships
- Unequipped school settings

SOURCES: CHILDMIND.ORG; S. HINSHAW / *AR CLINICAL PSYCHOLOGY* 2018 KNOWABLE MAGAZINE

ADHD emerges from a suite of factors, including both biological and environmental influences. Discordant family and peer interactions and a poor fit in the educational environment can maintain and promote ADHD symptoms.

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helps people productively think outside the box, or whether people with the disorder are generally too disorganized to benefit from their unusual ideas.)

Some experts, including Hinshaw, think the name ADHD is not that accurate. He sees the condition as more of an inability to control attention, especially in changing situations, rather than as a deficit per se.

There's no doubt about the dark side, however, for both girls and boys. A recent study by Russell A. Barkley and Mariellen Fischer compared 131 young adults with ADHD to 71 control cases, using a life insurance actuarial model to predict estimated life expectancy. The results, published in July 2019 in the Journal of Attention, show that those with the most severe form of ADHD could see life expectancies reduced by as much as 12.7 years. In explaining that finding, Barkley, a child psychologist and researcher at Virginia Commonwealth University Medical Center, points to studies showing that children with ADHD are less careful and conscientious, more likely to follow unhealthy diets and be overweight, and more prone to suicide. Other studies have also found some increased risk of early death.

Beyond the many misperceptions about girls with ADHD, another popular myth is that ADHD is limited to children. Hinshaw, Barkley and other researchers have shown that at least half of those diagnosed in childhood continue to have symptoms of ADHD as adults. Indeed, in recent years, Hinshaw has found, women have been seeking diagnoses in nearly equal numbers as men, often after they notice signs of the strongly hereditary disorder in their children.

While watching these trends, Hinshaw and other researchers have been calling on teachers and parents to get better at identifying girls who are struggling and to develop interventions that strengthen academic performance, build self-esteem and help girls avoid risky behaviors.

Trouble in the classroom

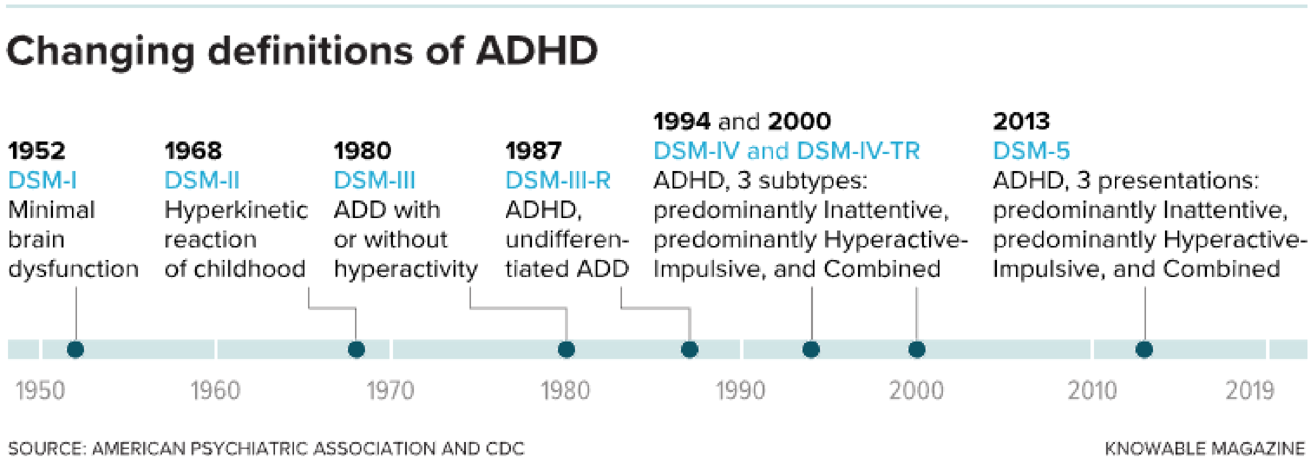
Despite a widespread assumption that ADHD is a late twentieth century phenomenon, it was more than two centuries ago that the Scottish physician Albert Crichton described an "unnatural or morbid sensibility of the nerves," causing extraordinary distraction. Writing in 1798, Crichton proposed that what he called "the disease of attention" could be due to heredity or accident. As compulsory education spread throughout Europe and the United States, children who had trouble paying attention in an institutional setting were at an increasing disadvantage, notes Hinshaw.

The expansion of public schools meant that "every kid had to go to school," Hinshaw says. "And guess what? A remarkably consistent percentage of kids in Europe and the United States have particular problems focusing, sitting still and learning to read."

With early education now mandatory in much of the world, the estimated prevalence of ADHD ranges from 5 to 7 percent in most countries, Hinshaw says. Diagnosis rates vary more widely. The United States, in which one in nine children are diagnosed, has one of the world's highest rates, a subject of major controversy.

Over the years, the disorder has had many different names, including "hyperkinetic impulse disorder" and "minimal brain dysfunction." It wasn't until 1980 that "attention deficit disorder" (ADD) — the first name to highlight distraction — was listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM), the hanARok relied on by mental health professionals throughout much of the world. Seven years later, a new DSM edition changed the name to "attention deficit/ hyperactivity disorder," or ADHD.

ADHD is a spectrum disorder, encompassing people with mild deficits as well as those with



SOURCE: AMERICAN PSYCHIATRIC ASSOCIATION AND CDC

KNOWABLE MAGAZINE

The diagnosis of ADHD has changed dramatically through time. The Diagnostic and Statistical Manual of Mental Disorders (DSM), which standardizes criteria for mental disorders, recognized ADHD officially in its 1968 edition. Prior to that, the closest diagnosis was "minimal brain dysfunction," which was used to describe hyperactive and impulsive children. Revisions in the current edition of the DSM include listing ADHD as a neurodevelopmental disorder rather than a disruptive behavior disorder.

serious impairments. Researchers today classify people as having one of three variations: hyperactive, inattentive or a combination. Boys are more often classified as hyperactive while girls are more often described as inattentive or as a combination of inattentive and hyperactive.

The inattentive girls' symptoms may be easier to miss, but observers' biases may also lead to under-diagnoses, according to a 2018 British study comparing parents' observations with more objective measurements. The study, involving 283 diagnosed boys and girls, found that parents perceive ADHD-related behaviors differently in girls and boys, sometimes underrating hyperactivity and impulsivity in girls while exaggerating those traits in boys. "The diagnostic criteria [are] based on male behaviors," says Florence Mowlem, a health consultant who did the study as part of her doctoral work at King's College in London. "Maybe we do need slightly alternative [criteria] for females."

An ADHD summer camp

Hinshaw recalls that when he and his team began the B-GALS project, their peers doubted they'd be able to find enough girls to study. Hinshaw spread the word among local physicians and posted an ad in the San Francisco Chronicle. In the first few days, the team received more than a thousand inquiries, filling up the tape on the project's answering machine.

After carefully screening candidates with questionnaires and an eight-hour assessment session, Hinshaw and colleagues selected 140 girls diagnosed with both the inattentive and combined types of ADHD and 88 girls without the disorder, all 6 to 12 years old and from different ethnic backgrounds. Each summer for three years, the girls attended a five-week camp offering art and drama classes and outdoor activities. The diagnosed girls volunteered to abstain from medication during this time.

The researchers observed the girls' interactions and tested them on their IQs, anxiety levels and relationship skills. Their first publication in 2002, in the Journal of Consulting and Clinical Psychology, described how girls with the disorder had serious trouble managing their thoughts, emotions and behavior. They also had the same kinds of academic problems as boys with the disorder. In some disciplines, such as math, they fared even worse than their male peers, says Hinshaw.

The girls' social lives also suffered. Researchers found that the girls with the

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combined presentation of ADHD were often disliked and rejected by their peers, which Hinshaw notes can be "devastating." He said such social isolation can lead girls to lose self-esteem and increases their risk of engaging in antisocial behavior, including substance abuse.

Years later, when Hinshaw's team observed the girls as adolescents, researchers found that the majority of the girls' childhood impairments persisted. Only a few of the girls showed improvements in math, memory or planning during this time. Moreover, some new problems had emerged, including eating disorders, suicide attempts and self-harm, behaviors Hinshaw links to ADHD-related impulsivity.

Unsolved puzzles

Patricia Quinn, a retired developmental pediatrician formerly associated with Georgetown University Medical Center in Washington, DC, has published extensively about ADHD in girls and women. She has worked with hundreds of adult women who have struggled with disorganization, distraction, poor planning and social problems without realizing that they had ADHD. "I think there's still a lot of misunderstanding about the disorder, and a lot of misdiagnoses," she says. Quinn, who herself has been diagnosed with ADHD, says such news "can be a very hopeful diagnosis. These women can be treated, and they can live a very successful life."

It's clear that ADHD medication helps many. But on its own, "it's rarely an adequate long-term solution," says Hinshaw. "Even if it works, it's not a cure." Learning social skills, for example, is an important part of overcoming the disorder. For adults, promising results suggest that cognitive behavioral therapy helps improve organizational and time-management skills, as well as emotion regulation.

The National Institute of Mental Health supported Hinshaw's B-GALS study for 23 years, but Hinshaw says the project is now on hiatus until his team can find a new funder. His goal would be to do a fifth follow-up study of the girls, who are now reaching their thirties. The UC Berkeley team and other researchers in the field say there are still lots of puzzles to solve. For instance: Why does ADHD manifest differently in boys and girls? What makes it more or less severe? What brain structures or hormones play the most important part? Is there a more objective way to diagnose ADHD, and to track how well various treatments work? And most important, how can our health and education systems do a better job of alleviating suffering and stigma for both boys and girls?

There has been some progress. Research suggests that there is a hefty genetic component, although exactly what and how many genes are involved is unknown, and it's clear that environment also plays an important role. Gender-based neurobiological differences may also help explain some of the differences in the way boys and girls experience ADHD. Three years ago, researchers compared the brains of boys and girls with ADHD and their neurotypical counterparts. They found that the volume and shape of the globus pallidus and the amygdala — brain regions important for emotions — were different in boys with ADHD, but not in girls.

Hormonal fluctuations may also play a role. "Estrogen levels seem to be influencing, in women, their ADHD symptomology," says Quinn. But, she notes, there are many more questions than answers at this point.

For Hinshaw, the way forward is to educate teachers, parents, doctors and especially children with ADHD on how to recognize it and its symptoms in both girls and boys. "We might be able to, in a generation or so, have a very different set of attitudes about mental health and developmental disabilities, as those kids grow up to be adults," he says.

— Additional reporting by Rachel Ehrenberg, Bridget Hunnicutt and Katherine Ellison

This article was originally published in Knowable Magazine. *Read the* original article

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Talking with U.K. journalist and author Lydia Wilkins

By Lisa Guthrie Deabill

U.K. freelance journalist and public speaker Lydia Wilkins recently added another title to her resume—author.

Wilkins, who has autism, published The Autism Friendly Cookbook in November, 2022. She also serves as ambassador for AccessAble, an accessibility guide in the U.K. and Ireland, for people with disabilities.

AfA: Tell us a little about yourself and how you got to where you are today.

Lydia: I'm a freelance journalist specializing in disability and social issues. At a very young age, I had always known that I wanted to do something wordy. I was the child who was always with their nose in a book! I learned pretty quickly I can't write fiction, which is sort of connected to my autism diagnosis, and switched to journalism almost by default, really. Since I graduated, I have covered disability related stuff such as when it came to people shielding millennials in the U.K. versus social issues like the fate of dolphins and overfishing where I live. I sometimes act as a speaker and can be found creating podcasts. It's quite mixed!

AfA: Congratulations on the publication of your book, The Autism Friendly Cookbook. Why did you decide to write it?

Lydia: It happened due to an accumulation of events around the first COVID-19 lockdown here in the U.K. I never thought I'd write a book! I was 21 at the time. Speaking to others sparked the idea. So, here is the sum of everything I have learned and researched with 100 recipes, illustrations, adaptations and more.

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Lockdown was a creatively challenging time, and I needed an escape.

AfA: Do you envision writing another book, perhaps a follow-up to The Autism Friendly Cookbook?

Lydia: Yes. I would like to, but I don't think I will ever write about anything autistic related! The amount of vitriol from autistic individuals—and I am one of them! —was so interesting. It's not a book for everyone as autism is a spectrum. I've never claimed to speak for all. I'm a journalist first. I am not an advocate or activist or anything else. I am working on finding myself an agent to represent me right now, but I have an idea for a memoir manifesto type thing. I'd like to do something like For Queen and Currency or even Mad Honey. But never again on cooking! Unless you can tempt me. Wink wink.

AfA: How representative is the media industry of people with disabilities? What more needs to be done? As a journalist, how has this affected you?

Lydia: In a word, no, the media industry is not representative of people with disabilities. It never has been. This is a huge issue, and it impacts every single one of us as the media is something of a cultural wallpaper regardless of the rise of things such as TikTok. We still talk about outrageous headlines, for example. I think we need to be more honest to start with. I recently wrote for The Unwritten about how disabled journalists have yet to have their #MeToo moment. Why? That is a barrier to us. And disabled women are more at risk! I think editors need to be far more aware and proactive. I am sick of the expectation that someone like me will just be a free educational resource, and yet newsrooms don't bother, they dismiss and/or invalidate. Ultimately, we need to create space.

AfA: How do you envision the relationship between publishing and people with disabilities in the future?

Lydia: As an autistic person, I find it almost impossible to envision a future. But independent media is doing a lot for us here in the U.K. There is power in community. Emma Gannon has written about how the social media game rules are changing. There's a real want for community. Maybe that's the future of news; we can and will do this for ourselves. I'm nervous on that as truth matters, but disabled writers and editors at the helm is just so exciting. I want to see more of this world before I depart for the next. I want the post pandemic world to be kinder and to be more curious and open.

AfA: In your work as a journalist, author and speaker, what significant moments or achievements stand out for you? Why?

Lydia: Back when I graduated, I was covering thalidomide. As far as I know, I was the only truly independent journalist to go to Germany and visit the headquarters of the manufacturer of that drug, which caused a disaster on a colossal, global scale. I am proud I went all the way to Germany solo. Travel is difficult for me as a disabled individual. I'll never forget it.

Interviewing Alan Rusbridger, former editor of The Guardian, the same year was great—my childhood self wouldn't believe that one. I also covered the publication of the Daniel Morgan Independent Panel. He was the subject of the podcast, Untold. I got an exclusive on that and did some data work for a newspaper in the aftermath. That story has had a life of its own and seems to be causing quite a fuss right now!

AfA: What advice would you give to other inspiring writers living with disabilities?

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Lydia: Think what your values are, write them out, tattoo them across your heart and don't let them go. We deal with so much extra, and I think the way we are with ourselves matters. I had one of my values, based on a New York Times clipping, engraved in a ring I wear often. Shame follows us around too often. Last year I read a quote that said, "to live without shame is a radical act." So, keep your ideas, write them down, believe in them and don't let anyone tell you otherwise because they are invaluable. Nurture your ideas, keep them, and keep writing. Keep dreaming of what you want to do. Shame silences and there is a power to speak and to question. It is not shameful to care or to feel either. I see too many individuals who moderate themselves for this reason. Surround yourself with people who have the best of intentions. Create and make space for others. If you screw up, apologize, and learn from it.

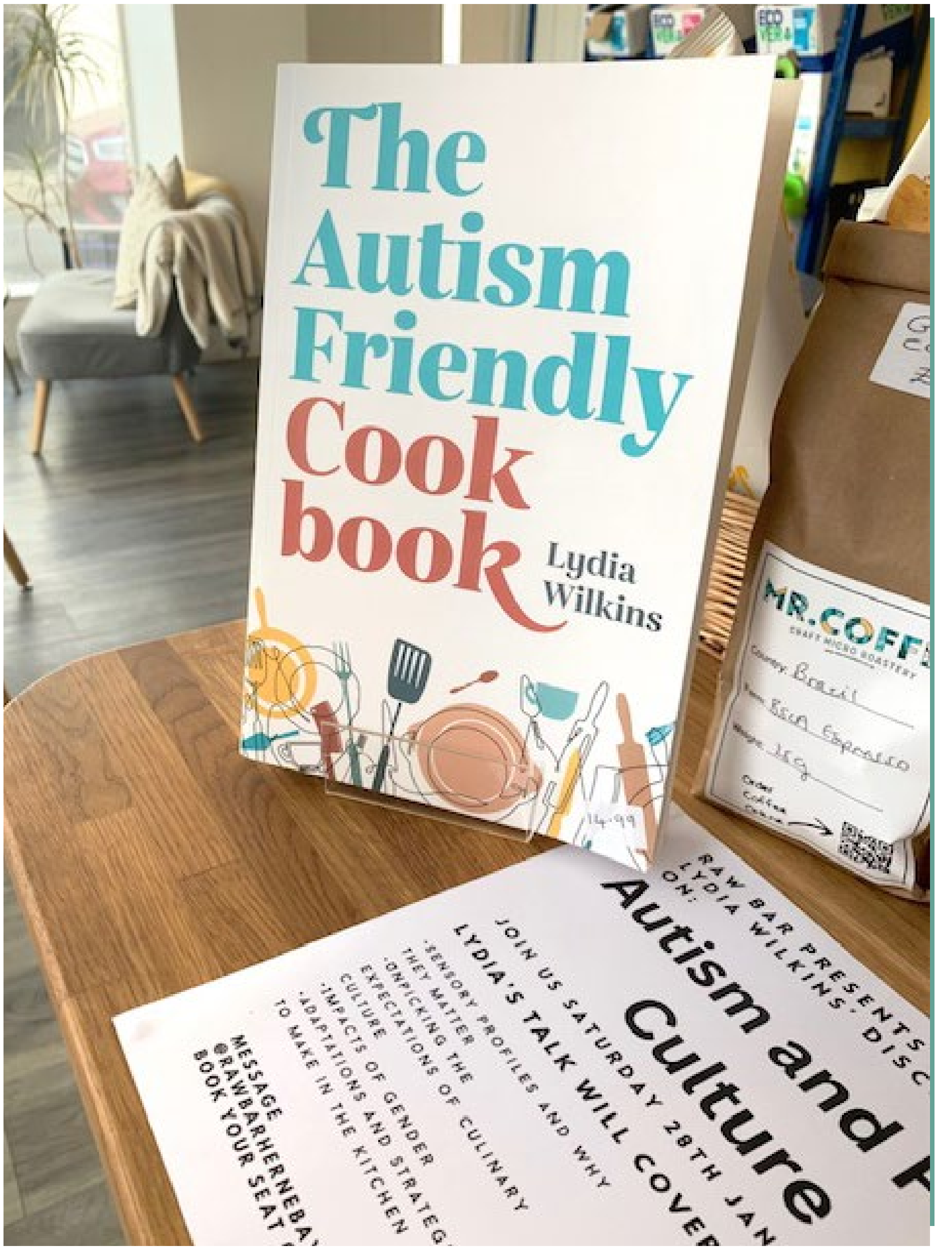
AfA: What can we expect from you next?

Lydia: I would really like to have an answer to this one. Sadly, I don't! I'm in a kind of transition stage. I left my last regular job. I'm also a Long COVID-19 individual, undergoing seemingly endless testing and appointments. I'd like to think there's another book at the very minimum. I'm always available for speaking related stuff online or in person! And a course is sort of being adapted off the back of the book. It's not a lot, but it's a start.

AfA: What message would you like to share with the world about the importance of inclusivity and the power of the media to unite people?

We speak so much about how words matter in the context of doing harm, but not really how they have a power of unity. I think we need to be reminded of this right now, especially post pandemic.

The book is available on [Amazon]



2023
baa
Blue Badge Access Awards

Hospitality Looks for Exceptional Accessibility with Style for the Disabled: The Blue Badge Access Awards 2023 OPENS and the Ludicrous Loo Award is Back!

The search is underway to find the very best in exceptional accessibility for disabled people and to reward hotels, restaurants, leisure, and tourism venues worldwide that are getting ‘Accessibility with Style’ right. The launch of the Blue Badge Access Awards 2023 sets the gold standard for ‘Access for All’ in the hospitality industry. It took place at the brand-new Sun Street Hotel, in London EC2 on Tuesday 25 April 2023.

- There are now 14.6 million disabled people in the UK increasing with an ageing population. (Source: FRS 2020/21)
- Nearly 1 in 5 working adults have some kind of disability and the spending power of disabled people and their households is worth over £274 billion per year to UK businesses. (Source: Scope/Purple Pound)
- 45% of disabled consumers say their choice of hospitality venues were limited because of their disability or access needs (Business Disability Forum/Open Inclusion 2022)
- Accessible tourism in England is worth a £15.3 billion a year (Source: Visit Britain)

Is the hospitality industry missing a trick?

The aim of the awards is to encourage hospitality industry bosses, architects, and designers worldwide to consider ways in which they can address the needs of disabled people and to make their experience more joyful and inclusive. The Blue Badge Access Awards are the only awards that recognise exceptional accessibility for disabled people through stylish thoughtful design, innovation, and liberty in the hospitality industry.

12 categories will award the best accessibility in bars, hotels, restaurants, historic buildings, and any public venue in the hospitality sector. Nominations can be made by the public, design professionals, venue managers and owners in the hospitality business.

- **NEW** for this year is the Best Accessible Spa award.
- The Access Champion of the Year Award and 2 Conceptual Design Awards
- Along with the most Accessible Toilet Award 2023, the BBAA announces that the **Ludicrous Loo Award is BACK!** *(The exception award for lack of accessibility)*

The BBAA awards are run by Fiona Jarvis and Robin Sheppard united by their mission to celebrate thoughtful and stylish inclusive design. Fiona Jarvis Founder and CEO of Blue Badge Style says*, “If you have gone the extra mile to make your venue accessible to everyone, and in doing so you have treated disabled guests as customers rather than ‘compliance issues’ then you are just what we are looking for”.*

Co-Founder Robin Sheppard, President of Bespoke Hotels is the leader of accessibility in the hospitality industry adds*, “We want to drive the industry to replace the DDA compliant rooms and re-title them ‘Liberty Rooms’. Disability is not only about wheelchair access. 9% of disabled people are wheelchair users, and 75% of disabled people have hidden impairments. We need to look after all our disabled guests. Many accessible hotel bedrooms can look more like a hospital than a hotel. This needs to change”.*

The BBAA Founders left to Right – (Josh Llewellyn Jones Interviewer) Robin Sheppard, Chairman Bespoke Hotels, Neil Heslop, CEO Leonard Cheshire, and Fiona Jarvis of Blue Badge Style

Baroness Tanni Grey-Thompson and Baroness Celia Thomas, Supporters of the Awards

How to nominate a venue: https://www.bluebadgeaccessawards.com/the-awards
Closing date: 18 September 2023

Categories for the Blue Badge Access Awards 2023

Venue awards:

- Best Bar - sponsor ANON Drinks
- Best Restaurant - sponsor Conran and Partners
- Best Boutique Hotel
- Best Luxury Hotel - sponsor HEWI
- Best Venue in a Listed/Historic Building - supported by Historic England
- Best Spa - sponsor Guarantee Laundries
- Best Accessible Bathroom/Toilet - sponsor Bespoke Hotels
- Above & Beyond - supported by The Institute of Hospitality
- Access Champion of the Year - supported by Blue Badge Style

International Award:
The Blue Badge International Venue Award - in partnership with Sleeper & AHEAD Awards

Conceptual Design Awards - with a £20,000 prize fund across the two awards.
The Celia Thomas Award for Conceptual Design for Disabled Guests (open to architects and designers)
The Microsoft Award for Inclusive Guest Innovation (open to all) sponsored by Blukite

Bespoke Hotels represents over 100 properties worldwide and is now the UK's Largest Independent Hotel Group. Ranging from specialist golfing hotels to award-winning spa resorts and chic city centre properties each with a unique, individualised management style.

Blue Badge Style is *'re-defining disability with style'* whatever the disability, whatever the style. It is the only source of disability information based on style which ranges from the latest places to go (their accessibility & facilities) to travel ideas and trendy equipment. BBS also produces ***Galleries*** for venues so disabled people can view their accessibility on the **BBS *App***.

www.bluebadgeaccessawards.com
www.bluebadgestyle.com
https://bespokehotels.com/

HEWI “bespoke” HOTELS blukite BLUE BADGE STYLE

The Google Maps of accessible businesses: AbleVu is opening up local businesses to people of all abilities

For someone with different accessibility needs, going out to dinner or grabbing drinks is anything but a simple process. While there are many businesses across the country that have accessible facilities in place, not all of them are designed to make their experience comfortable.

This is also true for people with neurodiversities, such as autism or social anxiety. In these cases and more, a patron may want to know specific accessibility features of a business before visiting, all to avoid a wasted trip. Meegan Winters, the woman behind a new app called AbleVu, has embarked on a mission to make the world of local businesses more accessible to people of all abilities:
"I've been in the accessibility industry for years, and the one thing that I've seen it's missing is a way for people of all abilities to enjoy local businesses as much as the next person. Whether it's wondering how high the tables are in a restaurant or whether there's an accessible stall in the bathroom. For a person with a physical or invisible disability, having decision-critical information about a business before you visit increases the chances that you'll go instead of staying at home."

AbleVu is a free map-based app that lets you search through a database of businesses across the United States who have completed their AbleVu profile and added their accessibility features. It also allows users to submit accessibility-related questions to the business, in case they are not answered through the profile alone. AbleVu supports virtual walkthroughs, photo walkthroughs, text information, as well as a section to show off accessibility features and/or programs.

Meegan and the AbleVu team are on a mission to help more people enjoy local businesses, no matter what their accessibility challenges may be. AbleVu has also begun certifying AbleVu Accessible Cities, which are cities throughout the country which have a high concentration of businesses with a high level of accessibility features.

AbleVu's website has just launched and is available for free to browse local businesses at www.ablevu.com.

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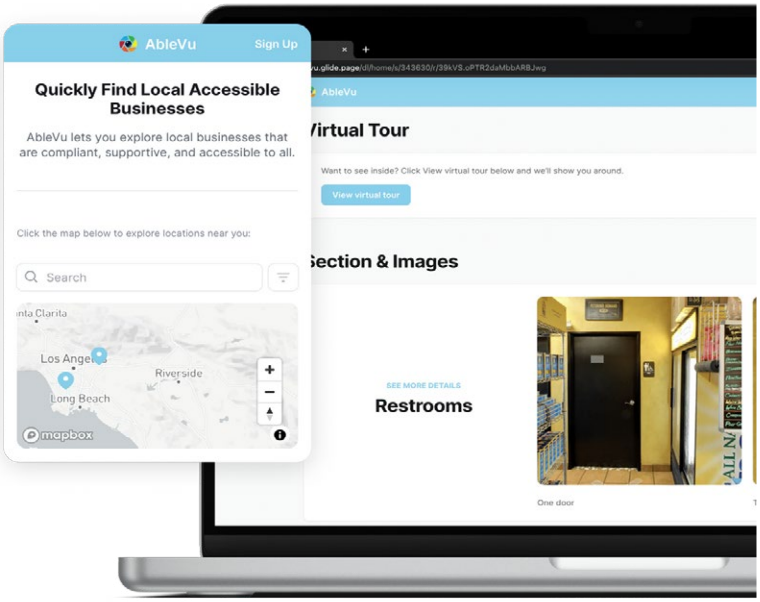
AbleVu
Know Before You Go

AbleVu makes it easy for people of all accessibility levels to find and prioritize your business.


AbleVu Sign Up

Quickly Find Local Accessible Businesses

AbleVu lets you explore local businesses that are compliant, supportive, and accessible to all.

Click the map below to explore locations near you:

Search

u.glide.page/dl/home/s/343630/r/39kVS.oPTR2daMbbARBJwg

AbleVu

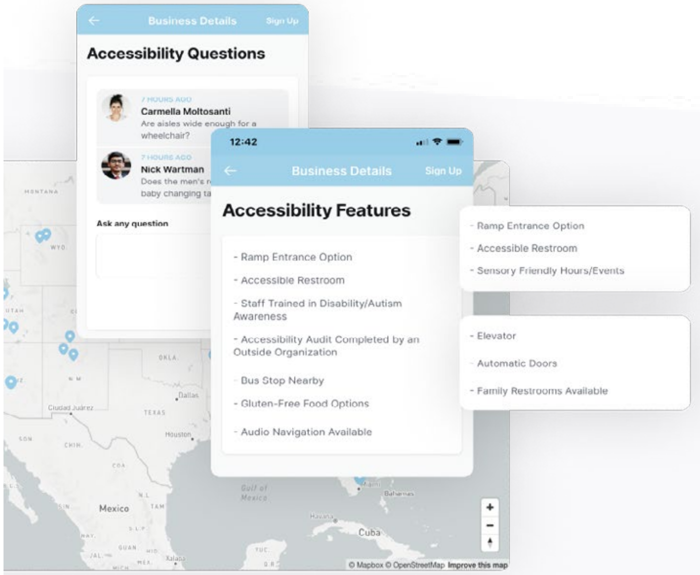
irtual Tour

Want to see inside? Click View virtual tour below and we'll show you around.

ection & Images

Restrooms

One door



Accessibility Questions

7 HOURS AGO
Carmella Moltosanti
Are aisles wide enough for a wheelchair?

7 HOURS AGO
Nick Wartman
Does the men's r
baby changing ta

Ask any question

12:42

Accessibility Features

- Ramp Entrance Option
- Accessible Restroom
- Staff Trained in Disability/Autism Awareness
- Accessibility Audit Completed by an Outside Organization
- Bus Stop Nearby
- Gluten-Free Food Options
- Audio Navigation Available

- Ramp Entrance Option
- Accessible Restroom
- Sensory Friendly Hours/Events

- Elevator
- Automatic Doors
- Family Restrooms Available

Why Do I Need AbleVu?

It can be tough to navigate the world when you have questions about accessibility.

According to the statistics presented by the World Health Organization, almost 15% of the world's population has a physical or invisible disability. When a venue lacks certain accessibilities, they often lose customers. If your business fosters a welcoming culture and supports inclusivity and accessibility for all, we invite you to set up your business profile on AbleVu at **www.ablevu.com**.

Make It Easier To Find You

Having your business listed on the AbleVu map will make it easier for people with accessibility challenges to find you and become your new favorite customers.

Upload Virtual Tours

AbleVu helps people shake off their nervousness by giving them a detailed preview of all of your business's accessibility features through virtual walk-throughs, checklists, and other details.

Ask Questions Directly

Our Q&A feature allows you to ask accessibility questions directly to the business and receive quick answers.

Your Comfort, Prioritized

AbleVu ensures that businesses uphold a comfortable environment and prioritize their customer's comfort above anything else.

Fosters Inclusivity

Some of us sit at home since businesses lack ways to give customers enough information to shake off anxiety. AbleVu helps businesses provide a safe and inclusive environment.

Know Before You Go with AbleVu

Get listed on AbleVu to access more local customers

Visit www.ablevu.com for more info

Scan to Sign Up

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Autism & unemployment

By Bart Vulliamy

Autism is a neuro-developmental condition of variable severity with lifelong effects that can be recognized from early childhood, chiefly characterized by difficulties with social interaction and communication and by restricted or repetitive patterns of thought and behavior.

The latest findings from The U.K. Office of National Statistics for 2021 estimated that 71% of autistic adults are unemployed, meaning that only 3 in 10 are in the workforce. Compared to the 84% rate for non-disabled individuals, there is a stark difference.

Autistic and disabled people in employment were also less likely to be employed in professional occupations and in senior roles (27.2% compared to 34.5% for non-disabled people). Furthermore, the majority of employed autistics are in low-skill level roles that don't leverage their talents, such as entry level positions in retail or kitchen jobs.

Autistic people are among those disabled people with the lowest employment rate.

As an autistic person who has worked and struggled with employment and the employment process, I feel that I am both capable and incapable of navigating the system. I have held jobs in retail – low pay/low skill labour positions, failed accommodations, and often been overlooked for raises and promotions. A common theme among autistics who are employed.

Two of the biggest barriers to overcome are the application process and the interview. The application process is now done almost solely with Automatic Tracking Systems, which are used to scan and filter applications, meaning that your application/resume most likely won't even be seen by a real person.

Once you're called upon for a job interview, more barriers are placed in front of you which makes sense. The employer/ business owner wants to hire the best applicants and make sure that they'll stay long term. But the ability to perform the job does not mean an autistic individual cannot perform

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the job because they don't meet the "prerequisite social conditions."

Interviewers are subconsciously trained to red flag autistic traits because of an unconscious bias called Thin-Slice Judgment. I'll break it down. Some things that job interviewers evaluate in the interview include strange body language, eye contact and handshake, confidence, rudeness or sloppiness (perceived or otherwise), and a lack of passion for the role. Body language, eye contact, physical touch and lack of neurotypical communication are common traits in autistic individuals.

Another common cognitive bias that occurs in job interviews is the Horn Effect, a bias that causes an interviewer's perception of another to be excessively influenced by a single negative trait. That negative trait could be a miscommunication, a stim, anxiety or nervousness.

It is understandable that a lot of people will have to give up the job search after many rejections, the reasons for which are simply their own well being. Most people will resort to whichever entry level positions they can get and make do with what they can find. And, as a result, a lot of autistic individuals will have to resort to masking to try to fit in and hopefully keep their job.

Masking is when a neurodivergent person tries to contort themselves into a box to conform to the societal standards of the community they're in, especially in employment. Work culture insists that we all fit into the same box to be a good employee. Many Autistics who work will mask, which greatly impacts mental and physical health and causes burnout.

This creates an even more pernicious cycle of underemployment. Without systemic societal changes, the underemployment of autistics will remain a major issue. It is my hope that unconscious bias education about autism makes its way among recruiters, providing awareness of the potential of the neurodivergent/autistic community when their workplace can make a few minor adjustments instead of trying to fit everyone in boxes. These adjustments will benefit everyone, not just those living with disabilities, as they'll create more sustainable and healthier work environments.

Do you know someone who is autistic?

Here are some things to consider

Educate yourself

Educating yourself about autism can help you understand and support people with autism. There are many resources available online, including books, articles and videos.

Avoid assumptions

Autism affects people differently, and no two people with autism are the same. Avoid making assumptions about what they can or can't do, and try to understand their unique strengths and challenges.

Be inclusive

People with autism may struggle with social interaction and making friends, so it's important to include them in social activities and events whenever possible.

Be patient and understanding

People with autism may struggle with social cues, communication, and sensory issues, so it's important to be patient and understanding. Try to communicate clearly and simply, and give them time to process what you're saying.

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Tim Vernimmen: Q&A with Neuroscientist John Donoghue

Bypassing paralysis

By decoding brain activity with electrical implants, computers can help disabled people move a robotic arm — or their own

What if a brain still worked, but the limbs refused to listen? Could there be a way to artificially translate the intentions of people with paralysis into movements? Over a four-decade career, neuroscientist John Donoghue, founding director of the Wyss Center for Bio and Neuroengineering in Geneva, convinced himself that he could do it. In 2002, Donoghue showed that monkeys could move a cursor with the help of a decoder that interpreted their brain activities. In the decade that followed, he and colleagues showed that the system worked in people too: Individuals with quadriplegia could use their brain activity to move a cursor. That line of research recently culminated in the demonstration that people with paralysis could control a tablet computer this way. Donoghue himself went on to further develop the system to allow people to open and close a robotic hand, and to reach, grasp and drink from a bottle by using a multijointed robotic arm. Last year, he was a coauthor on a study demonstrating how a similar system could help people do all those things with their own arms.

By now, more than a dozen patients have used the technology in experimental settings, but Donoghue's

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ultimate goal is to develop technology that they — and many others like them — can take home and use day-to-day to restore the abilities they have lost.

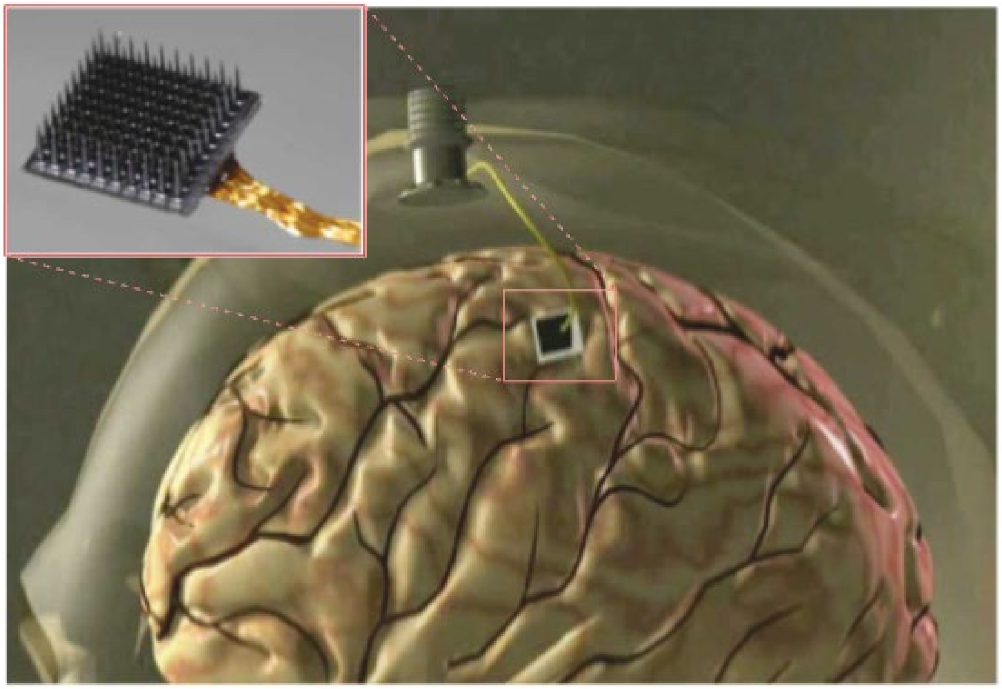
This conversation has been edited for length and clarity.

How do you find out which movements someone with paralysis would like to make?

We implant a small 4-by-4-millimeter microelectrode array into the brain's motor cortex, in a region that we know directs the movements of the arm. This array consists of 100 hair-thin silicon needles, each of which picks up the electrical activity of one or two neurons. Those signals are then transmitted through a wire to a computer that we can use to convert the brain activity into instructions to control a machine, or even the person's own arm. We are assuming that the relevant variable here — the language we should try to interpret — is the rate at which neurons discharge, or "fire."

Let me explain this using the example of moving a cursor on the screen. We first generate a movie of a cursor moving: say, left and right. We show this to the person and ask them to imagine they are moving a mouse that controls that cursor, and we record the activity of the neurons in their motor cortex while they do so. For example, it might be that every time you think "left," a certain neuron will fire five times — pop pop pop pop pop — and that if you think "right," it will fire ten times. We can use such information to map activity to intention, telling the computer to move the cursor left when the neuron fires five times, and right when it fires ten times.

An implant for brain-computer interfaces



SOURCE: M.L. HOMER *ET AL / AR BIOMEDICAL ENGINEERING* 2013 KNOWABLE MAGAZINE

To record brain activity, scientists implant a 4x4-millimeter microelectrode array (not drawn to scale here) into the motor cortex. This array consists of 100 hair-thin silicon needles, each of which picks up the electrical activity of one or two neurons. Those signals are then transmitted by wire, through a "pedestal" that crosses the skull and skin, to a computer that decodes them to control computers, prosthetic limbs or real limbs.

Of course, there are other decisions to be made: What if a neuron fires just three times? So you need a computer model to decide which numbers are close enough to five. And since neuronal activity is naturally noisy, the more neurons we can measure, the better our prediction will be — with the array we implant, we usually get measurements from 50 to 200.

For the arm prosthesis, we similarly ask people to imagine making the same movement with their own arm. There were people who thought you would have to build separate models for "flex and extend your elbow," "move your wrist up and down," and so on. But it turns out this isn't necessary. The brain doesn't think in terms of muscles or joint angles — the translation of intentions into movement happens later.

How do you find the exact spot in the motor cortex at which to implant the array?

In fact, I don't think the exact location matters that much. There is also no need for us to know exactly what each individual neuron is trying to do, as long as we can dependably predict the intended action from their combined activity. That goes against the standard old theory that there is a separate location for controlling each finger, for example. If that were the case, it would mean that if you put the array in a particular place you'd get great thumb control, but nothing else. I've spent my entire scientific career saying it is not true that doing something only engages a small and specific part of the brain. All our neurons form parts of large, interconnected networks.

Do people get better with experience in using the device?

Not really. The neurons often

This video describes how brain-machine interfaces can allow people with paralysis to control cursors on computer screens and, even more challenging, move prosthetic devices or their own limbs. You'll see Cathy Hutchinson use a robotic arm to bring a bottle up to her face and sip coffee from a straw — independently, for the first time in almost 15 years.

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change their activity, which can corrupt the map, so we have to recalibrate the model at the beginning of every session. This means people have to work with a different model every day, so they don't get better at it.

And if, as sometimes happens, something goes wrong and we give them control that isn't very good, they don't get over it on that day, which can be very frustrating for them. It appears the brain isn't plastic enough to change the activity of specific neurons quickly enough to overcome such problems the same day.

Some scientists are developing ways to allow people to feel what the prosthesis is doing, giving them some tactile feedback to keep track of how things are going. Maybe this could help.

The system has also been adapted to allow people to move their own arms.

How can a computer give movement directions to a real arm?

In the case of the patient that we've published about, it's electrical stimulation of the muscles themselves, which seemed the most practical. The energy cost is very high, however. It would be more energy efficient to stimulate the nerves that control the muscles, as they are excellent amplifiers of energy. Yet stimulating the right nerves in the right way

Bill Kochevar uses his own arm to feed himself a spoonful of mashed potato eight years after he lost use of both arms and legs in a bicycle accident. The setup of electrodes implanted in his brain's motor cortex, a brain-computer interface and a system to stimulate his arm and hand muscles also allowed him to do simple but important things such as scratch an itch on his nose. Brain instructions also help to control the black support device. Researchers say the temporary system could soon be adapted for long-term use. CREDIT: CASE WESTERN RESERVE UNIVERSITY

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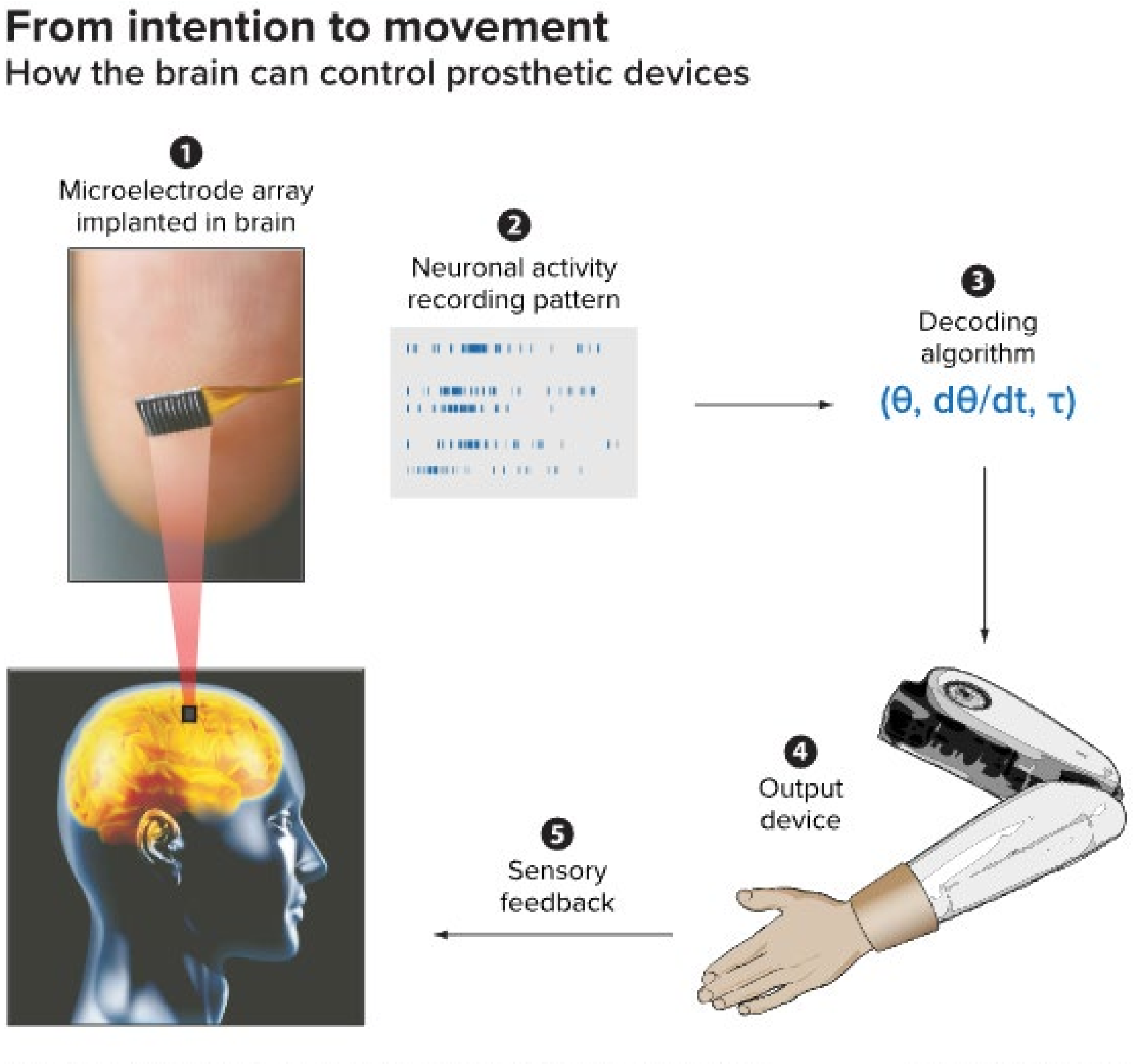
is pretty complicated — you can't simply shock them into action.

Having a person move their own arm is an important achievement, although it is slow and definitely not as dexterous as we'd like it to be. To a large extent, I think this is because of our lack of understanding of the signals going from our brain into the limbs.

The number of limbs we can use is tightly constrained by our evolutionary history. Can you imagine that our brain could ever be adapted to using an extra limb?

In a way, we already do that today, by using extensions



SOURCE: ADAPTED FROM N.G. HATSOPOULOS *ET AL / AR NEUROSCIENCE* 2009 KNOWABLE MAGAZINE

This diagram describes the basic steps for controlling prosthetic devices via brain activity. A microelectrode array (1) implanted in the brain records the activity of several neurons (2). These patterns are sent to a computer that uses a decoding algorithm (3) to translate them into instructions for an output device, such as a robotic arm (4). Sensory feedback (5), which is usually just visual but can be tactile as well, allows the user to adjust brain activity.

of our body such as tools, computers or cars. Some of those are quite complex and very different from our body, yet we learn to handle them reasonably well and largely without thinking. And just like the monkeys in our experiments — which were moving a cursor or a robotic arm with their brain activity, even though they still had functioning arms — people have a tendency to use their own bodies less if they can use a more efficient device instead.

Do you think that all of us might one day consider it practical to put an array into our brain so we can communicate with a computer or other devices more directly?

I don't. Evolution has given us such fabulous natural interfaces that I think the barrier of brain surgery will remain too high. There's always a risk of something going wrong, so I don't think we should use implants for pure augmentation like that. Some people will do dangerous things, of course, but fortunately, you can't easily stick an electrode in the right place in your own brain.

Have you heard of neurologist Phil Kennedy? He was the first person to implant an electrode in a human permanently, and he later had himself implanted in Belize, as no one in the United States would do anything like that. I find that disturbing — he's a perfectly healthy, very bright man.

I think the aim of the field should be to create the opportunity for people with paralysis to restore or achieve typical abilities. For people who want to be superenabled, I think we need some serious regulations, as that could be extraordinarily disruptive. It also raises other issues — if I am rich and you are not, and only my child gets a brain booster implant, this creates a very unfair situation.

How do you apply such ethical considerations to your own work?

I think we should always strive to make the technologies we create available to as many people as possible. That doesn't mean we should stop developing or producing them because they currently cost too much and we can't give them to everybody who needs them. But eventually, that should be the goal.

What is the biggest obstacle to getting this technology out there to people who need it?

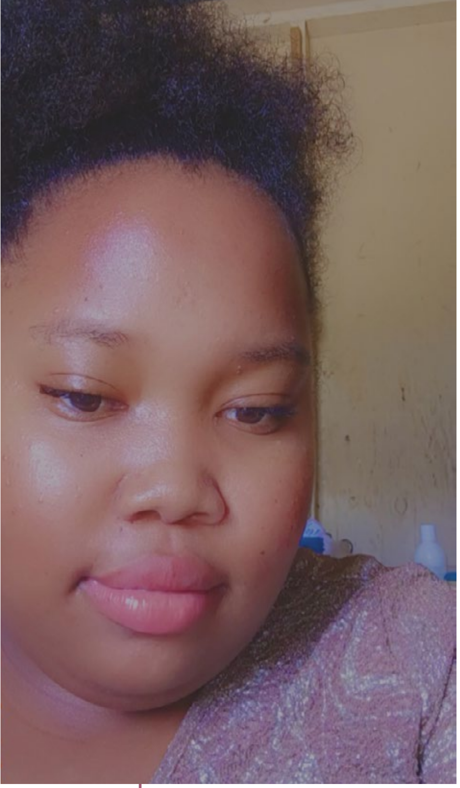
One issue is that the arrays tend to degrade over time in the rather harsh environment of the brain. But as some have lasted for over five years, I don't think this is the main obstacle, as you'll probably want to get a new one anyway after that much time has passed.

If you ask me, the biggest problem is that people have a plug on their head with wires everywhere connecting them to a computer. For this to become a product people can use at home, it will have to be largely technician-free and located entirely inside the skull.

At the Wyss Center, we are trying to do exactly that: develop an implantable system that can radio out the signals. That is very hard, because we need to make the entire device small, and it will need a very good battery. If you can use this only 45 minutes a day to save power, it's not worth it. So that's what we are working on right now.

This article was originally published in Knowable Magazine. *Read the* original article

Tim Vernimmen is a freelance journalist based near Antwerp, Belgium. He writes about the science of life.



The Journey to Acceptance

By Judy Sango

Waiting for acknowledgement
To wait for life to be seen,
To have your worth recognized keenly,
For equality to become serene,
Is a struggle the world has never seen.
Do I wait for others to see,
Their own humanity in me?
Decades of trying to be free,
In a world without empathy.
We struggle on, can't you see,
Living in a world without heat.

But we must wait,
patiently and with grace,
for the world to open its eyes
and truly see our faces.

We have fought so hard,
yet obstacles still remain,
but with unity and persistence,
our efforts will not be in vain.

We wait for unity, hearts made whole,
Intelligence merged one common goal.
To see the worth in every other,
To cherish the earth, our only mother.

Open doors, easy to grasp,
and embrace, love at last,
Waiting for decades, endless weight,
Hopeful hearts, we patiently wait.

This heavy burden we all share,
This weight of hate we cannot bear,
Despair clings to us like stagnant air,
But we rise up, despite the weight we wear.
So we wait, for dawn to break
Long hours pass, with no mistake
Patience wears thin, it's hard to take
But we hold on, for our own sake.

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We move with surety, intent
No need for validation, content
Crosswalks with no curb cuts
Can't hinder our forward thrust
Our humanity, we know and feel
No need for others to make it real
In every step, we claim our space
Our perseverance, an unshakable grace.

In those rooms, they sit and cry,
Their true selves are not being accepted,
But we stand, we wait, we try,
To ensure their lives are protected.

For those who seek a better life,
We offer love, we offer care,
And through the struggle and the strife,
Together, we can all be there.
We've longed for change, a shift from the norm,
Our hearts and minds are battered and worn.
But hope remains, as we stand and pray,
For heroes to come and pave the way.
Yet as we wait, let us not forget,
Our voices and actions can make an impact yet.

RESOURCES

FOR PEOPLE WITH DISABILITIES

ACCESSIBILITY CONSULTANTS

Maahs Travels, USA

Massiraa, Dubai

Marco Pasqua, Canada

BUSINESSES OWNED BY PEOPLE WITH DISABILITIES

Colletteу's Cookies, USA

www.retrophiliac.etsy.com, USA

CERTIFICATION COURSES

Rick Hansen Foundation
Accessibility Certification, Canada

CLOTHING

Intimately, USA

IZ Adaptive, Canada

DIGITAL ACCESSIBILITY

specialising in digital content (PDFs, ePUBs, eJournals, etc.)

www.jwdigitalinclusion.com, Dubai

DISABILITY-SERVING ORGANIZATIONS

Access Israel, Israel

Easter Seals, Canada

Easterseals, USA

FONHARE, Haiti

Friends of Access Israel, USA

The American Association of People
with Disabilities, USA

The Arc, USA

EMPLOYMENT

Bender Consulting, USA

HOSPITALITY TRAINING

The Slatin Group, USA

INCLUSIVE EMPLOYERS

Gabi & Jules, Canada

Lil E Coffee Cafe, Canada

Project Dignity, Singapore

GLOBAL PWD COMMUNITY

www.yoocanfind.com, Israel

LEARNING CENTRES

Achievement Learning Centre, Dominica

MEDIA

Accessible Media Inc., Canada

The Angela Lynn Show, USA

OUTDOOR ACTIVITIES

Paratrek, Israel

PRODUCTS & ACCESSORIES

Izzy Wheels, Ireland

The Alinker, Canada

TRAVEL

360Access, USA

AccessNow, Canada

Accessible Indonesia, Indonesia

Japan Accessible Tourism Center, Japan

European Network for Accessible
Tourism (ENAT), Belgium

Four Season Travel & Tours, Nepal

Travel-for-All, Canada

WEB ACCESSIBILITY

EqualWeb, Israel

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Embrace Differences

Let's build a more inclusive society

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WINTER 2022

“A disability changes the way we do life. No, it doesn't end it!”

JENNIFER ALLEN

The joys of travel for **FAMILIES WITH DISABILITIES**

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