

# mélange

Summer 2023

**Accessibility for All**

Twin sisters Liz and Maddie  
champion the power of  
**KINDNESS**  
and self-acceptance



# Disability Awareness Calendar

<b>August</b>	<b><u><a href="#">Spinal Muscular Atrophy Awareness Month(USA)</a></u></b>
<b>August 21</b>	<b><u><a href="#">National Senior Citizens Day (USA)</a></u></b>
<b>September</b>	<b><u><a href="#">World Alzheimer's Month</a></u></b>
<b>October</b>	<b><u><a href="#">ADHD Awareness Month (USA)</a></u></b>
<b>October</b>	<b><u><a href="#">Down Syndrome Awareness Month</a></u></b>
<b>October 10</b>	<b><u><a href="#">World Mental Health Day</a></u></b>
<b>October 13</b>	<b><u><a href="#">World Sight Day</a></u></b>
<b>November</b>	<b><u><a href="#">Epilepsy Awareness Month (USA)</a></u></b>
<b>December 3</b>	<b><u><a href="#">International Day of the Disabled Persons</a></u></b>

- **Assistive technology**  
Real time solution to improve and fix accessibility issues on your website.
- **Scanner and semi-automated fixer**  
With the Purple Lens system, websites can be scanned to identify accessibility issues. The system will advise, then provide simple solutions.
- **Purple Special UX/UI for visually impaired**  
The only solution that currently exists to help visually impaired users complete purchases on WooCommerce sites.
- **Purple Lens Web Accessibility Inclusion**  
Watch the video [here](#).



[www.purple-lens.com](http://www.purple-lens.com)





# Contents



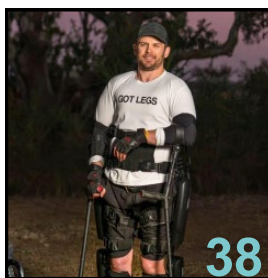
## Cover Story

**Twin sisters, Liz and Maddie Adams,**  
champion the power of kindness and self-acceptance  
By Alice Williams



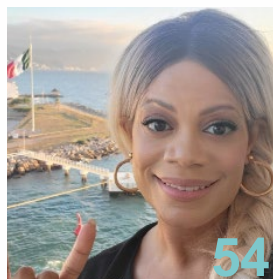
**Trailblazing disabled equestrian Veronica Gogan: galloping against all odds**

By Alice Williams



**I GOT LEGS: Facilitating access to exoskeleton technology**

By Nancy Baye



**Deaf and Hard of Hearing travelers**

By Angela Lynn



**What is rejection sensitive dysphoria**

By Bart Vulliamy

**8 Celebrating the next generation of accessibility leaders**

By Katie Kirker, Rick Hansen Foundation

**10 Unveiling a multifaceted star**

By Alice Williams

**18 The "You Can Do It All" wrap**

By Shana Jones

**20 Welcome to accessibility for everyone at Greater Fort Lauderdale**

**26 A disabled activist speaks out about feeling 'disposable'**

By Rachel Scheier

**34 Navigating love and connection as a person with a disability**

By Alice Williams

**44 Why it's hard to find safe homes for some people with disabilities**

By Amy Silverman

**50 The Valuable 500 is on a mission to end disability exclusion**

By Lisa Guthrie Deabill

**58 Q&A with Antoine Hunter, passionate urban dance warrior**

By Angela Lynn

**66 What is fatigue? Understanding fatigue among students with disabilities can help schools moderate it**

By Natalia Rohatyn-Martin

**72 Reading the mind with machines**

By Marla Broadfoot





# Welcome

## TO ACCESSIBILITY FOR EVERYONE

In Greater Fort Lauderdale, we're excited about welcoming everyone under the sun and providing access for all, from beach wheelchairs and accessible pathways to the Hidden Disabilities Sunflower Program at FLL airport. Learn more about local resources and plan your trip at [VisitLauderdale.com/Accessibility](https://VisitLauderdale.com/Accessibility).





# Editor's Note

Fred J. Maahs, Jr.



## Greetings and Happy Summer!

Welcome to our summer issue of *Mélange Accessibility for All* magazine.

The past few months have been amazing and enlightening for the disability community. We've seen the International Children with Disabilities Act and the Health Equity for People with Disabilities Act introduced into Congress. We've seen progress made with airlines allowing people with disabilities to remain in their wheelchairs. As predicted, people with disabilities are traveling more in a post-Covid world and sharing their experiences more frequently about what's accessible and what's not. We've also seen more and more people with disabilities attending conferences and summits in person versus virtually. I am encouraged by all of this. We're moving in a positive direction!

As you might expect, there were many events planned throughout the U.S.,

especially in Washington, D.C., to celebrate the 33rd anniversary of the Americans with Disabilities Act on July 26. The rest of this year will be just as busy for the disability community so keep reading *Mélange Accessibility for All* as well as the Tidbits Newsletter for more information as it becomes available.

As always, 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 sister magazine, *Mélange Accessible Journeys*. In this digital magazine, we share stories from all around the world about accessible travel destinations, written and experienced by people with disabilities. In each issue, you will find personal, firsthand accounts of what each traveler

experienced during their journey. It's a resource for anyone of any ability who wants to take an accessible journey! We hope you enjoy 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 assistive technology product you want us to write about, or if you want to invite us to visit your city, country, resort or place of interest so that we can write about its accessibility and share it with our audience. You can reach me at: [fmaahs@readmelange.com](mailto:fmaahs@readmelange.com).

*Fred J. Maahs Jr.*

[@FredMaahs - Twitter](https://twitter.com/FredMaahs)

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.

**Publisher:** Mélange Publishing Group  
**Editor in Chief:** Debbie Austin  
**Editor:** Fred Maahs, Jr.  
**Editor in Chief:** Debbie Austin  
**Designer:** Trish Palma  
**Senior Editor:** Nancy Baye  
**Editor:** Fred Maahs, Jr.

### Editorial Staff:

Nancy Baye  
Marina Apperley  
Lisa Guthrie  
Mae Forrester  
**Columnists:**  
Angela Lynn  
Bart Vulliamy

### CONTACT US:

**Comments:** Share a story  
Contribute an article  
**email:** [editor@readmelange.com](mailto:editor@readmelange.com)

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 Marina Apperley at: [marina@readmelange.com](mailto:marina@readmelange.com)

**CONTACT US:** Comments | Share a story | Contribute an article  
**email:** [marina@readmelange.com](mailto:marina@readmelange.com)

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](mailto:fmaahs@readmelange.com)



*Mélange Accessibility for All* magazine is published four times per year by:

Mélange Publishing Group 300-3665 Kingsway, Vancouver, BC, Canada V5R 5W2.

© 2023 Mélange Publishing Group All rights reserved.  
© 2023 Mélange Publishing Group All rights reserved.



# WHERE FUN IS ACCESSIBLE TO ALL.

As the nation's first Autism Certified City, visitors to Mesa are welcomed by a community that prioritizes compassion, kindness and understanding. Through helpful travel planning resources, technologies and programs enhancing the experience for visitors of all abilities, we are on a mission to be one of America's most accessible cities.



**VISIT MESA**  
CITY LIMITLESS®  
ARIZONA



[AccessibleMesa.com](https://AccessibleMesa.com)





**Caden Teneycke**

Photo courtesy of the  
Rick Hansen Foundation



# Celebrating the next generation of accessibility leaders

By Katie Kirker, Rick Hansen Foundation

Youth are the change we will see in the world, and they take incredible actions daily that deserve to be celebrated.

Annually, the Rick Hansen Foundation School Program (RHFSP) accepts nominations for the Difference Maker of the Year awards to reward the wonderful work youth are doing to make a positive impact in the lives of people with disabilities.

This year, RHFSP was thrilled to award 2 individuals and 3 groups for the work they are doing to make their communities more inclusive.

Mackenzie Agretto, Grade 12: Mackenzie organized an inclusive prom for students with disabilities within the Niagara Catholic District School Board. Alongside her school principal,

superintendent, and others, Mackenzie ensured all students could attend and enjoy the event.

Caden Teneycke, 18: Caden is an accessibility advocate, using his platform on YouTube, Instagram and TikTok to spread awareness about living with his rare form of dwarfism, and provide a community for others who face similar accessibility challenges.

Dear Everybody Design Team: This group of 13 Grade 6 students from Havergal College worked alongside students with lived experience at Bloorview School Authority to create accessible carnival games.

Mrs. Boucher's Grade 3 Class: After reading Rick Hansen's story, Boy in Motion, Mrs. Boucher's class of 20 Grade 3

students audited their school for accessibility and potential solutions. So far, their work has resulted in inclusive learning materials and accessible gym equipment.

Dante Accessibility Team: As part of a school project, the Dante Accessibility Team, which is comprised of seven students aged 13-18, created an educational video to raise awareness around accessibility and inclusion.

These are just some of the wonderful examples of students who are making a difference. To learn more about how you can nominate a youth making a difference, please visit [www.rickhansen.com/schools-communities](http://www.rickhansen.com/schools-communities).







# Unveiling a multifaceted star

Actress, journalist, writer, disability rights advocate, diversity consultant and keynote speaker. She is:

Samantha Renke

... winner of The Susan Mullen Award for Best Actress during the Los Angeles Diversity Film Festival in 2014, writer for The Huffington Post, PosAbility magazine, and Metro on a variety of topics such as living with disability, socio-cultural criticisms, patronizing attitudes, body image, bullying, LGBTQ+ issues and ableism. She is a speaker for the National Education Union, Viacom, Houses of Parliament, British Red Cross, Santander, Reed Fashion, UNICEF, ASOS, COS Fashion, Creative Equals and Valuable 500.

Here's our conversation with Samantha:

## From your perspective, who is Samantha?

As we would say in the U.K., I am very much a typical northern lass who is very outspoken, who is quite cheeky, and who is not afraid to work hard. I was born in Germany. My mom was a

German nurse, and my dad was in the British Army. They had a beautiful relationship, overcame their language barrier, and, in my opinion, were both very sexy people.

Neither of them was disabled, and neither is my sister Stephanie, who is nearly 5 years older than me. So, when I came into the world, diagnosed with a condition called Osteogenesis Imperfecta, it scared everyone. I talked in detail about my birth in my first memoir, *You are the Best Thing Since Sliced Bread*. A lot of that is looking at my birth and having those conversations with family.

My mom, in particular, said something quite heartbreaking there. She said, "You know, your birth was more like a bereavement than a celebration because everybody was partly negative about your arrival. And it's really hard because not only

did you come into this world with a label, but you also came with all the unconscious bias that is attached to that label." And that is something my parents were guilty of. They were both two young 20-somethings, with no experience of how to deal with disability, then all of a sudden, they had this child who everyone thought was going to be a failure and wouldn't survive past infancy. It was odd listening to the reaction to my birth from my family.

I had always felt that I was a happy, chatty and confident child growing up. If you ask me where I get my strength, my drive, my aspirations and so on, I think they would ultimately be from that innate sense of self-worth. I liked my uniqueness. I never really saw it as a hindrance in my formative years. I enjoyed being the center of attention. Being in a wheelchair, I didn't feel pitiful when I was approached

by people. I felt special wherever I went as I was showered with toys, sweets and gifts. In my book, I wanted to tap into that sense of self-worth I had back then because I feel that I've lost much of that along the way. As you grow up, you start to become aware that you are different because of your disability, and the challenges you face became tougher as people single you out.

### When did your self-awareness change and why?

There were two major instances that stuck out in my memory. One was in primary school. I had a powered wheelchair and an electric wheelchair that I kept at school. Over the summer holidays, though, the school was broken into and vandals spray-painted, urinated and defecated on my wheelchair. That was the first time that I recognized the cruelty of humans and I felt quite vulnerable.

The second time, in primary school, I wasn't allowed to go outside during breaks unless I was accompanied by a teacher. While I waited, my best friend would always wait with me and we would play with our dolls. But then they separated us because they were worried that she wasn't going to make other friends, or that we were spending too much time together.

It was difficult to comprehend

those moments. There was a term for it, but I guess it's that whole ideology surrounding disability that I was the problem, and I was the one that had to make sacrifices for my disability. If they were concerned about my friend not having other friends, where was the concern for me? They could have facilitated my friend to accompany me so we could all play together instead of me being left on my own.

### What led you to a life of activism?

Our family had decided to immigrate to America and go on a van life across the country, where I'd be home schooled. The plan was, after America to move to New Zealand where we had family. But my world came crashing down when my father died of a brain hemorrhage at the age of 38. Due to my father's death our family's plans got turned upside down and we stayed in the U.K., which meant that I had to find an appropriate secondary school that would accommodate my needs. At the time, many schools in the local district did not have wheelchair access, therefore I could not transition with my classmates into secondary school and so I started at a school where I knew no one. This is where I became the girl in the wheelchair rather than the

bubbly, cheeky, blonde-haired girl as I was known in my previous school. And I was bullied.

The college years changed me, however. I found my tribe there. I was in my early 20s and was doing a post-grad degree in teaching. I got to wear my own clothes, own makeup and regained a lot of my confidence as I felt part of a more liberal community of people who are thinkers and more accepting of others in the world.

One day, I was on a train going to the hospital to see my specialist. I met another girl in a wheelchair with a bone condition similar to mine. I thought that she was quite sexy. She had fishnet tights, bright red lips and piercings, with a can of beer in one hand, and I just thought she was so cool. We started chatting and we recognized that we were both very similar. She told me that



she was a trustee for the Brittle Bone Society and that they were looking for a new trustee, and she thought that I would be the best person for the job. After that conversation, I became a trustee for six years. During that time, I met a lot of people with disabilities and through them, I understood the importance of the community, the importance of having disabled friends and the importance of having a sense of pride in my identity.

As a trustee, I was privy to free media training, which coached me to use my voice to communicate. An extremely beneficial skill. Although I enjoyed teaching, my heart lay in charity work. After two years of being a schoolteacher in Lancashire, I decided to leave and move over 200 miles away to London. I shared a flat with two other wheelchair users as there weren't many places that were accessible to disabled people like me. However, even though it was a challenge living in an open-planned living room for 6 months, I was committed to helping others, which in turn meant being able to help myself.

### **Tell us about moving to London.**

I came full circle because all the friends that I had were members of the LGBTQ+ community. I would spend a lot of time clubbing and partying with my gay friends, and because of

that, we saw similarities in each other as we felt prejudiced and marginalized. I wasn't unique anymore.

I worked at a nightclub. I wore alluring outfits which boosted my confidence, especially in the way I looked. All of a sudden, people took an interest in this petite girl in a wheelchair with crooked arms, nipple hairs and scars, but who was totally in control of her life and lived it to the full.

### **Can you tell us about meeting people for the very first time?**

My natural character in any new environment or situation is to be very approachable, and I possess great communication skills. Even though it can be quite tedious because, at the back of my mind, there is still quite a lot of ignorance in society about disabled people and uncomfortable feelings surrounding the issue of disability. I can empathize with disabled people who are innately shy or introverted and can understand that new situations and meeting new people can be very difficult for them.

### **Is this your natural disposition?**

I think most of it is natural. If I'm quiet and demure, then there is something wrong with me. I'm

either very unwell or battling with anxiety. Sometimes when my anxiety is very, very high, it can impact the way I interact. I may be chatting, but just because I'm smiling or giggling, doesn't mean that I don't feel sadness or pain.

I'm very aware, however, that non-disabled people, on the whole, don't know how to cope with sick people. They don't know how to cope with pain, anger or frustration. So, I think a lot of disabled people should not hide from their true selves. This is where information is important. We would prefer an inspirational story over reality.

### **Share a bit about your teaching experience.**

When I was in primary school, one of the teachers asked me what I would like to be when I got older.

I remember confidently saying, "Well, I have to go to high school, and college, then university. And if I am at university, I'll probably either become an actress or a teacher." Ironically, that's exactly what I did. I studied French, German and European studies, and excelled at Sociology. And that's probably why I excel at disability studies and the consultancy work that I do now. But everyone kept asking, "Why aren't you teaching?" Halfway through my degree, I had to have a spinal operation. It was



a very significant operation to correct my scoliosis and the operation did not go very well. I suffered from spinal cord damage. I graduated but was quite weak. I had quite a co-dependent relationship with my mother. I wasn't very independent, even in my university years. I was very reliant on my mom. In my head, I thought my mom had given up her life to be my caregiver, so if I start to live my life, what would become of hers? That all led to my move to London.

But why did I get into teaching? It was because I wanted another year within the safety of education space, and in the UK, they were desperate for language teachers. I also love kids. I've always had that really good connection with children. I was the only disabled teacher in that space.

### **And how was that for you?**

I hated every minute of it. The establishment wasn't very accommodating of my needs. They saw me as more of a hindrance rather than an asset. A lot of the teachers were also not very respectful and the environment was one of ableism. Instead of calling me Miss Renke, for example,

they'd just go with Samantha in front of the students. It was not conscious malice but everything seemed like a challenge and I just wasn't very happy at all, so I was a teacher for only two years. Microaggressions - it's like death by a million paper cuts and this was exactly how I felt at the time.

### **From teacher to actress and broadcaster. Tell us about that transition.**

Coming from a small town, I faced a lot of physical barriers in London, going to interviews and a whole host of other barriers that I had never experienced before. For example, I'd turn up to interviews and the lift would be broken. I also went to a few interviews where all they said was that they didn't have a disabled toilet and that was the end of the interview. I struggled with that. I was applying for basic jobs, and office positions at entry levels and my situation was becoming quite desperate as I was 26 and thought I might have to give up my London dream. Then I went to a house party and I was the only girl there. The other people were all gay men and most of them worked in television. There was an editor and just crazy, amazingly creative people.

That's where I met my now business partner, Max Barber, and together we have a production company called Born This Way Media. He took a shine to me and wanted to know if I had done any acting, and I told him that I did. I did do a lot of acting as a child, not professionally – I didn't receive much encouragement from my teachers. So, when I was 15, I gave up my hopes of acting. Max gave me the opportunity to do an indie film called Little Devil, which I won best actress for at the L.A. Film Diversity Festival. I got an agent and, as they say, the rest is history. Max and I make sure that we give opportunities to those who feel that they can't get their foot in the door to be in front of or behind the camera.

### **What happened after the film?**

That was in 2013. It was strange back then to have a physically disabled female in a lead role. At the time, I thought that this was going to be my big breakthrough, and I think that rolled things on. Inclusion, equality and diversity weren't really on the agenda back then. It was just seeping through. Max went to every broadcaster to pitch the concept and idea, and to show that disabled talent

deserves to be on TV. I'm grateful for that, for me personally as an actress.

We know we should be doing more, but we're just not going to make that commitment. I think for me, I had two options: I could keep going or look at different avenues. At the time, I needed to pay for care and I needed to pay my bills. I started writing, broadcasting and disability awareness training. I used my various teaching hats and started to say yes to a lot of different projects to keep my motivation going. I love everything that I do. If I had stayed on, I'd probably be acting full-time. But we have to look at the realism of being a disabled actor - the extra costs and the rejections of being a disabled actress are hard. When you have a disability, the pot of opportunities is even smaller. And I was sick of even going to testing when they hadn't thought about access needs. I remember once I had to go audition for a commercial. They wanted wheelchair users, but they couldn't be bothered to find a wheelchair-accessible studio. All the actors who were in wheelchairs had to do their auditions in a café on the ground floor.

### **What inspired you to write your memoir?**

I always wanted to write a book about my life. There were a lot of things that have shaped me that I can't talk about. But the message

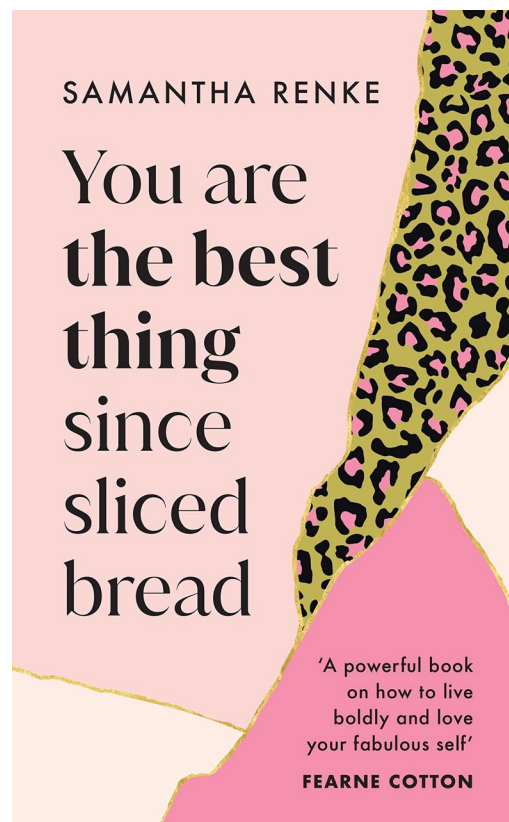
in the book is just to believe in yourself, returning to that innate sense of self-love I talked about earlier. And even when things are difficult, no matter who you are, just remind yourself that you are the best thing since sliced bread. The book is available on [Amazon](#).

### **What are your thoughts on inclusivity and the power of the media?**

Whenever I do a training session, I always say, "Leave your ego at the door!" What I mean by that is just because you think that you're a good, compassionate individual does not mean that you aren't indoctrinated by the unconscious bias which is often perpetuated by the media. We're all guilty of having preconceived stereotypical notions of other people, but we all can unlearn and relearn. If someone like me or anyone challenges your use of language or your ideologies, don't let your ego get in the way of making the world a better place.

### **How do you feel about yourself now as an adult as compared to when you were a teenager?**

I think I definitely got that confidence back. I think that comes regardless of who you are when you get a little bit older. You don't care as much about what people think or what people say. I don't go out with makeup on all the time, and that's quite



liberating. One of my favorite things to do is taking myself out to a cafe or restaurant and simply sitting, people-watching on my own. It's funny, because most people are intimidated by going out on their own and onlookers either view this as I'm incredibly cool or incredibly sad - either way I don't care because it's something that I enjoy.

But I am a human being and I still have my down days. I struggle with dating. I have a lot of traumas and I feel my lowest when it comes to the world of dating. That is something that I'm working on with a therapist at the moment. This is something that I wrote about in the book too. Whenever I have these moments, I try to change my

perception of the situation. I always use little analogies. When I was a teenager, around 17, I went through depression. There was an instance at Ikea with my mum and sister and I remember everyone just staring at me. At that time, it was devastating. I came out of Ikea, burst into tears and felt so ugly and disheartened. Then my sister, who is quite a sporty character, sat next to me and said, "Have you ever thought that maybe they stare at you because your outfit is impeccable, your makeup is gorgeous and what you are wearing is so great? Maybe they want to know where you got that hat?"

I've carried those words of wisdom with me ever since. In any given situation, I don't always jump to negative conclusions. I did a podcast recently with a host who was herself a disabled woman, and I shared the same story. She went, "Oh my gosh, really funny! I was on a train recently, and someone was staring at me, and when I got off, this woman said, "I'm sorry. Can I ask you where you got your trainers from?" So that's what it is about! There are always going to be nasty, rude and arrogant people out there but we have to remind ourselves not to think negatively at first.

### Can you tell us more about dating?

All the issues I have experienced from dating come from my disability and I did not have positive role models when it came to relationships. I've always had a very negative view of men, so that is something that I'm working on. Regarding my disability, all the non-disabled boyfriends I had when I was younger in high school, they would ask me to keep it a secret from my peers so that they would not have this stigma associated with having a disabled girlfriend.

I'm incredibly independent but I would love to have someone to be part of my life as a companion, although I don't feel I need someone to complete me. And that can be problematic on the dating scene because you're going into a world that is very heavily based on steps, intimacy and sex. I've been targeted by predators because of my size, and I had a sexual assault just before the pandemic. Someone weaponized my wheelchair to grope me and refused to get out of my house. I feel my most vulnerable around men and struggle with dating as I've had my boundaries and trust abused and ignored time and time again. I absolutely have

my guard up when it comes to men and dating, but can you blame me? This is something I'm working on because I most certainly do not want to tarnish all men based on a few bad apples, but I've got quite high standards because I don't just need to be in a relationship for the sake of being in a relationship. It's complex. It wouldn't surprise me if I met someone who was non-binary or someone who is not so linear in the way of being. I'm very much a person who sees another person for who they are.

”  
**I was committed to helping others, which in turn meant being able to help myself.**



# Samantha Renke



is a well-known disability rights activist, actress and presenter from England. She was born in Lancashire, England and has a genetic condition called Osteogenesis Imperfecta, also known as Brittle Bone Disease, which means her bones are very fragile and prone to breakage. Samantha, always a fighter, has achieved a lot. She completed her B.A. in German, French, European Studies and Sociology at Lancaster University, and her Post Graduate Certificate in Education at Saint Martins, now known as University of Cumbria. After graduation, she worked as a teacher mostly with children with diverse needs, but she quit that job and left her hometown of Lancashire to make the brave move to London. At the time she did not have a job although she was a trustee for the Brittle Bone Society and started to volunteer at Action for Children, a very well-known children's charity in the U.K. A chance meeting at a housewarming party brought her together with Max Barber, her now business partner, who is a producer and director, and they produced the indie film Little Devil in which she starred. Alongside filming, Samantha was also very much involved with the pan disability charity Scope, in which she received informal media training which then turned into her now career as a broadcaster and disability consultant.

Samantha has been a TV presenter for the BBC and Channel 4, covering topics such as disability rights and accessibility for people who are disabled. With various organization, such as Scope, she has been involved in many campaigns and initiatives to raise awareness about the challenges that disabled people face in society. In addition to her TV, film and advocacy work, which includes delivering DE&I training for ASOS, Samantha is also fashionista - she partnered with handbag company Mia Tui to develop a fully inclusive handbag. At every opportunity, Samantha uses her platform to promote body positivity and diversity.

Her latest accomplishment? She is the author of a book called, [You Are the Best Thing Since Sliced Bread](#), in which she shares no-holds barred stories of her life.

[www.samantharenkeofficial.com](http://www.samantharenkeofficial.com)

**And even when things are difficult, no matter who you are, just remind yourself that you are the best thing since sliced bread.**

# The “You Can Do It All” Wrap

By Shana Jones



**W**hen she first laid eyes on it, soft pink and decked out with dancing butterflies, all she saw was a “medieval contraption; a torture chamber; a hard, heavy piece of body armour”. It was to provide the support, stability and all the blah blah blah of the industry standard

that everyone was using, but.....no way. There had to be something else out there, and she would find it. The firebrand New Zealand mom who would later trailblaze with highly customized accessible restroom facilities would find a better alternative and if there were none, she would simply create one.

A few years earlier, Jenn Hooper’s daughter Charley had suffered a massive brain injury

shortly after birth that had left her with severe cerebral palsy and, among other conditions, low truncal tone. Low truncal tone, or limited muscle control and strength in the trunk of the body, prevents people from being able to stand or sit erectly. The muscle tone that holds the trunk in certain positions simply isn’t there, so

over time, the spine becomes more and more curved. In extreme cases like Charley’s, even holding a child upright for feeding is difficult, and supports must be positioned around the body to keep it in certain positions while the child sleeps.

The thoracolumbosacral orthosis (TLSO) brace has long been a default solution for various causes of unnatural spinal curvature, but getting patients to wear it consistently remains a challenge. It restricts spinal and general body movement, rendering exercise, dancing, and playing sports almost impossible. Patients complain of difficulty breathing and soreness due to pressure on different parts of the body. What’s more, the brace must be worn upwards of 23 hours per day often for extended periods of time (think years) to be effective. Even in successful cases where surgery is avoided, some residual spinal curvature remains. Upon initially seeing Charley’s brace and



then reading up on TLSOs, Jenn decided that it simply wasn't an option. After some extensive research, numerous consultations with different experts and a healthy dose of doubt from medical experts, she designed her alternative to the TLSO: the CharleyWrap.

The "CharleyWrap" name alone separates this device from other alternatives because it speaks of nurturing growth and healing, not encouraging restriction. In fact, X-rays confirmed that shortly after Charley's initial fitting for her namesake, her scoliosis (spine curvature) improved by 20 degrees. This was followed by a further 30 degrees three months later and a final 12 degrees, which keeps Charley below the threshold for corrective surgery. Clinton, a child with Marfan's syndrome (a genetic disorder that affects connective tissues), met Jenn for his initial fitting and to everyone's delight a little later, appeared to have forgotten that he was wearing anything!

Countless other testimonies poured in with accounts of children breathing more easily, having better posture and head control, and being easier to position and handle. An adult patient wrote in about her ability to wear clothes that she couldn't have before with her "plastic turtle shell thing".

Such consistently positive results were the fruits of Jenn's careful thought and concern for the CharleyWrap design. Understanding the importance of comfort to patient buy-in, she opted for a boning frame securely tucked between layers of soft, breathable material. The double layer of fabric adds sturdiness while isolating the frame, thus preventing uncomfortable contact with the skin (which inevitably leads to soreness). The possibility of skin contact in turn reveals a potential make-or-break point for many teenagers needing truncal support: it can be worn comfortably and discreetly under the clothes, meaning that it spends more time in

use and less time stuffed in a locker. More time on the body means more consistent truncal support, which, over time, could lessen or zero the likelihood of more spinal surgery.

At 17 years old, Charley, her parents and many other families around the world continue to reap the benefits of this "boned corset of sorts" and true to Jenn's belief that the child will outgrow it before outwearing it, many are on CharleyWrap number two, three, or even five! To the willing skeptics, she says to give it a try: while she can't guarantee specific results (the CharleyWrap has never been clinically researched or tested), she can point to her own and countless other success stories. And what's there to lose when other alternatives are significantly more expensive? At the end of the day, if the CharleyWrap succeeds only in making your child more comfortable, isn't that alone a worthy win?





# Welcome to Accessibility for Everyone

**G**reater Fort Lauderdale welcomes visitors of all abilities to enjoy a beach playground unlike any other, from 24 miles of golden beaches and incredible nature encounters to vibrant arts and culture, a thriving culinary scene and much more. The region's convention and visitors bureau, Visit Lauderdale, works to remove barriers to provide a quality experience for all, including people with visible and invisible disabilities.

"Accessible tourism is not only about human rights, but also

an opportunity to embrace and educate all visitors," said Richard Gray, Visit Lauderdale's SVP of Inclusion & Accessibility. "We embrace all visitors with wide open, welcoming arms, and we are dedicated to increasing awareness of accessibility features throughout the destination."

Greater Fort Lauderdale hotels, restaurants and attractions create a welcoming space for every guest. Many provide accessible amenities including accessible rooms – some specially equipped for the hearing-impaired – as well as

wheelchair ramps, accessible outdoor dining spaces including spacious outdoor patios, special sensory-inclusive websites, and sensory-sensitive live performances such as those at Broward Center for the Performing Arts.

Area resources are listed on [VisitLauderdale.com/Accessibility](https://www.visitlauderdale.com/accessibility), including information on where to find wheelchair accessible beaches and about the Fort Lauderdale-based Special Needs Group, which provides a wide range of equipment including rentals of wheelchairs, scooters, audio

and visual aid necessities, and other essentials. Equipment is delivered directly to cruise ship staterooms at Port Everglades, hotels, attractions, or the Greater Fort Lauderdale/Broward County Convention Center.

The Hidden Disabilities Sunflower Program at the Fort Lauderdale-Hollywood International Airport (FLL) offers guests with hidden disabilities a discreet way to request help or extra time while traveling through the airport. By wearing lanyards and pins displaying the sunflower – the symbol now recognized worldwide to raise awareness about hidden

disabilities – airport employees are alerted that consideration and assistance is needed. FLL airport guests can opt into the voluntary program in advance of travel dates by requesting a lanyard or pin to be worn by both disabled persons and caretakers by emailing [ContactFLL@broward.org](mailto:ContactFLL@broward.org). The airport also offers AIRA, a visual interpreting service that provides live, on-demand access to visual information for vision impaired travelers.

Greater Fort Lauderdale proudly hosted the Deaf Seniors of America 2023 Conference in June at the Seminole Hard Rock Casino & Hotel. The conference provided

more than 1,000 deaf senior citizens the chance to connect, learn and explore the area with guided tours.

As Florida's most diverse and inclusive destination, Greater Fort Lauderdale welcomes everyone to a vibrant community that's filled with both tropical beauty and cosmopolitan delights, home to golden beaches, endless waterways, sophisticated luxuries and unexpected adventures. Plan your trip and learn more about Greater Fort Lauderdale's accessibility offerings at:

[VisitLauderdale.com/Accessibility](https://www.visitlauderdale.com/accessibility).



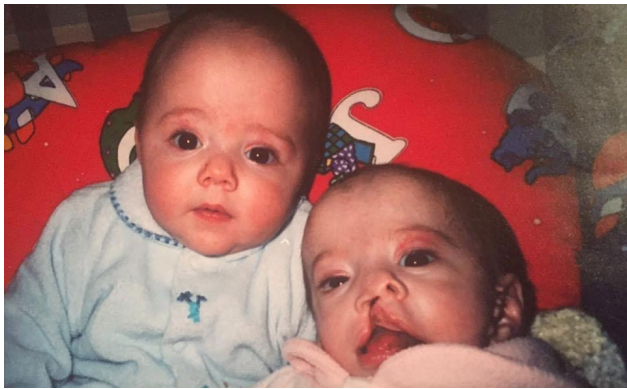






# Twin sisters Liz and Maddie champion the power of kindness and self-acceptance

By Alice Williams



In a world that often overlooks the beauty within, the extraordinary bond between twins Liz and Maddie stands as a testament to the power of love, care and family. Liz, born with Goldenhar Syndrome, has faced unique challenges throughout her life, but her journey has been defined by resilience, kindness, and an unwavering determination to make a difference. Their story is a beacon of inspiration for people with disabilities, reminding them that they too can create meaningful change in the world.

From an early age, Liz understood that she looked different from other children. It was in kindergarten when she realized that her classmates had princesses who resembled them, while she felt excluded. Instead of succumbing to bitterness, Liz transformed this experience into a catalyst for positive change. She recognized her ability to influence and empower others who felt marginalized.

As Liz and Maddie grew up, their inseparable twin bond became a source of strength and support. One poignant

memory was when Liz had surgery as a child, and Maddie, even at a tender age, took it upon herself to make their home a warm and loving space upon Liz's return. This early display of unconditional love set the foundation for their unwavering support of one another.

Liz's advocacy journey began to take shape in high school. With a close-knit group of friends and a growing sense of self-acceptance, she realized that she no longer needed to hide, or fear being seen. Maddie also played a crucial role in fostering

inclusivity and ensuring Liz felt valued within their social circles. Together, they exemplify the essence of mutual support and protection.

Liz's belief that she was born with a facial difference for a reason became a driving force for her advocacy. She started sharing her story through articles and interviews, discovering a community of individuals who faced similar challenges. The Faces National Craniofacial Association provided support when they needed it most, and Liz's involvement with the organization further fueled her passion for promoting facial equality.

Their journey continued into college, where Liz and Maddie are now pursuing degrees in communications. Their podcast, *Courageously Kind*, born out of a desire to spread kindness during the challenging times of the pandemic, rapidly gained a global following. Through their discussions and conversations, they seek to inspire others to embrace kindness in their daily lives. Their impact has been far-reaching, with listeners from 71 countries finding solace and inspiration in their message.

The sisters' involvement in various youth groups and initiatives further exemplifies their commitment to kindness. They actively participate in the

Christian women's ministry group on their college campus, nurturing relationships and cultivating a culture of compassion. They also served as emcees for Peace Camp, an event that emphasized conflict resolution and taught young children the value of accepting differences from an early age.

Dispelling misconceptions about Goldenhar Syndrome is an important aspect of Liz and Maddie's advocacy. They challenge the assumption that physical differences translate into internal disparities, reminding the world that appearance does not define abilities, intelligence, or emotions. Their hope is to foster a greater understanding and acceptance of individuals with facial differences and disabilities, encouraging society to recognize the inherent humanity in everyone.

Liz and Maddie's story serves as a powerful reminder that appearances can deceive, but the essence of a person lies within. They embody the courage to challenge societal norms and inspire others to look beyond physical differences. Their mission to spread kindness and create a more inclusive world resonates deeply, inviting us all to reflect on our own capacity for compassion and empathy.

As their podcast continues

to touch lives around the globe, Liz and Maddie remain dedicated to their purpose. They aspire to create positive change by raising awareness, advocating for accurate and positive representations.

[www.courageouslykind.org](http://www.courageouslykind.org)



**... even if we don't  
know what the  
solution to the  
problem is, even if  
we don't know what  
the future will look  
like, we can always  
be kind to ourselves  
and to others.**

Liz and Maddie Adams







Alice Wong, a writer and organizer in San Francisco, says the isolation and loss of the pandemic have shown society what it's like to be disabled. (Photo: Eddie Hernandez)

# A disabled activist speaks out about feeling 'disposable'

By [Rachel Scheier](#)

**S**AN FRANCISCO — In early January, one of the country's top public health officials went on [national television](#) and delivered what she called "really encouraging news" on covid-19: A [recent study](#) showed that more than three-fourths of fatalities from the

omicron variant of the virus occurred among people with several other medical conditions.

"These are people who were unwell to begin with," said Dr. Rochelle Walensky, director of the Centers for Disease Control and Prevention.

Walensky's remarks infuriated Americans with disabilities, who say the pandemic [has highlighted](#) how the medical establishment — and society at large — treats their lives as expendable. Among those leading the protest was San Franciscan Alice Wong, an

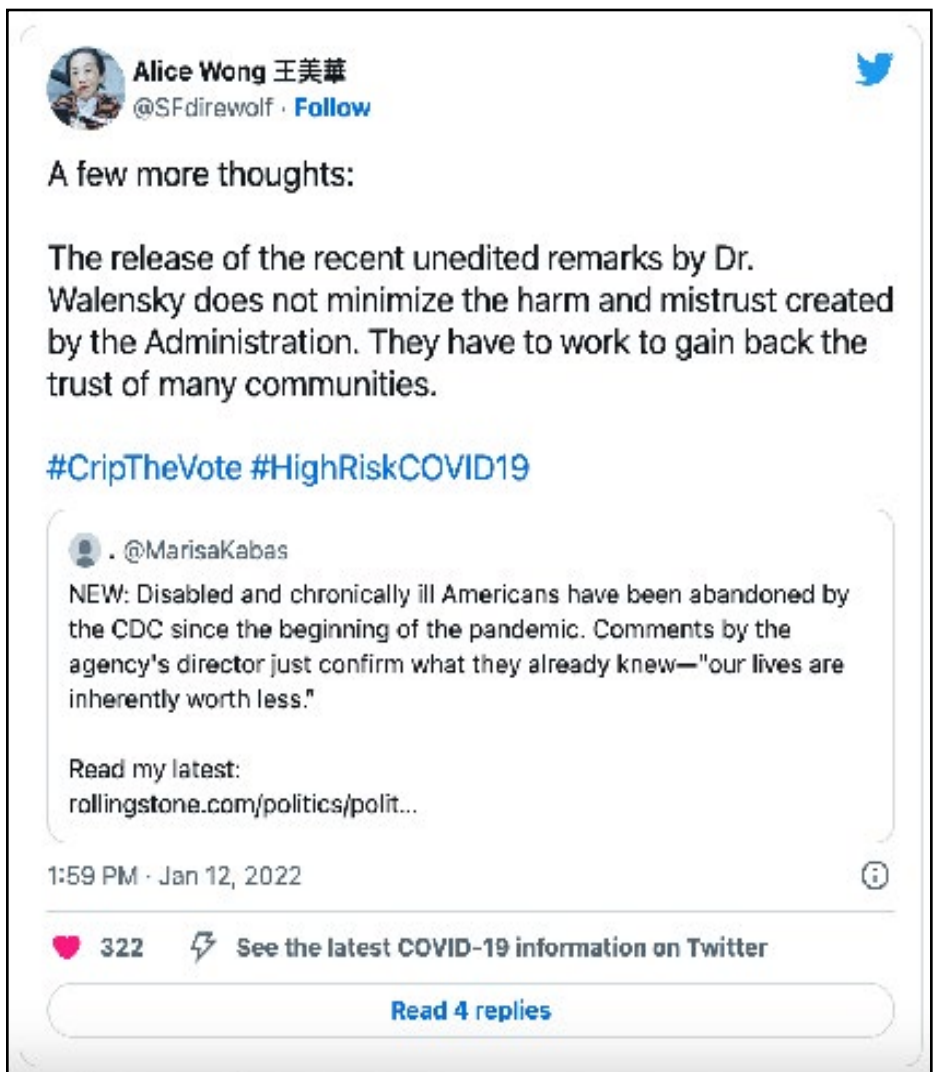


activist who took to Twitter to denounce Walensky's comments as "ableism." [Walensky later apologized.](#)

Wong, 47, moves and breathes with the aid of a power wheelchair and a ventilator because of a genetic neuromuscular condition. Unable to walk from around age 7, she took refuge in science fiction and its stories of mutants and misunderstood minorities.

Her awakening as an activist happened in 1993, when she was in college in Indiana, where she grew up. Indiana's Medicaid program had paid for attendants who enabled Wong to live independently for the first time, but state cuts forced her to switch schools and move back in with her parents. Wong relocated to the Bay Area for graduate school, choosing a state that would help her cover the cost of hiring personal care attendants. She has since [advocated for better public health benefits](#) for people who are poor, sick, or older or have disabilities.

The founder of the [Disability Visibility Project](#), which collects oral histories of Americans with disabilities in conjunction with [StoryCorps](#), Wong has [spoken and written](#) about how covid and its unparalleled disruption of lives and



institutions have underscored challenges that disabled people have always had to live with. She has exhorted others with disabilities to dive into the political fray, rallying them through her [podcast](#), [Twitter accounts](#) with tens of thousands of followers, and a nonpartisan online movement called [#CriptheVote](#).

Wong is nocturnal — she typically starts working at her computer around 9 p.m. On a recent evening, she spoke with KHN via Zoom from her

condo in the city's Mission District, where she lives with her parents, immigrants from Hong Kong, and her pet snail, Augustus. The interview has been edited for length and clarity.

### **Q: Why do you often refer to people with disabilities as oracles?**

Disabled people have always lived on the margins. And people on the margins really notice what's going on, having to navigate through systems and institutions, not

being understood. When the pandemic first hit, the public was up in arms about adjusting to life at home — the isolation, the lack of access. These are things that many disabled and chronically ill people had experienced. Disabled people had been trying forever to advocate for online learning, for accommodations in the workplace. The response was: “Oh, we don’t have the resources,” “It’s just not possible.” But with the majority inconvenienced, it happened. Suddenly people actually had to think about access, flexibility. That is ableism, where you don’t think disabled people exist, you don’t think sick people exist.

### **Q: Have you noticed that kind of thinking more since the pandemic began?**

Well, yes, in the way our leaders talk about the risks, the mortality, about people with severe illnesses, as if they’re a write-off. I am so tired of having to assert myself. What kind of world is this where we have to defend our humanity? What is valued in our society? Clearly, someone who can walk and talk and has zero comorbidities. It is an ideology, just like white supremacy. All our systems are centered around it. And so many people are discovering that they’re not believed by their doctors, and

this is something that a lot of disabled and sick people have long experienced. We want to believe in this mythology that everybody’s equal. My critique is not a personal attack against Dr. Walensky; it’s about these institutions that historically devalued and excluded people. We’re just trying to say, “Your messaging is incredibly harmful; your decisions are incredibly harmful.”

### **Q: Which decisions?**

The overemphasis on vaccinations versus other mitigation methods. That is very harmful because people still don’t realize, yeah, there are people with chronic illnesses who are immunocompromised and have other chronic conditions who cannot get vaccinated. And this back and forth, it’s not strong or consistent about mask mandates. With omicron, there is this huge pressure to reopen schools, to reopen businesses. Why don’t we have free tests and free masks? You’re not reaching the poorest and the most vulnerable who need these things and can’t afford them.

### **Q: How has your life changed during the pandemic?**

For the last two years, I have not been outside except to get my vaccinations.

### **Q: Because you’re so high-risk?**

Yeah. I have delayed so many things for my own health. For example, physiotherapy. I don’t get lab tests. I’ve not been weighed in over two years, which is a big deal for me because I should be monitoring my weight. These are things I’ve put on hold. I don’t see myself going in to see my doctor any time this year. Everything’s been online — it’s in a holding pattern. How long can I take this? I really don’t know. Things might get better, or they might get worse. So many things disabled people have been saying have been dismissed, and that’s been very disheartening.

### **Q: What kinds of things?**

For example, in California, it was almost this time last year when they [removed the third tier](#) for covid vaccine priority. I was really looking forward to getting vaccinated. I was thinking for sure that I was part of a high-risk group, that I’d be prioritized. And then the governor announced that he was eliminating the third tier that I was a part of in favor of an age-based system. For young people who are high-risk, they’re screwed. It just made me so angry. These kinds of decisions and values and messages are saying that certain people are disposable.



They're saying I'm disposable. No matter what I produce, what value I bring, it doesn't matter, because on paper I have all these comorbidities and I take up resources. This is wrong, it's not equity, and it's not justice. It took a huge [community-based effort](#) last year to get the state to backtrack. We're saying, "Hey we're here, we exist, we matter just as much as anyone else."

**Q: Do you think there's any way this pandemic has been positive for disabled people?**

I hope so. There's been a lot of mutual aid efforts, you know, people helping each other. People sharing information. People organizing online. Because we can't wait for the state. These are our lives on the line. Things were a little more accessible in the last two years, and I say a little because a lot of universities and workplaces are going backward now. They're doing away with a lot of the hybrid methods that really gave disabled people a chance to flourish.

**Q: You mean they're undoing things that helped level the playing field?**

Exactly. People who are high-risk have to make very difficult choices now. That's really unfortunate. I mean, what is

the point of this if not to learn, to evolve? To create a new normal. I can't really see that yet. But I still have some hope.

This story was produced by [KHN](#), which publishes [California Healthline](#), an editorially independent service of the [California Health Care Foundation](#).

*This article was originally published in [KFF Health News](#). Read the [original article](#).*



Disabled people had been trying forever to advocate for online learning, for accommodations in the workplace. The response was: "Oh, we don't have the resources," "It's just not possible." But with the majority inconvenienced, it happened. Suddenly people actually had to think about access, flexibility. That is ableism, where you don't think disabled people exist, you don't think sick people exist . . .

~ Alice Wong







# Trailblazing disabled equestrian, Veronica Gogan: galloping against all odds

By Alice Williams

**I**n a world filled with ordinary stories, there are those that shine with extraordinary brilliance. Veronica Gogan, a remarkable woman and adaptive athlete, is one such beacon of inspiration. As a mother of two boys and a fierce competitor in para dressage, Veronica's journey is defined by her indomitable spirit and unwavering determination. What sets her apart is not just her incredible talent, but her unwavering dedication to empowering others, especially women, with disabilities.

Veronica's story began 19 years ago, when she was diagnosed with multiple sclerosis at the tender age of 17. However, it wasn't until 2018 that she truly embraced her identity as a disabled individual. Throughout her life, Veronica's passion for horses burned brightly within her soul. From the age of five, when she embarked on a trail ride that ignited her love for these majestic creatures, she knew that horses were her calling. Riding

became her sanctuary, her escape from the trials of life.

A profound believer in the healing power of movement, Veronica has found solace and strength in the saddle. She recognizes the transformative impact of physical activity on overall well-being, especially for those with disabilities like herself. With boundless gratitude for her experiences, she embraces her role as an advocate, offering guidance and support to young women facing the challenges of disability, multiple sclerosis, and the delicate balance of family life.

What draws Veronica to the world of horses? She ponders this question, acknowledging that the allure is as enigmatic as the bond between horse and rider. For her, it is a visceral connection—a love that courses through her veins, unexplainable yet undeniable. It is a deep admiration for the intuitive nature of these

magnificent animals and the peace she finds in their presence. But beyond that, it is the thrill of competition that drives her. Unlike any other sport, equestrianism demands harmony between rider and horse. A language unspoken yet understood, a partnership built on trust and respect. It is a great equalizer—a sport where disabilities become irrelevant, where strength and determination prevail.

Veronica's advocacy extends far beyond her personal journey. She believes that horses possess an innate

ability to offer gifts beyond human comprehension. These extraordinary creatures possess an intuition that defies explanation. They can connect with non-verbal individuals, providing solace and companionship. They grant freedom to those whose bodies may be limited, becoming a conduit for empowerment and liberation.

In the world of competitive para equestrian sports, Veronica faces unique challenges. The physical demands of her disability require rigorous training,

encompassing both her strength and endurance. She commits herself to a carefully crafted regimen, working with adaptive gyms and trainers who understand the intricacies of her sport. Moreover, she navigates the financial constraints associated with her passion, relying on grants and sponsors to continue her pursuit of excellence.

Amid the complexities of her life, Veronica remains unwavering in her commitment to her family. She orchestrates a delicate balancing act, weaving her





training into the fabric of her daily routine. Her support system—her unwavering pillars of strength—ensure that her dreams are realized. They lend a helping hand, caring for her children and creating an environment where she can thrive.

Veronica's journey is a testament to the power of movement, the resilience of the human spirit, and the unwavering belief that anything is possible. Her story resonates with those who dare to dream, who refuse to be defined by their disabilities. She encourages individuals of all abilities—be it physical, cognitive or mental—to embrace the transformative power of sports. With goals as guiding beacons, we can rise above the challenges, uniting as a team to triumph over adversity.

In the end, Veronica's message is clear: seize the power of movement, embrace the extraordinary and dare to defy limitations. Whether your goal is to walk a few steps or conquer a hundred miles, the journey begins with a single step. Remember, plans are empowering, and with unwavering determination, you can conquer the seemingly impossible.

**[www.veronicagogan.com](http://www.veronicagogan.com)**



**Veronica's journey is a testament to the power of movement, the resilience of the human spirit, and the unwavering belief that anything is possible.**





# Navigating love and connection as a person with a disability

By Alice Williams

**I**n a world filled with swirling emotions and the promise of love, there lived a remarkable group of individuals with unique stories to tell. They were people with disabilities, navigating the complexities of dating with unwavering determination and unyielding spirit.

In this enchanting journey to find love and connection, they faced challenges that tested their resilience. Society, with its preconceived notions and misconceptions, often cast a shadow on their path. Ableism

lurked in the corners, causing some potential partners to hesitate and hold back, blinded by fears of the unknown. But our heroes refused to be discouraged; they knew their worth and carried on with hearts full of hope.

As they ventured into the world of dating, they encountered hurdles that could have deterred the faint-hearted. Accessibility was a tricky beast, lurking in the background, ready to disrupt the magic of a date. Inaccessible venues seemed to dominate the

landscape, threatening to limit their options and dampen their spirits. Yet, these intrepid souls were resourceful, finding inventive ways to create memorable moments despite the barriers before them.

Communication was the key to every heart, but for some, it seemed locked away. Those with speech impairments or communication difficulties struggled to express their feelings fully. But they discovered the art of unspoken connections, revealing the beauty of emotion through



glances, touch and the poetry of silence.

Deep within their hearts, they carried the weight of a fear that whispered unkind words. The fear of being perceived as a burden weighed heavily on their shoulders, but they refused to be bound by its chains. With courage as their armor, they embraced vulnerability and put themselves out there, daring to seek love despite the uncertainty.

In this enchanted realm, there was a decree that love should bloom only within the confines of similarity. But our heroes were rebels, defying the norm and seeking connections beyond the boundaries set by others. They knew that love transcends appearances, and a heart that understands and cherishes is worth its weight in gold.

Amidst the vast sea of online dating, they discovered both treasures and treachery. Some feared judgment and hid their disabilities, while others were hailed only for their uniqueness. But they learned to discern the genuine from the insincere, allowing the magic of true connections to illuminate their path.

In the depths of their souls, they faced their own inner battles. Low self-esteem and internalized ableism tried to shroud their light, but they

found the strength to banish these dark clouds. With newfound confidence, they embraced their identities and realized that love starts with self-acceptance.

Though their quest was daunting but in a world of understanding friends and allies, they found the support and encouragement needed to embark on this grand adventure. In disability-friendly dating realms, they discovered a sanctuary where understanding and compassion intertwined, nurturing the seeds of love and hope.

With every challenge they faced, our heroes grew stronger, wiser and more resilient. They knew that their journey was not without obstacles, but they refused to let these barriers define their destiny. Instead, they transformed the difficulties into stepping stones towards greater love and connection.

And so, their story became a beacon of inspiration for all who felt the gentle whisper of love beckoning from afar. They proved that love knows no limitations and that every heart, no matter its circumstances, deserves to find its soulmate.

In this tale of courage, hope and love, they discovered that within their hearts, a realm of boundless possibilities existed. And as they ventured forth into the world, hand in hand, they

knew that love would always find a way - a way to break barriers, conquer fears and ignite the magic of connection, regardless of their limitations.



**Love knows no limitations; it sees beyond disabilities and embraces the beauty of the heart.**

## **Haptic accessibility: making technology inclusive**

Making technology more inclusive for everyone is the goal in the emerging field of haptic accessibility. Haptic technology might revolutionize the way we interact with our digital devices by providing tactile feedback, allowing users to control devices using touch alone. [Read the full article.](#)

---

## **Michigan's Threads Fashion Show focuses on adaptive wear**

Adaptive clothing modeled by people with disabilities was featured this year in an annual student-run fashion show in Michigan, U.S. The focus on one-of-a-kind clothing included the creation of a skirt that fits like no other. [Read the full article.](#)

---

## **Retired Paralympic swimmer on her inclusive talent agency**

Inclusive talent management and disability consultancy agency, Touch Dubai, is on a mission to, "change culture, not just share stories." Founder Jessica Smith wants brands to go beyond merely ticking a box. [Read the full article.](#)

## **Canadian airport YVR launches Beyond Accessibility plan**

Flying in and out of Vancouver International Airport is about to get less challenging for visitors and employees with disabilities. The airport has embarked on a comprehensive three-year plan to offer more inclusive and accessible travel. [Learn more.](#)

---

## **Does long COVID create disability?**

An Australian woman living with long covid explains why it is a disability and how the illness has impacted her life. Fatigue, chest pains, headaches and memory loss continue for Alicia, so why won't her government and medical professionals recognize it as a disability? [Read the full article.](#)

---



## **Mashable's biggest assistive technology and accessibility triumphs of 2023**

Advancements in technology are expanding accessibility for countless people, from users who are blind to gamers with limited motor control. AI volunteers, upgraded iPhones, and other tech are expanding accessibility. See the wins and fails. [Read the full article.](#)

---

## **Albany Airport receives global accreditation for accessibility**

New York's Albany airport is only the fourth in the world to receive the Accessibility Enhancement Accreditation. The designation from Airports Council International is given to airports meeting the highest-level for accessibility. [Read the full article.](#)

---

## **Gardening is for everyone**

Cultivating a garden is possible for people with physical limitations. A professional offers tips on making gardening more accessible. [Read the full article.](#)

## **U.K. study finds that workplaces are still not inclusive**

A study by the Business Disability Forum, based in London, found that employees in need of adjustments to reduce or remove workplace barriers is taking too long. [Read the full article.](#)

---

## **New York City, I love you - but I have a disability**

Writer Kelly Dawson lives with cerebral palsy. As much as she loves New York City, she explains why the Big Apple wasn't built for people like her. [Read the full article.](#)

---

## **Millie Bobby Brown on how her disability impacts her role in Stranger Things**

One of the stars of the hit Netflix series talks about the key to her success and how she's been able to overcome the challenges of a disability. [Read the full article.](#)

---

## **Making Hollywood more inclusive**

Keely Cat-Wells, founder of talent management company C-Talent, is on a mission to make Hollywood more inclusive, placing disabled actors into all roles and changing the way the world defines disability. [Read the full article.](#)

# I GOT LEGS: facilitating access to exoskeleton technology

I am Adam Gorlitsky, the founder of a paralysis-related nonprofit organization called I GOT LEGS. I became paralyzed, from the waist down with a spinal cord injury, from a car accident on the night of December 30, 2005.

Doctors said I would never be able to walk again. Little did I realize that I would be walking again, thanks to a ReWalk powered exoskeleton that I started using in August 2015. Since then, I have used my exoskeleton to walk in more than 60 road races and have set a couple Guinness World Records.

## **Tell us about winning the Guinness World Record for exoskeleton marathon walking. What has it taught you?**

The Guinness World Record marathon experience was incredible because it was something that I was chasing after for nearly two years. It taught me that the journey is just as rewarding as the end goal. It was a great lesson in perseverance and resilience. My Guinness World Record for Exoskeleton Marathon Walking is my proudest accomplishment to date. I also have a pending world record for the Half-Marathon that I should be able to announce soon once Guinness looks over all my evidence from that race.







What started as a slogan on fundraising t-shirts, I GOT LEGS became an official nonprofit in 2016, helping people walk again via exoskeleton technology. AfA interviewed founder Adam Gorlitsky, whose vision is to propel “science and innovation towards reversing paralysis.” He holds the Guinness World Record, Fastest Marathon Distance in a Robotic Walking Device



exoskeleton like the lower half of a Terminator suit, which I strap onto the lower half of my body. It allows me to sit, stand and walk through an internal arrangement of sensors, batteries, motors and computer software all working together as one.

The walking motion is triggered by me doing side-to-side weight shifts with my abdominals and hips when the exoskeleton is in walk mode. When the exoskeleton senses those weight shifts, it will then physically move my leg by activating a motor within the leg of the exoskeleton. It's a perfect marriage of man and machine.

**Can you share client feedback on how the product has helped them? How do you measure the impact of your exoskeleton technology?**

**What inspired you to start your company, I GOT LEGS? How does the exoskeleton technology work?**

I GOT LEGS is a nonprofit organization I started to help paralyzed athletes walk again by assisting them to gain access to exoskeleton technology. One of our main goals is to turn exoskeleton

racing into a Paralympic sport.

I grew up playing basketball, running track and cross country, so what inspired me to start using the exoskeleton was an inherent need to regain the athleticism in the lower half of my body. Starting I GOT LEGS was, and continues to be, a way to help others do the same. In broad terms, I describe the

We do not manufacture or distribute the exoskeleton. We do, however, help paralyzed athletes, veterans organizations and physical therapy clinics fundraise to buy the exoskeletons. Then we create programs that empower clients to use the exoskeleton in a more recreational way. Through this process, we are working towards turning exoskeleton racing into an organized



adaptive sport that will one day be in the Paralympics.

From a feedback and impact perspective, exoskeleton walking has been scientifically proven to help paraplegics improve bowel/bladder function, improve circulation and spasticity, build core strength, improve posture, maintain bone density and help improve neuropathic pain. Many others, like myself, have also reported experiencing

psychological improvement with our moods, etc.

### **What can you tell us about companies in the exoskeleton technology industry?**

As I said, we do not manufacture or distribute the exoskeleton. In the U.S., the ReWalk and Indego exoskeletons are the two main ones that are FDA approved for home personal use. They are also the two main exoskeletons that

we use for racing.

In terms of the sport of exoskeleton racing, the Indego is the best exoskeleton for racing distances up to 5 kilometers (3.1 miles) since it has the Advanced Gait feature that allows it to walk nearly 34% faster than the ReWalk. But the ReWalk is more durable and has a much better battery system for walking longer distances, so it's the best exoskeleton for 10k's, half and full marathons. The ReWalk



is also currently the only exoskeleton that can climb stairs, which means we could use it for stair races.

### **How can the public support your business?**

People can donate, buy an I GOT LEGS t-shirt or learn more at our website: [www.igotlegs.org](http://www.igotlegs.org). You can also visit our Facebook, Instagram and TikTok pages at: [i\\_got\\_legs](https://www.instagram.com/igotlegs)

### **How do you envision your company's future and its role in continuing to improve the lives of people with disabilities?**

I envision I GOT LEGS leading the way in revolutionizing adaptive sports with exoskeleton technology and using this incredible

technology to help more people within the paralysis community obtain a better quality of life.

My goal is to eventually be able to walk a marathon as fast as an able-bodied person, so I can also see us becoming more active in the research and development of a new exoskeleton, and eventually getting involved with more advanced forms of paralysis research such as neuromodulation, stem cells, etc.

### **What can we expect from you and the company in the next year?**

I will be attempting to break my Guinness World Marathon Record later this year at the Kiawah Island Marathon near

my hometown of Charleston, South Carolina. I GOT LEGS is organizing an exoskeleton race in April 2024, at Clemson University. We might have a new exoskeleton prototype developed by then too.

### **What message would you like to share about the importance of inclusivity and the power of technology to unite people?**

From a physical standpoint, my spinal cord injury/disability might distinguish me from others, but it doesn't define who I am — so my message to the world is that inclusivity and technology empower us to become the best versions of ourselves and redefine what's possible.







# EMERGING MARKETS SUMMIT

Join us for an engaging experience of 2.5 days filled with panel discussions, workshops, and presentations featuring influential thought leaders and travel influencers from the industry and explore the opportunities in fields of accessible travel, sustainability, and DE&I all in one place.

**Friday, August 18th – Sunday, August 20th 2023**  
Hyatt Regency, Savannah, GA

## **BONUS**

The conference is conveniently co-located with ESTO, allowing attendees to make only one trip to attend two important industry events.

**REGISTER NOW**



[www.travelability.net](http://www.travelability.net)



415.339.0578



Cynthia Elliott reminds her daughter Zainab to stretch during a skating lesson at the Ice Den, Chandler, Arizona. (Rick D'Elia)

# Why it's hard to find safe homes for some people with disabilities

By [Amy Silverman](#)

To make this story more accessible to a wide range of readers, we are providing this plain language version, translated by [Rebecca Monteleone](#). Plain language is a writing style that makes difficult concepts easier for people with intellectual or developmental disabilities to read. [Learn more about this here.](#)

Zainab Edwards is an ice skater. Ice skating runs in Zainab's family. Zainab's mom is an ice skater too. Her name is Cynthia Elliot. Cynthia's other daughter used to ice skate too.

Cynthia and Dave are Zainab's foster parents. They have been fostering Zainab since she was 4 years old.

Zainab is 23 years old. She ice skated with an instructor in

Chandler, Arizona. She had a good day.

Zainab did not want to talk to a reporter.

Zainab has disabilities. She is deaf. She used to use American Sign Language and cochlear implants to communicate.

She does not have a colon. She wears an ileostomy bag. The bag holds her waste.

Zainab used to have a full life. She went to Disneyland. She had friends. She did the Special Olympics.

In 2014, Zainab got very sick. She had trouble walking and picking things up. She had many seizures every day. She could not wear her cochlear implants. She got angry and tried to hurt her mom and caregivers. She could not feed herself.



Zainab has autoimmune encephalitis. That means her body attacks her own brain.

Zainab did physical therapy after she got sick. She learned how to ice skate and ride her bike again.

Her mom said:

"She still can't write her name. She's lost all those cognitive skills. Those have never come back."

Zainab needs somewhere safe to live. Her parents worry about what will happen when they die.

They bought a house for Zainab. It is close to their house. They wanted Zainab to have a roommate. But Zainab did not get a roommate. Zainab might hurt someone else who lives with her.

Many people have disabilities like Zainab. These disabilities are called **intellectual and developmental disabilities** or **IDD**. People like Zainab are sometimes called **people with complex needs**. That means they need a lot of support. Sometimes it means they hurt themselves or other people.

Here are the ways people with IDD get support services:

- They or their families pay for services.
- Their families are their caregivers.
- A state agency pays for services.

Only 1 in 5 people with IDD get paid services from their state.

Most people with IDD do not get any help paying for services.

Some people with IDD wait for a long time to get help from their state.

Zainab gets services paid for by the state of Arizona. Arizona pays more than \$1 million a year to support Zainab.

But Zainab's family says her life is not good.

Having money to pay for services is not the same as having good services.

People do not agree on the best ways to support people like Zainab.

Zainab has many staff. She has:

- Two caregivers who stay with her all the time.
- A nurse who stays with her all the time.
- A sign language interpreter for the nurse.
- Another caregiver who stays with her during the day.
- A behavior coach.
- A sign language interpreter for the behavior coach.

Arizona pays for Zainab's staff. Arizona also pays for most of her medical costs and transportation.

But all of these services do not make Zainab's life safe, happy, or productive.

Zainab's mom Cynthia says that Zainab gets new staff a lot. She said they do not have the right training.

Cynthia spends a lot of time caring for Zainab herself.



Zainab Edwards skates while holding hands with her teacher Tammy Jimenez at the Ice Den, Chandler, Arizona. (Rick D'Elia)

Zainab has had 60 different staff people in the last couple of years.

The police have come to Zainab's house more than 100 times between 2018 and 2022.

Zainab's mom Cynthia wrote an email that explains why the police come to Zainab's house. She wrote:

"The behavior following some of her seizures is extreme, she has kicked out the van windows, broken her bedroom window that was plexiglass, she will hit, kick, bite, pull hair."

Zainab does not like taking medication. Her staff cannot hold her down to take it. So her staff call 911 to help. Zainab is getting better at taking

medication on her own.

Zainab does not have a good quality of life.

Zainab's staff do not talk with her very much. Zainab's mom Cynthia has to ask them to help Zainab do chores around the house.

Zainab got bad burns on her hands at home. Her mom Cynthia could not figure out how it happened. Cynthia put cameras in Zainab's home so she could see what was happening.

The cameras show that Zainab is alone a lot.

Zainab's mom Cynthia said:

"It's heartbreaking to see Zainab sitting alone at the

kitchen table eating a meal while three staff sit in the other room on their phones."

Cynthia thinks Zainab can do a lot more.

## Searching for solutions

Many people with complex needs like Zainab used to live in institutions. Institutions are large places where many people with disabilities live together.

Arizona's institution is called the Arizona Training Program. It is 1 hour from Phoenix.

Arizona also has a state mental hospital in downtown Phoenix.

In the past, people who lived in institutions did not leave very



Zainab Edwards skates with her teacher Tammy Jimenez at the Ice Den, Chandler, Arizona. (Rick D'Elia)



much. They lived far from their communities. People with IDD were tied down or kept alone if they did not behave well.

In 1999, there was a Supreme Court case that said people with disabilities deserve help to live in their community. The case was called *Olmstead v. L.C.*

The judges said forcing people to live in institutions broke a law called the Americans with Disabilities Act.

Zainab lives in her community. But she is isolated. It is like she lives in an institution all by herself.

Zainab has many needs. She has aggressive behavior. That means she might hurt herself or other people.

People with complex needs are often left out of their community.

Many people think Arizona is one of the best states to live in if you have IDD. No one with IDD has to wait on a list to get services. If you qualify, you can get services right away.

Arizona has a program for people with complex needs like Zainab. It is called the "Enhanced Transitional Group Home."

But people with complex needs are not getting what they need in Arizona.

A researcher looked at 8 people

living in Enhanced Transitional Group Homes in Arizona.

They said 7 of the 8 people did not have better lives in the group home than they had before.

The researcher wrote:

"The members did not make significant behavioral gains in either reduction of challenging behaviors or acquisition of social and self-determined competencies" and that "staff and member engagement in participatory, meaningful, and functional activities was staggeringly low."

This means the people in these group homes did not learn to do new things or go into their communities very much.

One of the people in the study was a young woman called RS. She has autism and mental illness.

The researcher said RS's caregivers did not spend much time with her. They only spent 30% of their time with her. That would be about 18 minutes of every hour.

The researcher said RS spent most of her time on her iPad.

RS also hurt herself. Having more staff did not make her life better.

RS's care cost a lot of money. Arizona pays more than \$1 million a year for RS's care.

The people who care for RS do not make a lot of money.

Some people say there are not enough rules about services for people with IDD.

Jon Meyers is the executive director of the Arizona Developmental Disabilities Planning Council. He is one of the people who thinks services are not working well. He said:

"It is clear to anybody with eyes that the way things are being handled right now simply isn't effective."

Jon said one big problem is that staff leave their jobs a lot. They do not have enough training. They do not make enough money.

He thinks just having more staff does not make caregiving better.

Jon said:

"It is not just a matter of not having enough money. It's a matter of using the money wisely. We are often just throwing money at it without knowing what is going to be effective."

Jon also said:

There are "questions we don't yet have answers to. There are people whose diagnoses are so complex that right now we can't fully provide for them. We can't fully provide the care they need."

What he means is that we don't know what everyone with IDD needs.

Brett Bezio is a spokesperson. He works for the Arizona Department of Economic Security or DES. DES runs the Division of Developmental Disabilities.

Brett said DES knows that the Enhanced Transitional Group Homes are not perfect. He said:

"While there were aspects of the pilot model that were more successful in providing individuals with an engaging living environment where their needs were supported, the Division continued its work to improve and enhance this service model."

Brett said DES is working to make Enhanced Transitional Group Homes better. He said:

"Using the information and trends that were identified in those initial years, review of models in other states, as well as working with external experts in this field, the Division has created an updated service specification for this type of residential placement setting that it hopes will make the service more effective in the future."

There are not enough staff to support people with IDD. They do not make enough money. They do not have enough

training. This is a problem all over the USA.

A study said 7 out of 10 caregiving companies cannot do everything their clients need.

This problem got worse because of the COVID-19 pandemic.

Barbara Merrill runs ANCOR. ANCOR is a group for staff who support people with IDD. She said:

"[States are] closing the smaller three-, four-bed group homes and moving people into [larger] group homes. And that is going in the wrong, wrong, wrong direction. It's not what we're trying to do as an industry, it's not what we're trying to do as a country."

This quote means some people with IDD are moving into homes with many other people with IDD.

Many institutions in the USA are closing.

Some people worry about institutions and group homes closing. They think there won't be enough places for people with IDD to live.

The University of Minnesota did a study in 2012. The study was about families of people with complex needs. The study said: Families "often have difficulty in keeping jobs; can have limited

opportunities for socialization friends and family due to social isolation; may be sleep deprived because their children are up all night; and may encounter frequent injury such as bites, bruises, hair pulled out of their heads and even broken bones. Even in these crisis situations, families wait for services."

This quote was written 10 years ago. Families still have these problems today.

Amy Hewitt is the director of the Institute on Community Integration at the University of Minnesota. She worked on the study from 2012.

She remembered a story about a person with IDD who had many staff members.

His staff did not have enough training. They were afraid of him.

She said:

"The staff would run and hide in the bathroom, in the kitchen, in the staff area. There'd be five of them."

Amy said the man was not part of his community.

She said he stayed at home to exercise:

"He had an exercise program where he would just walk the perimeter of the inside of his bedroom over and over and over and over."



Amy said:

"You can throw all kinds of money at something, and it's not going to make it work if you're just doing more of the same, which is sort of glorified babysitting. From that kind of money, you could buy the best behavioral consulting the world had to offer."

Wanting to help people with IDD is not enough.

Bob Kafka is a disability activist. He works with ADAPT. He said:

"Having philosophical values is fine, but where the rubber meets the road is how you're going to implement it."

## **Mobilizing against mistreatment**

Society does not know what to do with someone like Zainab.

In the past, people with

disabilities were:

- Kept by themselves
- Made fun of
- Abused

Society learned more about disabilities through science and medicine.

Learning more does not mean people's lives got better.

Dorothea Dix was an activist who lived in the 1800s. She wanted to make the lives of people with IDD and mental illness better.

She thought they should live in institutions run by the government.

Arizona's State Asylum for the Insane opened in 1887.

In the year 1912, 375 people lived there. Some of the people who lived there had IDD.

Arizona wanted to build an

institution just for people with IDD in the 1940s.

But many people spoke out about how bad institutions were. Some people who spoke out were:

- People who refused to fight during World War II. These people were sent to work in institutions instead.
- Families of people with IDD. These families formed the National Association for Retarded Citizens. This is now called the Arc.

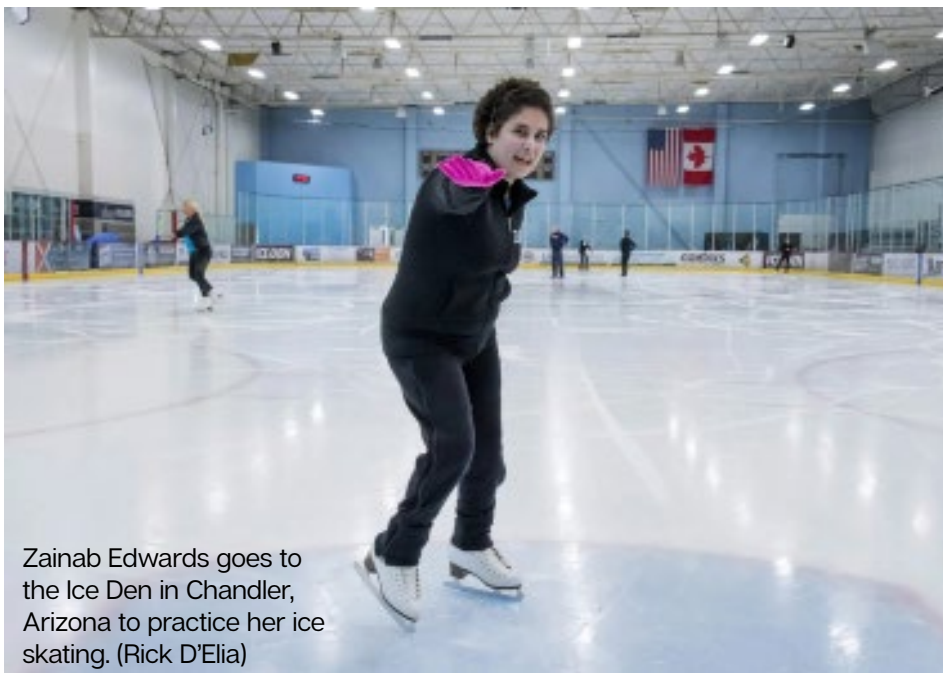
The disability rights movement grew in the 1960s. President John F. Kennedy and his family supported the movement. President Kennedy had a sister named Rosemary. Rosemary had IDD.

"Christmas in Purgatory" was a book of photos published in 1966. It showed how bad living in an institution was.

In 1972, a TV reporter named Geraldo Rivera did a story about Willowbrook State School. Willowbrook was an institution in New York. This story showed many people how bad it was to live in an institution. [Read the rest of this article here.](#)

*This article was originally published in The Center for Public Integrity.*

[Read the original version of the story.](#)



Zainab Edwards goes to the Ice Den in Chandler, Arizona to practice her ice skating. (Rick D'Elia)

# The Valuable 500 is on a mission to end disability exclusion

By Lisa Guthrie Deabill



Caroline Casey

Communications Director at The Valuable 500, Ryan Curtis-Johnson, spoke to us about company founder Caroline Casey, the organization's vision, their 2025 Accountability Summit in Tokyo and an inspiring new mentorship program. Learn more at [thevaluable500.com](https://thevaluable500.com)

## A fearless push against barriers

**T**he Valuable 500 founder, Caroline Casey has a fearless nature of pushing boundaries, which might be how she convinced 500 companies to join the organization. Based in England and launched at the World Economic Forum in Davos, 2019, the group's vision is to end disability exclusion through synchronized collective action. Caroline grew up in Ireland.

She was diagnosed at birth with ocular albinism, a genetic condition that causes extremely blurry vision. But it wasn't until she was a teenager that she found out she was legally blind.

Ryan Curtis-Johnson, Communications Director at The Valuable 500, said, "She knew no different. She just thought that was how people saw and so it didn't hold her back in life." He added, "The stigma surrounding disability, the negative connotation, spurred

her to drive change so people can develop in a career of their choice."

But Caroline did not jump into advocacy right away, having worked in the corporate world, where she didn't disclose her own disability for many years. She worked in change management within Accenture, which drove her to push for disability inclusion within the workplace. In addition to being an entrepreneur and founder of The Valuable 500, Caroline is also



president of the International Agency for the Prevention of Blindness (IAPA), and she sits on several diversity and inclusion boards including those for L'Oréal, Sky and Sanofi.

## Partnership to drive change

The Valuable 500 is a partnership of 500 multinational companies and organizations with the common goal of making change. Of those companies, 46 are Fortune 500 companies. Each one is taking steps to end disability exclusion. Take for example Airbnb. Ryan pointed out how efforts by the online rental marketplace

to accommodate travelers with disabilities has increased business and in turn, Airbnb's bottom line, adding, "Airbnb recently launched their adaptive category that now has 1,100 listings around the world with hosts earning over 5.5 million since the launch." L'Oréal, the world's largest cosmetics company and Valuable 500 partner, is also keeping people with different abilities in mind. They recently launched accessible packaging which allows consumers to hear information about a product by scanning a QR code with their cell phone. "This is the beauty of where inclusive design starts at the outset rather than as an afterthought," said

Ryan. The internal culture of a business is just as important. Lloyds Banking Group, another Valuable 500 partner, is on track to meet its goal of doubling the number of employees in senior roles by 2025. Lloyds has gone on record with its hiring plan. This transparency will breed trust, according to Ryan. "That's what we need to see—more accountability of businesses putting facts and figures out there."

## Ending disability exclusion

The Valuable 500's partners are working together to accelerate disability inclusion within companies, believing



# Annual Meeting



that, “inclusive leaders create inclusive businesses; inclusive businesses create an inclusive society. Working together accelerates and scales systems’ impact.”

“The strategy for The Valuable 500 is accountability and trying to fill the gaps in data, self ID, representation and inclusive reporting. Leadership and C-suite storytelling is a key factor—we need to see people at the top being able to openly disclose or speak of their lived experience, which will cascade within an organization which automatically feeds into society.”

To make that happen, Ryan said businesses need to stop looking at people with disabilities as having a separate identity. Additionally, inclusion should happen because a business genuinely wants change, not because everyone else is doing it. “We’re at a stage now that it’s actually risky for businesses not to take this seriously within their organizations.”

But despite their best efforts to include employees and consumers with disabilities, businesses face failure without a proper plan. “You can only tap into that market if you have the

knowledge, the understanding, the expertise within your organization to develop, deliver and execute products or services that can deliver to that demographic,” said Ryan. He adds that it is important for companies to show consumers and employees their inclusivity plan in action, so they can “see themselves and see that you are genuinely doing something for people with disabilities.”

Some of the most important pieces of advice from The Valuable 500 are: don’t be scared to say the word disability, and don’t let disability hold you back. “Take



# eting 2023



the time to understand, look at it within your organization, reach out to the individuals,” suggests Ryan, adding, “If you don't know what to do, ask. And if you don't have the skill set within your organization, there are companies and individuals out there who do have the skills, knowledge and solutions to drive change within your organization.”

## Looking ahead

The company is planning The Valuable 500 Accountability Summit in Tokyo, Japan, in 2025. All partners will be invited to share the progress

they have made using the group's three synchronized collective actions of leadership, reporting and representation. Experts will be on hand at the summit to provide business leaders with information on inclusivity.

The Valuable 500 also highlights a new program they recently launched, Generation Valuable. This unique mentorship for people with disabilities will help build the future of executive leadership and drive disability inclusion through systematic change.

Ryan adds, “One of the beauties of The Valuable 500 companies is that all the CEOs have committed to driving disability inclusion. They've created their own personalized commitments which are all connected to their organization. We won't stop until everyone is seen and valued equally.”

---

**The Valuable 500's partners are working together to accelerate disability inclusion within companies . . .**

---



## In the know

with Angela Lynn

# Deaf and Hard of Hearing travelers

**T**he truth that often surprises many hearing people is that Deaf people not only travel, but they do so independently and in groups. I vividly remember an encounter with a hearing woman who was amazed to learn that I am a Deaf international traveler that is comfortable to venture out alone or with companions. I am deeply grateful to my hearing parents for the incredible travel opportunities they provided, taking my hearing siblings and me to countless destinations around the globe.

For Deaf people, embarking

on a journey can be an equally transformative adventure, brimming with unique experiences and opportunities for personal growth. In this article, we will explore the realm of Deaf and Hard of Hearing travels, shedding light on the positive aspects as well as the challenges they may face. Unfortunately, I currently lack sufficient information to delve into DeafBlind travels, but I hope to share insights on that topic in the near future.

### Positive experiences

Many Deaf travelers have reported an increased sense

of self-confidence and independence when they are abroad. They feel empowered to rely solely on their own skills and knowledge to navigate unfamiliar places. Here is a list of some of their positive experiences:

**CULTURAL EXCHANGE AND CONNECTION:** Deaf and Hard of Hearing travelers excel at connecting with people beyond their individual language barriers. Through sign language, they foster genuine cultural exchanges and establish meaningful connections with people from diverse backgrounds.





### **ENHANCED VISUAL**

**EXPERIENCES:** Deaf and Hard of Hearing travelers embrace the world's beauty through their heightened visual perception. They immerse themselves in breathtaking landscapes, vibrant cities and artistic masterpieces, truly cherishing the wonders of their destinations without distraction from the sounds around them.

### **COMMUNITY SUPPORT**

is vital for Deaf and Hard of Hearing travelers, because they form a tight-knit network

that offers valuable assistance and resources. Through this network, the Deaf and Hard of Hearing can rely on community recommendations for accessible accommodations, attractions and transportation options, guaranteeing enjoyable and stress-free travel experiences.

### **INCREASED EMPOWERMENT AND INDEPENDENCE:**

Traveling holds the remarkable ability to empower Deaf and Hard of Hearing people by promoting self-advocacy and self-reliance. The process

of navigating unfamiliar environments, managing logistics and conquering obstacles cultivates essential life skills, leading to increased confidence and independence.

## **Challenging experiences**

As a Deaf traveler, I have personally encountered numerous challenges during my journeys. It's important to acknowledge that my experiences may differ from those of other individuals. One common difficulty I face is the limited availability of information regarding accessibility of tourist attractions and transportation services in unfamiliar countries. Listed below are some of the challenging experiences faced by Deaf and Hard of Hearing travelers.

### **COMMUNICATION BARRIERS:**

One of the key challenges faced by Deaf and Hard of Hearing travelers is communication. While some countries offer sign language interpretation services and have Deaf-friendly infrastructures, many destinations still lack adequate accommodations. Limited access to information, difficulty in obtaining assistance, and miscommunication can hinder the travel experience. By improving communication channels, training tourism professionals and utilizing technology solutions, we can create a more inclusive and enjoyable travel experience

for Deaf and Hard of Hearing travelers.

**SAFETY CONCERNS:** In emergency situations or when traveling alone, Deaf and Hard of Hearing travelers may face additional safety challenges. The inability to hear announcements, alarms, or warnings can potentially put them at a disadvantage and at risk for their lives. It is crucial for Deaf and Hard of Hearing travelers to be prepared, remain vigilant and have contingency plans in place.

**LACK OF AWARENESS AND ACCESSIBILITY:** Travel destinations have made strides in accessibility, but there is still room for improvement in providing Deaf-friendly facilities and services. Accessible accommodations, visual notifications and inclusive tour experiences are key aspects that need attention to ensure an inclusive travel environment for all.

**ATTITUDINAL BARRIERS:** Deaf and Hard of Hearing travelers sometimes face negative attitudes or misconceptions from people who may lack awareness or understanding. Stereotypes and assumptions about deafness can result in uncomfortable or exclusionary situations. Raising awareness and promoting inclusivity are crucial steps towards

addressing their challenges and will assist in creating a more welcoming environment for them.

Deaf and Hard of Hearing travelers greatly benefit from a range of apps to enhance their travel experiences and address communication barriers. Here are some commonly used apps available on Google Play and the Apple App Store:

**1.** Sign language translation apps convert spoken or written language into sign language, aiding communication with non-sign language users.

**2.** Captioning apps offer real-time captioning or transcription services, enabling Deaf travelers to comprehend spoken conversations or announcements. These apps utilize voice recognition technology to convert spoken words into text. Popular choices include Ava, Google Live Transcribe, and Otter Voice Meeting Notes.

**3.** Travel and navigation apps play a crucial role for Deaf travelers, assisting them in trip planning, locating accessible attractions, and navigating unfamiliar destinations. Apps such as Google Maps, Citymapper, and Triplt provide valuable features like directions, public transportation information and

points of interest to ensure a smooth and enjoyable travel experience.

**4.** Communication apps: Instant messaging apps with video call capabilities are essential for Deaf travelers to communicate with friends, family, and local contacts. Apps like WhatsApp, Skype, FaceTime or Zoom enable real-time communication through sign language or text messages.

**5.** Hearing aid control apps, such as ReSound Smart, Phonak Remote and Widex Beyond empower Deaf travelers who use hearing aids or assistive devices. These apps allow users to conveniently adjust volume, settings and equalization, ensuring an optimal hearing experience throughout their journeys.

**6.** Social media apps like Facebook, Instagram and Twitter are widely used by Deaf travelers to connect, share experiences and seek travel recommendations within the Deaf community.

**7.** Emergency and safety apps offer vital safety information and emergency alerts, benefiting Deaf travelers who may not have access to auditory announcements or alarms. Apps like Emergency SOS, Red Panic Button and



TravelSafe Pro provide an extra layer of security and peace of mind during travel.

Deaf and Hard of Hearing travelers embark on journeys filled with positive experiences, personal growth and memorable encounters, despite the unique challenges they may encounter. With resilience and determination, they navigate the world, embracing cultural exchange, enhanced visual perception and community support. By promoting accessibility, awareness and understanding, we can create an inclusive environment where all travelers, regardless of their hearing abilities, can explore the world and embrace the joys of travel.

As a Deaf traveler, I have personal preferences when it comes to finding efficient apps for communication and enhancing my travel experiences. These apps have greatly contributed to the success and positivity of my journeys. It's important to explore various app options based on individual needs and preferences to enhance travel experiences. Availability and popularity of apps may vary depending on personal preferences, location and technology. Happy travels!

If you have any questions, comments or concerns, please feel free to contact me at: [\*\*angelalynn@theangelalynnshow.com\*\*](mailto:angelalynn@theangelalynnshow.com)

*Angela Lynn*



**For Deaf people, embarking on a journey can be an equally transformative adventure, brimming with unique experiences and opportunities for personal growth.**









# with **Antoine Hunter, passionate urban dance warrior**

By Angela Lynn

## **Tell us a little about yourself and what brought you to where you are today.**

I am Antonie Hunter, the Founder and Artistic Director of the Urban Jazz Dance Company in Oakland, California. Being based where the Black Panthers organization was once headquartered, I am a multi-talented individual, teaching dance to both Deaf and hearing students at the Urban Jazz Dance Company. As an award-winning African, Indigenous, Deaf, Two-Spirit producer, choreographer, film/theater actor, dancer, dance instructor, model, poet, speaker, mentor, and Deaf advocate, I am deeply involved in the world of art. With a strong belief in the profound impact of art, I use dance to inspire and convey emotions.

Despite facing challenges in understanding my identity as a Deaf, Black, and male individual, I embarked on a transformative journey of self-discovery. In my household, I was surrounded by 11 women, and I shared a close bond with my mother.

While I once faced a point of hopelessness, dance became my lifeline during high school, helping me regain trust and heal. Dancing became my passion, allowing me to express my true feelings through art. Through my dance experiences, I discovered my soul and superpower, forging a deep connection with this expressive form.

My legacy stands as a testament to the transformative impact of art, inspiring others to find their voices and superpowers through creative expression. Grateful

for who I am, I continue to help others harness the power of dance and art.

## **You have enjoyed an impressive professional career. What inspired you to first get into the world of dance?**

My deep passion for dance encompasses performing, directing, and choreographing with limitless creativity. I have had the privilege of showcasing my dancing skills on various stages and at festivals, captivating audiences both nationally and internationally. This passion ignited during my high school days when I discovered my unique voice and superpowers through dance, setting me on an extraordinary journey across the USA and beyond.

To my surprise, my performances inspired both Deaf and Hearing individuals to break free from their constraints and express their true emotions through art and dance. Witnessing this transformative power has been truly beautiful as people unveil their inner selves through the art of movement. I find immense fulfillment in seeing others liberate their artistic spirit through dance, fostering a profound sense of connection and unity within humanity.

### **Tell us about your Urban Jazz Dance Company, and how it came to be.**

I vividly remember the start of my dance journey when I began teaching dance classes. Little did I know that this humble beginning would pave the way for my dream, the Urban Jazz Dance Company. The turning point came at the Art and Soul Festival in Oakland when I was mistakenly introduced as the show's presenter. Without hesitation, I went with the flow and delivered a captivating solo performance with my troupe that left the audience in awe. Word of our mesmerizing performance quickly spread, leading to the creation of the Urban Jazz Dance Company.

Over the past 16 years, the company has grown stronger, attracting dance enthusiasts who share a passion for the

art. I feel incredibly blessed to witness the company's growth and am excited about the opportunities that lie ahead for our continued expansion in the coming year and beyond.

### **What is your proudest accomplishment to date?**

I take immense pride in the experiences I have encountered throughout my journey. One of the most memorable moments was my time in Cuba, where I participated in a vibrant costume carnival and performed on both small and grand stages, alongside the Urban Jazz Dance Company. It was an unforgettable experience for all of us.

Furthermore, the Bay Area International Deaf Festival has been a thriving annual dance festival. The upcoming festival scheduled for August 4-6th, 2023, promises to showcase various dances and art forms, providing a platform for people to freely express themselves. Since its inception in 2016, the festival has grown strong, attracting diverse communities, including BIPOCs and Deaf Spaces, coming together to share their passion. I am amazed by the international attendance each year, reflecting the festival's impact in fostering unity and breaking down barriers between Deaf and Hearing individuals on the dance floor.

### **What advice would you give to other aspiring dancers living with disabilities?**

Despite facing challenges as a Deaf individual and dealing with a back injury at L1 L2, my passion for dance remains unwavering. I firmly believe in following one's spirit, trusting instincts, and embracing the body as an expression of identity. My multiple disabilities have not hindered my ability to inspire others, as I encourage people to push beyond limits and find various ways to stay connected to the art of dancing.

Currently, I thrive as a director and choreographer for performance stages. My journey serves as a powerful example, demonstrating that disabilities should never dampen one's love for dance. I empower others to discover their true selves through dance, proving that passion knows no boundaries. My determination and resilience continue to inspire people to break free from limitations and embrace the limitless possibilities of expressing themselves through the art of dance.

### **Your work as a disability activist is inspiring – how did that begin? What advice do you have for others**



# BAY AREA INTERNATIONAL DEAF DANCE FESTIVAL

AUGUST 14-16, 2020

A VIRTUAL SHOWCASE

PRESENTED BY ANTOINE HUNTER'S  
URBAN JAZZ DANCE COMPANY

## WITH PERFORMANCES BY

Urban Jazz Dance Company (Bay Area)

Samantha Figgins (New York)

Deaf Pride Dance Company (Bay Area)

Danzaluz (Venezuela)

Natasha Bacchus (Canada)

Irit Spektor (Los Angeles, CA)

Carlos Javier Ortega Opisno (Colombia)

Matthew JPosh Schwartz (New York)

Proyecto Paz (Mexico / Bay Area)

Fusion in Motion (San Diego, CA)

Lark Detweiler (Los Angeles, CA)

Shruti Neelesh Kelkar (India)

Visceral Roots Dance Company (Bay Area)

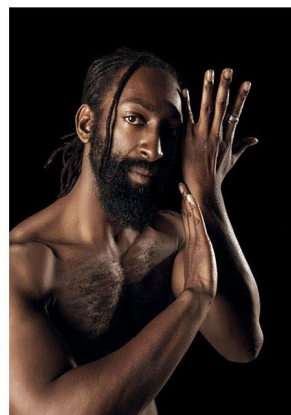
Listen With Your Eyes Dance Troupe (Arkansas)

and MORE local, national, and  
international artists!

FRIDAY, AUGUST 14 | 6 PM PST

SATURDAY, AUGUST 15 | 6 PM PST

RECOMMENDED DONATION: \$5-25



Fiscally  
sponsored by  
Intersection for  
the Arts.

Asian  
Art  
Museum

intersection  
FOR THE ARTS

DANCE  
USA

CA  
ARTS

NDC  
National Arts & Disability Center

GRANTS  
FOR THE ARTS

Kenneth  
Rainin  
FOUNDATION

HI USA

odc

SHAWL-ANDERSON DANCE CENTER

Zellerbach  
FAMILY FOUNDATION

For more information, including WORKSHOP DETAILS, please visit

**REALURBANJAZZDANCE.COM**

To Table of Contents





The Cells - Deafs IMPRISONED- Urban Jazz Dance Company  
Photo Credit: Robbie Sweeny



Dancers: Marissa Head and Zahna Simon  
6antuanh UJDC in Russia





PHOTO: PECHE TURNER

## hoping to become disability activists?

I strongly believe in being authentic and fostering mutual support and learning. As a disability activist, my mission is to unite and assist others. This dedication has led me to become an advocate for various communities, with a particular focus on the Black Deaf Community. My involvement goes beyond one organization; I serve as a board member for the Bay Area Black Deaf Advocates and actively participate in seven other organizations. My ultimate goal is to create better and more inclusive communities for

everyone.

I emphasize the significance of hearing individuals truly listening to the voices of the Deaf Community and supporting one another. This fosters a harmonious and integrated world. I firmly believe that understanding and supporting each other can lead to a more compassionate and inclusive society.

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

I am filled with excitement for the upcoming year and beyond with my company. One of my goals is to establish sister

companies with the Urban Jazz Dance Company in India and Turkey, spreading the joy of dance to new horizons. Additionally, I dream of producing a captivating dance movie, showcasing my artistic vision on the silver screen. Who knows, you might see me on TV more often in a lighthearted manner.

However, my true passion lies in extensive travel to collaborate with other artists in Canada and various international countries, including Africa, to create magnificent dance projects. Working alongside the talented artist Zula Star brings me great enthusiasm. Despite

my busy schedule, I will remain dedicated to teaching dance, choreographing performances, and captivating audiences on school stages and beyond, inspiring others with my boundless passion for the art of dance.

**What message would you like to share about the importance of inclusivity and the power of the arts, especially dance, to unite people?**

My philosophy centers on inclusion and unity, ensuring that no one is left behind as we

journey together. I encourage others to draw inspiration from the notion that if they can't find their place, they possess the ability to create a new one. Embracing creativity plays a crucial role in discovering one's true self along the journey.



**ANTOINE HUNTER**

Award-winning African, Indigenous, Deaf, Two-Spirit producer, choreographer, film/theater actor, dancer, dance instructor, model, poet, speaker, mentor and Deaf advocate.

”

**I began to understand that my performances inspired both Deaf and Hearing individuals to break free from their constraints and express their true emotions through art and dance.**

~ Antoine Hunter



# BAY AREA INTERNATIONAL

## AUGUST 11-13

# DEAF DANCE FESTIVAL

## 5th Year Anniversary!

Antoine Hunter's Urban Jazz Dance Company  
presents

## DEAF UNITED LOUDER 2017



**Dance Mission Theater**  
3316 24th St. | San Francisco  
(415) 863-9824

**Fri-Sat, Aug 11 & 12 | 8pm**  
**Sun, Aug 13 | 4pm**  
*Meet the Artists Brunch on August 12th*

### FEATURING

Urban Jazz Dance Company (Bay Area)  
Rosa Lee Timm (Bay Area)  
Ian Sanborn (California)  
Jacob Kujo Lyons (Los Angeles)  
Chris Fonseca (United Kingdom)  
Nikita Dance Crew (Germany)  
Fun Forest Deaf Dance Crew (Hong Kong)  
Magic Finger Entertainment Prod. (Nigeria, Africa)  
Art Tour Company (Russia)  
Distraction Society (Australia)  
Batuqueiros do Silêncio (Brazil)  
Visceral Roots Dance Company (Bay Area)  
Isidore Niyongabo (Texas)  
Afro-Kinetic Fever (New York)  
Brandy Mimms (Missouri)  
Christian Briceño (Colombia)  
And More...

### Workshops:

**August 8th and 9th**

details at  
**RealUrbanJazzDance.com**



text by: abhago.com

## Tickets at **BROWNPAPERTICKETS.COM** or **1-800-838-3006**

\$30 (at door) | \$25 (online) | \$12 (kids under 16) | Group Discounts: (415) 863-9824



Fiscal Agents: Zaccho Dance Theatre & EBCPA

Dance Brigade's  
**DANCE MISSION THEATER**



# What is fatigue? Understanding fatigue among students with disabilities can help schools moderate it

By [Natalia Rohatyn-Martin](#)

**D**uring the COVID-19 pandemic, we heard about people experiencing different kinds of fatigue, whether related [to burnout](#), [being unmotivated to follow pandemic restrictions](#) or [as a symptom of infection](#). But what exactly is fatigue?

Fatigue is [not synonymous with tiredness](#). When one is tired, sleep helps. Fatigue results when cognitive, emotional or physical attentiveness is required for prolonged periods of time resulting in feelings of [tiredness, exhaustion or lack of energy or desire to continue a task](#). It is not resolved by a nap.

Fatigue regularly includes difficulties in concentration, feelings of anxiety and increased distractibility. Medical professionals and researchers currently define fatigue by differentiating types of exertion: [physical, cognitive](#) and as it has more recently been conceptualized, [social-emotional](#).



I am working with colleagues to provide a means for students with disabilities and their educational teams to understand the impact of fatigue, [to advocate for appropriate strategies and programs](#) and to moderate fatigue in educational contexts.

motor processes and executive functions, inevitably leading to poorer academic performance.

The same researchers also found that decreasing cognitive functioning was also related to a [decrease in intrinsic motivation](#) and consequently,

[is frequently](#) experienced by [people with disabilities](#). Research has documented how [young students who are deaf or hard of hearing experience fatigue daily](#) related to the need for constant and ongoing physical, social-emotional or mental effort for:

- Listening and watching both their teacher and classroom support personnel such as a sign language interpreter or educational assistant;
- Communicating with peers through a communication device or lip/speech reading;
- Attending to classroom instruction through an amplification device.

The cumulative effects of such experiences lead to [poorer quality of life outcomes](#) for these students, including limiting educational and vocational choices, increased mental health concerns and negative impacts on family and friend relationships.

### Poorly understood impact

Currently, the impact of fatigue in educational settings for students with disabilities is poorly understood by teachers, administrators, policymakers and parents or caregivers and students themselves.



Understanding students' experiences of fatigue and the impact of it matters to students' lives. (Allison Shelley/EDUimages), CC BY-NC

### Fatigue in school-aged children

Fatigue among school-aged children can have many negative effects. One study based in Japan found about 16 per cent of elementary and 34 per cent of junior high school students [reported experiencing fatigue throughout a typical school week](#). In this study, self-reported fatigue was associated with difficulties with

poor academic performance.

In addition, fatigue has been associated with a variety of psychoeducational issues, such as [reduced physical activity](#), [slower educational progress](#), [more frequent school absences](#), [less socializing with friends and family](#) and [increased stress in children](#).

### Students with disabilities

In educational settings, [fatigue](#)



The cumulative effects of fatigue related to constant effort for listening and communicating can lead to poorer quality of life outcomes. (ENVATO)

Educators frequently [fail to understand the importance of providing educational supports to mitigate fatigue](#), or mislabel symptoms of fatigue with terms like laziness, stubbornness or a behavioural problem.

Students often [fail to recognize fatigue symptoms](#), lack understanding of how their learning is compromised by fatigue and have limited coping strategies. As a result, they frequently cannot or do not openly name or express their fatigue.

There have been some efforts made within educational systems to address acknowledging and responding to fatigue to support student engagement and wellness (such as options for flexible scheduling or periodic breaks). Yet, our research team found when we interviewed junior high and high school students who are deaf or hard of hearing that [none of the students we interviewed](#) were consistently afforded such accommodations.

Instead, students were left to cope with increased levels of fatigue on their own.

## Next research steps

As a next step towards better understanding the impact of fatigue for students with disabilities, my colleagues and I designed the Fatigue in Educational Contexts (FEC) survey.

The purpose of the survey is to accurately identify, describe and interpret the presence and intensity of

fatigue and to inform how students' fatigue can be alleviated in educational contexts. Our current focus is on students who are deaf or hard of hearing, but we plan to expand our focus to all students once the survey is refined.

Most available fatigue surveys examine workplace or injury related fatigue in adult populations. A commonly used standardized survey

designed for children and adolescents, [the PedsQL-MFS](#), has significant limitations for our purposes:

- It was not developed for individuals with disabilities nor is it inclusive of the heterogeneity of the disabled student population;
- None of the items on the survey specifically address fatigue in classrooms.



## Including wider student, family responses

The child version of the recently published [Vanderbilt Fatigue Scale](#) includes some survey questions addressing fatigue in classroom environments. However, it focuses exclusively on fatigue as a result of auditory effort (for deaf or hard of hearing individuals using amplification devices and spoken language) and is accessible only in written text format.

Currently, there is no survey suitable for a diversity of students with disabilities, including among deaf students who are sign language users and/or who are dual language users, meaning they both sign and use spoken language, but not simultaneously.

The FEC survey will be innovative because it will be designed to capture experiences of these students, and it will include the perspectives of

students, their families and educational teams about how they understand and see student fatigue.

This research can help educators and policymakers propose relevant changes in education, such as policy or curricular changes, educator training or resource allocation or protocols for relating with students, families or communities to better respond to and mitigate students' fatigue.



This article was originally published in [The Conversation](#). Read the [original article](#).

A study found that no junior high and high school students who were deaf or hard of hearing were afforded accommodations to mitigate their fatigue. (Shutterstock)

# AUTISM



## What is rejection sensitive dysphoria?

By Bart Vulliamy

Rejection sensitive dysphoria (RSD or rejection sensitivity) is an affliction common amongst people with ADHD, autism, personality disorders and other mental health conditions.

RSD is the heightened emotional sensitivity to real or perceived rejection, criticism or feelings of inadequacy, causing overwhelming emotional and/or physical responses. This is not just limited to negative social feedback but also neutral feedback, meaning that the intent of the person from whom the feedback comes does not have to be negative for this to be felt.

RSD is thought to be a result of emotional dysregulation, which 70% of adults with ADHD struggle with, or trauma, which 80%-85% of them have. "By the time a child with ADHD

turns 12, they hear 20,000 more negative, corrective or critical messages than the average child who doesn't have ADHD," said Michael Jellinek, MD. This can lead to worsened mental health in adulthood and can make one further insecure or damage their self-esteem.

Rejection sensitivity makes friendship, relationships, employment and any social situations difficult. In the workplace, RSD can show up in interviews, performance reviews and in communication, giving the feeling of a hostile environment when it is not necessarily the case.

Everyone experiences RSD differently. It can come in brief, intense reactions to a specific trigger, or it can be experienced daily as a constant. No matter how rejection dysphoria is experienced, it is debilitating for social interactions. People with RSD can quickly become people-pleasers or social hermits to avoid feeling humiliated.

When in the workplace or in social situations, I'm what's called a high-masking neurodivergent meaning that I can hide my disability from others. The flip side of this is that for every social



interaction I use scripts and carefully curated responses to maintain this facade. Whether communicating face to face or electronically, the fear of saying the wrong thing uses a lot of energy. The crippling tendency to blame ourselves for any misunderstandings can also result in exploitation and bullying in group environments, such as the workplace.

Emotional dysregulation is another common symptom of ADHD and autism and is also one of the core criteria for adults looking to get diagnosed. Emotional dysregulation, by definition, is an inability to manage or regulate a person's emotional responses. For people with ADHD or people on the autism spectrum who are constantly processing internal and external stimuli, this can be meltdown inducing.

This can look like explosive reactions to what may seem like minor setbacks/ challenges. For me, failing a job interview and having the WIFI go down elicit the same level of crushing distress. Neurodivergent people who struggle with RSD tend to create coping mechanisms to combat the uncomfortable feelings of rejection.

Perfectionism, isolation / avoidance, bullying, people-pleasing, overcompensation,

addiction and masking can all be attributed to symptoms of emotional dysregulation.

I have personally gone through all the above because of my rejection sensitivity and emotional dysregulation. I react so strongly to stimuli that it quickly becomes unbearable to be around. The rare times I venture into the public, I wear sunglasses, headphones, a mask and long sleeves to limit the amount of unwanted sensory input and to avoid having to feel my feelings.

Rejection sensitive dysphoria is a debilitating aspect of neurodiversity. People with RSD are usually ashamed of their over-reactions and hide them so that they won't be further embarrassed and thought of as mentally or emotionally unstable and therefore shunned from their social circle. Learning about RSD is another important step further in understanding oneself as a neurodivergent individual but also to learn to take better care of the people around us who are dealing with it. Each person will have their own needs. Learning to take them into account can mean a world of difference to someone you know who may deal with this.

Do you know someone who is autistic?

Here are some things to consider

## **Don't Disregard Sensory Sensitivities**

Many people with autism have sensory sensitivities, and certain sounds, lights, textures, or smells can be overwhelming or distressing for them. Be mindful of the environment and try to create a calm and accommodating space.

## **Don't Overwhelm with Information**

Be mindful of the amount of information you provide at once, as individuals with autism may find it challenging to process a large volume of information. Offer information in a clear and concise manner.

## **Avoid Overreacting to Repetitive Behaviors**

Repetitive behaviors are common in autism and can serve as coping mechanisms. Avoid drawing undue attention or making a big deal out of these behaviors, as it may cause embarrassment or discomfort.

## **Don't Assume Lack of Interest**

People with autism may not always display their emotions or interest in a typical way. Avoid assuming that they are uninterested or indifferent if they don't respond in expected ways.

# Reading the mind with machines

By [Marla Broadfoot](#)

Researchers are developing brain-computer interfaces that would enable communication for people with locked-in syndrome and other conditions that render them unable to speak

In Alexandre Dumas's classic novel *The Count of Monte-Cristo*, a character named Monsieur Noirtier de Villefort suffers a terrible stroke that leaves him paralyzed. Though he remains awake and aware, he is no longer able to move or speak, relying on his granddaughter Valentine to recite the alphabet and flip through a dictionary to find the letters and words he requires. With this rudimentary form of communication, the determined old man manages to save Valentine from being poisoned by her stepmother and thwart his son's attempts to marry her off against her will.

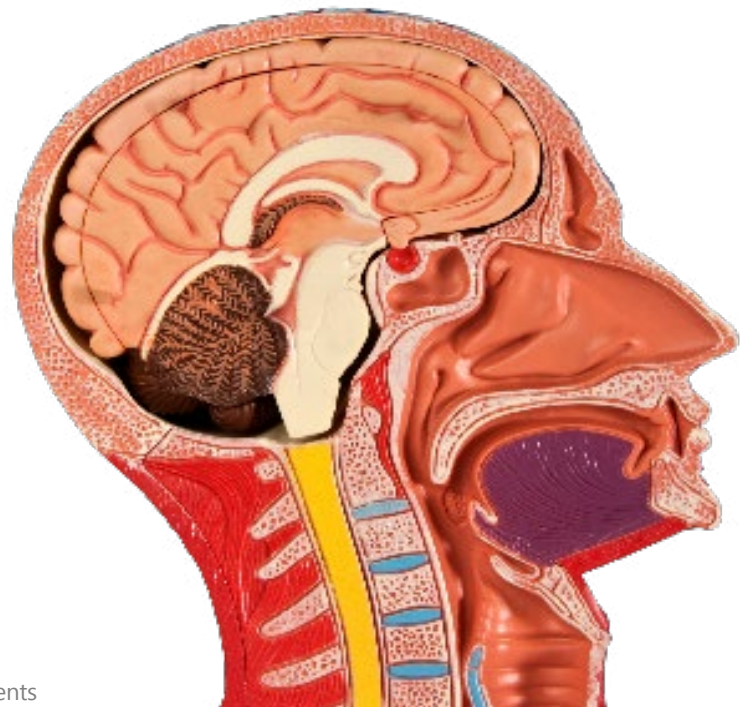
Dumas's portrayal of this catastrophic condition — where, as he puts it, “the soul is trapped in a body that no longer obeys its commands” — is one of the [earliest descriptions](#) of locked-in syndrome. This

form of profound paralysis occurs when the [brain stem is damaged](#), usually because of a stroke but also as the result of tumors, traumatic brain injury, [snakebite](#), substance abuse, infection or neurodegenerative diseases like amyotrophic lateral sclerosis (ALS).

The condition is [thought to be rare](#), though just how rare is hard to say. Many locked-in patients can communicate through purposeful eye movements and blinking, but others can become [completely immobile](#), losing their ability even to move their eyeballs or eyelids, rendering the command “blink

twice if you understand me” moot. As a result, patients can spend an average of [79 days](#) imprisoned in a motionless body, conscious but unable to communicate, before they are properly diagnosed.

The advent of [brain-machine interfaces](#) has fostered hopes of restoring communication to people in this locked-in state, enabling them to reconnect







In *The Count of Monte-Cristo*, Monsieur Noirtier de Villefort cannot move or speak but communicates with his granddaughter through words and letters in a book.

**CREDIT:** [PROJECT GUTENBERG](#)

with the outside world. These technologies typically use an implanted device to record the brain waves associated with speech and then use computer algorithms to translate the intended messages. The most exciting advances require no blinking, eye tracking or attempted vocalizations, but instead capture and convey the letters or words a person says silently in their head.

"I feel like this technology really has the potential to help the people who have lost the most,

people who are really locked down and cannot communicate at all anymore," says Sarah Wandelt, a graduate student in computation and neural systems at Caltech in Pasadena. Recent studies by Wandelt and others have provided the first evidence that brain-machine interfaces can decode internal speech. These approaches, while promising, are often invasive, laborious and expensive, and experts agree they will require considerably more development before they can give locked-in patients a voice.

## Engaging the brain — but where?

The first step of building a brain-machine interface is deciding which part of the brain to tap. Back when Dumas was young, many believed the contours of a person's skull provided an atlas for understanding the inner workings of the mind. Colorful phrenology charts — with tracts blocked off for human faculties like benevolence, appetite and language — can still be found in antiquated medical texts and the home decor sections of department stores. "We, of course, know that's nonsense now," says David Bjånes, a neuroscientist and postdoctoral researcher at Caltech. In fact, it's now clear that our faculties and functions emerge from a web of interactions among various brain areas, with each area acting as a node in the neural network. This complexity presents both a challenge and an opportunity: With no one brain region yet found that's responsible for internal language, a number of different regions could be viable targets.

For example, Wandelt, Bjånes and their colleagues found that a part of the parietal lobe called the supramarginal gyrus (SMG), which is typically associated with grasping objects, is also strongly activated during speech. They made the surprising discovery

while observing a tetraplegic study participant who has had a microelectrode array — a device smaller than the head of a push pin covered in scads of scaled-down metal spikes — implanted in his SMG. The array can record the firing of individual neurons and transmit the data through a tangle of wires to a computer to process them.

Bjånes likens the setup of their brain-machine interface to a football game. Imagine that your brain is the football stadium, and each of the neurons is a person in that stadium. The electrodes are the microphones you lower into the stadium to listen in.

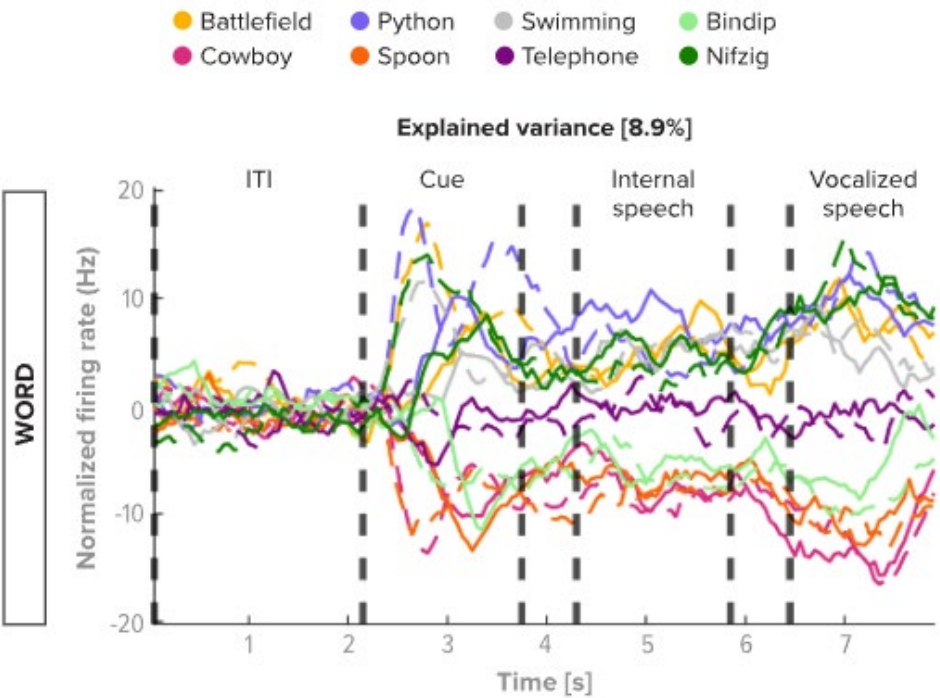
“We hope that we place those near the coach, or maybe an announcer, or near some person in the audience that really knows what’s going on,” he explains. “And then we’re trying to understand what’s happening on the field. When we hear a roar of the crowd, is that a touchdown? Was that a pass play? Was that the quarterback getting sacked? We’re trying to understand the rules of the game, and the more information we can get, the better our device will be.”

In the brain, the implanted devices sit in the extracellular space between neurons, where they monitor the

electrochemical signals that move across synapses every time a neuron fires. If the implant picks up on the relevant neurons, the signals that the electrodes record look like audio files, reflecting a different pattern of peaks and valleys for different actions or intentions.

The Caltech team trained their brain-machine interface to recognize the brain patterns produced when a tetraplegic study participant internally “spoke” six words (battlefield, cowboy, python, spoon, swimming, telephone) and two pseudowords (nifzig, bindip). They found that after only 15

## Decoding words



SOURCE: ADAPTED FROM S.K. WANDELT ET AL / ONLINE INTERNAL SPEECH  
DECODING FROM SINGLE NEURONS IN A HUMAN PARTICIPANT PREPRINT 2022

KNOWABLE MAGAZINE



minutes of training, and by using a relatively simple decoding algorithm, the device could identify the words with over 90 percent accuracy.

Wandelt presented the [study](#), which is not yet published in a peer-reviewed scientific journal, at the 2022 [Society for Neuroscience conference](#) in San Diego. She thinks the findings signify an important proof of concept, though the vocabulary would need to be expanded before a locked-in patient could foil an evil stepmother or procure a glass of water. “Obviously, the words we chose were not the most informative ones, but if you replace them with yes, no, certain words that are really informative, that would be helpful,” Wandelt said at the meeting.

## Thoughts into letters into words

Another [approach](#) circumvents the need to build up a big vocabulary by designing a brain-machine interface that recognizes letters instead of words. By trying to mouth out the words that code for each letter of the Roman alphabet, a paralyzed patient could spell out any word that popped into their head, stringing those words together to communicate in full sentences.

“Spelling things out loud with speech is something that we do pretty commonly, like when you’re on the phone with a customer service rep,” says Sean Metzger, a graduate student in bioengineering at the University of California San Francisco and the University of California, Berkeley. Just like static on a phone line, brain signals can be noisy. Using NATO code words — like Alpha for A, Bravo for B and Charlie for C — makes it easier to discern what someone is saying.

Metzger and his colleagues tested this idea in a participant who was unable to move or speak as the result of a stroke.

The study participant had a larger array of electrodes — about the size of a credit card — implanted over a broad swath of his motor cortex. Rather than eavesdropping on individual neurons, this array records the synchronized activity of tens of thousands of neurons, like hearing an entire section in a football stadium groan or cheer at the same time.

Using this technology, the researchers recorded hours of data and fed it into sophisticated machine learning algorithms. They were able to [decode 92 percent of the study subject’s silently spelled-out sentences](#) — such as “That is all right” or “What



This video describes a brain-computer interface under development at UC San Francisco. The team worked with a volunteer who survived a brain stem stroke and can no longer articulate words. An electrode was implanted over an area in the brain that controls the vocal tract. The setup successfully decoded words the volunteer was trying to speak. Read more [here](#).

CREDIT: UC SAN FRANCISCO (UCSF)

time is it?" — on at least one of two tries. A next step, Metzger says, could be combining this spelling-based approach with a words-based approach they developed previously to enable users to communicate more quickly and with less effort.

### **‘Still in the early stage’**

Today, close to 40 people worldwide have been implanted with microelectrode arrays, with more coming online. Many of these volunteers — people paralyzed by strokes, spinal cord injuries or ALS — spend hours hooked up to computers helping researchers develop new brain-machine interfaces to allow others, one day, to regain functions they have lost. Jun Wang, a computer and speech scientist at the University of Texas at Austin, says he is excited about recent progress in creating devices to restore speech, but cautions there is a long way to go before practical application. "At this moment, the whole field is still in the early stage."

Wang and other experts would like to see upgrades to hardware and software that make the devices less cumbersome, more accurate and faster. For example, the device pioneered by the UCSF lab worked at a pace of about

seven words per minute, whereas natural speech moves at about 150 words a minute. And even if the technology evolves to mimic human speech, it is unclear whether approaches developed in patients with some ability to move or speak will work in those who are completely locked in. "My intuition is it would scale, but I can't say that for sure," says Metzger. "We would have to verify that."

Another open question is whether it is possible to design brain-machine interfaces that do not require brain surgery. Attempts to create noninvasive approaches have faltered because such devices have tried to make sense of signals that have traveled through layers of tissue and bone, like trying to follow a football game from the parking lot.

Wang has made headway using an advanced imaging technique called magnetoencephalography (MEG), which records magnetic fields on the outside of the skull that are generated by the electric currents in the brain, and then translating those signals into text. Right now, he is trying to build a device that uses MEG to recognize the 44 phonemes, or speech sounds, in the English language — like ph

or oo — which could be used to construct syllables, then words, then sentences.

Ultimately, the biggest challenge to restoring speech in locked-in patients may have more to do with biology than with technology. The way speech is encoded, particularly internal speech, could vary depending on the individual or the situation. One person might imagine scrawling a word on a sheet of paper in their mind's eye; another might hear the word, still unspoken, echoing in their ears; yet another might associate a word with its meaning, evoking a particular feeling-state. Because different brain waves could be associated with different words in different people, different techniques might have to be adapted to each person's individual nature.

"I think this multipronged approach by the different groups is our best way to cover all of our bases," says Bjånes, "and have approaches that work in a bunch of different contexts."

---

Marla Broadfoot is a freelance science writer who lives in Wendell, North Carolina. She has a PhD in genetics and molecular biology. Follow her @mvbroadfoot and see more of her work at [marlabroadfoot.com](http://marlabroadfoot.com).

This article was originally published in [Knowable Magazine](#). Read the [original article](#)





33.337325° N, 112.056291° W

**Trade constant scrolling  
for winding trails.**



Visit a new state of mind.

[HEREYOUAREAZ.COM](http://HEREYOUAREAZ.COM)

**ARIZONA**  
THE GRAND CANYON STATE





Read Accessible Journeys  
magazine [here](#)

Sign up to have new issues  
delivered to your inbox.  
[Click here.](#)