mélange

Accessibility for All

May 2025

DANIEL & FREDERICK

The weight of care and the power of friendship

INSIDE SOUTH AFRICA'S

inclusive employment success story

ISSN 2563-5697

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Accessible meets unforgettable.

In Arizona, adventure is everywhere and inclusive experiences abound. Make some memories against a spectacular backdrop.

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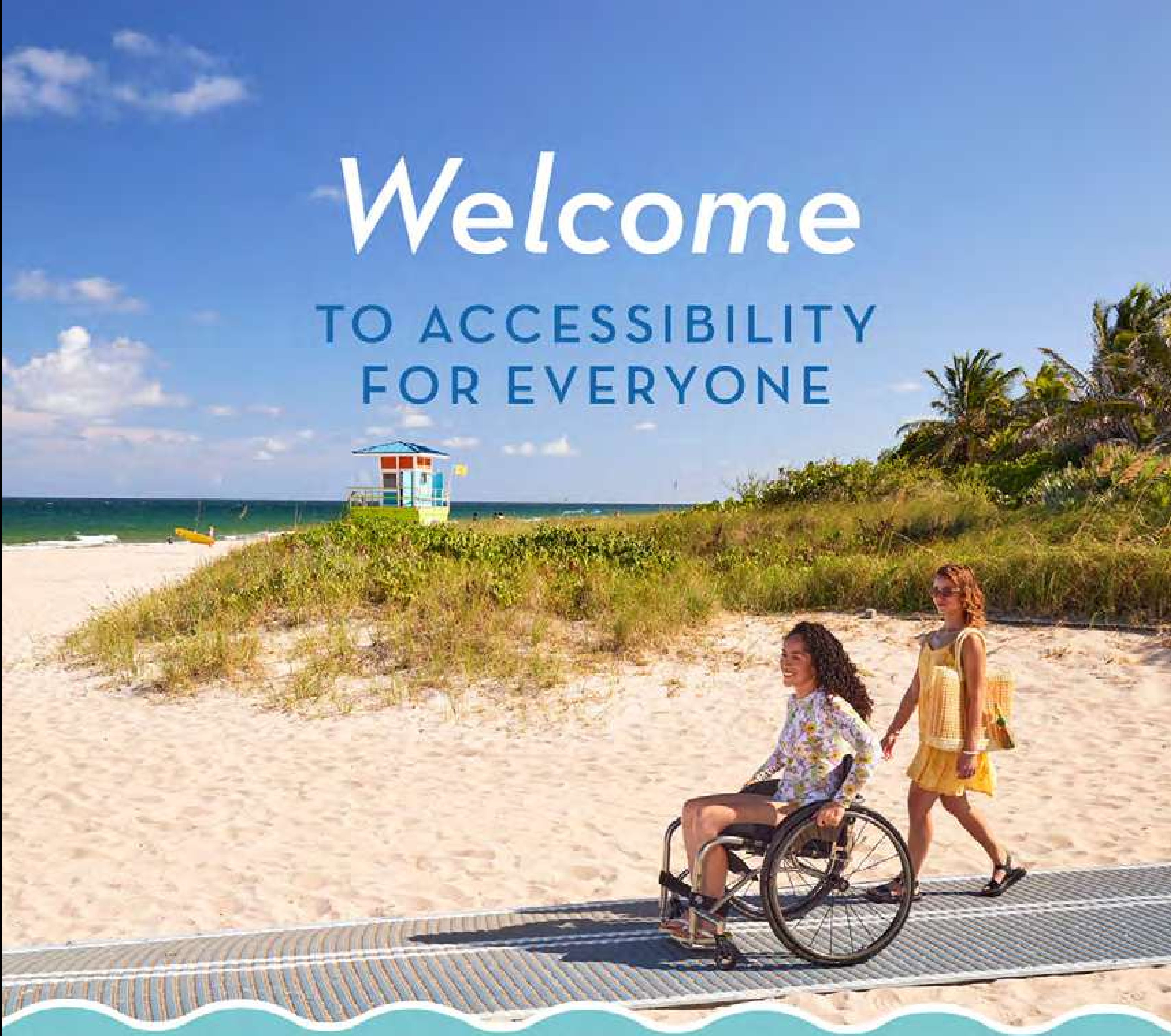
Welcome
TO ACCESSIBILITY
FOR EVERYONE

Editor's Note

Welcome to this issue of Accessibility for All where we highlight the voices, ideas, and efforts shaping a more inclusive world.

In this edition, Christine E. Staple Ebanks, known as “The Special Needs Mama Bear,” shares how she turned confusion and fear into advocacy and strength. Her story is a reminder that expertise often comes not from formal training, but from lived experience, and many of us are building that knowledge every day.

You'll also meet Mae, who shares her personal journey with an arteriovenous malformation (AVM), offering a powerful reflection on identity, resilience, and visibility. And we spotlight Warren “Wawa” Snipe, whose work as a Deaf artist is transforming how we experience music, making it something you can see, feel, and believe in. Wawa is the brainchild behind WAWABILITY 2025, a celebration happening July 11–12 at The Anthem in Washington, D.C. This landmark event marks 35 years since the Americans with Disabilities Act, featuring performances by Kodi Lee, Mandy Harvey, Lachi, Josh Blue, and the inclusive Omnium Circus. It also includes a live-streamed Virtual Summit focused on accessibility and tech innovation. Full details are at www.wawability2025.com.

From global advocacy to local impact, we also take you inside South Africa's inclusive employment initiative, a standout example of how companies, communities, and individuals can create meaningful opportunities for people with disabilities, not as an afterthought, but as a priority. In our health and wellness section, we focus on living with Type 1 disabilities and feature DEBRA Ireland, an organization supporting those living with epidermolysis bullosa. Their work exemplifies what happens when care, research, and dignity come together.

All this, and more, in the pages ahead. There's no single guide to navigating disability, but every story shared and every solution found adds to our collective wisdom. We hope this issue gives you insight, encouragement and a sense of connection.

Happy Reading

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CLICK HERE to read the previous issue

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

Mélange Publishing Group
300-3665 Kingsway,
Vancouver, BC,
Canada V5R 5W2.
1.866.384.8257
www.melangeandco.com

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Inside South Africa's inclusive employment success story

The Association for the Physically Disabled in Nelson Mandela Bay, South Africa (APD NMB), was established 84 years ago. This organisation has evolved into a remarkable force for inclusive employment, practical skills training and socioeconomic empowerment, not through speeches or symbolic campaigns, but through real, structured, everyday work.

In a country where an estimated 90% of people with disabilities remain unemployed, APD NMB did not wring its hands or wait for policy to catch up. Instead, it built systems that work. Factories, training programmes, partnerships with corporates, recruitment pipelines and follow-through support. While others continue discussing the theory of inclusion, APD NMB is busy implementing it.

The word charity may immediately come to mind but this is not their story. What is it, you might ask. It's about empowerment, precision, systems, standards and a deeply held belief that opportunity should not be rationed based on physical ability.

The model is elegantly robust: one arm is non-profit, offering training and support services; the other is a fully operational commercial business, a competitive clothing factory producing uniforms, protective wear and branded garments for major corporate clients. These two work together. The business generates income and jobs. The non-profit supports, trains and equips. Together, they form a cohesive engine that drives real progress.

What sets APD NMB apart is the intentionality in how learners are prepared. The organisation does not train individuals and release them into a job market with limited capacity. It builds direct pathways to employment often identifying opportunities before the training even begins. A learner entering APD NMB's flagship sewing programme is taught how to operate a machine but they also learn how to manage their time, conduct themselves in a workplace and handle a pay cheque. They learn how to contribute to a team and adapt to production targets. They learn real life lessons that allow them to function confidently in society and make a meaningful contribution to their communities.

"We feel that we cannot give a person a skill if we don't give them life skills as well" says Gemma Ebersohn, APD NMB's Resource Development Manager.

Clinton Kay-Clark, a consultant overseeing the manufacturing strategy, brings with him over

three decades of industry expertise. His insights into production efficiency, quality control and workforce development have helped position APD NMB's factory as a respected player in the industry and he can attest to the business case for hiring people with disabilities. "As soon as you give somebody a skill, their whole life changes. They feel like they're contributing to a greater good," he said. "What we found was that... people with disabilities were actually probably one of the most productive people that you could have in the business." APD NMB's programs should not be perceived as a shelter workshop. It is a business with standards and clients. One that happens to be driven by people society has too often overlooked.

Among the most compelling stories to emerge from the organisation is that of Chenenvor Saays, a young man from one of the country's most disadvantaged communities, living with an intellectual disability. Initially enrolled in APD's adult daycare programme, it was his quiet curiosity around the branding department that sparked a shift. He began watching the team as they operated screen-printing machinery. In time, he was given the opportunity to try. His strength? The ability to focus on a single task with extraordinary accuracy. That same quality, once viewed as a limitation, has now made him one of the factory's most dependable screen printers.

Chenenvor Saays

Today, he holds full-time employment, earns a salary, contributes to his household, and represents something that's harder to quantify: a shift in possibility for his peers and his community. His success has inspired others to step forward and apply, changing not only individual lives but altering the expectations of what is possible in the environments they come from.

This idea of cascading impact is central to APD NMB's model. Learners are not treated as temporary participants. The organisation stays connected, following their progress long after employment, maintaining relationships with employers and offering support when needed. Employers are not left to figure things out alone; they are engaged through workshops, accessibility audits and sensitization training. One such initiative, Wheelchair Wednesday, puts corporate participants in a wheelchair for 67 minutes — a nod to Nelson Mandela's legacy — offering firsthand experience of the barriers faced by persons with disabilities. It's not theatrical. It's transformative.

And it's catching on. Retail chains

like Checkers have worked closely with APD NMB to upskill individuals with disabilities for roles in customer service, administration and retail operations, not just backroom roles, but front-facing, visible jobs that challenge old assumptions. These partnerships don't end at graduation. Employers often report back months later, noting that the learners they hired are now excelling, leading teams, or relocating for promotions.

The success rate speaks for itself. Over 80% of APD's graduates find employment or start their own ventures. But behind the numbers is a methodology: training that includes digital literacy, budgeting, hygiene, time management, workplace communication, emotional intelligence and self-confidence. In short, learners do not leave with skills only. They leave equipped for life.

The intake process is equally thoughtful. Rather than apply a one-size-fits-all approach, the team evaluates each applicant's abilities, environment, and needs. If someone is not a fit for one programme, they are often directed to another more suitable option. Exclusion is never the organisation's default response. Redirection is.

It would be tempting to call the APD NMB model a blueprint for inclusive development. But even that feels too generic. It is more exacting than a blueprint. It is a well-calibrated system of parts: people, knowledge, patience, infrastructure, relationships and grit. It works because every piece matters. From social workers to trainers, from factory managers to fundraisers, every team member is aligned to a clear purpose.

Asked what legacy APD NMB hopes to leave behind, the response is deeply personal. It's not about institutional reputation. It's about individuals — people who come into the building unsure of themselves, and leave with their heads held higher, with the confidence to stand on their own, to contribute, to matter.

This is not an ordinary success story. It is the outcome of discipline, structure and deep conviction. And perhaps most importantly, it is proof that real inclusion — the kind that changes lives — is not just possible. It is already happening.

APD NMB simply chose to stop talking and start doing. ■

Click here to read a Mélange interview with Mandela Bay's Gemma Ebersohn, Resource Development Manager and Clinton Kay Clark, Consultant

Visit APD NMB for more

Gemma Ebersohn

APD NMB's Resource Development Manager, plays a pivotal role in shaping the organisation's future. She not only secures vital funding and drives the implementation of learnerships but also oversees recruitment and sensitization initiatives. Her strategic focus and deep commitment have been instrumental in building APD's blended model — one that merges social impact with commercial viability.

Clinton Kay-Clark

Clinton, a seasoned consultant with over 30 years in the clothing manufacturing industry, brings technical expertise and strategic vision to APD's commercial operations. His guidance has been central to developing the organisation's new factory and scaling its production capabilities, ensuring that APD NMB's learners are not only trained but integrated into a competitive, high-performing industry environment.

How employers can tackle misconceptions about disabled people in the workplace

By Chloe G K Atkins, Visiting Associate Professor, Department of Political Science, University of Toronto and
Isabelle Avakumovic-Pointon PhD Student in History, University of British Columbia

Disclosure statement
Chloe G K Atkins receives funding from the Social Sciences and Humanities Research Council of Canada and TechNation.
Isabelle Avakumovic-Pointon receives funding from the Social Sciences and Humanities Research Council of Canada and TechNation.

Disability is a common part of the human experience: the United Nations estimates that 16 per cent of the world's population is disabled, and a 2019 study from the United States found that over half of American adults aged 18 to 34 have at least one chronic illness.

Unfortunately, being disabled can often mean being poor. One recent report from the U.S. found the poverty rate for people with disabilities was just over 25 per cent, whereas the poverty rate for non-disabled people was under 12 per cent. These percentages are very similar in Canada, although the recently passed Canada Disability Benefit may help alleviate this situation.

One reason for this is that people with disabilities can often lack access to good, well-paying work. Many countries have tried to solve this problem by adopting legislation that protects disabled people from employment discrimination and guarantees them reasonable accommodations at work. Despite these laws, people with disabilities around the world still have much lower rates of employment than non-disabled people.

Researchers are trying to understand why these laws have not closed the disability employment gap, and what governments, organizations and individuals can do to fix it.

The PROUD Project

We are part of a research team called The PROUD Project based at the University of Toronto. The project is focused on understanding how disabled people can beat the odds and find work.

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To do this, we interviewed disabled employees, disabled entrepreneurs and managers of disabled workers. For this project, we only included workers with evident physical or sensory disabilities, because they face different challenges than people with invisible disabilities.

We interviewed people in five developed countries: Canada, the U.S., the United Kingdom, France and Belgium. We wanted to see if different laws, cultures and physical environments had an impact on disability and employment. The more than 80 semi-structured interviews we conducted revealed several factors that allowed disabled people to find work.

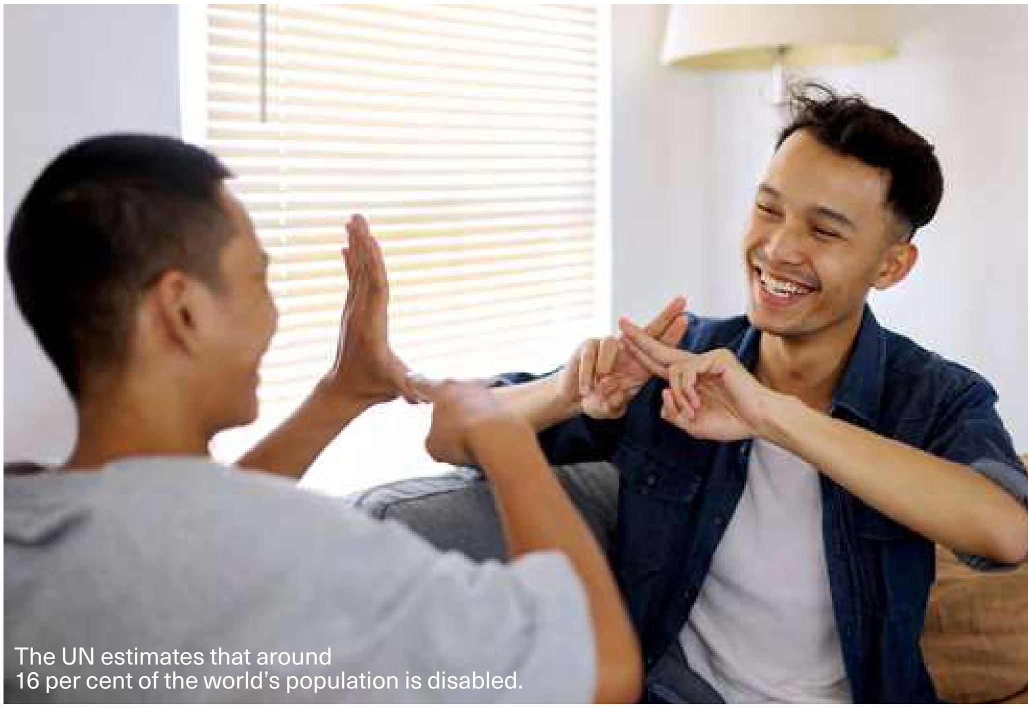
What we found

Legislation is an important mechanism for supporting disabled workers. In the U.S., many people used the Vocational Rehabilitation program (created by a 1973 law) to establish careers. Meanwhile, France enforces a quota which requires businesses with more than 20 employees to have six per cent of their workers identified as disabled or pay an annual fine.

However, many companies do not meet the quota. In 2021, only 29 per cent of companies met their obligations. Several of our interviewees observed that some companies even explicitly decide to pay the fine instead of hiring disabled people. Yet, having the quota law forces companies to think about disabled workers. While the majority of employers pay the fine for not meeting the quota, many admitted the annual audit makes them think about the issue.

Endurance and persistence were common themes in the interviews — many participants described themselves as "fighters." Some of them went to dozens of job interviews before finally landing a position.

In addition, having formal and informal support networks were important for interviewees. In the U.S., the Vocational Rehab program can facilitate this through their counsellors. Often, persistence was encouraged by parents, teachers and other mentors. Several participants said their parents had always treated them as "normal," and expected them to have a "normal" life path, including a career.



The UN estimates that around 16 per cent of the world's population is disabled.

Accessible transportation is also essential for a successful career. Many of the participants we spoke to lived within walking or rolling distance from their workplace. Some took accessible public transit, while others had adapted transportation to work.

Designing and implementing accessible public transit systems is an important step that governments must take to ensure people with disabilities can get where they need to go. Without the ability to move around, disabled individuals simply cannot get to work. For example, the Access to Work program in the U.K. pays for disabled workers to take taxis to work. This means that people can financially provide for themselves and their families.

Reforming government programs

Read more: How Canada can make better progress on disability inclusion

In some countries, disability pensions prevent disabled people from working. Many participants talked about the stress they felt when deciding to take the risk of working and potentially losing their benefits.

Others still received some benefits, but had to be very careful about how much they worked. On the other hand, some participants had independent financial resources that were not subject to restrictive state policies. Governments need to move away from viewing disabled people as burdens and only providing them with subsistence support and move toward

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Fears, misconceptions and prejudices about disabled persons create barriers to professional inclusion.

facilitating their contribution and participation in communities.

Disabled people also need access to high quality education. In general, disabled people tend to have lower levels of education than the general population. However, the participants we interviewed had higher levels of education than the average in all five countries.

In fact, many disabled workers were overqualified for their current positions. This suggests that disabled people need to have higher levels of education than non-disabled people to get the same job.

They also have to contend with other barriers and preconceptions about their abilities. Fears, misconceptions and prejudices about disabled persons create barriers to professional inclusion.

Supportive workplaces vital

Our project found that it was much easier for disabled people to find work in sectors, industries and companies where employers were aware, supportive and proactive about disability inclusion. For example, employees with disabilities in all five countries tended to work in non-profit or government sectors, where attitudes toward disability may be more positive than in the private sector.

Once again, France was an outlier; private industry employers we spoke to expressed enthusiasm for hiring individuals with disabilities. They recognized the contributions made by disabled employees and expressed a desire to hire more disabled workers.

Read more: Why it makes good business sense to hire people with disabilities

Several French managers wanted to educate non-disabled workers and supervisors about the benefits of including their disabled colleagues. Others argued that social stigma means that some employees who qualify do not want to receive an official designation of disability.

However, it is important to acknowledge that, even for disabled people who had managed to find work, there were still significant problems. Some experienced little or no career development, staying in the same roles for which they had been originally hired. Others could only find work in disability-related positions, even if their education, training and skills were tailored to other industries.

Disabled people are capable, flexible, adaptive and creative. Governments and private companies must do more to include disabled people in the workforce. By not doing so, communities will lose out on the contributions talented people could make. ■

Originally published in The Conversation.
Read the original article here.

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DISCOVER
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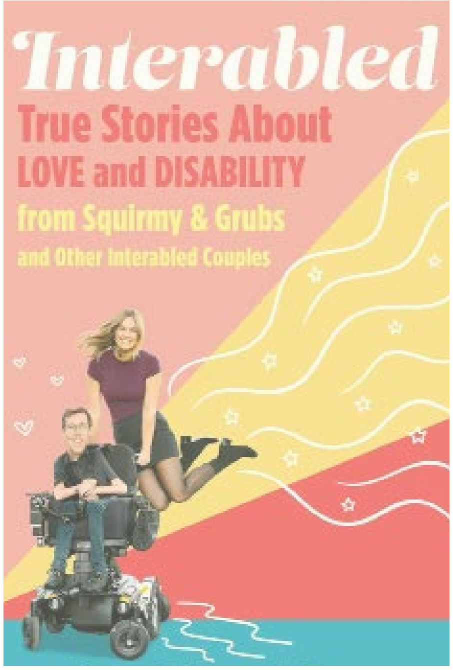
Accessiblity
— MEETS —
Adventure

LANCASTER COUNTY, PA welcomes visitors of all abilities. Visit Discover Lancaster's accessible attractions, lodging options, historial sites, sports, recreational activites and more!

PLAN YOUR ADVENTURE NOW

Laughing At My Nightmare offers emergency relief

By Marcia Frost



Activist and influencer Shane Burcaw is probably best known for his social media following of nearly two million. Squirmy & Grubs, as he and wife Hannah refer to themselves, shares the couple's life as they travel and delves into how they tackle challenges of everyday life. The duo have even written a book which looks deeper into their relationship, as well as that of other couples where one is disabled and the other is not. It's called, "Interabled: Stories About Love and Disability."

Behind the scenes, Shane has also worked the last 10 years with his cousin Sarah Burcaw on the passion project they started together, Laughing At My Nightmare (LAMN).


Shane and Hannah Burcaw


Laughing at My Nightmare Cofounders, Shane Burcaw & Sarah Burcaw

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Laughing at My Nightmare Grant Recipients

Laughing at My Nightmare Grant Recipient,Liz

The non-profit organization donates equipment to those in need. Shane, who has Spinal Muscular Atrophy (SMA), has also overseen $70,000 in scholarships to students with muscular dystrophy, of which SMA is a form of.

“All of our programs are focused on helping individuals gain greater independence and access to essential mobility tools. Over 90% of our recipients live in low- to moderate-income households, which highlights the critical need for this support.”

LAMN recently announced the No More Nightmares Relief Fund. It is to provide emergency relief for those who have urgent needs, such as personal hygiene products, transportation costs related to relocation or evacuation, and critical expenses to help those with disabilities regain their independence.

Shane acknowledged that the recent weather disasters, such as the California fires, and southern flooding, brought the emergent need to the forefront, “While this program has been in development for a while,” he explained, “the fires in LA were certainly another awful example of how disabled individuals are disproportionately affected in times of crisis. Hannah and I were lucky enough to avoid any direct fire damage, but we saw how devastating they were for so much of the disabled community.”

Between LAMN and social media, Shane also remains an advocate for the disabled and is concerned about the effect from the changes in the U.S. government, “The rhetoric and policy intentions of this administration are spiraling out of control and it’s going to have severely negative consequences for disabled people.”

The accomplishments of Shane and Sarah Burcaw so far have been beneficial to many, and they are not finished yet.

“There are so many things we’re all proud of at LAMN,” according to its leaders, “One of the biggest things we’re most proud of at Laughing at My Nightmare is the tangible impact we’ve made in the disability community by providing over $1.1M in assistance since 2015 through adaptive equipment, emergency financial relief, and assistive technology.”

“We take immense pride in the community we’ve built—one that values humor, resilience, and support. “Whether it’s through our equipment granting programs, social media outreach, or direct assistance, we’re dedicated to making a real difference in people’s lives.”

Laughing At My Nightmare relies on donations to be able to fulfill the needs of recipients. If you would like to donate to LAMN, visit their website. ■

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Smarter blinds for greater independence

Leafi Home

For individuals facing mobility or dexterity challenges, something as simple as adjusting window blinds can become a daily barrier. Leafi, a Canadian-based smart home technology company, is lifting that barrier—bringing increased independence, comfort, and control into homes with their innovative device: the Nova by Leafi.

Unlike traditional smart blind systems that are expensive and require professional installation, Nova converts existing horizontal tilt-wand blinds into smart blinds in just minutes—no tools or technical expertise required.

The system is easily controlled via an app or by voice using Google Home or Amazon Alexa. The app also allows for custom scheduling, so users can set their blinds to open with the rising sun or close in the evening.

Whether you're in a wheelchair, recovering from surgery, or simply looking to age in place, the Nova puts control within reach. For many, this small change results in a big shift in quality of life. Greater autonomy in the home environment means increased confidence and reduced reliance on others for everyday tasks.

Leafi's approach proves that smart home products don't need to be complicated to be life-changing. By offering a simple yet powerful tool to enhance daily living, they are helping redefine what independence can look like in a modern, accessible home.

Learn more about the product and compatibility options at www.leafihome.com ■

Visit leafihome for more

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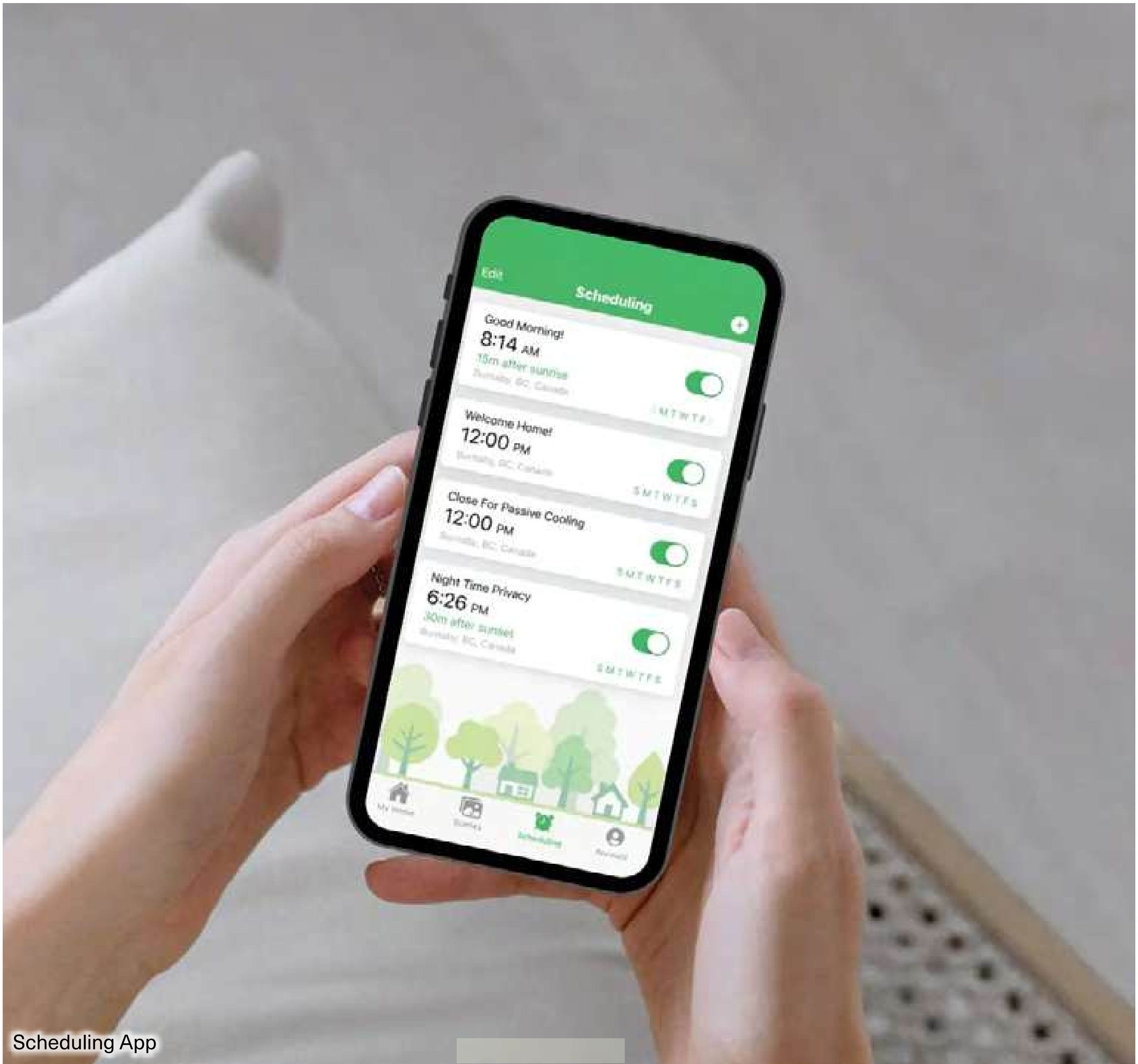
Homeowners choose Leafi because we make everyday life a little easier and more accessible.

Product on blinds



Scheduling App

The Empowered Special Needs MAMA BEAR Journeys

No one gave me a guide
So I became the expert

By Christine E. Staple Ebanks, The Special Needs Mama Bear

How I turned fear and confusion into strength—and why you're already doing the same.

Nathan and Christine

In the last issue, I introduced you to the Special Needs Mama Bear—the fierce, unwavering advocate we become when the world doesn't know what to do with our children or with us. But before the roaring and rising comes something quieter. Something harder.

Before we become advocates, negotiators, and system navigators... we're just parents. Often overwhelmed, under-supported, and left to figure it all out on our own.

As mothers, we're told our eyes should see possibility in our babies. Wonder. Joy. The sparkle of discovery. We're told to dream of all that could be.

But for many of us, that isn't how it begins.

When my son Nathan was diagnosed with cerebral palsy at nine months, my eyes were retrained. I stopped seeing his spirit and started seeing medical reports, sterile clinics, therapy schedules, and worst-case outcomes. I fixated on the "dis" in disability—missing the undeniable will and brilliance of my child right in front of me.

His diagnosis didn't just shape my thoughts—it consumed them.

Every toy had to serve a developmental purpose. Every book needed sensory features. Every conversation became clinical, focused on what was lacking—not what delighted. The avalanche of diagnosis buried my child beneath it.

Maybe you've felt that too—that slow erasure of joy under the weight of responsibility.

If so, let me say this clearly: You are not failing.

You are carrying more than most can imagine. And you are not alone.

Here's what no one tells you: there's no manual for this. No step-by-step guide to therapies, school meetings, or emotional landmines. There's just you—and your child.

But here's what I learned: Every moment of confusion became a catalyst.

Every hard-earned answer built something inside me. And eventually, I became the expert.

For twenty years, I've been a student of this life. I dove into every training I could find—early intervention, inclusive education, system design. I wasn't chasing credentials. I was chasing answers. But along the way, I earned a Master's degree in Human Services, focused on creating inclusive systems for families like mine. Because my son needed me to know. And

because I knew I wasn't the only one.

Specialists bring their training. But we—parents—are the experts on our children. We know their rhythms, quirks, cues. We speak their language when no one else can. We coax smiles through meltdowns. We translate gestures into conversations.

Still, no one trains us for this. So we improvise. We make it up as we go. And still—we rise.

One moment that solidified this for me: a respected Jamaican pediatrician read my book How to Cope: Parenting a Child with Special Needs. Afterward, he said, "Until I read your book, I never truly understood what special needs mothers go through. I thought I did. But I didn't."

His training had prepared him to diagnose—but not to see the parent behind the diagnosis. Our lived stories changed that.

That's what this movement is about. We weren't given tools. We built them. And now, we're passing them on.

I'm creating the **Special Needs Mama Bear Playbook**—a practical, heart-led resource shaped by real life. It's not theory—it's wisdom earned through experience. Because we deserve more than just survival. We deserve to thrive.

Just as important as the guide is community. Too many of us have walked this road believing no one could understand. But we're out here—wise, weary, hopeful, strong. We come from different countries and cultures, but we're united by love, resilience, and the knowing that our families deserve the best life has to offer.

That's the vision for the **Special Needs Mama Bear Community**—a space to lift each other up, share what we've learned, and grow stronger together.

Because here's the truth:
If you're raising a child with special needs, you are already becoming the expert. Your love, your persistence, your every "figuring it out" is shaping not just your child's life—but the systems around them.

No one gave me a guide.
So I became one. And now, I'm writing the guide we all deserve.

You'll be the first to know when the **Playbook** is ready.
In the meantime, let's stay connected. Follow me @ thespecialneedsmamabear on YouTube, Facebook, and Instagram for updates and encouragement. And if this article spoke to your heart, share it with another mama who might need it. You can always reach me at contact@thespecialneedsmamabear.com.

Let's build it together. ■

Author Bio:

Christine E. Staple Ebanks is an award-winning author, international speaker, and advocate for children with disabilities. She is the founder of Raising Special Needs Inc. and the Special Needs Mama Bear Empowerment Movement. Through her books, workshops, and online community, she empowers parents to find their voice, build capacity, and create thriving lives alongside their children with special needs.

Nathan's 2025 school portrait

Join the Special Needs Mama Bear community

We invite you to join the Special Needs Mama Bear community of empowered special needs parents. In this segment, we will share inspiring stories, practical strategies, and expert insights to help you navigate your journey with confidence.

Share your story for an opportunity to be featured.

Join our community on social media by following us:

Facebook @cstapleebanks

Instagram @cstapleebanks

LinkedIn: christinestapleebanks

and tag a friend or five, whoever can benefit from joining our movement. Your voice is vital in building a stronger, more connected network of Mama Bears.

Like bears in the wild, we are stronger together. Let's celebrate our victories and advocate for a more inclusive world for our children.

Want to share your story?
Email me at:
contact@thespecialneedsmamabear.com

Your journey may inspire and uplift others in our community.

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WE ARE ALL EQUAL AT THE STARTING LINE!

Just Hands gives hand control drivers the opportunity to get behind the wheel of a track car and experience high performance driving. Whether learning the techniques of high-speed driving on a track, improving your technique on the autocross, or experiencing the thrill by sitting in the passenger seat on a ride-along, Just Hands Foundation is here to make it happen. Because we believe that everyone is equal no matter what appendages they use to drive.

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Maria & Lindsay

The bold life and work of Maria Dalmon

Maria Dalmon's life is a clear demonstration that physical or societal limitations are no match for determination, intellect and a refusal to accept less than what one deserves. Born in 1955 in Sydney Australia's western suburbs and diagnosed with cerebral palsy at 18 months, one would assume that Maria's path was set by circumstance, but she exercised her right to choose and her choice was to engage fully with life.

Her early years were shaped by the Spastic Centre (now the Cerebral Palsy Alliance), where she received both treatment and a solid education. At a time when expectations for people with disabilities were unfairly narrow, Maria's future widened steadily. In 1973 she began work at Centre Industries, a factory that encouraged integration by employing both disabled and able-bodied people side by side. By 1990, she had secured a position in open employment at her local Returned Services Leagues club which was a significant achievement in an era when

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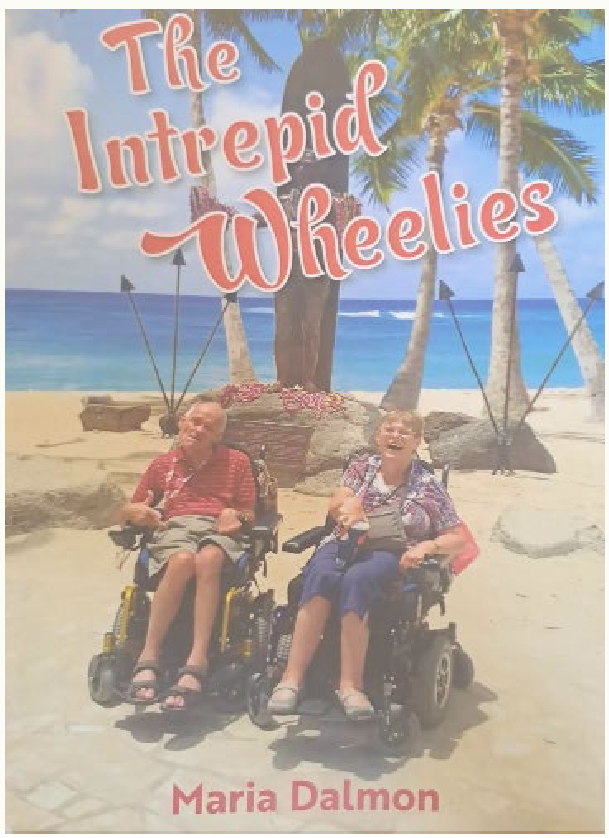
inclusion in the workplace was far from guaranteed. Maria's life, however, is not only marked by employment milestones. It is also rich with personal achievements, adventures and meaningful contributions to the broader community. She married in 1986 and with her husband, Lindsay, who also has cerebral palsy, live in their own home, with the support of care workers. Together, they have built a full and active retirement life, one that includes travel, social activity and sailing, a passion they share through the Sailability program.



Most recently, Maria has turned her attention to writing, having published two books. Her autobiography, Don't Tell Me I Can't, released in 2019, candidly lays out her personal narrative. Her follow-up, The Intrepid Wheelies, continues her literary work with the same clarity and impact. Both books have resonated widely, not just within the disability community, but with anyone who values insight and authenticity.

She writes, in part, to challenge assumptions. The persistent underestimation of people with disabilities is a theme she confronts directly. Her work encourages a shift in public perception through grounded

Boat


Maria signing books

Maria giving her speech

storytelling and lived experience.

While she does not currently plan to publish a third book, Maria is far from finished. She is turning her attention to advocacy, especially around the issue of accessibility in travel. A passionate cruise enthusiast, she has noted, with growing frustration, the lack of infrastructure that allows wheelchair users to go ashore at ports where tenders are used. Cruise ships that anchor offshore leave many disabled travellers stranded on board, excluded from the very experiences they paid to enjoy. Maria plans to write to cruise lines to urge practical changes.

Reflecting on her travels, she shared “I loved London. There is so much history to see. I am an avid fan of the Royal family and a lover of live theatre. To enjoy a tour inside Buckingham palace and attend a performance of Les Misérables in the West End was simply a dream come true.” She and Lindsay are passionate travellers: “We love to travel! “We love adventure. We love to get away and experience different cultures, meeting their people and seeing interesting sights. We love going on cruises, unpack once, relax, have fun and visit different ports along the way.”


At the Tower o London

But she is concerned with the absence of accessibility information in the travel media.

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Travel programmes frequently showcase destinations without acknowledging whether those places can be accessed by wheelchair which is an inconvenient omission.

Despite these ongoing challenges, Maria speaks with optimism and focus. She credits much of her success to a supportive network and her own sense of purpose. "There have been many accomplishments in my life, she reflected. "In 1971, I achieved the Queen's Guide, the highest award in Girls Guides; my marriage to Lindsay and buying our home; competing in sailing in Osaka, France and Italy; writing my two books and sailing single-handed around Scotland Island (with a support boat following)." Her message to other disabled writers is simple and powerful: Tell your story! Write your book! Help make society totally inclusive! ■

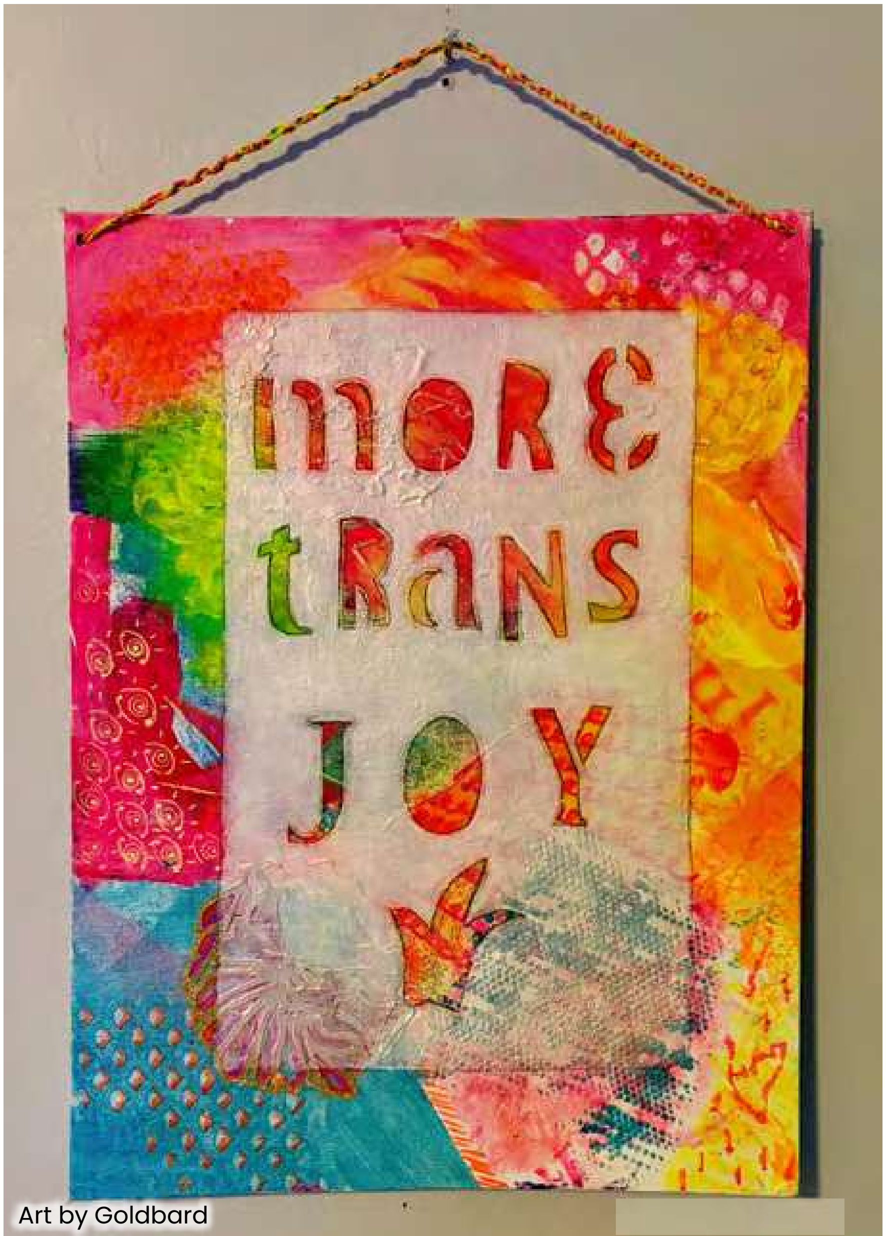
Maria with Cerebral Palsy Alliance staff

Q&A

with Bart Vulliamy about the

Disabled and Disorderly Art Show

At Cross and Crows, 2836 Commercial Drive, Vancouver



Art by Goldbard

DISABLED&
DISORDERLY
nothing about us without us

What inspired you to organize a disabled-artist-only art show?

I am a disabled artist. I had continually been let down with how inaccessible art shows, art markets, and galleries are still inaccessible to the majority of disabled artists, financially and physically

The last three trips I went on were to culturally and artistically rich cities – Paris, Montreal, and San Francisco. I began reflecting on what I loved about those cities, and what I thought Vancouver was missing, from a disabled artists point of view. Vancouvers rich cultural hubs have been diminishing in favour of

Art by Adishi Gupta

expensive coffee shops and car dealerships.

The first Disabled and Disorderly art show: April 25, 2025, Cross and Crows 2836 Commercial Drive, Vancouver. It will be open for one month. The opening night was also an open mic poetry night. Tickets were $5.00 at the door and monies went directly to Cross and Crows books.

How do you define "disabled artist," and what criteria did you use for participation in the show?

The artists involved identify as disabled, mentally ill, and/or neurodivergent. The theme of the series is counterculture and protest art.

Counterculture art reflects an artist's cultural beliefs by challenging societal norms and expressing dissenting views. Artists must use their artworks to critique mainstream culture, politics, and social issues, especially within the realm of disability.

Did you encounter any challenges while planning this event?

Accessible venues! People in wheelchairs should be able to go through the front door without struggle, or to the bathroom without issue.

How do you think this show will benefit the local art community and disabled artists in particular?

I very much see it as community building in a time where community is needed. The American government just declared war and gutted DEI (Diversity, Equity, Inclusion) which ensured that people with disabilities have equal

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Art by Grae Salisbury

opportunities and are valued in all areas of society, including education, work, and social engagement. Disabled people know, and have always known, that we cannot rely on the government for help. We are always the first minority to be cast aside anytime there's a crisis.

Can you talk about any specific artwork that featured in the show?

MORE TRANS JOY by Goldbard is one of the pieces. Joy and rest are both acts of resistance in our economic system that prioritizes profit and productivity, and with the threats from the government to undo trans rights, it couldn't be more direct.

How do you envision the audience responding to the art presented in this exhibition during this month?

I hope the people in attendance take their interests in disabled artists and protest art and carry it with them. Disability justice is asking the question whether the goal is having a seat at the table, or recognizing that the table is broken and needs to be rebuilt entirely.

What role do you think art plays in advocating for disability rights and awareness?

It's huge, but I think it's weird that it's always left out of the protest art discussions. I have collected a sizable amount of protest art books, and not one of them has a section or a paragraph on disabled artists. Protest art has always been important in society, from graffiti to advertisements. It's a sign of a healthy society, or rather, an unhealthy one.

With the Disabled and Disorderly shows, I want it to be focused on how awful disabled people are still treated and stigmatized. Many of us have the proverbial boot to our necks, especially financially. 1.5 million disabled people (that we know of, and that are approved for PWD) are below the poverty line in Canada.

Are there any specific accommodations or support systems in place for visitors with disabilities during the show?

The venue is mask mandatory and wheelchair accessible. I am still trying to find other venues that are like this.

What lasting impact do you hope this exhibition will have on the broader art landscape?

Ideally, I want other galleries, venues, and business leaders to change how they do and see things. I also hope that non-disabled people also start noticing where there needs to be change. ■

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Art by Bugcru

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Adishi Gupta

Meet Adishi Gupta, a boundary-pushing artist whose work is as bold, layered, and unapologetic as the title of the show was a part of—Disabled and Disorderly. With a style that's as much about emotion as it is about rebellion, Adishi uses her art to explore identity, visibility, and the lived experience of disability. Whether her work is confronting stereotypes or celebrating the power of chaos, it's always rooted in authenticity. We caught up with her to talk about her pieces in the show, the beauty of making a mess, and why disorder can be a form of creative power.

Can you tell us about the pieces you're showing at the exhibition. What stories or ideas are woven into them?

My digital collage piece reminds me of Adrienne Rich's words: "To be a female human trying to fulfill traditional female functions in a

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the conflicting and constrictive expectations placed on me as a queer, racialized, and disabled woman. The bird, the flower, and the figure capture what it feels like to be constantly picked apart by outside forces while also, somehow, growing, changing, and blooming through it all. It's about the tension between being scrutinized and being transformed. The work is both a portrait of that pressure and a refusal to submit to it. A refusal to abandon everything that is disabled, disorderly, and defiantly alive within me.

What's one feeling or truth you poured into your work for the Disabled and Disorderly art show that people might not see right away?

There are a lot of layers to this piece and I am curious to know what stands out to people the most. I wonder if people will see the anger, tenderness, and grief it holds. Anger at being constrained. Tenderness for what survived. Grief for what didn't/couldn't.

Adishi Gupta Brain Pickings 2024 Digital Collage

Adishi Gupta Rest

The show's title, "Disabled and Disorderly," is bold and brilliant. How does your work connect with or disrupt that theme?

The underlying tensions and emotions in the collage connect deeply with the show's title. I love that the title re-claims "disorderly" as something powerful instead of shameful. My work embraces the tangled, non-linear forms that ideas and emotions take. It refuses order. It's messy and sometimes contradictory. It shows disorder not as dysfunction, but as defiance.

If someone could only glance at your work for 5 seconds, what do you hope stands out the most?

I hope they catch that strange, tender tension between growth and disruption.

tension between growth and disruption. That blooming isn't always gentle; it can be both messy and uplifting.

To invite deeper insight into identity and process, how does your lived experience with disability shape the way you create—or what you choose to create?

I move through the world picking up fragments of images, textures, patterns and half-formed thoughts. My art process mirrors that. Collaging and working with found materials feels natural because they allow for brokenness, imperfection and pause. They allow me to work with what's left behind or discarded. The work is shaped by a bodymind that doesn't always move in "order."

What do you hope someone feels, questions, or carries with them after standing in front of your work?

I hope they carry a softened idea of what "order" means. That maybe disorder isn't something to be feared or fixed. Maybe it's something you can feed, nurture, and find wonder in.

What's your favorite part of your creative process—and what's the most delightfully chaotic part?

Favourite part: When seemingly disparate images and materials come together to form a narrative
Most chaotic part: Collecting and managing found materials, as exciting as it is, it is also very cumbersome when you are stretched for space both digitally and physically

Do you ever create with accessibility in mind—visually, conceptually, or otherwise? How does that influence your work?

Adishi Gupta Home 2024 Digital Collage

Adishi Gupta Buzzin 2025

While creating my work, I hope people feel something even if they don't know every reference or follow a traditional way of reading an image/ “appreciating art”. I try to leave space for different kinds of seeing, different ways of making sense of things. Accessibility, for me, starts with making work that doesn’t assume everyone experiences the world in the same way. I'm still learning how to make my work more accessible across different sensory experiences and it's something I think about more and more.

Art world spaces aren’t always built for disabled artists. If you could disorder one part of the mainstream art world, what would you flip on its head?

I would flip the assumption that disabled artists are an exception to the rule. In most spaces, accessibility feels like an afterthought, something you add on once the “real” work is done. I dream of spaces built with disabled artists at the center from the start. Spaces that expect different bodies, different speeds, different ways of thinking and feeling. Spaces that don't demand you fit a mold just to belong.

What makes your work in Disabled and Disorderly impossible to ignore?

Maybe the fact that it is a bit odd to look at. It is not easily digestible, it needs a slower kind of attention. It asks one to sit with contradiction.

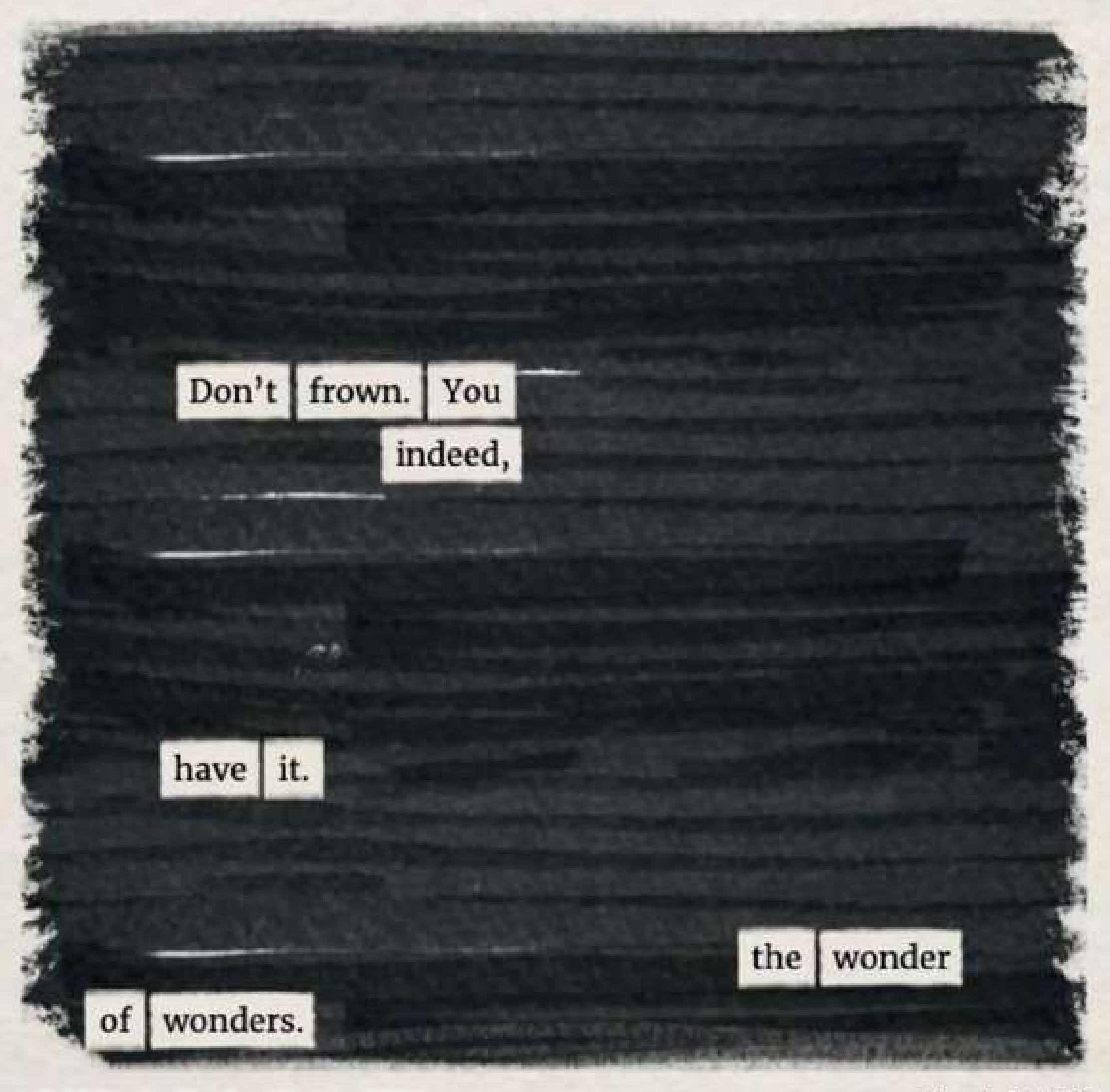
What advice would you give to other disabled creatives trying to carve out space for themselves in the arts?

You don’t have to be inspirational, perfect, or fast. Make the art you need to make. Take your time. Take up space. Be disorderly.

What’s something unexpected about your art or practice that might surprise people? Any secret materials, strange rituals, or guilty-pleasure inspirations?

Some people might find it surprising that I never set out to become an artist, because I never thought that I could. I do not have any formal training in the arts. I have always felt I’m too clumsy with my hands to make anything worthwhile. I started because I am a very tactile person and I needed to put my anxious hands to work. Collaging and blackout poetry became my best friends. When I realized people actually liked what I was creating (which still feels unbelievable to me), I decided to stop doubting myself so much. I started taking chances I never even dreamed of (this exhibition being one of them). ■

Follow Adishi Gupta on Instagram



Adishi Gupta Blackout Poetry 2024

@FoundArtByAdishi

Lachi speaking disability

Blind singer-songwriter Lachi is shaping a more inclusive music world

Award-winning recording artist, CEO of RAMPD, Disability Culture Icon

Can you tell us about your journey into music and how your blindness has influenced your songwriting?

As a quirky little outcast, I turned to my piano as a creative outlet. Through song, I was able to understand myself and the world around me better, and in turn, have others understand me and my different perspective. Back then I was super shy and ashamed as a result of my blindness and neurodivergences. Today, I'm definitely not shy and am super confident, but I'm still blind and neurodivergent, so obviously the disabilities were not the problem. Society was and is. With that said, today I use music to celebrate my differences.. My song "Diseducation" is a joyful scat-filled combat to ableism, charity-model and erasure. My song "Say the Words" is about using the word disability instead of corny euphemisms. My song "Black Girl Cornrows" is a lyrical self description, which gives blind folks access, And my song "Lift Me Up" celebrates Disability community and our disabled ancestors who lift us up.

What artists or genres have inspired you the most, and how do you integrate those influences into your work?

My mom played classics in the car and on Saturday mornings, like the Beatles, country artists like Dolly Parton, and the pop rock bands that took over the late 90s and early 2000s. I didn't have any blind female role-models, so I settled for the few Black female heavyweights and visionaries

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that came up during that era like Alicia Keys, Lauryn Hill and Missy Elliot. This exposure to a mix of genres definitely influenced my blending of genres as an artist. Being made up of many things, words, thoughts and experiences, I like to reflect that through my art by blending genres and switching up vocal styles.

How do you approach the songwriting process? Do you follow a specific routine or method?

My creative process is different every time, but essentially, I catch a vibe, a feeling, a churning in my gut or in my heart, and then the thing just pours forth. Whether it starts in the backseat of a car, in the shower, in front of a piano, or in a room with collaborators, it's a truly organic experience. My art is informed by the lives I and my ancestors have lived, gunning for first place in a society that was not built for our victory. Where I am now, my lyrics and melodies are a one-to-one discussion of me, my specific lived experience, and sharing lessons learned through my very unique perspective.

What is the most important message or theme in your lyrics?

My ultimate goal is to infiltrate pop culture with "Different." From elements of Dance instrumentation and jazzy vocals to folk story-telling with the lyrical wit of hip hop, I connect them all with a message of radical self-love, empowerment, and a touch of F***'em-energy.

How do you prepare for live performances, and what do those experiences mean to you?

I absolutely love live performances, going on tour, and connecting with the real energy of real people! I do keynotes, concerts, and keynote concerts—which are a blend of storytelling, humor, and music. I perform with ASL artist Indi Robinson who signs all my lyrics while I play the piano and sing. I prepare by crafting a narrative through my set list, intertwined with personal stories. And of course, I get my nails did up, pack a fabulous outfit, and travel with my makeup artist! These live shows give me so much energy between the engaged crowds, my collaboration with Indi, and being on the road with the team. Being able to talk to folks after the show and hear how my music connected with them means everything to me.

What are some of the biggest challenges you've faced as a blind artist, and how have you overcome them?

When I began pursuing music full-time, I ran into some serious barriers as a blind woman. Some studios were inaccessible, and due to certain stigmas I did what I could to hide my disability. As I looked around at my peers in the industry, I couldn't find anyone that had a story similar to mine. I googled "disability and music" and nothing substantive came up. So I decided to be the representation, build the community that I needed, and help shape the industry that I wanted. I traversed the industry looking for as many professionals with disabilities, neurodivergence, or chronic or mental health conditions. I brought them together and formed Recording Artists and Music Professionals with Disabilities aka RAMPD—a consultancy group equipping music industry partners with access tools and solutions as well as a professional affinity network amplifying Disability Culture and safe accessible spaces in the music industry. We've now worked with major players like

The Recording Academy, Live Nation, Netflix, TIDAL and more to bring opportunities to our networks and inclusive programming to music and live entertainment.

How do you use technology in your music creation and promotion?

Accessible technology has helped improve my music creation. In fact, during COVID, I was able to build a studio at home that is completely accessible to me. It's equipped with assistive technologies like screen magnifiers, screen readers, and speech to text. I've also become a keyboard-warrior, navigating my digital audio workstation with very little use of the mouse.

Are there any misconceptions about blind musicians that you would like to address?

Blind musicians aren't super-natural oracles! Blindness is not super-natural, but a natural part of who I am and how I show up. Whether you're talking about me or Stevie Wonder or any other blind musician, our musical talents are because we love music and work hard, despite society telling us this career isn't for us.

What advice would you give to aspiring singer-songwriters who may have disabilities or face other challenges?

Embrace all of who you are - even the parts society tells you to hide. Lean into your strengths, what you love and who you are, and infuse that unique part of yourself– the thing that makes you stand out– into your art and/or your

At the Grammys

Lachi is a globally touring recording artist, award winning social entrepreneur, GRAMMYs Chapter Board Governor, and host of PBS' American Masters series 'Renegades'. Born legally blind, Lachi uses her platform in music, storytelling and fashion to amplify identity pride and Disability Culture. Her U.N.-recognized organization RAMPD (Recording Artists and Music Professionals with Disabilities) has collaborated on disability-inclusive solutions with the GRAMMYs, Netflix, Live Nation and more. Her recent song Lift Me Up in homage to Judy Heumann peaked at #29 on U.S. Adult Contemporary radio. Named a USA Today Woman of the Year, an ADCOLOR Innovator of the Year, a "new champion in advocacy" by Billboard, and "a foot soldier for Disability Pride" by Forbes, her cultural activism has landed her spots on national ads and TEDx stages, discussions with the White House, BBC, Good Morning America and the New York Times.

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personal brand. Then you can focus on just being undeniable at your craft. Whether it be hours learning from YouTube, rehearsing, taking lessons, or interning, every successful career begins with honing your craft. And of course, show up! Virtually or in person, get out there. Network, scope out and support your colleagues in the industry. Then rinse and repeat.

What projects are you currently working on, and what can fans look forward to in the future?

SO many projects are in the works! I've got new music coming out monthly, including my recently released track "Diseducation (Dance Mix)" co-created with Apl. de.ap (Black Eyed Peas), my book I Identify as Blind will be published through Penguin Random House next year, I'm working on a children's album elevating these deep discussions with Grammy-winning collaborators, we've got endless appearances, shows and keynotes around the globe, and a heck ton of other things I can't quite talk about yet. Keep up with me @LachiMusic on socials for upcoming projects, dates and how you can get involved in infiltrating pop culture with Different! ■

Lachi in fur with her black glamcane

Full background bio:
As a globally touring performer, charting recording artist and award-winning social entrepreneur, Lachi—born legally blind—uses her platform in music, storytelling and fashion to amplify identity pride and Disability Culture to mainstream discussion. From walking the New York Fashion Week and Barbie Premiere carpets with a bejeweled cane to belting ballads on the TEDx stage, Lachi incorporates her disability identity into all aspects of her art, and art into all aspects of her activism. Her work has been lauded in the New York Times, Billboard, Forbes, Good Morning America and USA Today, where she was named a 2024 Woman of the Year.

Lachi is Founder of the U.N.-recognized organization RAMPD (Recording Artists and Music Professionals with Disabilities), which—through collaborations with firms like Netflix, Live Nationt, TIDAL and more—brings disability-inclusive programming to the industry and career opportunity to music professionals with disabilities, neurodivergence, and chronic and mental health conditions. RAMPD partners with the GRAMMYs and other notable concerts, festivals and events on high-visibility accessibility and inclusion. In 2023 RAMPD received Ford funding, a Music Business Association award, and a Borealis Philanthropy award for working to bridge the inequality gap for hundreds of music professionals. In 2024 Lachi was named Innovator of the Year by ADCOLOR for her work with RAMPD.

Lachi also governs on the GRAMMYs New York Chapter Board and advises on the National Independent Venue Association, Songwriters of North America and Audio Engineering Society DEI Committees.

As an artist and personality, Lachi partners with international artists and brands, touring globally, to bring her positive spin on disability to international audiences through purpose-driven projects. Her 2023 pop track "Lift Me Up", celebrating American Sign Language and disability community, peaked at #29 on the national Adult Contemporary Radio charts, airing on BETSoul, MTV.com, and receiving millions of streams across platforms in its first week. She has twice appeared on PBS, hosting segments amplifying disabled rebels, voiced audio-description for Netflix's Kanye West docu-series, published her NYU study assessing accessibility in the recording industry at the 2023 Audio Engineering Society convention, and regularly holds discussions with top music entities on actionable accessibility and inclusion strategies.

Outside of this, Lachi consults or keynotes and performs at festivals, national firms, nonprofits, universities and cultural centers globally to advance disability, identity and culture. She's done so with the White House, UN, the BBC, CNBC, Lincoln Center, Julliard, Google, Amazon, FOX corp and many others.

Named a "dedicated foot soldier for disability pride" by Forbes, Lachi's been featured in Essence, Vogue and LA Times for her advocacy work. She has been listed in Cranes Business 40 Under 40, received a Social Justice Award from New York City Nightlife United, was honored in 100 Women to Know presented by JPMorgan / Chase, named a 2023 Leading Woman by Adage and recognized by both GRAMMY.com and LinkedIn as a go-to voice in disability inclusion.

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Reimagining Hollywood:

Why this moment matters for disability inclusion

A Multi-Voice Interview Featuring Nancy Weintraub, Emily Ladau, and Nicole Lynn Evans


Nancy Weintraub EasterSeals


Emily Ladau


Nicole Lynn Evans

People with disabilities exist in the entertainment industry. But how often do you see them on screen? They're either missing, written as afterthoughts, or often portrayed by non-disabled actors.

In an era when the entertainment industry is critically examining who gets to tell stories and who is represented in them, Easterseals Southern California has released Reimagining Hollywood: A New Lens on Disability Inclusion. This comprehensive report aims to shift industry norms and offers a roadmap for structural change, rooted in experience.

Easterseals Southern California first explored disability inclusion in entertainment with its 2018 report, Abilities Unlimited, created in partnership with Variety to coincide with Easterseals' centennial. That initial report established a baseline for understanding representation in Hollywood and aligned with the broader mission to redefine how the world sees and understands disability. Five years later, recognizing the need to assess progress and identify new opportunities for growth, Easterseals launched a more robust, community-driven follow-up: Reimagining Hollywood. Co-led by Emily Ladau and Nicole Lynn Evans, the new report combines national survey data with insights from focus groups of disabled creatives to present a bold, actionable framework for industry transformation, moving beyond mere visibility to true inclusion and leadership.

Nancy Weintraub, Chief Advancement Officer at Easterseals Southern California, calls the report a "game-changer" for Hollywood. Emily Ladau, media consultant and author of Demystifying Disability, speaks to its broader cultural relevance, while Nicole Lynn Evans, a multi-hyphenate actor, producer, and advocate, offers first-hand insight into how disabled creatives are leading the charge.

Milestones

Several high-profile moments have served as milestones for disability representation. CODA won an Oscar, Ali Stroker broke barriers on Broadway, and documentaries like Crip Camp garnered critical acclaim. Each milestone helped spotlight disability and push the conversation forward.

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But isolated wins are not enough. Systemic change requires consistency, scale and infrastructure. “The impetus for this second round of the report was to capitalize on the momentum we've seen and take it further,” said Ladau. “What we heard from the community was that every time there was a watershed moment, it got some media buzz but soon after, things reverted to the status quo, with limited and often inaccurate representation.”

While there are signs of progress—a growing awareness and moments worth celebrating, both anecdotal feedback and hard data from Easterseals’ latest survey reveal a more complex reality. According to Ladau, over the past four years of data collection, there has been a measurable decline in the number of respondents who report seeing disability represented on screen. Authentic representation remains inconsistent, and in some areas, has regressed.

“What this shows us,” Ladau explained, “is that there’s still a vast, untapped market being overlooked. We keep saying disability inclusion is a movement, not a moment. But that only becomes true if the industry stops treating us like a trend and starts viewing us as essential.”

Nicole Lynn Evans, Best Actor winner in the Easterseals Disability Film Challenge and star of Special and Superstore added: “People with disabilities are not going anywhere. We’re talented, passionate, and driven, with amazing stories to tell. Yes, we’ve made huge strides, but we still need a bigger seat at the table. My call to action is for more people with disabilities to be in executive and leadership positions.”

Nicole Lynn Evans

Authenticity

When asked how her early experiences shaped her drive, Evans reflected, “I grew up in a creative household. Performing was always a part of me. I didn’t see myself (someone in a wheelchair) reflected on screen but that didn’t stop me. I started writing my own content and pushing forward anyway.”

Her breakthrough came through the visibility created by the Easterseals Disability Film Challenge. “Ryan O’Connell saw my work and cast me in Special. That opportunity changed everything.”

Evans’ authenticity is personal. “Every character I play has a disability, because I have one. That, in itself, is authentic representation.”

Data meets lived experience

The report draws on a national survey of 800 adults with disabilities and interviews with more than 50 disabled professionals in the entertainment industry. It’s this combination of depth and breadth, Weintraub noted, that makes the findings so powerful.

Evans and Ladau helped shape the report through Easterseals’ blue-sky brainstorming sessions. “Everyone has a different way of talking about their disability,” Evans said. “That diversity of experience informed every recommendation from casting to workplace design to storytelling itself.”

One especially meaningful example for Evans came during the Film Independent Spirit Awards. “They added candlelight to the tables so ASL interpreters could be seen. That was a beautiful and thoughtful solution to make the event accessible.”

The power of Production Accessibility Coordinators (PACs)

A central recommendation in the report is the formalization of the role of Production Accessibility Coordinators (PAC), a position Evans says transformed her professional experience.

“When I was younger, I didn’t have the language or confidence to ask for what I needed on set,” she shared. “A PAC serves as a liaison between the talent and production. They understand access needs and advocate on your behalf. That takes so much emotional labor off the actor.”

She emphasized the broader significance: “When a production includes a PAC, it tells me they have an ‘access mindset’- it changes everything.”

Ladau added, “People often think accessibility is expensive, but 90% of accommodations cost less than $500. It’s about mindset, not money.”

“We had to explain why disability needed to be at the table in our first report,” said Weintraub. “Now, we’ve moved past that conversation. The focus is now on systemic change.” That change includes roles behind the camera, in boardrooms and in writers’ rooms—not just on-screen as the background disabled character.”

“What we’re hearing,” Ladau said, “is that we don’t want to be limited to disability stories. We want to be in romantic comedies, Marvel movies, courtroom dramas. Disability isn’t a genre. It’s just life.”

The business case for inclusion

At its core, Hollywood is a business, and decisions often hinge on return on investment. The Reimagining Hollywood report makes a strong financial case for disability inclusion: more than one in four U.S. adults lives with a disability. That’s a vast, underrepresented market hungry for authentic stories.

“We wanted to reframe the conversation,” Weintraub said. “This isn’t about charity. It’s about tapping into a powerful audience and creative pool that’s been overlooked for too long.”

Ladau echoed that sentiment: “Authentic stories resonate and when disabled characters are written with depth and realism, they connect with all viewers. It’s not about writing ‘disability stories.’ It’s about telling human stories that include disability.”

Evans cited director and writer Shaina Ghuraya, whose quote in the report said:

“We need so much more authentic content featuring folks with disabilities. There is a definite gap in the romance department. My hope is that more authentic content around intimacy and relationships is greenlit, because I believe that romance deepens folks’ empathy. Also . . . we’re hot.”

The road ahead

Reimagining Hollywood is both a call to action and a blueprint for disability inclusion. It insists that disabled talent be recognized not just as participants, but as leaders, producers, and changemakers. As the report powerfully illustrates, authentic inclusion isn’t a favor, it’s an imperative!

Explore the full report: Reimagining Hollywood ■

Emily Ladau

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Warren “Wawa” Snipe:

Making music you can see, feel and believe

You may know him from one of the Super Bowls, or maybe from the TV show, Black Lightning . . . PBS? Or maybe, you don’t know him at all. But after this, you’ll remember his name: Wawa. Deaf rapper. Dip Hop originator. Disruptor of silence.

When Warren ‘Wawa’ Snipe performs, the world listens differently. Your ears are not needed to understand what he’s saying. You just need to watch. To feel. To pay attention.

Born in Philadelphia, a city bursting with rhythm, soul and sound, Wawa was immersed in music from the very start. But for him, it was never just something you heard, it was something you experienced. His family played R&B, Jazz, Rock N Roll and Hip Hop. The house was alive with beat and melody and though Wawa is Deaf, he was right there in the middle of it, absorbing it, questioning it, pulling it apart and putting it back together again.

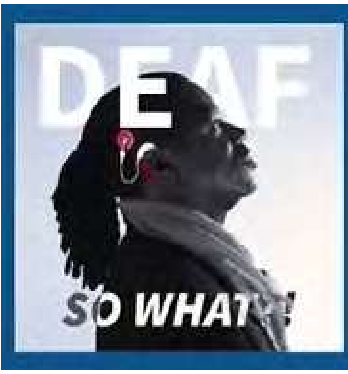
He was a child of the '70s and '80s, the decades when hip hop was still writing its own rules. When Wawa first encountered Rapper’s Delight by the Sugarhill Gang, he didn’t catch all the words but he caught the vibe, the rhythm, the flow, the energy and it gripped him. He asked his sister to write down the lyrics, he sat beside the speaker and soaked in the beat through his body. It wasn’t about hearing the music, it was about feeling it, decoding it, and making it his own. This sparked the beginning of a whole new way to experience hip hop. The bass became heartbeat. The lyrics became movement. The music became his.

That’s where the seeds of Dip Hop were sown—hip hop through Deaf expression. Long before the term was coined, Wawa was already carving it into existence. He invented that. Not out of rebellion, but out of need. Nobody made space for Deaf artists, so he carved his own.

From poetry scribbled in the corners of college notebooks to full-blown international performances, Warren’s evolution did not involve thoughts of proving people wrong. It was about showing what was always possible. His work teaches. His voice, spoken through motion, educates. His existence in the industry? It forces the conversation. And when the music stops? He

UNAPOLOGETICALLY____

Wawa's World



DEAF: SO WHAT?!

Wawa's World

doesn't. He flips to dance, to acting, to advocacy, to standing up in boardrooms and saying, "Where's the interpreter?" before you even realised you forgot one.

But his early performances were not met with standing ovations. They were met with confusion. Skepticism. People didn't understand why a Deaf person would want to perform music. Some even told him it wasn't possible. But Wawa kept writing. Kept signing. Kept creating. He transformed spoken lyrics into visual rhythm. He developed a performance style where American Sign Language collided with musicality, where handshape, expression and movement worked like instruments. And slowly, he built a bridge across what others assumed was an uncrossable divide.

Today, Wawa is known internationally as a pioneer of Dip Hop. He coined the term, defined the genre and gave it shape. It's not a novelty or offshoot. It's a fully formed, thriving expression of culture that belongs to both Deaf and hearing audiences alike. His performances bring language to life in a way that disrupts assumptions and flips expectations. He's performed for presidents, Super Bowl halftime shows and major festivals. He's opened the eyes of industries that didn't even realise they were closed.

But his influence goes deeper than performance.

Wawa is an educator, a mentor, a strategist. He's had doors closed because people thought Deaf meant "unable." But none of that has deterred him. He's spent decades mentoring young Deaf artists, encouraging them not to follow in his footsteps, but to go further. To create boldly, speak visually and take up space.

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He's also an advocate for accessibility, not in a theoretical sense, but in the daily grind of travel, work and performance. From being stopped at airports for not "looking disabled enough," to advocating/educating venues about the importance of having interpreters for Deaf/Hard of Hearing people attending professional events with the help of the ADA, Wawa knows how much of the industry is still built without Deaf people in mind. And he's pushing back, not through outrage, but through excellence. Every stage he steps on, every hand he raises, every beat he signs—it's a declaration: we belong here.

He is deeply committed to inclusion in the arts, particularly for Black Deaf artists, who face an even more complex set of barriers. Too often, he says, roles that should go to Deaf actors are passed over. Stories that should be told from within the community are diluted or ignored.

So, Wawa continues to build space for himself, for those like him and for those coming up behind him.

Introducing WAWABILITY 2025!

This will be no ordinary event. It will be a cultural eruption. Taking place on July 11th – 12th, 2025 at The Anthem in Washington, D.C., the birthplace of the Americans with Disabilities Act (ADA). This landmark celebration will mark the 35th anniversary of the ADA with unfiltered brilliance. Conceived by Wawa, Wawability will spotlight a global lineup of renowned artists with disabilities: musicians, dancers, comedians, actors. Each one will walk onstage not to inspire, but to own their narrative. This is not a tribute nor is it a favour. This is equity. From Mandy Harvey to Kodi Lee, Josh Blue to Lachi, to the inclusive marvel of the Omnium Circus, Wawability will not whisper its message. It will shout it from the rafters: creativity knows no limit, and neither do we. Wawa and his team—Foo Dog Productions, Inc and TDIfor Access will be heralding the start of a movement.

Warren Snipe never asked for permission to create music. He just did it. He made music you can see. Music you can feel in your chest. Music that demands your attention, not because it's different, but because it's powerful.

He's not interested in being the exception. He's interested in shifting the standard. And he's not done yet. He shares the mic. Shares the stage. Shares the space. Why? Because he knows the grind and refuses to be the only one shining. He's holding the gate open, even when it slammed on him over and over. He's been told no. And through all that noise, he made his voice louder than any mic ever could. But Wawa knows the Deaf world isn't sad, lacking, or waiting for pity. It's vibrant. It's powerful. It's full of stories that just have not been told loud enough.

So, if you're wondering how to support Deaf artists, start here: show up. Don't just applaud. Learn to sign "thank you." Don't just tweet a hashtag. Buy the music. Share the videos. Amplify the silence you never knew had a pulse.

And the next time someone says, "But how does Deaf people even hear the beat?" point them to Wawa. Better yet, turn up the volume. Watch him move. Listen with your eyes. And feel what he's been saying all along: We're not waiting for permission. We belong here! ■

Follow Warren "Wawa" Snipe

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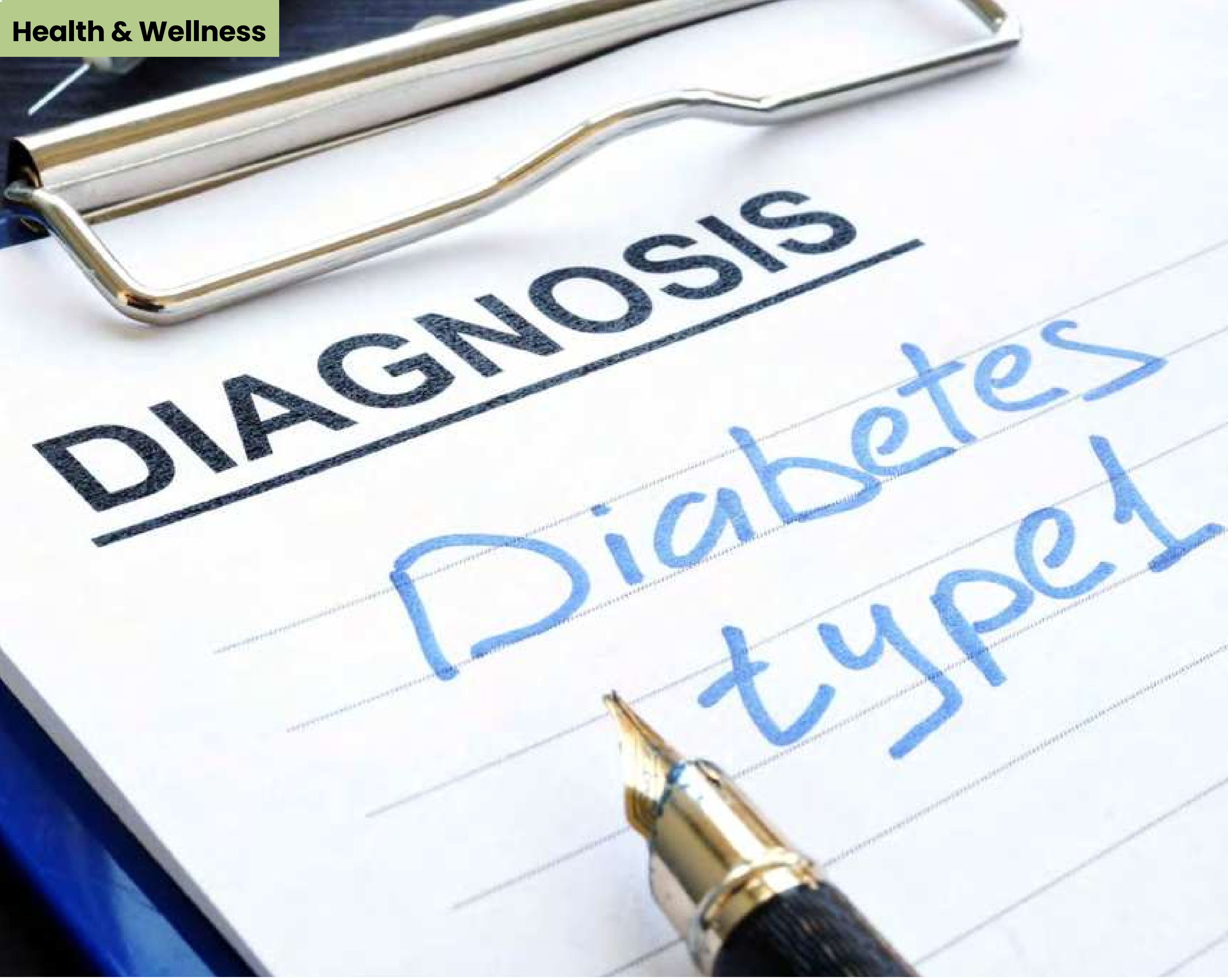

Breakthrough T1D is working towards a world free from type 1 diabetes with bold action

Let's talk about type 1 diabetes (T1D).It's about people who wake up every day knowing their bodies need extra vigilance just to stay alive. For Jessica Diniz, President and CEO of what was once known as JDRF—now rebranded as Breakthrough T1D—the mission is to make every day better for people living with it while working towards cures for tomorrow.

Type 1 diabetes can be diagnosed at any age. Once thought to be a disease that only affected children, this autoimmune condition can be diagnosed in kids, teens, adults and even seniors. And in Canada? This country has one of the highest rates of new diagnoses globally.

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Breakthrough T1D, through its global affiliates (in the United States, UK, Australia, Netherlands and Israel)funds research in 22 countries, bridging the best minds and the best research labs to accelerate progress in all areas of T1D research. As Diniz puts it, “We don’t care where the breakthroughs come from. We care that they happen, fast.”

A misunderstood disease

There are many misconceptions about type 1 diabetes. No, it’s not caused by eating too much sugar. It’s an autoimmune disease where the body’s immune system mistakenly attacks the cells in the pancreas responsible for producing insulin. By the time of diagnosis, very little to no insulin is being made anymore . . . Thus begins the full-time job of managing T1D through constant blood glucose level checks and insulin administration balanced against food, rest and play that starts the second you’re diagnosed.

If you’ve ever felt overwhelmed by the idea of managing your calendar, imagine balancing a literal life-or-death situation every single day. Managing type 1 diabetes is a constant balancing act that is 24/7. There are no days off, no weekends or vacations from T1D.

Making waves, not ripples

In November, 2024, the organization marked a major milestone making the name change to Breakthrough T1D,” to reflect the evolving nature of the disease and their mission. This was a bold acknowledgment that the organization’s work aims to support everyone affected by T1D, at any age and any stage of the disease, whether newly-diagnosed, or living with T1D for decades. But the mission remained the same. Improving lives today and tomorrow by accelerating life-changing breakthroughs to cure, prevent and treat T1D and its complications.

“When people think of breakthroughs, they think of some distant, almost unreachable concept,” says Diniz. “But our mission is to achieve breakthroughs. And how do we do that? We're the leading type 1 diabetes research and advocacy organization and we help to make every day better for those living with this disease while we drive towards curing it.” She continued, “By making every day better that could mean mental health, accessibility, making sure that we're reducing complications and people are living healthier lives while at the same time, funding the best research to ensure that we can work towards curing this disease.”

The organization’s advocacy efforts in Canada, together with the T1D community have helped to secure better access to life-saving devices, including insulin pumps and continuous glucose monitors (CGMs) for people who need them. Diabetes technologies, while making T1D easier to manage, and helping to alleviate both the physical and emotional burden of living with this disease, come with a financial burden—and an inequitable system where coverage depends on the provincial healthcare where you live.

In a particularly powerful story, a mother and her son, both living with type 1 diabetes, struggled for years without CGMs. The mother endured a terrifying hypoglycemic even (where blood glucose levels get dangerously low, leading to complications potentially even including death), leading to severe injuries and surgeries. Today, thanks to improved policies due to the organization’s unrelenting advocacy efforts, they now both use CGMs—and the difference is night and day. The device provides a continuous blood glucose level measurement that can be checked at any time, and more importantly – and alarm that lets you know if your levels are going to low, so you can adjust before it gets unsafe.

An often invisible disease

One of the toughest aspects of type 1 diabetes can be the appearance of ‘invisibility’. Even when wearing insulin pumps or glucose monitors, Teenagers living with this disease often hear, “But you don’t look sick” as if outward appearances could reflect the sleepless nights, the moments of disorientation, the constant balancing of food, activity and sleep or the fear of potential diabetes-related complications.

“We call it an invisible disability,” Diniz explains. “And that invisibility makes it harder for people to understand just how much work goes into managing it.”

Take a high schooler, for example. At 16, she’s not just thinking about getting her driver’s license—she’s grappling with proving she’s medically stable enough to drive. Or the 18-year-old planning her university life but wondering if she can risk moving away from her parents, who are her safety net when blood glucose levels plummet in the middle of the night.

Navigating the daily challenges

It is hard to imagine the challenges faced by parents of young children with type 1 diabetes. For many, the anxiety of sending a four-year-old off to kindergarten is already significant. Adding the complexity of managing a chronic disease like type 1 diabetes makes it even more overwhelming.

Schools without nurses pose additional hurdles, as young children cannot be expected to manage their insulin or administer injections on their own. In many cases, parents must visit the school during the day to check on their child. Managing type 1 diabetes in young children requires constant vigilance and effort.

Parents often take on the role of educator, meeting with teachers to explain the nuances of type 1 diabetes and training school staff on what signs to look for if their child is going low. They advocate for accommodations, such as allowing their child to have juice or fast-acting sources of sugar snacks at their desk in case of a low. These parents work tirelessly to ensure their children's safety and well-being in a school setting.

They also teach their children to recognize signs from their own body when they are going too low or too high. This is a continuous process of education and adaptation, both for the children and their caregivers.

Community power

But there is strength in numbers. Breakthrough T1D's Bag of Hope program for newly diagnosed families provides essential tools, including a teddy bear named Rufus. Rufus is cute but practical. Kids practice giving him insulin shots, making the overwhelming a little less scary. One parent said, "Rufus gave us a way to make diabetes less intimidating. He gave us hope."

Their annual Breakthrough T1D Walk fundraising event, with Walks taking place across the country throughout June, is another cornerstone of community building. It's a fundraiser that brings together the T1D community for solidarity and for kids to meet others like them and realize they are not alone.

Hope on the horizon

There are breakthroughs happening right now in research labs across the country and globally. Clinical trials using stem cells to that can be implanted with the hope they will start producing insulin are already underway. "We're not talking science fiction," says Diniz. "This is happening today, and Canadians are part of these trials."

But for Diniz and her team, success encompasses both research and changing lives. They're fighting for a future where no parent has to send their four-year-old to kindergarten worried about whether they'll be safe without a nurse. They're advocating for policies that erase the absurd disparities in healthcare coverage across Canadian provinces. And they're doing it all while holding fast to the belief that a cure is not just a possibility but an inevitability.

"We're here for the people living with Type 1 diabetes today and tomorrow," Diniz emphasizes. "And we won't stop until the cure is real."

That's not just optimism. That's momentum. ■

The breakthrough begins with us—every step, every voice, every bold action brings us closer to a better world!

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Briella Panton dance photo


Ambassador, Briella Panton 2012-2025 ambassador

Briella's Diabetes Story

I am 17 years old! I have had Type One Diabetes (T1D) for 13 years alongside my dad, who had begun his battle in 1986 at just 3 years old. I am a Christian and I enjoy attending my youth group, teaching Sunday school and church with my family and friends. I love spending time with my family and friends, I am without a doubt blessed with the best! I adore working with kids, and I plan on becoming a school teacher after high school. I am a competitive dancer, which has blessed me with several incredible opportunities to travel and meet incredibly talented people from around the world.

This last year I completed a solo dedicated to T1D that earned a scholarship to dance in Disney with the Walt Disney World Lightning Elite Performance team! My choreographer did an excellent job of not only displaying the hardship tied to type one diabetes but also the beautiful testimony behind each insulin pump, insulin injection, CGM, etc. Each device holds countless testimonies of bravery and resilience that are deserving of celebration! Following my attendance as a leader in training at a camp for diabetic children this past summer, an inclination to enhance my contribution to spreading diabetes awareness had formed. The definition of bravery is found in each of those campers and staff, which has inspired me to explore ways to expand Type 1 diabetes awareness and expand my participation in the T1D community! As a former JDRF ambassador at the age of 5 years old (2012), I figured that it was the perfect opportunity to do so!

Share your personal experience with Type 1 Diabetes

I was diagnosed at the age of 4, subsequently displaying the 4 T’s of Type One diabetes (thirsty, thinner, tired and toilet.). Diabetes has impacted my daily life and has proven itself to be a challenge, consequently resulting in severe burnout. Watching diabetes strain my dad's health from the same disease we share is despondent; however, type one diabetes has yet to steal our joy, passion, and drive. My dad continues to defy the restrictions diabetes attempts to enforce, and I hope that one day I accumulate half the strength that he has. Diabetes has granted me several opportunities, such as serving as an ambassador at the age of 5 for JDRF, being an ambassador for Breakthrough T1D, serving as a Dexcom warrior, attending a camp for kids with T1D, and performing a dance lyrical solo titled Dear Type One. Type one diabetes has played a significant role in my life since before I can remember, and I am determined to rewrite the narrative for T1Ds and create a better tomorrow for those living with it.

How do you think living with Type 1 Diabetes

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affects mental health for young people?

The mental exhaustion associated with type one diabetes is half of the fight! You become your own nurse from the minute you are diagnosed. The constant reminder that you are different, as each beep becomes louder and each comment cuts deeper. The constant care and attention correlated to diabetes care often damages the relationship individuals with the disease express. Lack of motivation for diabetes care is a common symptom of burnout that is often found in many diabetics. The absence of an escape from diabetes often creates a sense of defeat. As we become fixated on achieving the perfect A1C, each glucose reading exceeding or below target can cause a sense of failure to cloud our heads. It is so important to recognize that maintaining ample care of your diabetes does not mean your blood glucose will be 100% perfect all of the time.

Type One diabetes is extremely difficult to manage, and out-of-range readings are inevitable. Exercising kindness to yourself as you reflect upon your readings is crucial. As a teenager with type one diabetes, feelings of isolation and lassitude often flood my head; however, as I have grown and explored my disease, I have altered my viewpoint regarding my disease, as I truly believe resilience and perseverance are both superpowers found in each type one diabetic. Difficult days will always be present; however, optimal strength is shown in those moments, and the wins regarding diabetes will exceed the shadows of the dark.

What are some common emotional challenges you face, or have faced, as a result of managing your diabetes?

I was hospitalized with an eating disorder in the summer of 2024 due to the significant burden that accompanies Type 1 diabetes. Diabetes had never managed to leave my focal point as the countless needles pierced my skin, and the heightened sense of carb counting consumed my mind. However, the moment I was informed that the hospital stay had the potential to interfere with my final year of school and competitive dance, a spark had ignited in me to redefine my relationship with type one diabetes. I was told my stay could exceed two months; however, thanks to God, my wonderful doctors, family, and friends, I was out of the hospital promptly. I had returned to dance the day following discharge, and I performed in Disney World with the Lightning Elite performance team just two months later.

What strategies or activities do you use to cope with the mental health challenges related to diabetes?

My faith has guided me through every shadow of my entire life. Through prayer I have been able to conquer each endeavor presented my way. You will often find me reading my Bible or dancing to alleviate the burden my struggle with mental health has created. Dancing has served as a primary outlet with regard to navigating the tribulation that accompanies the disease. It has provided an alternate world to enter as the music guides each step. I have found incredible comfort in the T1D community and growing in fellowship with my diabetic and nondiabetic friends! One of my closest friends is type one diabetic, and the bond we share is like no other. We share our struggles and elevate one another with words of encouragement and support. Spending time with my friends and family has always been at the forefront of my life as they serve as a pillar of support and a ray of sunshine on rainy days!

Tell us a bit about your support system

Briella Panton dance photo

My support system is second to none, whether it is providing aid during a low blood sugar, holding my hand during a site change, etc., they are on top of it. They continue to expand their knowledge on the disease as they love and support me through my battle. They erase the isolation that is often felt. and they allow me to be myself, beyond diabetes. There are far too many people to mention by name, which is a testament to how many incredible people have impacted my life. The Stollery Children's Hospital, as well as the U of A hospital, has played a crucial role in getting me to where I am today. Without the constant support from Jesus, my family medical team, dance studio, school teachers, church, and friends, I would not be where I am today. They are all Diasuperheroes!!!

Have you experienced stigma or misunderstanding related to Type 1 Diabetes and its effects on mental health? How do you address this situation?

Unfortunately, misinformation and lack of education regarding the disease are extremely common issues. Many people believe the false rumor that T1D is a result of poor health choices, prompting harmful comments. Insecurity used to flood my body as each beep pierced the air, and others would turn to stare. I have spent many days wishing that I would be seen beyond the beep of my Dexcom. However, through introspection, I have discovered that the beep of my Dexcom is a small piece of who I am! The beeping sound serves as an opportunity to not only spread awareness regarding T1D but also to share the incredible opportunities that accompany the disease! Type one diabetes is often overlooked in terms of the difficulty surrounding it, leading many to brush off the struggles faced by my T1Ds daily. When I am faced with a scenario similar to those listed above, I utilize the opportunity to abolish poor understanding of the disease and to enlighten others on diabetes education.

Why do you think it's important for youth ambassadors to speak about mental health in relation to chronic illnesses like diabetes?

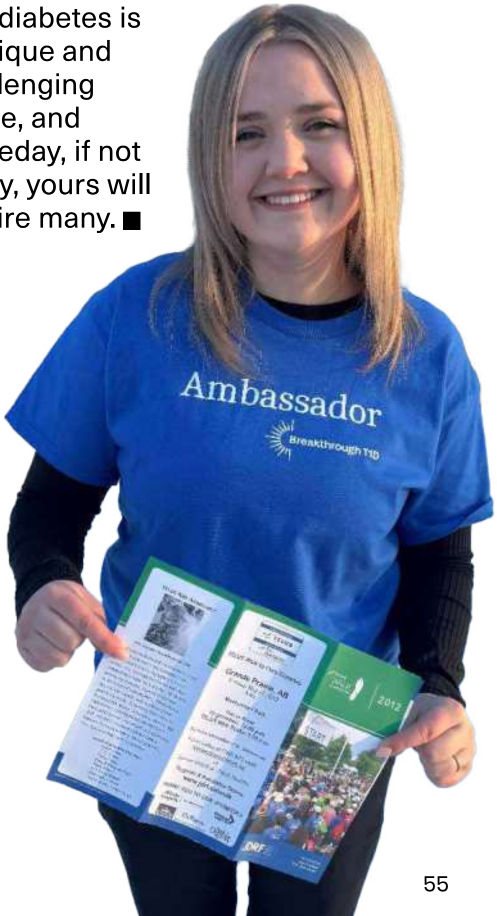
I believe representation must be prevalent to eliminate isolation and encourage confidence. There is a direct correlation between the quality of your mental and physical health. Mental health is often neglected due to the extreme attention to a type one diabetic's physical health; however, it becomes increasingly more challenging to meet the needs of your physical health when burnout is apparent. Seeing fellow T1Ds conquering the disease has played a huge role in my confidence as a T1D and motivation to continue fighting. Instilling confidence in T1Ds young and old, is extremely important and holds the potential to inspire T1DS as well as non-T1Ds!

Are there specific resources, tools, or communities you recommend for young people trying to manage their diabetes and mental health?

I highly recommend exploring camps designed for kids and youth with the disease, as engaging with fellow T1Ds is second to none!

What advice would you give to other young people with Type 1 Diabetes who might be struggling with their mental health?

Type one diabetes is a conjoint battle of the mind, soul, and body. It is crucial to be kind to yourself as you face each mountain before you, as it is such a difficult mountain to climb. It is important to acknowledge that there are countless individuals admiring your resilience as you continue to persist. through each storm. I recommend exploring your interests and finding a way to celebrate your journey as you incorporate your diabetes in a positive light! For example, drawing a character with a Dexcom, writing a poem reflecting the beauty of the disease, etc. Reflect upon your journey and acknowledge that you have survived 100% of your high and low blood sugars. Journal each win as you encounter them and share your success with those you hold close. Type one diabetes is a unique and challenging battle, and someday, if not today, yours will inspire many. ■



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Opinion

How racism in early life can affect long-term health

By Jack P. Shonkoff, pediatrician, professor of child health and development, and director of the Center on the Developing Child at Harvard University.

OPINION: Excessive adversity activates biological reactions that can lead to lifelong problems in physical and mental wellbeing

Research shows that adversity early in life — including the effects of racism – activates stress responses that can lead to lifelong problems with health.

The scientific evidence is crystal clear: Early experiences literally shape the architecture of the developing brain. This widespread understanding is driving increased public support for universal pre-K to enhance school readiness for all children and level the playing field for kids who face adversity. But here's something that's less well-known by the public: Since the brain is connected to the rest of the body, early experiences affect all of our biological systems, for better or worse, beginning in

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utero and all the crucial years that follow.

This broader message is sending an important wake-up call: We all need to start paying closer attention to the science that explains how excessive adversity can undermine lifelong health as well as early learning. This knowledge can help us better understand why people of color in the United States are at greater risk of developing chronic medical conditions and aging prematurely than white people.

Given growing evidence of the early origins of disparities in both physical and mental health, focusing on brain development and learning alone confronts only one dimension of the pervasive inequalities linked to racism that loom over American society. Case in point: Although gaps in academic achievement between Black and white children have decreased by 30 percent to 40 percent since the 1970s, reducing racial disparities in health has been more challenging. For example, preterm birth and low birth weight, which are associated with greater risk for later cardiovascular disease and diabetes, occur at a rate that is approximately 1.5 to 1.6 times higher for non-Hispanic Blacks compared with non-Hispanic whites — and those gaps have persisted for decades.

Mounting scientific evidence is telling us that the foundations of lifelong health are built during the prenatal period and early infancy. Factors that promote positive outcomes include supportive relationships, safe physical environments and sufficient resources to meet basic needs such as food and shelter. Take away any of these protective factors or add the weight of excessive hardship or threat outside the family, and you tip the scale toward a greater risk of later problems.

Despite the critical influence of these early years, long-term outcomes are neither inevitable nor biologically predetermined. Certainly, physical and mental health is influenced by our genetics, but the chances of problems actually developing are strongly influenced by the environments in which we live. Policies, conditions and resources that address inequities and assure health-promoting conditions for young children, as early as possible, will help build a healthier society. Stated simply — it's racism, not race, that's at the root of persistent disparities in physical and mental well-being.

Race is a social invention. All humans, regardless of skin color, share 99.9 percent of the same genome. Residential segregation — one of many converging consequences of systemic racism, personal discrimination and poverty — results in significant inequities in exposure to air pollution, other environmental toxins and neighborhood violence, as well as unequal access to nutritious food, stable housing, and high-quality education and health care. Black-white differences in preterm birth have been well-documented and linked to stress associated with discrimination, independent of socioeconomic status. Black children are three times more likely than white children to lose their mother by age 10.

How can the impacts of adversity due to racism in early childhood affect a lifetime of health? One answer lies in the particular sensitivity of young, developing bodies to the physiological effects of a stressful environment. All of us know what stress feels like physically, and science explains the source of those sensations.

When confronted with an acute challenge or threat, stress response systems inside our body become activated. Blood pressure and heart rate increase. Stress hormones such as cortisol are elevated. The immune system triggers an inflammatory response to prepare for wound healing and fighting infection. Metabolic systems mobilize blood sugar to fuel the "fight or flight" response. Once the threat has been managed, the stress response (which can be lifesaving) returns to baseline. But if the level of adversity remains high for long periods of time (from chronic discrimination or poverty, for example), continuous activation of the stress response can have a wear-and-tear effect inside the body that leads to "toxic stress" and a host of health impairments.

For example, excessive inflammation can affect multiple organ systems and increase the probability of developing heart disease and autoimmune disorders. Prolonged elevations of blood sugar can lead to insulin resistance, obesity, metabolic syndrome and diabetes. Once we understand the biology of adversity and resilience, we can see how excessive stress activation early in life does not lead to inevitable disease but increases the risk of later problems, many of which include the pre-existing medical conditions associated with more severe disease from Covid-19. The high prevalence of these conditions among people of color may thus explain part of the

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marked racial/ethnic differences in the pandemic's rates of hospitalization and mortality.

Much of the public debate about disparities in health outcomes focuses on unequal access to medical care, unequal treatment in the health-care system, and the impacts of lifestyles and individual responsibility in adulthood. But science is telling us that preventing or mitigating the effects of adverse experiences and exposures in early childhood might be as important for long-term health as the conditions in which we live as adults and the medical care we receive.

Greater understanding of how the synergistic stresses of systemic racism, interpersonal discrimination and intergenerational poverty may be built into the body can be a powerful tool on the road toward a healthier and more just world. Science tells us that road must begin in the earliest years of life.■

Originally publlished in the *Knowable magazine*
Read the original article here.

> **Stated simply — it's racism, not race, that's at the root of persistent disparities in physical and mental well-being.**
> ~Jack P. Shonkoff

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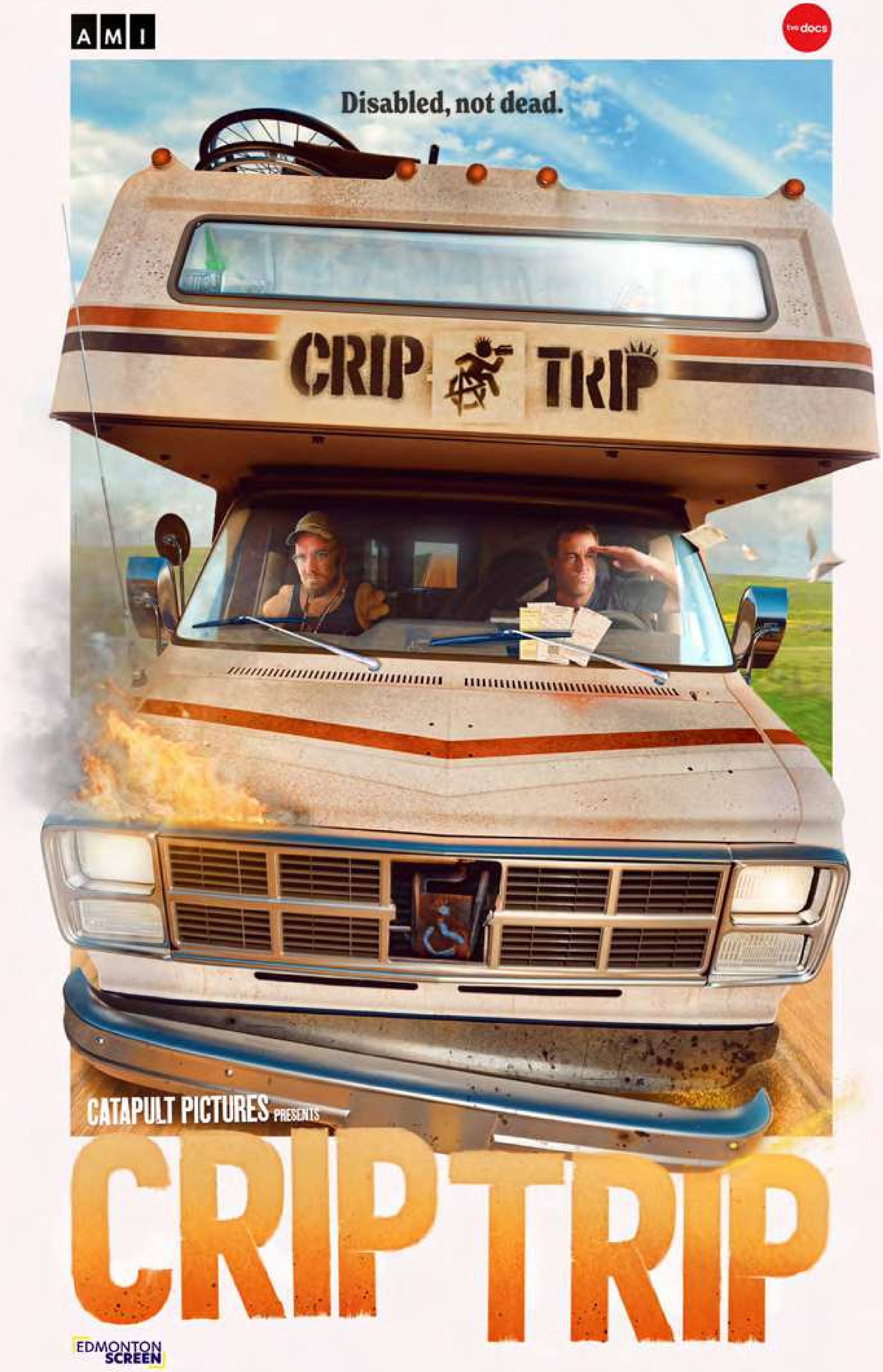

Crip Trip 2025 Highway Hero

CRIP TRIP

The weight of care and the power of friendship

If you thought a road trip was hard work, try doing it in an RV that had no business being on the road, with two best mates, one of them a quadruple amputee needing full-time care. Meet Daniel Ennett and Frederick Kroetsch, the buddies behind this brutally funny and wildly important docuseries, Crip Trip. It's six episodes of chaos, friendship, full-throttle caregiving, and raw honesty, barreling down roads across Canada and the US in an RV that probably should have been condemned around the same time cassette players went out of fashion.

Forget sad music and inspirational speeches. Daniel and Fred wanted none of the polished rhetoric. Instead, they chose the hard road. Literally. Six weeks documenting the real, gritty, ridiculous, beautiful business of living and caring for someone with a disability.

Crip Trip's first episode aired on 25 April 2025 and will continue on Fridays at 9 p.m. Eastern Time on AMI-tv. The series can be streamed on demand, for free, on AMI+. It will also be coming to TVO in late 2025.

At the heart of Crip Trip sits a job few people outside the disabled and senior community really understand: caregiving. Real caregiving. Not the occasional help with groceries, not the "push the wheelchair up a ramp" photo op. We're talking about the unrelenting, full-body, full-brain, soul-exhausting grind that keeps a disabled person alive and mobile. Fred thought he knew what he was signing up for, but he really didn't. Ten hours in, somewhere between the RV's engine failure and the first minor meltdown, he realised he had sprinted blindfolded into something that would tear chunks out of his spirit. He was neck-deep in a job he barely understood: full-time caregiver to his best friend! He quickly learnt that caregiving was an invisible marathon, stretching

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Accessible Graffiti

across every tiny, grinding daily need. It's messy, brutal, exhausting, and when it's done well, hardly anyone even notices. It is way more than just being there. It's about swallowing your own needs whole and putting the needs of the disabled person you're caring for first, at all times. All this, and still being able to have a laugh afterwards?

Fred cracked wide open. First came the resentment, a sour thing bubbling up during the seemingly endless care routines. Then came the guilt, hitting harder than any physical strain. After all, Daniel was his best buddy, and it wasn't his fault. Full-time care became brutal emotional labour piled onto physical exhaustion, day after day after day.

By some miracle, probably helped by humour, inappropriate jokes, and a lot of shouting, Fred and Daniel didn't fall apart. They were stitched together with friendship, banter, and stubbornness, and found a way to survive the mental storms that brewed inside that dilapidated RV.

And they caught it all on camera.

The series isn't polished. It's gloriously raw, stuffed with wrong turns, fried tempers, and too many moments where you think, "Oh no . . . they're not really going to do that, are they?" (Spoiler alert: they do.) Yet somewhere in the madness, you're hit with the real deal, the shocking, infuriating truth about living with a disability in a world built for everyone else but them.

Underneath the laughter, a bigger storm brews. Crip Trip lifts the lid on how care work—vital, life-saving, daily care work—is treated with scant regard by policymakers. In North America, the system locks disabled people into poverty, limits their care hours to absurd, laughable minimums, and then acts surprised when people burn out or disappear into institutions. And no, this isn't an exaggeration for dramatic flair. Daniel lived it. His mother cared for him for 30 years with no pay, sacrificing her own health while fighting a system that pretended Daniel's needs did not exist. When he fought for more hours, it was a heartless bureaucratic nightmare seemingly designed to keep people with disabilities living in poverty.

Danny in Campground

Fred, Danny and their broken down RV

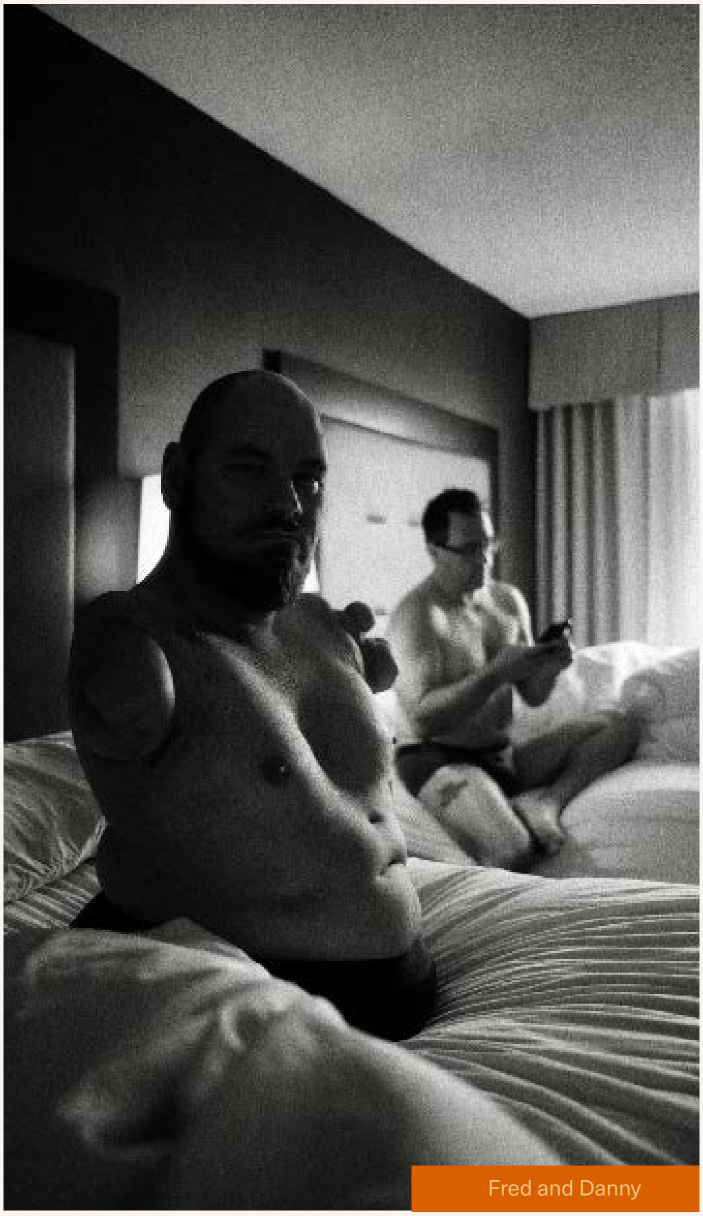
Danny Painting at Night

"Poverty is such an intrinsic part of this process in North America," Daniel said. "You simply can't escape it, and you can't get enough care hours. The system doesn't work—every disabled person we met said the same thing." He continued, "It simply is not a functional system."

Fred saw it up close for the first time, and through this series, you will too.

The pair didn't just stumble across these ugly truths. They went looking. Meeting other disabled artists and activists along the way, they found the same crushing barriers repeating themselves: no support, no autonomy, no real escape. Yet Crip Trip never sinks into misery. They knew that delivering an angry lecture would have audiences bolting faster than you can say "government cuts." So instead, they loaded up on sharp jokes, ridiculous stunts, and enough chaotic banter to stock an entire pub for a year. And it's genuinely hilarious. You can't possibly endure a nightmare RV shower scene with these two best friends without learning to laugh. At one point, Fred ditched his clothes entirely because trying to shower Daniel fully dressed in a bathroom roughly the size of a cereal box was about as effective as fighting a house fire with a water pistol. You don't survive constipation, broken toilets, and the relentless, soul-shaking mystery of "what the hell is that smell?" in a rolling tin can without weaponising humour as both shield and sword. Daniel, completely unfazed, treated the whole ordeal with the kind of deadpan sarcasm usually reserved for sitcom characters who've fully given up on life—and it's glorious.

Through the biting humour and jaw-clenching honesty, Crip Trip exposes a hidden truth: many people with disabilities are treated like



Fred and Danny

second-class citizens in their own country. Daniel doesn't sugarcoat it. He believes care work keeps disabled people alive, but bureaucratic policies and poverty kill them slowly.

One of the unexpected charms of Crip Trip is that Fred, despite occasionally behaving like a lovable jerk, learns to see disability differently. He started off thinking this was Daniel's adventure, but before the trip even started, he'd suffered a stroke and lost his father—two blows that knocked him sideways into a reality he'd never planned for. Their stories, once so different, started to bleed into one another. Fred's personal crash course into invisible disabilities and Daniel's lifelong battle against visible barriers collided in the dust and diesel fumes of that broken-down RV.

My doctor says I'm disabled now," Fred said, half-laughing. "But I don't really know how to feel about that. I don't feel disabled... but maybe that's part of it too."

Crip Trip isn't just Daniel's story. It's also Fred's chaotic, reluctant crash course in disability awareness and caregiving. Once you've seen what it really requires, you can't pretend that care work is easy or disposable. Daniel and Fred want a world where caregivers are paid what they're worth. Where disabled people aren't punished by the system for needing help. Where asking for dignity doesn't make you a burden. They didn't make Crip Trip to offer pity but to expose the truth as messy as it really is.

If you watch Crip Trip—and you should—be ready to laugh heartily, cry when you least expect it, and maybe leave motivated to help tear down the old broken systems. Because if two friends in a half-dead RV can use humour to make you care, you're definitely ready for the real trip ahead. Change is needed. ■

Follow Crip Trip on Instagram

Daniel Ennett

Daniel Ennett is a Canadian media creator, storyteller, and advocate. Based in Edmonton, Alberta, Daniel holds an Honours degree in Psychology, though he later pivoted into media to tell disability stories that challenge stereotypes and demand real change. Having spent over a decade creating content around disability, Daniel brings both sharp humour and uncompromising honesty to every project. He spent 30 years being cared for by his mother, giving him a firsthand understanding of the cracks in the care system that many never see. When he's not dismantling ableism one brutal truth at a time, he's likely plotting another chaotic adventure.

Frederick Kroetsch

Frederick Kroetsch is an Edmonton-based filmmaker and co-founder of Catapult Pictures. With over 12 years of experience in both community television and independent documentary production, Fred specialises in creating bold, often hilarious, disability-centred media. Though he entered Crip Trip thinking it would be a laugh, the project challenged him personally and professionally, especially after surviving a stroke just before filming began. Never shy in front of a camera, Fred uses his mischievous energy and shameless sense of humour to bring important, overlooked stories to life. His mission? To make content that's not only vital but wildly entertaining.

In RV with cameras

The crew in New York City

My Life in Three Parts

Photo taken shortly before her first brain operation

My life, so far, has unfolded in three distinct chapters: the day I was born, the day I had my first brain operation, and the day I had my second. ~ **Lucky Mae Fornoles Quilao**

Mae and her extended family

Photo taken shortly before her second brain operation

Here's my AVM Story

In my younger years, life was kind. I had my mother, my aunties and uncles, my grandparents, neighbors, teachers, classmates, and friends. You could hear my voice in the church choir or see me in the streets during a Santacruzan or Flores de Mayo. I was among the top students in my class and known to be a dutiful, disciplined girl.

But everything changed thirteen days before my grade school graduation.

I was taking a bath when I suddenly felt an intense pain in my right ear. It was so unbearable that, to this day, I believe only divine intervention helped me make it out of the bathroom and call for my aunt. When she saw me, she held out a cotton ball soaked in ammonia. The moment I smelled it, I lost consciousness.

When I woke up, a month had passed. I was in a hospital room with five other patients. Slowly, I learned what had happened. My aunt had rushed me to Manila Central University (MCU) Hospital, where she worked as an assistant nurse. My other aunt called my mother, who was working in Saudi Arabia as an administrative assistant at King Fahad National Guard Hospital (KFNGH). Thanks to the kindness of her Canadian coordinator, my mother was able to come home right away.

The doctors diagnosed me with arteriovenous malformation, or AVM—an abnormal tangle of blood vessels that disrupts the

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connection between arteries and veins. But to a twelve-year-old girl, that medical term translated into an asymmetrical face, a shaved head, poor eyesight, hearing loss, and the inability to walk. It also meant losing a year of school and returning to a class full of students younger than me.

With therapy, I eventually regained my balance and coordination. My right ear's hearing was permanently gone, but my facial asymmetry became barely noticeable to most people. My hair began to grow again—enough that a neighborhood hairdresser once thought I was copying the look of a popular local singer.

Six months later, I faced another operation: a non-invasive procedure called gamma knife surgery. My neurologist had discovered another lesion in my brain that could rupture at any moment. My mother did everything she could to save up the $10,000 it required. She also arranged for me to undergo an embolization procedure at Riyadh Military Hospital, a facility typically reserved for the Saudi royal family. Through the help of her colleagues at the Post Graduate Training Center, I was admitted.

Despite it all, I graduated from high school. I graduated from college. Then I joined my mother in the United Arab Emirates, where she had moved to work as a medical secretary at Tawam Hospital. Hoping to pursue something in journalism, I was fortunate to find work as a reporter for a city newspaper and as a writer for a real estate periodical and an interior design magazine. I threw myself into these roles, grateful and motivated.

One day, while preparing for an art exhibit at Emirates Palace, I felt a sharp, familiar pain. This time, it struck the right side of my forehead—eerily reminiscent of the headaches Harry Potter often complained about in his stories.

My mother immediately called a friend of mine, a physiotherapist, who advised us to head to the hospital right away. I got dressed, dragged myself to the elevator, and climbed into a taxi. I remember looking at those around me and asking them to take care of my mother—just in case—before I lost consciousness again.

It happened once more.

And this time, the aftermath was even worse: permanent facial asymmetry, complete loss of vision in my right eye, and permanently weakened balance and coordination. The only thing that remained unchanged was the hearing loss in my right ear—something that had never truly bothered me until recently. Two Decembers ago, I began struggling to hear my mother clearly. I asked her to repeat herself, panic rising in my chest. I prayed to God, once again, that I wouldn't lose the ability to hear from my remaining ear. That very month, an otolaryngologist reassured me that my hearing could still be preserved.

Mae and her mom in 2024

I continue to pray that it stays that way.

And I keep praying that my arteries and veins never tangle again. AVMs are extremely rare—occurring in less than one percent of the population—and my life has shown just how rare and relentless they can be.

But something even rarer? A mother who never gave up. A woman who sacrificed everything to make sure her daughter could live again—and again. A family who never wavered. Friends who stayed, who showed up, who extended time, effort, and love despite the difficulties.

My life, indeed, has three beginnings: when I was blessed to live, when I was blessed to live again, and when I was blessed to live again—and again.

My reflections on identity and acceptance

It took me days to realize how much I had changed after my first brain operation. At the rehab center, I turned to face the mirror and saw a girl with a shaved head, missing right eye, and an uneven face—someone who couldn't even hold the bars. That girl was me. I cried when I returned to my room, despite the therapist saying I had a good chance of recovery because I was young.

I don't remember exactly when I stood or walked again, but within five months, I was doing both. I no longer looked sick—wearing glasses and a black crocheted fedora when I went out. My right ear remained deaf, and I couldn't write with my right hand, so I taught myself to use my left.

People often only saw my impairments, but I stayed focused on my studies, books, magazines, music and plays. When I had another brain operation ten years later abroad, I was prepared. I attended therapy, practiced walking with family at the park, and used an FES machine on my face.

What I hadn't expected was the permanence of my side effects. I still can't walk alone and my face remains asymmetrical. But with my mother's encouragement and a supportive therapist, I kept going—exercising and typing my thoughts to this day.

What I hadn't expected was the permanence of my side effects . . . people often only saw my impairments.

Stigma and Social Perceptions

I remember the first time I went to a mall in my home country after my second brain operation. A man stared at me the entire time my mother and I approached him. He didn't even try to look away. My mother just smiled and said he was awestruck by my beauty.

I've had other unpleasant experiences—like being denied PWD discounts or judged immediately because of how I look. But there have been good moments, too. During Pope Francis' visit to UST in 2015, strangers helped me through the crowd, off the sidewalk, and into a better spot. More recently, a woman helped my mother carry our bags at a bus terminal—such a relief since my mother was assisting me at the same time.

But my favorite memory is meeting Karl Kaufman, my former editor at GMA News Online. It was brief, but in that moment, I was seen not as someone disabled—but as a writer, spoken to with respect and sincerity.

[the meeting] was brief, but in that moment, I was seen not as someone disabled—but as a writer, spoken to with respect and sincerity.

Advocacy and Empowerment

After my second brain operation, I came up with many plans to help persons with disabilities like me. The ones I remember most are Plans A, B, and C.

Plan C was to study further. I already had a journalism degree, and I believed a master's would let me teach students with disabilities. I applied to De La Salle University in the Philippines, but my mother reminded me that no one could accompany or care for me if I returned home. She couldn't leave her job—we needed the income.

Plan B was to go to Chiang Mai, Thailand, to study Thai massage for children with disabilities. But at the time, I still couldn't walk on my own.

Plan A was to write. I launched a blog, The PWD Forum, to push for inclusive education in the Philippines. I stopped in 2018 after the government began implementing similar policies. I don't claim credit, but I'm glad the message got through.

I also worked as a stringer for GMA News Online, mostly for their "Pinoy Abroad" section. Though not focused on disability issues, it helped me grow as a writer.

My biggest dream is still to write a book—one that could fund an education scholarship for Filipinos with disabilities.

And so, with every word I write and every step I take—no matter how slow—I continue to move forward, hoping my journey lights the way for others to rise, to heal, and to believe that they, too, can begin again. ■

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People with disabilities and their families often have an even greater need for support over time, especially if a disability is progressive or family members experience their own health challenges.

Governments must ensure caregivers have support to keep doing their vital work

By Heather Aldersey, Professor and Canada Research Chair (Disability Inclusive Development), Queen's University, Ontario
This article was co-authored By Donna Thomson, a caregiver, author and educator.

April 1 marks National Caregivers Day in Canada. The day is meant to recognize the carers who provide vital care and support to those in need.

We all need care and support to navigate challenges in life. Help can come from formal support (paid professionals and government programs), and from natural support networks (family, friends and neighbours).

People with disabilities and their families often have an even greater need for support over time, especially if a disability is progressive or family members experience their own health challenges due to aging.

The Canadian Centre for Caregiving Excellence (CCCE), a program of the Azrieli Foundation, released its National Caregiving Strategy on Feb. 18, stating that caregiving is the next frontier in Canadian public policy. As the CCCE's executive director, Liv Mendelsohn, said: “Millions of Canadians are navigating

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caregiving with minimal support, and it's simply unacceptable."

This article's co-author, Donna Thomson, is a caregiver, author and educator. She is the mother of two grown children, one who has severe cerebral palsy and medical complexity. Thomson also helped care for her mother who lived with dementia until she passed away in the summer of 2018 at the age of 96.

Family caregivers often need support themselves in order to keep working both inside and outside of the home. Parents of adult children with developmental disabilities in Canada are hardly ever asked: "What do you do for your son or daughter that paid helpers cannot?" Even less often, that question might be followed by: "Wow, that's a lot. Would you like some support to continue doing those things?"

Importance of natural caregivers

Our research recognizes that both formal and informal supports are essential in enabling people with disabilities and their families to live their best lives. We want to understand how individuals, families, organizations and communities can best come together to get people with disabilities and their families the types of supports they need and want, when they need and want them.

Over the course of our research, we conducted a document and literature review, alongside interviews and focus groups with people with disabilities, family members and formal disability support providers. We identified that family or friend caregivers often support a person they care for with a sense of love and commitment to a depth that is rare in formal support relationships.

Unbound by professional obligations, safety standards or employer/funder priorities, these natural supporters can often be vocal advocates for the best interests of those they are supporting.

However, sometimes finding and sustaining natural support in the community doesn't come easily for people with disabilities and their families. In those instances, organizations and facilitators (formal supports), can help broker the creation and maintenance of natural support networks.

Community organizations offering formal supports and supporting the creation and maintenance of natural supports can sometimes be beholden to funder obligations. This can limit the flexibility and adaptability required to best meet the needs of those they support.

Additionally, organizations are often constrained by safety considerations, aversion to risk or the challenges posed by overly bureaucratic systems. Sometimes, this can mean the support provided to a person or family does not directly respond to what the individual or family needs. Even more frustrating is that waiting times can be so long to access formal supports that identified needs or priorities change in the meantime.


Sometimes, finding and sustaining natural support in the community doesn't come easily for people with disabilities and their families.

CCCE's caregiving strategy

The CCCE strategy is a recognition that care work makes all other work possible. It echoes our research findings that both paid and unpaid caregivers need financial support as well as targeted programs and services.

The strategy calls upon the Canadian government to make caregiving a priority while ensuring a sustainable care provider workforce.

Supports are also a provincial issue. For example, in Ontario, the Ministry for Children, Community and Social Services has published a framework that offers a long-term vision for transforming developmental services so people with developmental disabilities fully participate in their communities and are supported to live their lives.

Care and support can also be a gender issue, given that in Canada and around the world the majority of both formal and informal support is being provided by women and girls.

Missing perspectives

Our research also highlighted a notable gap in the research landscape. Research on natural support in Canada is often not explicit about or does not incorporate understandings of natural support from the perspectives of Indigenous, Black, rural, LGBTQ+ and other marginalized groups.

People belonging to these groups may have their own needs and experiences that relate to navigating natural and formal support systems in Canada. Future-focused research agendas into natural supports, such as those proposed in the CCCE strategy's recommendations, must intentionally seek to understand support and care experiences from these perspectives.

At the Global Disability Summit taking place this week in Berlin from April 2-3, we will join voices from around the world to call on national leaders and decision-makers to ensure disability policies translate into tangible actions and inclusive practices.

Our research shows the deep, important impact of federal and provincial policy and funding both for formal and natural supports to flourish. With a federal election on the horizon, Canadians can call on their governments to improve support for caregivers, ensure support systems are in place and flexible enough to respond to individual and family needs, and enable natural support networks to flourish. ■

Originally published in Conversation.
Read the original article here.

> This is important, because the care we give to each other, regardless of age or ability, is what will sustain us as families.

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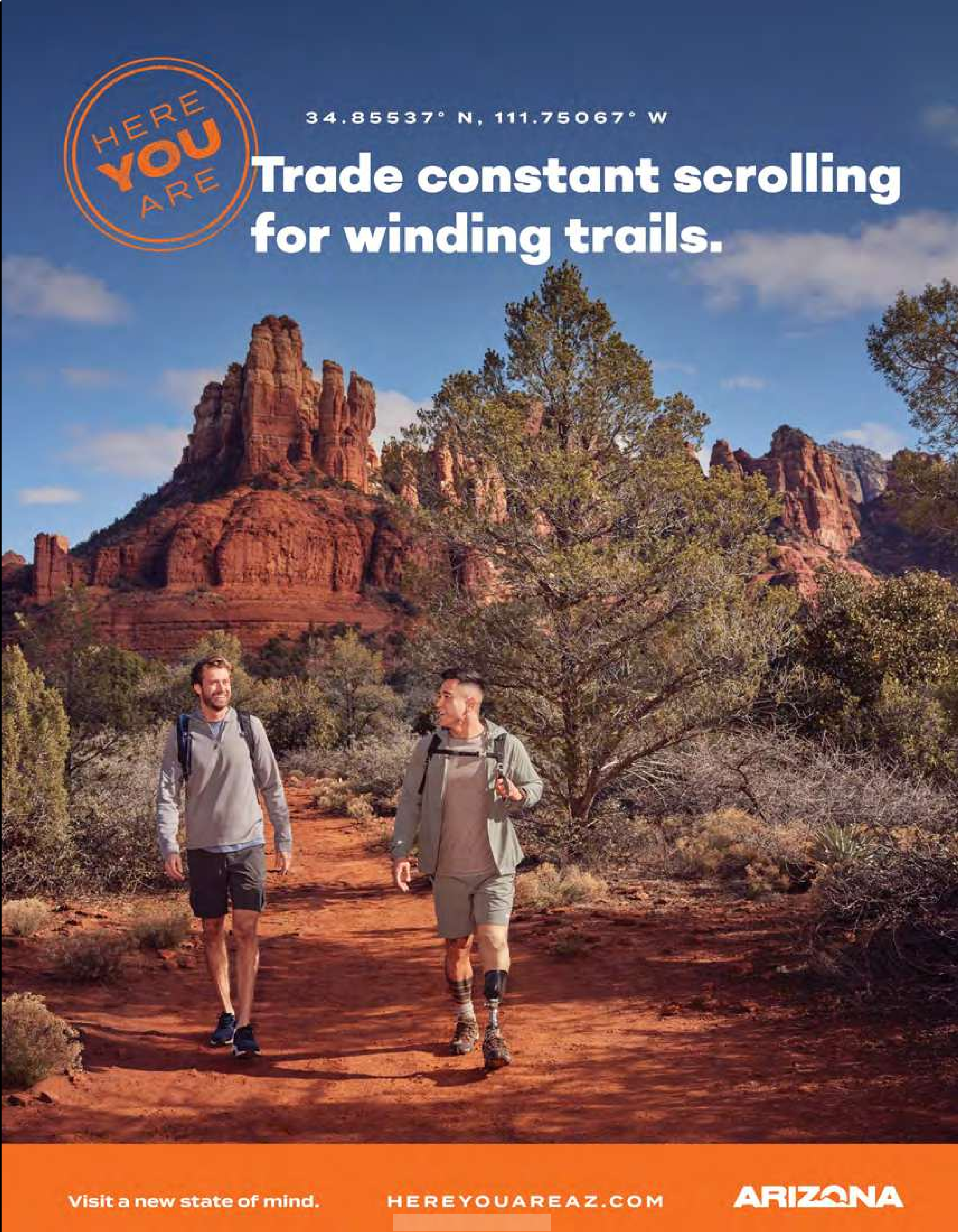
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High Fives Foundation

High Fives Foundation is known for its incredible work supporting athletes with life-altering injuries. Can you tell us about the inspiration behind starting the foundation and how it has evolved over the years?

The High Fives Foundation was founded in 2009 by Roy Tuscany after he sustained a life-altering spinal cord injury while training for professional skiing. During his recovery, Roy received overwhelming support from his community, inspiring him to create an organization that would provide similar resources to others facing similar challenges. What started as a way to help a few individuals has grown into a nationwide nonprofit that has supported over 800 athletes across multiple adaptive sports disciplines.

The foundation focuses heavily on adaptive sports. What do you think is the most transformative impact that adaptive sports can have on someone's physical and mental health after a life-changing injury?

Adaptive sports empower individuals to regain independence, confidence, and a sense of purpose. Physically, they help with strength, mobility, and overall health. Mentally, they provide an outlet for overcoming adversity, fostering resilience, and reconnecting with the joy of movement and competition.

What are some of the biggest challenges individuals with disabilities face when trying to get involved in adaptive sports, and how does High Fives help overcome those barriers?

Cost, access to specialized equipment, and finding knowledgeable instructors are among the biggest challenges. High Fives helps by providing grant funding for equipment and training, organizing adaptive camps, and fostering a supportive community where individuals can learn and grow in their sports.

The High Fives Foundation provides grant funding to adaptive athletes. Can you share a memorable success story of an athlete who received a grant and went on to achieve remarkable things?

One example is Trevor Kennison, who received High Fives support after his spinal cord injury. With his adaptive equipment and training, he became a pioneer in adaptive freeride skiing, even sending it massive off the famed Corbet's Couloir in Jackson Hole. His story is a testament to the

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power of determination and community support.

Another incredible success story is Tim Burr, High Fives Athlete #78. After sustaining a spinal cord injury in a snowboarding accident, Tim was determined to get back to doing what he loved—adventuring in the outdoors. With support from High Fives, he received grant funding for adaptive equipment and training, which helped him regain independence and confidence. Tim's passion for motorsports and the outdoors led him to launch Return to Dirt, a groundbreaking program under the High Fives umbrella that gives individuals with mobility challenges the opportunity to explore rugged terrain in adaptive off-road vehicles. What started as a personal goal to get back behind the wheel has grown into a program that provides life-changing experiences for others facing similar challenges.

For individuals new to adaptive sports, what are some accessible lifestyle tips you would recommend, especially for those looking to transition into a more active, sports-focused routine post-injury?

Start slow and find activities that bring you joy. Connecting with adaptive sports organizations, setting realistic goals, and building a strong support system can make the transition smoother. All are welcome to check out one of our High Fives Hangouts in Denver,

San Diego and Reno! More info available on our online events calendar.

What advice would you give to people with disabilities who are interested in outdoor adventures but are unsure where to start?

Look for local adaptive programs that offer introductory experiences in activities like skiing, mountain biking, or surfing.

High Fives Foundation also emphasizes community support. How important is peer mentorship and community for athletes recovering from severe injuries, and how do you foster those connections?

Community is at the heart of recovery. Connecting with others who have been through similar experiences provides motivation and emotional support. High Fives fosters this by hosting camps, athlete gatherings, and mentorship programs that create lifelong friendships and support networks.

In terms of accessibility, how does High Fives advocate for more inclusive spaces in outdoor and sports environments, particularly in terms of infrastructure and policy?

High Fives collaborates with resorts, parks, and organizations to improve adaptive accessibility in outdoor spaces. We recently partnered with Sky Tavern to create fully adaptive mountain bike trails.

What future initiatives or programs does High Fives have in the works to continue empowering athletes with disabilities, and how can the broader community get involved in supporting your mission?

We are expanding our adaptive camps, increasing grant funding, and working to make more outdoor destinations accessible. The community can support us by donating, volunteering, and spreading awareness about the importance of adaptive sports. Come join us at an upcoming event in your area like one of our Shred-A-Thons in Tahoe, Colorado or Vermont!

At High Fives, we believe in the power of positivity and perseverance. Every athlete we support is a testament to what's possible with the right resources and community. We're grateful for everyone who helps make our mission a reality! ■

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Community Spotlight

No one should navigate the pain of EB alone: Debra Ireland is here

When skin is as delicate as a butterfly's wing, life's simplest acts—a handshake, a hug, or a stroll down the street—can feel like climbing Everest barefoot. This is the raw reality of living with epidermolysis bullosa (EB), a rare genetic condition where the skin's layers refuse to stick together, making them prone to blistering and tearing at the gentlest touch. And at the heart of the fight for dignity, care and awareness for people with EB is Debra Ireland—a lifeline for those who face this unthinkable challenge every day.

Founded in 1988 by a group of parents who refused to let their children's pain be their only legacy, Debra Ireland (Dystrophic Epidermolysis Bullosa Research Association) started as an act of defiance against silence and ignorance. These parents did not wait for someone else to fix things; they rolled up their sleeves and created a network of support that has grown to become a national charity, encompassing care, advocacy and hope. Today, Debra Ireland is a community that refuses to let fragility define lives.

What exactly is EB?

Imagine if your skin didn't heal. A minor scrape becomes a wound, a wound becomes a scar and scars stack upon scars. In its most severe forms, EB affects the outside and can extend to the throat, the

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esophagus and other internal linings, turning meals into obstacles and mobility into a marathon. For some, it's a lifelong struggle; for others, it's a fight tragically cut short.

This condition is as rare as it is misunderstood, affecting approximately 300 people in Ireland—a number that might seem small until you've met someone living with EB. Then, it feels monumental. Globally, about 500,000 people live with some form of this condition.

Debra Ireland's fierce dedication

Debra Ireland provides essential services and in so doing creates a world where people with EB can breathe a little easier. Emotional and psychological support, financial assistance and a family support team are just the starting points. They also advocate for the rights of people with EB, ensuring the government and healthcare systems take notice. When rare diseases get ignored, Debra Ireland speaks loudly.

The organization's services cover the full arc of life with EB: from diagnosis to bereavement. "We're here for anyone living with EB, caring for someone with EB, or mourning someone lost to EB," head of communications, Alejandra Livschitz, explains. They offer everything from educational materials for schools to ensure children with EB are supported, to grants for siblings—acknowledging the ripple effect this condition has on entire families.

One particularly moving effort is their bereavement support. Families who've lost a loved one to EB aren't left to navigate their grief alone. The scars of this condition, both physical and emotional, run deep. Debra Ireland ensures no one is left to heal in isolation.

Fragility meets fierceness

Despite the harrowing nature of EB, the stories coming out of Debra Ireland radiate with courage and love. Like Bonnie, a four-year-old with a grin so infectious it lights up every room she enters. From the moment her parents saw their newborn's

Maria Maciukas and Casey Connors barretstown 2023

Bobby Clifford

Seamus Graham holding his EB medical card

delicate skin, life took on a new meaning. Her parents, with the support of Debra Ireland, have mastered the art of dressing her wounds, easing her pain and making space for joy amid the challenges. Bonnie's story, like so many others, is both heartbreaking and inspiring. Another unforgettable chapter in Debra Ireland's storybook involves Irish rugby legend Johnny Sexton and Hollywood's own Colin Farrell. These household names have used their platforms to amplify the voices of those living with EB, proving that awareness can come from the most unexpected allies. Sexton's ongoing advocacy and Farrell's high-profile involvement in a marathon fundraiser have brought much-needed attention to the cause.

Advocacy that changes lives

Debra Ireland has always punched above its weight, challenging systems to adapt and forcing conversations about rare diseases into the mainstream. One of their proudest moments came recently when the Irish Minister for Health announced funding for comprehensive care pathways for EB. After years of tireless campaigning, this victory means people with EB will now have

access to specialized consultants, smoother transitions from pediatric to adult care and better overall treatment options.

But Debra Ireland isn't resting on its laurels. "Our work is never done," Livschitz emphasize. There's always a new barrier to dismantle, a new story to tell, or a new family to help.

How you can be part of the story

Debra Ireland thrives on community support. Fundraising remains a cornerstone of their work and every contribution strengthens the safety net for people with EB. The organization also marks significant dates, like Rare Disease Day on February 28th, to rally public attention.

If you're wondering how to help, think creatively. Host a bake sale, run a marathon, or organize a quiz night. Your efforts raise awareness, turning rare into recognized. And if fundraising isn't your forte, simply sharing the stories of people like Bonnie or attending an event can make a world of difference.

The Butterfly Effect

EB is often described as making skin as fragile as butterfly wings. But if there's one thing Debra Ireland proves, it's that even the most delicate creatures can spark powerful ripples. With its blend of compassion, advocacy and relentless determination, this organization is reshaping what's possible for those living with EB—one blister, one bandage and one breakthrough at a time.

So, the next time you see a butterfly, don't just admire its beauty. Think of the extraordinary strength it takes to soar despite the fragility. That's what Debra Ireland stands for: not just surviving but soaring.■

**There are now over 50 Debra organizations worldwide.
Search here for a Debra in your region.**

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AI-Learners Flyer

AI-Learners: A new kind of classroom magic

Adele Smolansky is the founder and CEO of AI-Learners, an EdTech company dedicated to making education more accessible and engaging for students with all abilities. Inspired by her sister, who has a disabilities, Adele is passionate about using AI to personalize learning and empower all students. She holds a Computer Science degree from Cornell University and a Masters from Stanford in Learning Sciences. Adele is committed to transforming special education through innovative, inclusive technology.

When the world slammed shut during the COVID years, most people baked bread, binge-watched TV series or finally cleaned out that spare room. Adele Smolansky did something else entirely. When she saw her younger sister struggling to learn during lockdown, she didn't wait for someone else to help her sister through this period. She built AI-Learners, a platform designed to listen, adapt and celebrate the way every student learns. No more forcing square pegs into round holes. No more 'one size fits all.'

Adele built a breathing technology that shifts itself around the child instead of demanding children twist themselves into impossible shapes to fit the tech. It's smart, it's playful and it's got heart stitched into every line of code. So, what's the secret sauce? Simple. AI-Learners is a digital platform that helps students with disabilities sharpen their math, literacy, and social skills, but it doesn't slap the same content at every child. It listens. It learns. It morphs. A bit like a favourite teacher who just gets you.

Each student has their own account. The platform watches how they play. It clocks how fast or slow they work, how many tries they need, whether they prefer

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things bright and bubbly or muted and calm. Then it adjusts itself to their speed, their quirks and their rhythm. No two learning paths look alike and with AI-Learners, no kid gets lost in the shuffle.

And the teachers? They finally get to breathe. Instead of drowning in piles of worksheets and endless grading marathons, they get sharp, clean data served up on a silver platter. Real insights, real fast. They can tell in seconds whether little Sam needs a nudge in numeracy or if Mia's smashing her literacy goals like a champ.

It's life-changing technology. Take Ann Arbor Public Schools in Michigan, USA. They ran a pilot with AI-Learners: 60 students and 10 teachers. Within a month, students were begging to log in. "Can we use the AI game today?" they'd shout across classrooms. Today, almost 200 students there tap into the magic and the numbers are still climbing.

But the road was not paved in gold. Adele has been the sales team, the marketer, the boss, the brainstormer, and the coffee-fetcher. Selling to schools isn't exactly a stroll in the park either. Budgets are tight, staff are stretched, sceptics are everywhere. Yet somehow, she's making it happen, one conference, one meeting, one connection at a time.

AI-Learners is a standalone powerhouse. Export the reports, shuffle them wherever they're needed, done. No messy integrations. No hair-pulling IT drama. And because Adele cares about kids' privacy, AI-Learners is built with serious security muscle. No data hoarding. Everything's squeaky clean and legally watertight.

The bigger picture? Adele reckons the future of education isn't robots replacing teachers with soulless screens. It's teachers having more time to do what they do best: connecting, inspiring, laughing, listening, building kids up. The machines take the grunt work. Humans keep the magic alive.

Special education needs that personal touch even more fiercely. Every student is a puzzle with a different pattern. AI-Learners give teachers the tools without swallowing the heart of teaching.

And the mission? It's growing. New features keep rolling out like a never-ending stream of good ideas: social story generators, self-management exercises, ways for kids to build emotional muscles, not just academic ones. After all, what good is math if you can't handle a playground fall-out?

For schools watching their budgets, AI-Learners hit a sweet spot too. Pricing starts at about $100 per student per year, which is pocket change compared to the future it builds. And because it's pure software, there are no shipping disasters and customs headaches. Adele is even eyeing expansion beyond the US, tapping into countries ready to level up their approach to special education.

The goal? Give every student, no matter how tangled their needs, a platform that flexes and grows with them. Put power back into the hands of teachers and parents and make learning a joyful experience.

We live in a world that's obsessed with racing ahead, but Adele Smolansky slowed down just enough to ask: How can we do better? She did not set out to change the world but to help her sister, and along the way, she built something that's helping hundreds of students find their own way forward. AI-Learners proves that when technology is shaped by empathy, it becomes something powerful. ■

Adele Smolansky

AI÷Learners

MouthPad^ by Augmental:

Rethinking Digital Access, One Tongue Tap at a Time

Virgie Hoban,
Communications & Operations, Augmental

When it comes to designing assistive technology, listening matters just as much as engineering That’s something the team at Augmental understands well. Speaking about the company’s groundbreaking device, the MouthPad^, Virgie Hoban offers an inside look at how this small, tongue-operated interface is redefining digital access for users with limited mobility, and potentially for all of us.

From its beginnings in user-led design to the ongoing development of new features, Virgie shares how the MouthPad^ came to be, and where it's headed next.

The humble computer mouse has served us for decades, but its design has barely evolved. For many, it’s a tool taken for granted. For others, particularly those without hand mobility, it’s a daily challenge, a point of friction between intention and action. Augmental, a forward-thinking assistive technology company based in San Francisco, decided to challenge that status quo, not with minor tweaks, but with a radical reimagining of the

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human-computer interface.

Their solution? The MouthPad^, a Bluetooth-enabled touchpad that fits discreetly inside the mouth and allows users to control digital devices using their tongue and head movements.

It may sound like science fiction, but for those who've used it, it's a deeply practical reality. Client, Esther Klang said in her blog [The MouthPad^] has not only restored my independence but also empowered me to perform tasks that were once out of reach . . . The happiness, joy, and satisfaction I experienced when I took a picture and recorded a video for the first time cannot be described. This simple act may seem insignificant to most people, but it meant the world to me."

The inspiration behind the MouthPad^ came, in part, from an unlikely source: a diagram that co-founder Tomás Vega had seen in a neuroscience class called the homunculus, which maps how much brainpower is devoted to different parts of the body. The hands dominate, but interestingly, the tongue comes a close second.

That insight sparked a question for Tomás and his co-founder, Corten Singer: if the tongue is so neurologically gifted, why aren't we using it more creatively in digital contexts?

With backgrounds in cognitive science and computer science, they had long been building assistive devices—wheelchairs with obstacle sensors, head-tracking software, eye-tracking tools. But they kept running into the same limitations: many existing tools were awkward, highly dependent on external equipment and often performed poorly in less-than-ideal environments. Eye-tracking in bright sunlight, for example, can be unreliable. Head-mounted devices draw unwanted attention. Voice dictation lacks privacy. The solution needed to be intuitive, discreet and flexible. So, they looked inward, quite literally, and created the MouthPad^.

How it works

Each MouthPad^ is custom-made using a 3D dental scan. The device fits comfortably against the roof of the mouth, similar to a retainer. Within that small footprint lies a capacitive touchpad that responds to tongue movements with remarkable precision. A light tap can act as a click. A directional sweep becomes a drag. It even supports "sip" gestures for right-clicking and includes a built-in motion sensor to allow for head-tracking. This allows users to choose their preferred cursor mode. The point is choice, the freedom to engage with technology on one's own terms.

The device connects wirelessly to any Bluetooth-compatible hardware—computers, phones, tablets, even smart TVs—and functions like a standard mouse, translating user input into familiar commands.

It also charges in a compact case, designed for ease of use. Some users are able to pick up the device from the case independently with their mouth, while others require assistance.

Built with people, not just for people

When Augmental began developing the MouthPad^, they prioritised user input. They

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conducted extensive interviews to understand how people interacted with technology, what their pain points were and where current assistive tools were falling short.

One of the clearest insights? Many tools are not only physically demanding but socially intrusive. Devices that sit on or around the face or require exaggerated movements, can make people feel exposed. Another common frustration was the lack of privacy, particularly with voice dictation. One interviewee noted how having to speak their thoughts aloud, especially in public or shared spaces, created emotional fatigue.

Privacy became a core design principle, along with comfort and precision. And the feedback didn't stop at the early stages. In fact, many of the MouthPad^'s most popular features were inspired directly by users:

- A directional pad system for tongue-tracking was developed during a week-long hackathon with a gamer who recommended the system and understood the value of smooth, responsive input.
- A ratcheting mechanism that allows users to re-centre the cursor without having to look away or reposition their head, particularly useful for navigating large or multiple screens.
- Upcoming tongue gesture shortcuts and user setting profiles, which will allow for customised configurations across devices, are also being added based on user suggestions.

"I love the MouthPad^ because it finally feels like an interface that moves at the speed of thought. You can read freely without worrying about accidental clicks, and when you're ready to act — it's just a tongue tap. It gives back that sense of control." — Virgie Hoban, Communications & Operations, Augmental

Expanding possibility

The MouthPad^ was designed with individuals who have limited or no hand mobility in mind including users with quadriplegia as a result of spinal cord injuries, ALS, or other conditions. But its appeal is beginning to stretch beyond the disability community.

Musicians, surgeons, lab technicians, even astronauts have expressed interest in the device for hands-free control during complex tasks. Anywhere precision is needed, and hands are occupied or unavailable, the MouthPad^ presents a compelling alternative.

There's also a future-facing dimension to this. Augmental is currently developing MouthPad^ Whisper, a new version of the device that integrates a microphone and additional sensors to capture speech with barely any sound. The goal is to enable people to "speak" inaudibly, through breath, tongue movement or a whisper, and still issue commands or type text. Ideal for quiet environments like libraries, classrooms or public transport, it also caters to those who rely on voice assistants but lack a private setting to use them comfortably.

At its heart, Augmental's mission is simple: build technology that adapts to people, not the other way around. Every mouth is different. Every user is different. And the design reflects that. Whether it's improving comfort for individuals with few teeth, refining gesture recognition or building devices in small batches to ensure quality, the MouthPad^ is as much about craftsmanship as it is about innovation.

The future of computing for Augmental is focused on removing barriers, quietly, thoughtfully and, in this case, one tap of the tongue at a time. ■

Quick demo of the MouthPad^

Visit Augmental Tech to learn more.

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BLINDE

What GAAD reveals about the internet’s accessibility crisis

Joe Devon Headshot

Joe Devon doesn’t treat digital accessibility as a footnote in tech development. He presents it as a foundational flaw in the internet’s architecture, one that has been quietly ignored by the mainstream for far too long. And he should know. Fourteen years ago, he wrote a blog post that would become the spark behind Global Accessibility Awareness Day (GAAD), now observed on May 15th in over 20 countries and counting. Just one post, one idea, then a global ripple effect.

But Joe is not satisfied, because the gaps are still enormous. Accessibility, to him, is a matter of professional pride. If you design a red and green toggle without a label, someone with colour blindness sees two identical blobs. That’s not a minor oversight, it’s failure of design. “You should be embarrassed,” he says plainly. “You didn’t do your job well.”

GAAD has always been about raising awareness, but Joe wants the conversation to move beyond

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surface-level empathy. He wants culture change. He wants web developers, designers, product leads, all of them, to see accessibility not as a costly add-on, but as a mark of quality and future relevance. The internet is ageing, after all. And so are its users.

For businesses just starting to think about accessibility, his advice is deceptively simple: try using your own website with nothing but a keyboard. No mouse. No shortcuts. Can you complete a form? Buy a product? Navigate clearly? If not, you've already excluded someone. Maybe many someones.

While GAAD began as a blog post, today, it's a global movement. And while Joe isn't interested in taking centre stage, the work he's doing, quietly, relentlessly, is shaping the web's future. One line of code, one question, one collaboration, one refusal to accept "good enough."

Devon, who has been at the forefront of digital accessibility advocacy for more than a decade, is also the originator of a foundational body of research, the State of Accessibility Reports (SOAR). These studies, which began with a focus on the web, eventually pointed to a glaring blind spot: mobile apps. "We realized mobile apps were a missing piece of the puzzle," Devon noted. As a spin off from that report and with Devon in a consultant role, ArcTouch, in collaboration with real assistive technology users with disabilities and lived experiences who tested the apps from Fable, prepared The 2025 State of Mobile App Accessibility Report (SOMAA) which offers a comprehensive snapshot of how well native mobile applications across five key industries are meeting the needs of users with disabilities. The report evaluated 50 widely-used apps against 14 accessibility criteria using four assistive technologies, revealing widespread gaps and opportunities for inclusive design.

"I thought things would've improved more," Devon admits. Out of the 50 top apps, only two achieved strong accessibility scores. And the worst offenders? Shopping platforms, the very apps designed to take people's money. "It's not even about innovation, he says. It's oversight. Or worse, indifference."

The SOMAA report paints a sobering picture. Nearly three-quarters (72%) of app user journeys tested across five essential industries: food delivery, payments, fitness, shopping, and streaming delivered either a poor or


Emily Barbenza and Michael Elgo of the ServiceNow team

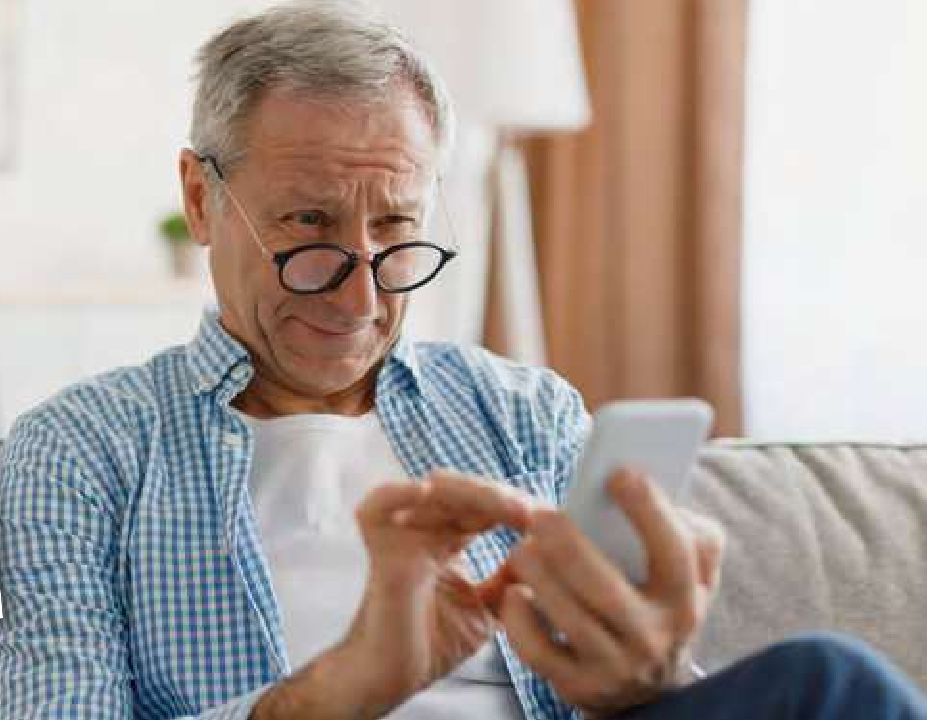
Pratik and Tony-Morales of the ServiceNow team


ARCTOUCH

The State of Mobile App Accessibility

Report

ArcTouch SOMAA Report Cover



outright failing experience for people with disabilities. With the shopping industry, despite its obvious commercial incentives, coming in with the lowest overall score, the report authors write: “If a user can’t successfully shop in an e-commerce app, then that app has failed its primary purpose.” Sadly, that failure has consequences far beyond the checkout screen.

“There are lots of unlabeled buttons,” said one Fable tester. “Image descriptions are barely enough to indicate that it could be a product.” Without something as simple as a properly labeled button, blind and low-vision users are effectively locked out. Customers with access needs would spend more if digital experiences were more accessible. That translates to a massive, missed opportunity: trillions of dollars left on the table by brands that treat accessibility as an afterthought.

This is a recurring theme in the user interviews that accompanied the SOMAA report: frustration and hope. In one transcript, a Fable tester put it bluntly: “I had to struggle so much with just trying to input my payment information. If the app can't get that basic interaction right, I just delete it. I'm done.” Another explained: “I use Voice Control on iOS because of limited mobility in my hands. Half the time, the app doesn’t respond properly or skips buttons. It’s exhausting.”

For ArcTouch’s Head of Accessibility, Ben Ogilvie, that feedback is exactly the point. “Native components and tools provide a foundation,” he says. “But you still need to build the rest of the house, the complete user experience, with accessibility in mind.” That user experience is where so many apps fall short. The SOMAA report tested four key assistive technologies across 50 top-ranked iOS and Android apps: screen readers, alternate navigation, font scaling, and orientation. And across the board, orientation support, which allows users to view content in both portrait and landscape modes, was dismally low. Average cross-industry support scored an 8 out of 100.

That’s more than an oversight. For users, it’s a barrier to access. Despite progress in awareness, accessibility remains siloed. It’s either bolted on at the end of development or handled by a single compliance specialist instead of being embedded in the design process from the start. And that’s a mistake. One of the biggest myths is that accessibility is expensive or difficult, but it’s not if you plan for it from the beginning. However, it can be expensive if you have to retrofit everything later. Users must also be involved. You cannot design accessible experiences in a vacuum. You need to test it with real users who rely on assistive technologies. And not just once, continuously.

Ben Ogilvie believes automated tools will catch some problems, but added, “Only real-world testing

Ben Ogilvie, ArcTouch

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shows you whether your app actually works for someone trying to use it with a screen reader or voice control."

As for the broader regulatory landscape, the report highlights a coming wave of enforcement, particularly in Europe. The European Accessibility Act (EAA), due to take effect on June 28, 2025, expands requirements beyond public sector websites to include private sector services like e-commerce, banking, and transport, and unlike many earlier regulations, it explicitly includes native apps in its scope. That means brands with global reach must pay attention or face legal and reputational risk.

Joe Devon believes there's hope. "AI has the potential to simplify the process of building accessible apps and websites," he explained. "But that still requires a commitment from brand leaders and product builders to support digital accessibility. Take the lessons from the SOMAA report. Understand the opportunity, not just to do what's right, but to do what's best for your business and brand."

Devon's own journey, from blog post to global movement, is proof that accessibility doesn't start with perfection. It starts with intention, and with listening. "Reports like these help us look at the big picture. I've seen accessibility experts so focused on the minutia that they miss the larger goal: improving the percentage of accessible applications," he noted.

And then there's AI, the ever-expanding frontier. Joe's excited about its potential, especially in assistive technology. Screen reading, audio description, real-time guidance for navigating visual content, all powered by tools that are improving at a breakneck pace. But he's equally clear-eyed about the danger: if accessibility is once again treated as an afterthought, the AI revolution will widen the digital divide even further. So, in collaboration with ServiceNow, they are working on an open-source AI accessibility conformance tool to launch in May. "Accessibility used to be an afterthought. We can't afford that with Gen AI moving so fast," ServiceNow's Eamon McErlean said.

"The tool will check for missing alt text, tab order, ARIA usage, document language, the fundamentals," he explained. "Importantly, it will be LLM-agnostic, making it available for any organization to evaluate accessibility in their AI-generated code." He continued, "It is open-source, no cost. And we want companies to take it, run with it, and improve it collaboratively." But tools alone aren't enough. ServiceNow also maintains an internal accessibility panel of nearly 250 employees, people with disabilities and champions of inclusive design. "We solicit their feedback on new features before release. It's been invaluable," he shared.

McErlean is also proud of practical innovations: force colors, dark themes, custom keyboard shortcuts, and real-time accessibility checkers built into the platform. "Customers can check their theme or app conformance before publishing. It helps scale accessibility across the board."

Still, challenges persist. The platform's extreme customizability means clients can introduce inaccessible components unintentionally. "It's a double-edged sword," McErlean admitted. That's why built-in checkers and ongoing customer education are critical. So too is the input and feedback of real users. It might seem like a long, tedious process, and that can make anyone hesitate. But it all starts with a simple truth: "If you build tech without considering people with disabilities, you've built it wrong," McErlean said forcefully. And if you're a tech company still treating accessibility like an annual compliance chore, Eamon's advice is simple: "Start earlier, bake it into your design and get real users in the room. Let them break your shiny prototype before it breaks someone else's experience."


Eamon McErlean Headshot

Through the work of these companies and organizations, we are reminded that accessibility goes beyond checkboxes and code, it centers on people. It means recognizing the individual on the other side of the screen and choosing to care, to include, and to make them feel seen and valued. Let this be a call to all of us: to build with empathy, to design with intention, and to ensure no one is left behind. ■

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Deaf Insights

with Angela Lynn

Belonging in a world built for sound

Belonging is a word many people use, but few truly understand, especially when it comes to the Deaf community. This article is a warm invitation to pause, reflect, and sip on something thoughtful like a quiet cup of coffee with an old friend. It will help you understand what it is like to be Deaf in a sound centered world, and why creating spaces of true belonging matters so much.

For many of us, being present is not the same as being included, and being included is not the same as belonging. In a world shaped by sound, where communication moves through voices and volume, Deaf people are often expected to adjust, adapt, and find a way in. But real belonging does not ask us to shrink. It invites us to be fully ourselves. And it starts with being seen, valued, and understood for who we are, not how quietly we enter the room.

A World Not Designed for Us

Deaf people live in a society that was not designed with them in mind. From communication access to cultural expectations, nearly every space such as schools, hospitals, workplaces, and even relationships ask Deaf people to adjust, adapt, or wait. The world is loud, fast, and often unaware of its own dependence on sound.

To many hearing people, offering an interpreter, captions, or a seat at the table feels inclusive. And it is. But inclusion without awareness can still feel like distance. True belonging means creating space where Deaf people do not have to explain their presence or prove their worth. It is about shifting the question from “Can you fit in here?” to “What do you need to thrive here?”

What Deaf Eyes See

What Deaf eyes see that ears cannot hear are the moments when someone truly listens, not with words, but with openness. We notice when someone turns to face us, when they gesture instead of speaking with their back turned, when they learn a sign just to say hello. These acts say, “I see you.” Not as an afterthought. But as someone who matters.

Belonging also means being seen as a whole, not broken, not missing something, not needing to be fixed. Deaf culture is rich in expression, community, and resilience. Sign language is more than words. It is rhythm, emotion, identity. It is our voice.

The Culture of Connection
In hearing culture, connection often happens through sound, small talk, laughter, and voice tones. But in Deaf culture, connection lives in the eyes, in the hands, and in intentional presence. Where hearing people may speak quickly, we observe deeply. Where sound fills the air, we watch for meaning.

When hearing people embrace that, rather than simply tolerate it, the shift from inclusion to belonging begins.

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Credit - Anthony Tran - Unsplash

The Call to Belonging

We do not just want space. We want to understand. We want to belong in conversations, in decisions, in dreams. That starts by recognizing that sound is not the only way to connect. And that silence is not emptiness. It is another kind of language.

So, the next time you invite a Deaf person into your space, ask: Are we truly including them or are we ready to let them belong? Do not just make space for Deaf people. Make them feel like they belong. Because when you do, you will see a world that sound has been too loud to notice. Because what Deaf eyes see - that ears cannot hear - is everything you have been too loud to notice.

Keep the Conversation Going

If you have ideas or questions, I would love to hear from you. Feel free to reach me at angelalynn@theangelalynnshow.com. I look forward to hearing your thoughts and continuing this connection through kindness and shared understanding. ■

Sunflowerly Yours

Angela Lynn

> For many of us, being present is not the same as being included, and being included is not the same as belonging.

Read more 'Deaf Insights' by Angela Lynn

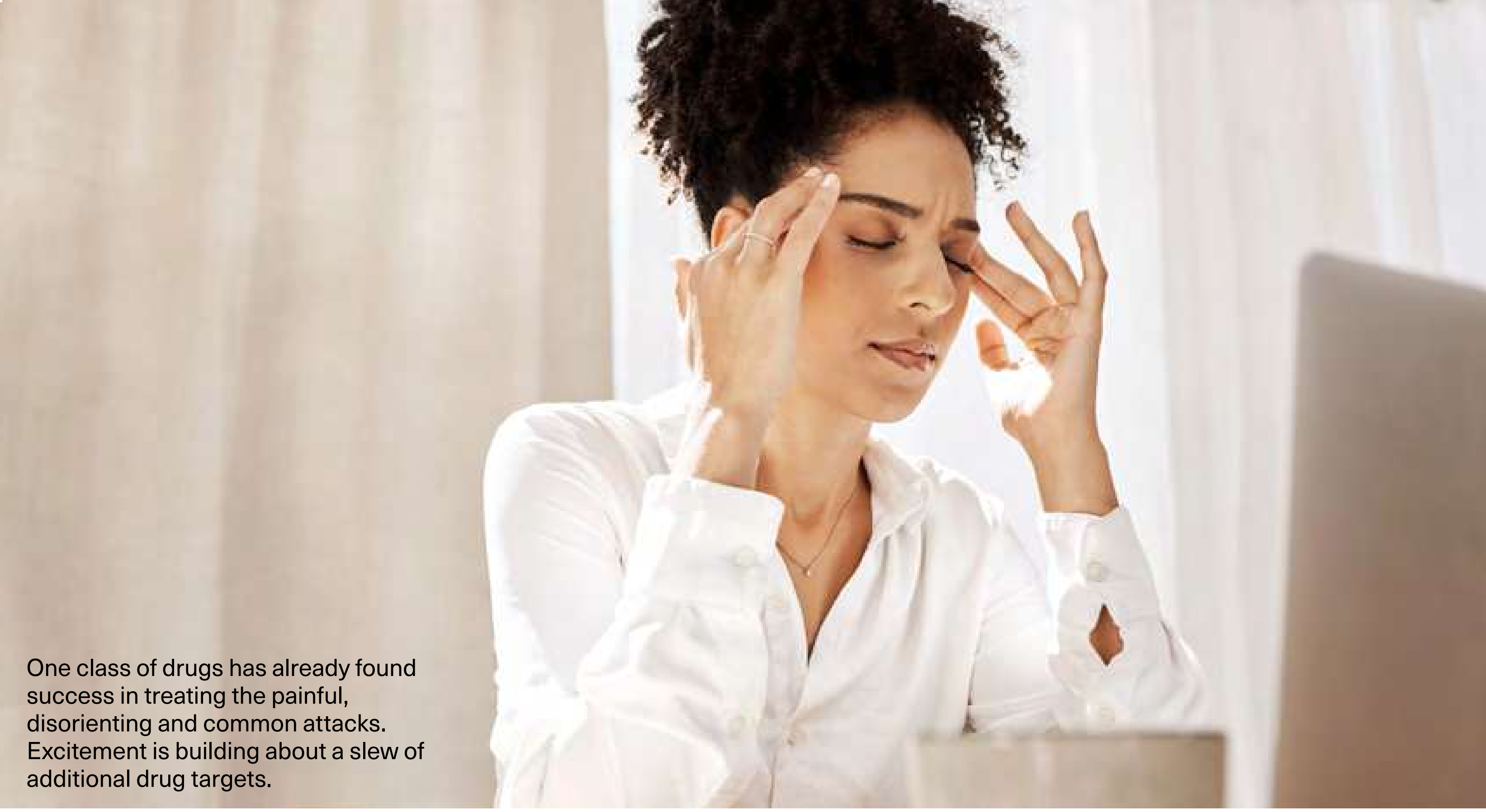
Breaking Barriers: Advocating for Inclusion and addressing audism

Inclusion and Awareness

Celebrating diversity & inclusion: Reflections on World Inclusion Day

Deaf and hard-of-hearing travellers

Deaf etiquette



One class of drugs has already found success in treating the painful, disorienting and common attacks. Excitement is building about a slew of additional drug targets.

HEALTH & DISEASE

Studies of migraine's many triggers offer paths to new therapies

By Amber Dance, freelance science journalist
in the Los Angeles area and a special contributor for Knowable Magazine

For Cherise Irons, chocolate, red wine and aged cheeses are dangerous. So are certain sounds, perfumes and other strong scents, cold weather and thunderstorms. Stress and lack of sleep, too.]

She suspects all of these things can trigger her migraine attacks, which manifest in a variety of ways: pounding pain in the back of her head, exquisite sensitivity to the slightest sound, even blackouts and partial paralysis.

Irons, 48, of Coral Springs, Florida, once worked as a school assistant principal. Now, she's on disability due to her migraine. Irons has tried so many migraine medications she's lost count — but none has helped for long. Even a few of the much-touted new drugs that have quelled episodes for many people with migraine have failed for Irons. to tet elesere cuptas explabore accus a nonsect atibus, quasped milliquaerit inum eati dolestrum nusciae nonsequae vero cullupt aturio. Olore inum ut aborestibus, verferum harunt velique etur a core sitiae laudanditas esernam quatia doluptas utem soles rehentibus et adignis il et quis de vel int laccum fugia quod moloren iatatis repe pre, ullatusam eniam doluptat verchilit incte nobitionem et molut volorrunt.

Though not all are as impaired as Irons, migraine is a surprisingly common problem, affecting 14 percent to 15 percent of people. Yet scientists and physicians remain largely in the dark about how triggers like Irons's lead to

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attacks. They have made progress nonetheless: The latest drugs, inhibitors of a body signaling molecule called CGRP, have been a blessing for many. For others, not so much. And it's not clear why.

The complexity of migraine probably has something to do with it. "It's a very diverse condition," says Debbie Hay, a pharmacologist at the University of Otago in Dunedin, New Zealand. "There's still huge debate as to what the causes are, what the consequences are."

That's true despite decades of research and the remarkable ability of scientists to trigger migraine attacks in the lab: Giving CGRP intravenously to people who get migraines gives some of them attacks. So do nitric oxide, a natural body molecule that relaxes blood vessels, and another signaling molecule called PACAP. In mice, too, CGRP and PACAP molecules can bring on migraine-like effects.

All these molecules act as "on" switches for migraine attacks, which suggests that there must be "off" switches out there too, says Amynah Pradhan, a neuroscientist at Washington University in St. Louis. Scientists have been actively seeking those "off" switches; the CGRP-blocking drugs were a major win in this line of research.

Despite the insights gleaned, migraine remains a tricky disease to understand and treat. For example, the steps between the molecular action of CGRP and a person experiencing a headache or other symptoms are still murky. But scientists have lots of other ideas for new drugs that might stave off migraine attacks, or stop ongoing ones.

"It's important to have an expanded toolbox," says Pradhan.

Deciphering migraine mechanisms

Migraine is the second most prevalent cause of disability in the world, affecting mainly women of childbearing age. A person may have one migraine attack per year, or several per week, or even ongoing symptoms.

Complicating the picture further, there's not just one kind of migraine attack. Migraine can cause headache; nausea; sensitivity to light, sound or smell; or a panoply of other symptoms. Some people get visual auras; some don't. Some women have migraine attacks associated with menstruation. Some people, particularly kids, have "abdominal migraine," characterized not so much by headaches as by nausea, stomach pain and vomiting.

Initially, the throbbing nature of the head pain led researchers to suspect that the root problem was expansion of the blood vessels within the membranes surrounding the brain, with these vessels pulsing in time with the heartbeat. But, as it turns out, the throbbing doesn't really match up with heart rate.

Then researchers noticed that many signs that presage migraine attack, such as light sensitivity and appetite changes, are all regulated by the brain, particularly a region called the hypothalamus. The pendulum swung toward suspicion of a within-brain origin.

Today, scientists wonder if both in-brain and beyond-brain factors, including blood vessels releasing pain-causing molecules, play a role, as may other contributors such as immune cells.

What all these proposed mechanisms ultimately point to, though, is pain created not in the brain itself but in the meninges — a multilayered "plastic bag around your brain," as described by Messoud Ashina, a neurologist at the University of Copenhagen and director of the Human Migraine Research Unit at Rigshospitalet Glostrup in Denmark. These membranes contain cerebrospinal fluid that cushions the brain and holds it in place. They also support blood vessels and nerves that feed into the brain. The brain itself cannot feel pain, but nerves in the meninges, especially the trigeminal nerve between the face and brain, can. If they're activated, they send the brain a major "ouch" message.

Physicians and pharmacists already possess a number of anti-migraine tools — some to prevent future attacks, others to treat an attack once it's started. Options to stop a current migraine attack in its tracks include over-the-counter painkillers, such as aspirin and ibuprofen, or prescription opioids. Triptans, developed specifically to counter migraine attacks once they've begun, are drugs that tighten up blood vessels via interactions with serotonin receptors.

However, scientists later recognized that constricting blood vessels is not the main way triptans relieve migraine; their action to quiet nerve signals or inflammation may be more relevant. Ditans, a newer class of migraine drugs, also act on serotonin receptors but affect only nerves, not blood vessels, and they still work.

For migraine attack prevention, pre-CGRP-era tools still in use today include antidepressants, blood pressure medications, epilepsy drugs and injections of botulinum toxin that numb the pain-sensing nerves in the head and neck.

Most of these medicines, except triptans and ditans, weren't designed specifically for migraine,

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and they often come with unpleasant side effects. It can take months for some preventive medicines to start working, and frequent use of triptans or painkillers can lead to another problem, the poorly understood “medication overuse headache.”

A powerful new player

The CGRP drugs provided a major expansion to the migraine pharmacopoeia, as they can both prevent attacks from happening and stop ones that have already started. They also mark the first time that clues from basic migraine research led to an “off” switch that prevents migraine attacks from even starting.

CGRP is a small snippet of protein made in various places in the body. A messenger molecule that normally clicks into another molecule, called a receptor, on a cell’s surface, CGRP can turn on activity in the receiving cell. It’s found in pain-sensing nerve fibers that run alongside meningeal blood vessels and in the trigeminal ganglia near the base of the skull where many nerves are rooted. The molecule is a powerful blood vessel dilator. It also acts on immune cells, nerve cells and the nerve-supporting cells called glia.

All of these features — a location in the meningeal nerve fibers with several actions that might be linked to migraine, like expanding blood vessels — pointed to CGRP being a migraine “on” switch. Further research also showed that CGRP is often found at higher levels in the body fluids of people who get migraines.

The many manifestations of migraine

Migraine does not just describe one set of symptoms, but can occur in a variety of ways.

MIGRAINES DEFINED BY SYMPTOMS	
Migraine without aura	This is the most common type of migraine. It usually involves throbbing pain on one side of the head that worsens with activity. Nausea and vomiting and sensitivity to light, sound or smells may also occur.
Migraine with aura	About one-third of people with migraine will experience sensory changes known as auras, most commonly visual effects such as flashing lights or blind spots. The aura typically occurs before the headache, or sometimes on its own.
RARE SUBTYPES OF MIGRAINE WITH AURA	
Hemiplegic migraine	In this form of migraine, the sensory auras include weakness on one side of the body. It may run in families. Hemiplegic migraine may also be triggered by head trauma.
Migraine with brainstem aura	This migraine includes neurological symptoms such as vertigo, ringing ears, double vision or slurring of speech — but not body weakness.
Retinal migraine	Retinal migraines usually affect one or the other eye with sudden, temporary symptoms such as vision loss or blurred vision.
Vestibular migraine	This kind of migraine features vertigo, dizziness or balance problems, possibly alongside other symptoms.
OTHER TYPES THAT OCCUR WITH OR WITHOUT AURA	
Menstrual migraine	Most women who have migraine find menstruation to be a trigger, but it’s rarely the only time they experience a migraine attack. Menstrual migraine attacks are probably due to hormonal changes and tend to be more severe and longer lasting than other types.
Abdominal migraine	Most common in children, it involves stomach pain, nausea and vomiting, but not headaches. Many children who experienced abdominal migraine have migraine headaches when they grow up.
Cyclical vomiting syndrome	This condition involves regular attacks of illness and vomiting. It’s not quite clear how cyclical vomiting syndrome is associated with migraine, but it often happens in people who have migraine or who have family members with migraine. Children who have cyclic vomiting syndrome may have more traditional migraine attacks when they grow up.
Migraine-related condition: Medication overuse headache	Regular use of painkillers and migraine treatments such as triptans can cause medication overuse headache. It manifests as a dull, ongoing headache present on most days in a month. Migraine attacks can still occur as well.
MIGRAINES DEFINED BY FREQUENCY	
Chronic migraine means headaches at least 15 days per month, with at least 8 of those being migraines, for at least 3 months.	Migraines at lower frequency are called episodic migraine.

People may experience migraine in very different ways.

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In a small 2010 study, 12 out of 14 people with migraine did report a headache after receiving intravenous CGRP; four of them also experienced aura symptoms such as vision changes. Only two out of 11 people who don't normally get migraine attacks also developed a headache after CGRP infusion.

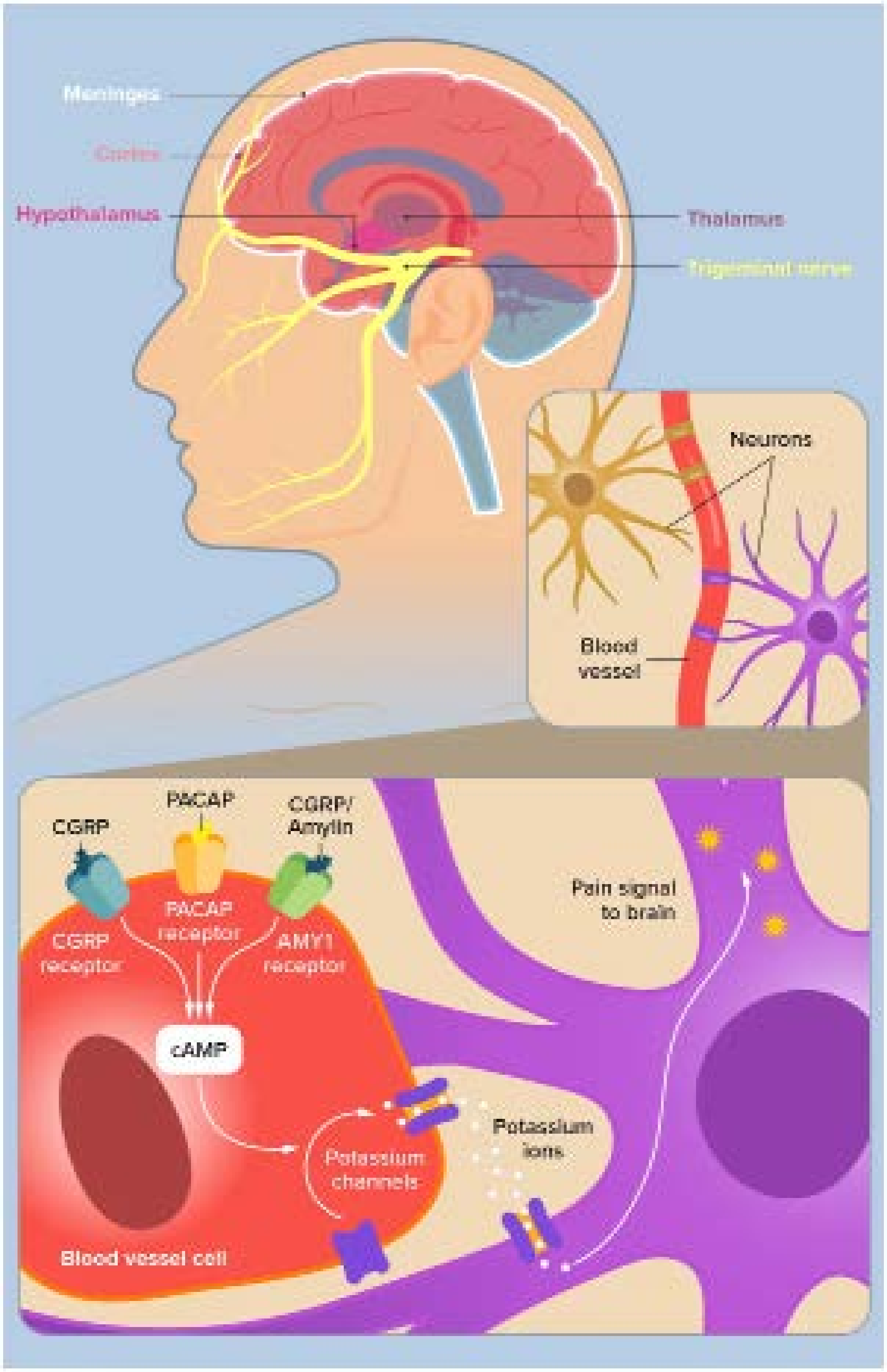
CGRP also caused mice to be extra sensitive to light, suggesting it could have something to do with the light sensitivity in humans, too.

The steps between CGRP in the bloodstream or meninges as a trigger and migraine symptoms like light sensitivity aren't fully understood, though scientists do have theories. Ashina is pursuing how CGRP, PACAP and other substances might trigger migraine attacks. These molecules all stick to receptors on the surface of cells, such as the ones in blood vessel walls. That binding kicks off a series of events inside the cell that includes generation of a substance called cyclic AMP and, ultimately, opening of channels that let potassium ions out of the cell. All that external potassium causes blood vessels to dilate — but it might also trigger nearby pain-sensing nerves, such as the trigeminal cluster, Ashina hypothesizes.

It's a neat story, but far from proven. "We still don't really know what CGRP does in the context of migraine," says Greg Dussor, a neuroscientist at the University of Texas at Dallas. ■

Originally published in The Knowable.
Read the rest of the original article here.

Many signals lead to migraine



In one possible model for migraine, various molecules can activate blood vessel cells to release potassium, which activates nearby neurons that send a pain signal to the brain. Various strategies that seek to interfere with this pathway, including the anti-CGRP drugs, are of great interest to migraine researchers.

http:// Snippets from the www

A horse therapy program in Namibia brings joy to children with learning disabilities

Through her program, Susan de Meyer creates a unique therapeutic environment that fosters emotional growth and communication skills in children who might struggle in traditional educational settings. The interaction between the children and the horses serves as a powerful tool for building confidence and improving social skills.

Read the full article.

More Funding for Disability Support, Summer Respite

The announcement of a $9.3 million investment in individualized funding programs for Nova Scotians with disabilities and their families represents a significant step forward in supporting individuals who often encounter unique challenges in their daily lives. This investment reflects a commitment to enhancing inclusivity, dignity, and empowerment, ultimately contributing to a more equitable society for all.

Read the full article.

Artificial Intelligence in Disability Care: Unlocking Agency

When AI is developed with a focus on social good, it can significantly enhance the lives of individuals with disabilities by promoting empowerment, independence, and personalized care.

Read the full article.

From Sex to Ghosting, These Are the Realities of Dating with a Disability

When Frances Ryan began researching her new book Who Wants To Be Normal?, she discovered that there's one part of life that's stuck in the dark ages for disabled women.

Read the full article.

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Mobile apps are failing users with disabilities

Many apps are falling short of being accessible to disabled users, according to a recent report from software developer ArcTouch and the online platform Fable. Ben Ogilvie, head of accessibility at ArcTouch, explains how mobile app developers can improve on their accessibility features.

Read the full article.

Microsoft finally makes this inaccessible accessibility feature more...accessible

Microsoft's commitment to making Windows more accessible has indeed gained significant attention in recent years, particularly with the launch of Windows 11. The focus on accessibility features, such as voice access, highlights the company's intention to create a more inclusive operating system for users with disabilities. However, the ease of locating and utilizing these features is equally important for ensuring that they are effectively integrated into everyday use.

Read the full article.

Surrey Schools defines accessibility in third part of animated video series

The Surrey, BC, district is continuing its four-part animated series on accessibility, highlighting and defining the keyword of accessibility and what that truly means, to persons with and without disabilities.

Read the full article.

Great Falls film makers work to raise awareness of disabilities

The Easterseals Disability Film Challenge is an exciting initiative that provides an opportunity for filmmakers, including those with disabilities, to showcase their talents and tell their stories through the medium of film. Jenniffer Robinson's five-year participation highlights not only her commitment to this platform but also the importance of representation in the film industry.

Read the full article.

Jiang Yuyan Wins Laureus Award for Sportsperson of The Year with A Disability

Jiang Yuyan earned one of sport's most prestigious awards on April 21 as she was named the winner of the Laureus Award for Sportsperson of the Year with a Disability. The Crystal Gallery of the Cibeles Palace played host to the 25th edition of the prestigious awards ceremony—often called sport's version of the Oscars—which took place Monday evening.

Read the full article.

How the London Underground is evolving in 2025: AI, accessibility, and safety

The London Underground, one of the oldest and busiest metro systems in the world, is undergoing important changes in 2025. With over five million journeys made daily, keeping the network efficient, accessible, and safe is a constant challenge. This year, Transport for London (TfL) is focusing on technology, safety, and inclusive design to meet modern-day demands and prepare for the future.

Read the full article.

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