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## COVER STORY

### THE WEIRD AND WONDERFUL TOKYO PARALYMPICS

The 2021 Paralympic Games will be remembered for the unprecedented delays and precautions that came with the COVID-19 pandemic. We enlisted the athletes to tell their stories and take us inside the games to understand what the Paralympic experience was like and to learn what the mainstream media missed out on.

**20**



## FEATURES

**14 DEMYSTIFYING DISABILITY** An excerpt from EMILY LADAU'S insightful new book, "Demystifying Disability: What to know, what to say, and how to be an ally."

**16 ERIC HOWK FEELS IT STILL** Grammy Award-winning guitarist Eric Howk is back on the road with Portugal. The Man and TEAL SHERER reports he is just as busy behind the scenes advocating for mental health and substance abuse awareness.

**29 NEXT-GEN DISABLED THESPIANS** GREG MOOMJY checks out the growing number of organizations dedicated to finding and nurturing actors with disabilities.

**33 FINDING A DISABILITY LAWYER** To find out how to choose the legal counsel for your specific needs, we turned to KELLEY SIMONEAUX, the founder of the Spinal Cord Injury Law Firm.

## DEPARTMENTS

- 4** BULLY PULPIT
- 5** BEHIND THE STORIES
- 6** SHARE
- 8** NEWS ANALYSIS
- 11** UNITED NEWS
- 12** HOW WE ROLL
- 36** DAILY DILEMMAS
- 37** REFRAMED
- 39** CLASSIFIEDS
- 40** LAST WORD



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# BULLY PULPIT

By Ian Ruder

## QUADSPLAINERS

Arnedo had no reason to think the video he posted on Sept. 6 would garner a different reaction than the 75 or so videos he had previously shared. His channel offers a selection of quad how-tos, cooking videos and day-in-the-life montages, and Sept. 6's entry, "A Girl's Day," was more of the same.

He uploaded the video, shared it to some of the leading SCI forums on Facebook and went about his day. Then came the comments.

*"I'm sorry ... but, you're in very serious need of an experienced long time, accomplished quadfather!"*

*"You need a knowledgeable, professional and experienced 'gimp' trainer. Unfortunately, I'm in California otherwise I'd be all over you and your dependencies! Sorry ... someone had to say it."*

*"You choose to be lazy and let others do everything for you. You could learn to be better and to do more things for yourself but you don't. If you can hold a stupid beer then you can be alone for more than an hour. Smh."*

That's just a small sampling of feedback Arnedo received. At last check, his post had racked up almost 400 comments in the two forums I saw. From a mom suggesting Arnedo meet her son with spina bifida because "he had never complained and always figured out a way to do something," to a slightly more supportive fellow quad who wrote, "It kills me to see you (or anyone else) who is at my injury level and using a power chair and not trying harder," commenters crushed Arnedo for being a lazy bum.

The harsh comments have nothing to do with the actual video, which shows Arnedo rolling solo around his Florida home, watching his girlfriend put her makeup on and explaining how to use iMovie. They are in response to the video's short description:

*My girlfriend and I are 24/7 together. We never go apart. We live together alone and it's*

*kinda difficult for her to go to the hair salon or nails salon. So, from time to time she has her sister come over and they have a girl's day.*

With those 47 words, Arnedo had unknowingly unleashed the quadsplainers. Slightly less toxic than their mansplainer cousins, the quadsplainers are the self-appointed SCI experts committed to saving the lazy, dependent wheelchair users they think are failing to maximize their function.

As the all-knowing mom above showed, you don't even have to be a quad to be a quadsplainer — you just have to be unjustifiably confident you know more about someone else's life than they know about themselves.

Had any of these experts actually watched the video they would have understood why Arnedo chose The Happy Quadriplegic as his channel name. The dude is obviously happy. His girlfriend seems to be, too — despite the assured comments of the quadsplainers.

I love that the internet has made it easier for our community to share our knowledge and connect with people needing help, but I'd hope we could be smart enough to not overstep and impose where we are not wanted or do not know the whole situation.

To his credit, Arnedo never lost his cool and showed a thick skin in responding to many of the quadsplainers. Via email, he told me he created the video thinking people would enjoy seeing that a quad can be in a happy, fulfilling relationship. "Apparently, it's not 'healthy,'" he writes, his sarcasm bleeding off the screen. "Apparently, it's 'toxic.'"

"I will always try to focus on the positive comments. I'm in love and every day is a love adventure with my significant other," he adds. "At the end of the day, I'm living a perfectly happy life and negativity doesn't affect me."

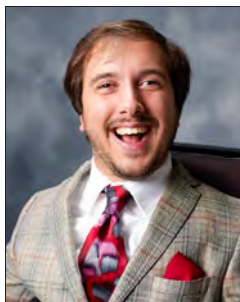




# BEHIND THE STORIES

With Ian Ruder

For every questionable submission I receive, a talented writer or unique story idea seemingly falls into my lap. Last year, **Greg Moomjy** presented me with the rare gift of both when he proposed a story on the Metropolitan Opera staging Lars Von Trier's *Breaking the Waves*. Reading his insightful analysis will show you why I was so thrilled when he pitched this month's story on acting programs for disabled people. Moomjy got some first-hand experience as an acting coach when he consulted with an actor playing a character based on his life as a 20-year-old wheelchair user with CP. "It was kind of funny telling him about my dating experience so he could understand the role," says Moomjy.



Over the years of working with **Teal Sherer**, I've learned to trust her instincts. So, when she told me that the topic for her media column for this issue had grown too big for a simple column, I didn't hesitate to greenlight a longer feature. The fact that she was writing about Portugal. The Man guitarist Eric Howk made my decision even more of a no-brainer. "I approached Eric with a cool idea for an article, and he opened up about a whole other story I had no idea about," says Sherer, whose story touches on Howk's struggles with substance abuse. "I wanted to do justice to his story and his decision to share such intimate details with me. It was an honor."

I've always been a fan of puns, and when it comes to wheelchair-related job titles, **Kelley Simoneaux** came up with a great one when she branded herself as The Pushy Lawyer. A lawyer, mom, wife and fierce advocate, Simoneaux lives up to all the best aspects of her chosen moniker. She started The Spinal Cord Injury Law Firm after moving to Washington, D.C., and has the perfect blend of personal and professional experience to write this month's feature. "There's still not enough awareness about how powerful litigation can be in affecting change," says Simoneaux. "You have to have a lot of tools in your box when you're addressing a legal situation and having the right ones is important."



Please send queries, manuscripts or feedback to Ian Ruder: [iruder@unitedspinal.org](mailto:iruder@unitedspinal.org)



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SEPTEMBER 2021

## When Colleges Abandon Us

### Consider Filing a Complaint:

I think that shutting down [Edinboro's program] without consultation with the affected individuals to find a compromise that is financially feasible is an act of housing discrimination under both state and federal law. Was a complaint ever filed with HUD, or in this particular case, with the PA Human Relations Commission?

**Joanne Tosti-Vasey, Commissioner, PA Human Relations Commission**

*Newmobility.com*

## Yes, Homecare is Infrastructure

### #RaiseTheRate State-by-State:

The crisis in recruiting and retaining community attendants in Medicaid Home and Community Based Services does not get enough attention.

Medicaid rate setting is subject to state legislatures appropriations and state agencies' processes. Statistics on community attendant wages lump together different funding sources making the state rates look higher than they actually are.

We need to raise the urgency of this issue or the HCBS advances we have made may diminish.

**Bob Kafka, National ADAPT**

*Austin, Texas*

## Winnebago makes #VanLife Fully Accessible

**Crowded but Cool:** I purchased a Roadtrek Carado Banff on a 19-foot-long Dodge RAM Promaster chassis and had it made accessible. Out of

"I think this is discrimination. Was a complaint ever filed?"

all the Class B RVs I looked at, this was the easiest one to modify. It's bare-bones, but has a shower, sink and toilet, a mid-ship galley, one twin bed that can be converted to a double, and a BraunAbility under-vehicle wheelchair lift. Up front, I have hand controls and transfer into the driver's seat.

**Gail**

*Newmobility.com*

## Dating with a Disability and Accepting Care

**Love Fiercely:** Three years ago, I met my wife on a dating app. She loved that I said if a chair scares you, move on. We met and fell in love. She helps me if I need it, but I am fiercely independent and live a fierce life with her!

**Dotti Longobardi**

*Facebook*

## Please Remain Seated

**Here's What Happened:** There I was at the ticket booth for the USS Midway Museum in San Diego. The ticket sign read, "The ship is 60% wheelchair accessible." I ask the ticket seller, "Does this mean I get 40% off

the ticket price?" She responds, "No, you have to pay the full amount." Up on the flight deck is the entrance to the bridge. Docent says it is not wheelchair accessible — it is four stories of ladders. I told him I was a SCI walker and asked him to please take my wheelchair to the exit for me. It was a bit slow, lots of cussing and swearing (mostly by the other visitors behind me) but I got to the top.

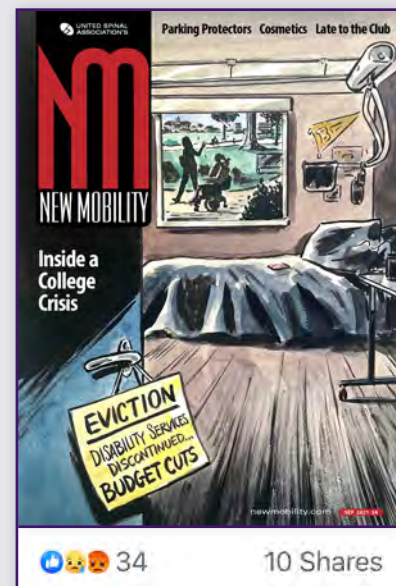
Once inside the bridge, another docent approached me and asked with some authority, "Excuse me sir, are you the wheelchair user?" I replied, "Yes sir, I am." He snapped back, "Well due to your stunt ..." I'm thinking to myself, "Oh crap." The docent finishes, "We're going to get these able-bodieds out of your way so you can take your time. Are you retired Navy?" "No sir, former oilfield trash." He smiles and winks, "Close enough. Take the XO's chair, the bridge is yours. Enjoy!"

My chair was waiting for me at the exit along with several docents asking questions.

Ask. Make the attempt. Find a way. Open your mind and someone else's eyes.

**Luis Nok Outumuro**

*Facebook*







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By Tim Gilmer

## DISABILITY AND CIVIL RIGHTS ADVOCATES SOUND ALARM OVER VOTING RIGHTS RESTRICTIONS

It has always been hard to vote in Texas for many wheelchair users, but Toby Cole fears it's about to get even harder. On Sept. 7 Texas Governor Greg Abbott signed Senate Bill 1, a law that will go into effect Dec. 2 and contains numerous new voting restrictions. Disability and civil rights groups say the new law will unfairly impact minority voters, including wheelchair users and other people with disabilities.

Cole is a board member of the Houston chapter of United Spinal Association and a past president of the Houston Trial Lawyers Association. Harris County, where Cole lives, is Texas' largest. Many of its 750 polling places have accessibility problems, including non-compliant ramps, walkways impassible for wheelchair users and locked gates along access routes. Cole, a C5 quad, had problems when voting at a church. "I had to wait a long time in line outside. Someone finally saw me, came out and said, 'Sorry you won't be able get to where you need to vote from here.'" They took him to a back kitchen entrance. There was a high, 3-inch threshold and no ramp. "Somehow I managed," he says. "But I wondered what would happen if I had had to wait in line even longer. In Texas we have heat issues, and as a quad I can only sit for a limited time."

The new law, he says, creates new problems by unnecessarily including complicated processes that discourage voting.

Prior to S.B. 1, Cole helped the Justice Department implement a 2019 consent decree that ordered Harris County to survey and fix physical access issues at polling places and provide effective curbside voting options for people with disabilities. In 2020, he surveyed several curbside voting locations in Harris County. They were intended to provide a convenient way for people with disabilities to vote — you drive up, push a button on a post and an election worker comes out to help. He found them inefficient and some even unusable. "The sites I visited were in parking lots, difficult to see, with no signs pointing to them," he says. "Sometimes the buttons don't work, no one will answer, or someone will answer but they don't know what to do."

Cole may now have to vote by mail, but the state's signature requirements create potential problems. "Mail-in scares me to death because of the signature verification process," he says. Cole uses attendants to help him sign any document. "They are already auditing Harris County and other mostly Democratic counties. It has never been an issue prior to 2020. What happens if some untrained person hired by the audit, who knows nothing about whether Toby Cole is a quad and how he makes his signature using different attendants, looks at my ballot and it doesn't match with what's on record and they toss my vote out?"

"Whether intentional or not, people with disabilities will most likely be affected disproportionately by laws that restrict voting access."

Then there's the problem of how to get your mail-in ballot to election officials. You can send it by mail, but considering postal delays, you need to send it a few days or longer before election day. In years past, Harris County had 12 locations where voters could directly drop their ballot. Then in October 2020, Gov. Abbott, himself a wheelchair user, signed an order that reduced drop box locations to one per county. "To force hundreds of thousands of seniors and voters with disabilities to use a single drop-off location in a county that stretches over nearly 2,000 square miles is prejudicial and dangerous," wrote Chris Hollins, the Harris County Clerk, in a statement after Abbott's order.

Now, the enactment of S.B. 1 eliminates all drop boxes in Texas.

Another option, drive-thru voting, became available at the onset of the





Toby Cole, a Houston lawyer, is alarmed by new voting restrictions in Texas that he says will make it harder for him and other wheelchair users to vote.

pandemic and was available to anyone, regardless of disability. However, S.B. 1 eliminates drive-thru voting and also does away with 24-hour voting, which Harris County implemented during the pandemic to limit lines and make it safer and easier for residents to vote.

S.B. 1 imposes yet another requirement that could make voting more onerous for voters who need an attendant's help. Cole says that because Texas provides limited public assistance for PCAs, many rely on undocumented workers to keep out-of-pocket costs down. For in-person voting, an application for an attendant's assistance must be requested, filled out by the attendant and returned prior to voting. The attendant must also present identification at the polling place, as well as recite an oath in front of an election official proclaiming that they in no way influenced the vote or did not "pressure or coerce" the voter to choose them. Undocumented attendants are fearful of being deported. "Many of them don't want to do it," Cole says.

## A Nationwide Problem

Texas S.B. 1 is the latest of dozens of voting laws passing through state legislatures across the country. Whether these laws restrict or increase voting access is dependent largely on which political party controls the state house. In many Democrat-controlled states, legislators have passed laws that expand and improve mail-in voting, make voter registration easier, expand early voting and restore voting eligibility for people with past felony convictions. In contrast, many Republican-controlled states have passed laws that restrict mail-in and early voting, limit or eliminate drop boxes, impose new voter ID and registration requirements, and erect barriers on people who assist voters.

Republicans say these new voting regulations are meant to ensure election integrity by preventing voter fraud. Before signing the Texas bill, Gov. Abbott made a statement that is representative of Republican rationale for new voting restrictions: "One thing that all Texans can agree [on] and that is that we must have trust and confidence in our elections. The bill that I'm about to sign helps to achieve that goal. The law does, however, make it harder for fraudulent votes to be cast."

There is no evidence of widespread voter fraud. Research studies consistently find only a handful of cases nationwide in any given year. According to a study by the nonpartisan Project Vote: "A review of news stories over a recent two year period found that reports of voter fraud were most often limited to local races and indi-

vidual acts and fell into three categories: unsubstantiated or false claims by the loser of a close race, mischief and administrative or voter error."

Democrats and civil rights advocates say that recent voting restrictions unfairly target Black voters, people of color and other minorities, and that the restrictive voting laws are simply an attempt to suppress the vote among these groups. "This wave of restrictions on voting — the most aggressive we have seen in more than a decade of tracking state voting laws — is in large part motivated by false and often racist allegations about voter fraud," said the Brennan Center for Justice, a nonpartisan law and policy think tank.

Caught in the middle is the disability community, which, politically, tends to mirror the American electorate as a



Curbside voting was intended to provide equitable polling access for people with disabilities in Texas, but a recent survey found the system inefficient and even unusable.

whole, leaning left by a few percentage points. Whether intentional or not, people with disabilities will most likely be affected disproportionately by laws that restrict voting access, says long-time disability advocate Lex Frieden, a C5 quad and a chief architect of the ADA.

"If the test of differential effect means people with disabilities will be more greatly affected than others, then yes, these bills are a violation of the ADA," says Frieden. "In addition, we will be more disproportionately affected because our minority set crosses all lines." Frieden is director of Independent Living Research Utilization in Houston, which runs the Southwest ADA Center, and was appointed chair of the National Council on Disability twice by two different presidents — Ronald Reagan and George W. Bush.

Civil and disability rights groups have filed numerous lawsuits in opposition to S.B. 1, alleging that it violates the Americans with Disabilities Act and the Vocational Rehabilitation Act of 1973, as well as multiple civil and voting rights laws.

Frieden sees numerous difficulties with the new law. "Limits on hours, and on curbside and drive-thru voting will surely affect people with disabilities. Paperwork requirements, especially for people who need assistance voting, will be burdensome if not forbidding," he says.

Cole agrees. "We need as many options as we can get. There are so many obstacles that we already have. Start with inaccessible polling places — the fixes they put in are still not great. The consent decree was entered in an environment where we had expanded voting. Now they have

banned 24-hour voting, drop boxes, put limits on hours you can vote. All this creates long lines, difficulty with assistants and documentation," he says. "There are so many things that get cut out of our lives ... voting can't be one of them. It's our only way to make our voice heard."

As of late July, prior to S.B. 1, 18 states had enacted laws that restrict voter access. Many other states are either considering or already deliberating similar bills. It is likely that by the primary election season in 2022, dozens of states will have enacted similar laws.

The Texas legislature's enactment date of Dec. 2, 2021 for S.B. 1 makes it doubtful that any of the lawsuits filed recently will bring about a final judgment prior to primary elections in Texas.

"This is intimidating," says Cole. "Slowly, we are being disenfranchised."

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# UNITED SPINAL ASSOCIATION ORGANIZES WHITE HOUSE ROUNDTABLE TO SUPPORT CAREGIVING LEGISLATION

United Spinal Association joined forces with the White House to organize a Sept. 29 roundtable in support of the Better Care Better Jobs Act. If passed, this legislation would represent an historic investment in home and community-based services through Medicaid. This funding would eliminate waitlists for community-based care and allow more people to have the opportunity and means to live in the community rather than in a congregate setting such as a nursing home. This bill also addresses the chronically underpaid direct care workforce by providing funding to increase caregiver pay and benefits. The goal is to attract and retain more workers in the field of caregiving, allowing people with disabilities to have both more stability and choice when it comes to their caregivers.

"As negotiations continue in Washington on legislation to improve the social safety net, it is so important that United Spinal members made their voices heard in support of this transformative proposal that would eliminate waitlists for home and community-based services and keep as many people as possible living in their own homes in the communities of their choice," said Steve Lieberman, director of policy and advocacy for United Spinal Association.

Speakers included United Spinal board member Keaston White from Georgia, as well as members Kyla Claussen from Iowa, Ken Ryno from Pennsylvania, and Carol Dunn from Maine.

"There is no greater currency in Washington than personal stories, which shape the conversation about public policy and serve to ground it in the real world," said Lieberman. "We are so proud of our members for sharing their stories with policymakers and we encourage all of our members to contact their members of Congress to share their own stories about how critical caregiving is for them."

## Disaster Relief Grants Now Available

In response to another year of devastating natural and human-caused disasters, United Spinal Association is once more offering Disaster Relief financial grants to individuals with spinal cord injury/disease who have been impacted. Qualifying individuals have until Dec. 10 to apply online at [unitedspinal.org/disaster-relief-grant](https://unitedspinal.org/disaster-relief-grant).

The grants were made possible by a generous financial award from the Craig H. Neilsen Foundation. United Spinal is committed to helping people with SCI/D prepare for, respond to and recover from all types of disasters. For more on the organization's Ready to Roll program, visit [unitedspinal.org/ready-to-roll](https://unitedspinal.org/ready-to-roll).

## New Staff

Longtime member **Michele Lee** joins United Spinal as a program director to oversee Ready to Roll, Pathways to Employment and VetsFirst. Lee, a quadriplegic who uses a power wheelchair, has over 10 years of experience working in finance. She is a disability advocate, fighting for disability inclusion in the workplace and universal access to transportation and healthcare.

**Michaela Devins** is taking over United Spinal's Tech Access Initiative while Director Brook McCall is on leave. In addition to running the TAI, Devins, a professional counselor, is developing a mental health initiative with Director of Member Initiatives Lindsey Elliott. Devins is a member of the Boston chapter and a C4-5 quadriplegic. Find out more about her in this month's How We Roll on page 12.

New Program Coordinator **Erin Taylor** brings 20 years of experience in residential services and health and wellness for people with disabilities. She most recently worked at the Oregon Office on Disability and Health and the University Centers for Excellence for Developmental Disabilities. She will be splitting time between the Tech Access Initiative, the Peer Mentoring program, New Mobility and the National Chapter Network.

**Jimmy Zuehl** returns to United Spinal's Accessibility Services team after opening and managing his own accessibility compliance business for the past eight years. Zuehl holds a bachelor's degree in architecture and 20 years of architecture and construction experience. He will focus on accessibility inspections, streamlining procedures to improve on ACS services and revitalizing the architecture program.

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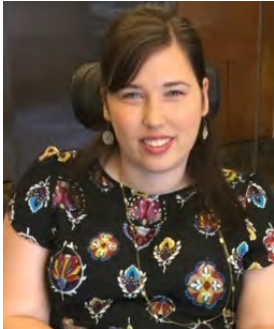
United Spinal has 75 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.



# HOW WE ROLL

MENTAL HEALTH COUNSELOR

## Michaela Devins



Inspired by her own struggles, Michaela Devins decided to become a mental health counselor working with kids and adults.

## Finding Her Voice Again

Devins, 31, was a vocal performance and music education major at Ithaca College who had dreamed of singing professionally for her entire life. A botched dive in 2010, the summer of her junior year of undergrad, resulted in a C4-5 spinal cord injury that damaged her vocal cords and robbed her of the breathing control she needed to sing. Devastated by this loss of identity, she spiraled into a deep depression.

"More than the ability to walk or go to the bathroom by myself, singing was what I wanted back. I felt like the Michaela that was had completely shattered. I wondered, what do I do with these pieces? Where do I go from here?" says Devins.

Her family did its best to help her, but no one knew how, including the mental health professional at rehab, who did "less than nothing" for her. She found herself hiding the depth of her emotional and psychological suffering.

She didn't seek therapy again for years. She cried when people weren't around and endured many sleepless nights, numbing herself with TV. At one point, she told her best friend she wanted to die. "She held space for me. She didn't judge me or freak out, and that was my first taste of what



Michaela and husband, Kyle, got a new perspective on Badlands National Park via a helicopter tour.

therapy could be like, even though she was not a trained mental health professional. Just being able to say it out loud and not have someone tell me that I was wrong, or bad, or evil for feeling that way was healing," says Devins.

Devins' mom kept pushing her forward, too, encouraging her to keep rehabbing and pursue an undergraduate degree in music education. But music was still too painful for Devins to embrace.

She eventually obtained a master's degree in literacy education but didn't get any job interviews after graduating. Between that and the stress of figuring out how to live as a quadriplegic, she started to have anxiety attacks. Now she's married and living independently for the first time. Her husband suggested counseling.

"My God, it was transformative," she says. "Just having an objective third party listen to you, reflecting things back to you and helping you unravel the things that get tangled in your brain, helped in ways I never anticipated. I gained so much insight about myself, especially my grief and even being able to name it that."

Devins was substitute teaching and doing literacy tutoring for kids at the time, and she realized that many kids in her class couldn't learn because they weren't getting proper mental health support.



### MOST ACCESSIBLE PLACE YOU'VE BEEN:

Philadelphia. I could get around so easily. I know that city gets a bad rap, but I love it. The public transit was very accessible.

### COOLEST THING YOU'VE EVER

**DONE?** I took a helicopter ride over Badlands National Park in South Dakota. There are some accessible trails and lookouts there as well.





"I felt there was a real need there, and I had this feeling like, oh my God, therapy works," she says.

She got dual certified in mental health and school counseling. In her first placement at an outpatient agency, she worked with clients aged 6 to 60. She wasn't sure at first how they would receive her disability.

"With kids, you have that initial conversation, and then it's a non-issue," says Devins. "With adults, sometimes there is that awkwardness, but I've found my disability to be a real asset in the mental health arena. Folks come in because they've been through, or are going through, some difficult things. And I have found that when people first lay eyes on me, there's this shared understanding of, 'Oh, you've been through some things too. You get it.'"

Devins currently works at Advocates Community Counseling in Marlborough, Massachusetts. She couldn't be happier.

"I just feel that having a disability gives me that little extra relatability that I wouldn't otherwise get without one. It kind of makes all my struggle to get here worth it because it informs the way I help people through their own challenges."

## Good Help is Hard to Find

Michaela Devins details her struggle covering her care since moving to Cambridge, Massachusetts, in 2020 — right in the middle of the pandemic — and only being approved for 30 hours a week by MassHealth.

“I grew up in New York, so I had a support system and never struggled to find caregivers. But moving to Massachusetts in the middle of a pandemic, it's difficult to find people who want this kind of work and will be reliable and do a good job. I do have someone now who has been very good, but it's been a difficult process. I have set up an agency for emergencies, but we must pay \$30 an hour out of pocket because MassHealth does not cover agency staffing. On days when we must pay out of pocket, I'll only schedule three hours because I can make it work if I'm set up a certain way. It's not ideal, but I have no other choice. It's a precarious balancing act.”



Devins with Chicory, her service dog.



### WHAT DO YOU DO TO RELAX?

I enjoy reading fantasy stories like *Lord of the Rings*, the *Wheel of Time* series, and *Harry Potter*. Brandon Sanderson is my favorite author.

### WHAT DO YOU GET OUT OF YOUR UNITED SPINAL MEMBERSHIP?

Community and a sense of shared understanding. There are so many things that resonate about our shared experience that it means a lot.

# THE DISABILITY GUIDE WE'VE BEEN WAITING FOR

**R**ooted in Rights Editor Emily Ladau has gifted the disability community with a short, simple book that packs in just about everything we wish our friends and families understood about disability but don't know how to tell them.

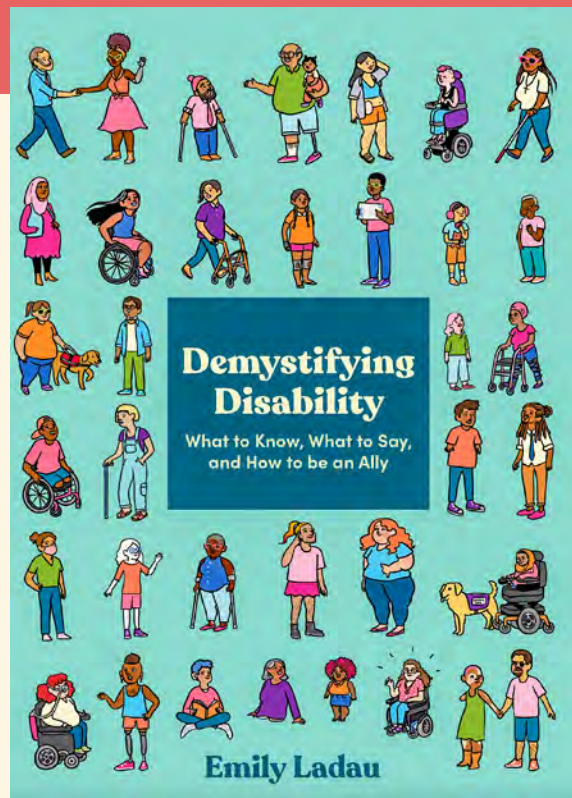
In less than 200 pages, Ladau demonstrates intersectionality and a cross-disability approach, breaks down all the various models we're subjected to and even presents an updated etiquette guide. She enlists quotes from fellow thinkers with disabilities, such as doctoral student D'Arcee Neal, a Black wheelchair user with cerebral palsy. "Being part of one marginalized community doesn't absolve you from understanding discrimination from marginalized people whose experiences are different from your own," he says in her book. She juxtaposes heady quotes like Neal's with down-to-earth language in the etiquette chapter that spells it out more simply: "Follow the Golden Rule and treat others as you'd like to be treated. But, also, try not to make assumptions about what that may mean."

Although honest, Ladau's book is especially kind. She understands that we don't know all there is to know about each other, where we're from, what abilities we may or may not have or the life experiences that brought us to her book. It's written for the nondisabled student taking a class and the jaded old activist who'll go to the mat for the correct (although slightly outdated) person-first language formula.

Read Ladau's book if you want a primer on the various disability rights movements. Read it if you are interested in our combined history or how language is evolving around all types of disabilities. And give it to a friend or family member or prospective personal assistants to read if you'd like them to understand, gently, where you're coming from.

The following excerpt from chapter two of Ladau's book deals with what it means to identify as disabled. It's an insider's look at who we are, how we see ourselves and how we'd like to be seen.

— JOSIE BYZEK





## DEMYSTIFYING DISABILITY

Excerpted from *Demystifying Disability: What to Know, What to Say, and How to Be an Ally* by Emily Ladau with permission from Ten Speed Press, an imprint of Penguin Random House.

### CHAPTER 2: UNDERSTANDING DISABILITY AS PART OF A WHOLE PERSON

My relationship status with disability is complicated. On one hand, my disability is an integral facet of my being. It is completely intertwined with how I think and how I move. I consider it to be an identity — in many ways, my defining identity, although I don't want to be solely defined by it. Confusing, I know. I take pride in being disabled, and it's brought me to a whole culture and community that I love. But on the other hand, it's not always sunshine and roses. I struggle with physical pain every day. I feel the emotional toll from lack of acceptance, sometimes from others, sometimes within myself. But I am disabled. It's part of me.

Here's some food for thought: Disability is the only identity that anyone can suddenly take on at any time. Don't worry, though! That's not a threat. Disabled people are actually pretty cool, in my humble opinion. Disability is deeply personal and means different things to different people. Some people consider disability to be an identity. Some consider it part of who they are, but not an identity. And some who technically have disabilities choose not to identify as disabled at all. This choice is based on any number of factors and is totally up to each individual person.

Let's think of disability identity as a pizza. The crust is the foundation of who you are — your actual being. While every pizza has a crust, it's the toppings that make each individual pizza what it is. There can be infinite combinations of toppings. And even though millions of pizzas are made with the same toppings, no two slices are exactly alike. Having or not having a disability might seem like the most straightforward of the factors that influence what disability means to a person, but it's actually not quite that simple. Not only does everything on the following list influence what "disability" means to someone, but each factor also determines whether a person chooses to identify as having a disability — or reveals their disability at all. What toppings might be on a person's metaphorical pizza?

### NOTHING ABOUT US WITHOUT US

Many in the disability community use the slogan Nothing about us without us as a bold reminder of the fact that we're the ones who must be in charge of every aspect of

our lives. All too often, people with disabilities are relegated to the sidelines in conversations about issues that directly affect us — everything from individual circumstances to major policy decisions. I'd say this is due to an assumption that we can't communicate and advocate for ourselves, but it often goes beyond that. In far too many situations, it doesn't seem to occur to nondisabled people that disabled people can and do have our own thoughts, viewpoints and opinions. Journalists interview parents and "specialists" about us instead of coming directly to us. Doctors and teachers talk to caregivers about us instead of talking to us. Policymakers consult nondisabled "experts" about us instead of consulting us. You get the idea. But, as always, disabled people are the experts on our own lives. So please, don't speak for us, about us, or over us. Speak to us and with us.

In the same vein, many nondisabled people deem themselves advocates "for" the disability community. Believe me, I'm all about the power of advocacy, but it's absolutely crucial to make sure that people with disabilities are leading the charge in any and all efforts. Advocate alongside us, rather than on our behalf. Stand (or sit!) in solidarity with us, rather than moving ahead of us.

### PASS THE MICROPHONE

If you are in a position of privilege, rather than using that position to amplify your own voice, ask yourself whose perspectives are missing from the conversation. Then lift up and amplify the perspectives of those people who should be centered instead. This isn't necessarily just about keeping quiet and listening, though that's always a crucial part. It's often also about actively redirecting people who may be overstepping or who are ignoring the perspectives of disabled people entirely. It's about ensuring that disabled people are respectfully given the platforms, opportunities and space to make our messages known.

We need to remember that passing the mic isn't something that only nondisabled people need to do. Disabled people aren't off the hook. All of us must recognize the ways in which we are both marginalized and privileged, and to know when to step up and when to step back. I asked author and artist Naomi Ortiz — whose poignant work focuses on Disability Justice, intersectionality, and self-care for activists — what we all need to understand about passing the mic. "[It] is not a one-time thing," she said. "It's a series of choices to build relationships, learn together, disagree without silencing the other. It's about building up our capacity to honor difference and appreciate the messiness."



# Guitarist Eric Hawk Feels It Still

BY TEAL SHERER





“There are clothes in the washer, in the dryer, in a suitcase and on the floor,” says Eric Howk, the guitarist of the Grammy Award-winning Portugal. The Man. Tomorrow, he is flying from his home in Seattle to Los Angeles to do a show at the Beach Life Festival. After COVID forced him to take the longest break of his 25-year music career, he is trying to get back in the groove of life on the road. “I was awesome at looking at exactly how long I was going to be gone for and eye-balling exactly what I needed. I lost all those skills. I totally forgot how to pack.”

Instead of traveling the world and playing to sold-out stadiums, Howk, 40, spent much of the pandemic unpacking his long history of substance abuse. The isolation and uncertainty led him to confront what had become a dangerous and growing problem and seek treatment. Now sober, Howk is committed to raising awareness about the lack of accessibility in residential substance abuse rehab centers and helping others struggling with substance abuse.

#### THE FALL FROM THE TOP

When the COVID pandemic hit March 2020, Portugal. The Man had just come off the most intense run of its career with the global smash hit “Feel It Still.” “At that point, it was close to three years post-release of that song,” says Howk. “We had played it everywhere that would listen to it. And we were still promoting the hell out of it.”

Howk had two suitcases packed, his passport in his pocket and had checked into a flight to Mexico City for a two-week tour when the shows were canceled because of the coronavirus. It would be 16 months until Portugal. The Man would do a live performance again.

With their calendar clear, the band immediately started seeking out ways to fill it. “I don’t think any of us at that point knew how to take a day off,” says Howk. “I know I didn’t. So, we really poured ourselves into songwriting and recording, and we put the focus heavily onto our foundation.”

Howk kept busy during the day with Zoom meetings, appearances on nonprofit boards and press obligations, but the second those responsibilities finished, he’d start drinking alcohol and taking drugs. “I went to bed blacked out pretty much every night, and just stayed in that cycle,” he says.

Howk had been abusing alcohol for years and has a family history of it. “It took my grandfather



## PTM FOUNDATION AND UNITED SPINAL JOIN TO FIGHT SUBSTANCE ABUSE

Portugal. The Man's PTM Foundation is partnering with United Spinal Association to help bring awareness of the need for more accessibility in residential substance abuse and mental health treatment facilities. Howk would also like for there to be a database or other easy-to-access way of getting accessibility information.

"Addicts, people chemically dependent: the justifications, the excuses — it's something we're all really good at," Howk told United Spinal Association. "It's not good, because of lack of access, to provide one more excuse to not seek treatment. It's not good to have the best facility saying, 'I don't know if you can get in, maybe through the side door.' Or, 'The bathroom can't work, well ... but maybe we can take the door off the hinges, but you'd have no privacy.'"

Howk also wants to bring awareness to the over-prescribing of opioids for pain control. "When I left physical rehab in 2007, they were like great, go live your life — also here's your grocery bag full of pills." Howk later patted himself on the back for getting off these prescriptions, but in turn, he drank more alcohol. "I sure felt like it was making my nerve pain and my spasms better when really the damage I was doing to my body was so much worse."

If you or someone you know has encountered access issues at substance use disorder and mental health disorder treatment facilities, United Spinal wants to hear your story. Please contact the Online Help Desk at [askus-resource-center.unitedspinal.org](mailto:askus-resource-center.unitedspinal.org).

You can also view the Fact Sheet on Drug Addiction and Federal Disability Rights Law at [hhs.gov/sites/default/files/drug-addiction-aand-federal-disability-rights-laws-fact-sheet.pdf](https://hhs.gov/sites/default/files/drug-addiction-aand-federal-disability-rights-laws-fact-sheet.pdf).

To find the protection and advocacy agency in your state, visit [ndrn.org/about/ndrn-member-agencies/](https://ndrn.org/about/ndrn-member-agencies/).

out, and it took my father super early," he says. Howk wanted to get sober, but he always came up with excuses. "There's work to be done. There're things to do. There are singles coming out, promo opportunities and all that stuff. Which was all bullshit at the end of the day," he says. Howk was also using alcohol to help manage his nerve pain and spasticity due to a T4 spinal cord injury. In 2007, he was sitting against a wall in a friend's yard when the wall collapsed, and he fell 12 feet. "I was in a nonstop loop of making things much, much worse for myself," says Howk.

In September 2020, Portugal. The Man rented a theater in Portland to get back on a stage and record. "The first day, I showed up on time, sound-checked, got all my gear sounding good, and gave a bunch of fist bumps to my guys and the crew," says Howk. "We had a very productive day." When Howk got back to his hotel room that night, he drank so much that he didn't wake up for work that next morning. No number of phone calls or people from the hotel knocking on the door could rouse him. "It was definitely concerning," says Zach Carothers, Portugal. The Man's bassist and Howk's close friend. "I was worried if he was alive or not."

Howk scared a lot of people that day, including his fiancée, Cassandra. "We'd had

conversations in the months leading up to that moment where we had talked about it [Eric's substance abuse], and all of my biggest fears came rushing into my head," she says. In the end, Howk and Cassandra felt relieved that it was out in the open and that they didn't have to keep pretending that everything was OK. "He held himself accountable right away," says Carothers. "He said, 'Sorry! I think it's about time for your boy Eric to check himself into rehab.' I'm very proud of him."

## GETTING SOBER

Howk began researching in-patient substance abuse treatment centers. "When you picture a rehab facility in your mind, it's typically a cliff-side Malibu staircase kind of situation that doesn't scream out accessibility," he says. After a series of phone calls and Google image searches, Howk struck out in finding a place that was wheelchair accessible.

"I know people in the disability community that have white-knuckled or cold-turkeyed their way off different substances. Or they've just quit drinking altogether and more power to them," says Howk. "That is something I tried doing myself personally many times, and it just never took. For me, I needed more of a solid foundation because my relationship specifically with alcohol was something that so baffled me."

Howk settled on a facility in Seattle that had previously been a nursing home, built long before the ADA. He checked himself in on October 10, 2020. They had no accessible rooms but offered Howk a "big room," which he shared with other patients. Howk brought a raised toilet seat to help with transfers as the toilet was low and there were no transfer bars. The bathtub was totally inaccessible for Howk, so Cassandra ordered wipes and towelettes off Amazon so he could clean himself. "I've done tours in Eastern Europe, in South America, I've stayed at some pretty dicey places, made my way through some pretty dicey sidewalks, and used some pretty questionable restrooms. So, that was how I was able to make it work," says Howk.

While Howk was in rehab, Cassandra dove headfirst into a program for family



When not on the road, Howk hangs out with his pup, Diane Keaton.





Of his new bride, Cassandra, Howk says, "We're each other's people."

members of people in recovery. "I was also reading all the books and going to Al-Anon," she says.

Howk stayed at the facility for 28 days and credits it for saving his life. "In my darkest days, there were so many things that I was ready to leave behind. I didn't want to take care of myself, I didn't want to take care of my body, and that's the vigilance required of us as disabled folks. When I'm taking off days from myself, like my bowel program and the simplest bits of self-care, that could potentially kill me."

Howk and Cassandra got married in August at Snow Peak Farm in Wasilla, Alaska. "It's wild — that spot is actually a place she picked out, not knowing that I went to elementary school a mile down that road," says Howk. "It is the specific part of my weird area of Alaska that John and I and Zach from the band are all from."

"We're each other's people," says Howk about his now-wife. "We know what's going on with each other, and we're both super weird."

Howk also turned 40 in August and is embracing the milestone. He bought a pop-up tent, has been going camping, and fishes every chance he gets. "I've never been an 'I hope I die before I get old' kinda guy," he says. "I was always excited to continue on with the journey


of life. I didn't know how quickly I'd turn the corner, I guess, and how dramatically I would make this shift into wearing moccasins and listening to James Taylor, but I'm super here for it."


## BACK IN THE GROOVE

Portugal. The Man has been easing back into a show schedule — playing at festivals and doing shorter runs across the country. They have a tour set for early spring. "We really want to get out and play shows, but we are we're coming at it with an abundance of caution," says Howk. "The last thing a band wants to do is get together and get people sick."

Howk says it's going to take a lot for him to be comfortable back on a tour bus. "For the record, I was never comfortable on a bus anyway. I'm the odd man out with the wheelchair situation."

Howk is in his home studio putting the finishing touches on some song ideas. He has been sober for a little over a year and has an AA online meeting login and a password for every time zone in the world. "If I wake up at 3:15 a.m. and I'm feeling a little weird, I know there is a meeting waiting for me in Ireland that I can go jump on," he says. "I have transformed my life. I don't know that I would have been able to marry the love of my life and keep this career that is just starting to come back to me that I missed so much." NM





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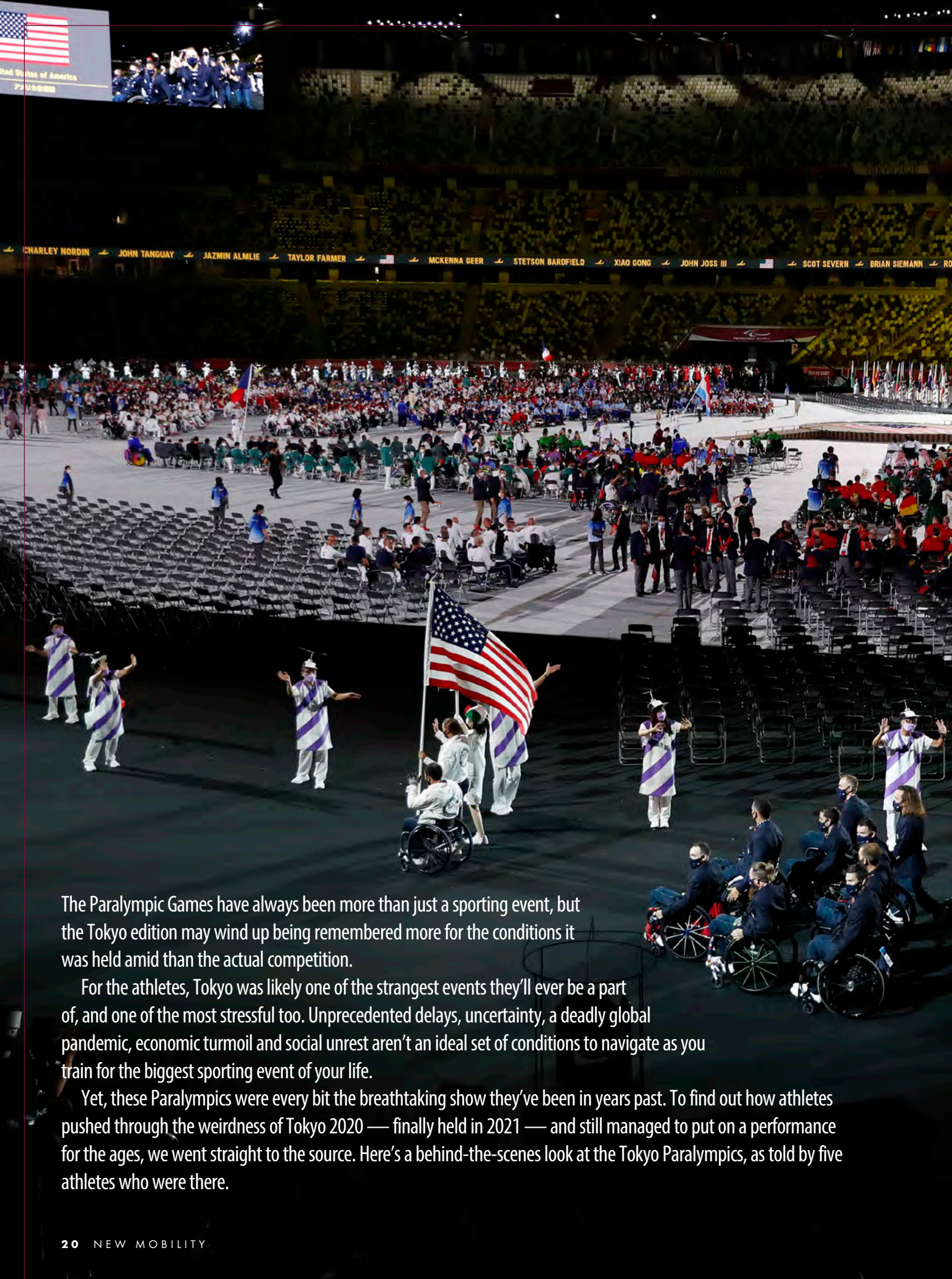
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The Paralympic Games have always been more than just a sporting event, but the Tokyo edition may wind up being remembered more for the conditions it was held amid than the actual competition.

For the athletes, Tokyo was likely one of the strangest events they'll ever be a part of, and one of the most stressful too. Unprecedented delays, uncertainty, a deadly global pandemic, economic turmoil and social unrest aren't an ideal set of conditions to navigate as you train for the biggest sporting event of your life.

Yet, these Paralympics were every bit the breathtaking show they've been in years past. To find out how athletes pushed through the weirdness of Tokyo 2020 — finally held in 2021 — and still managed to put on a performance for the ages, we went straight to the source. Here's a behind-the-scenes look at the Tokyo Paralympics, as told by five athletes who were there.



# AN ATHLETES' HISTORY OF TOKYO 2020 ONE



SHELBY BARON

**Sport:** Wheelchair tennis  
**Age:** 27  
**Disability:** Spina bifida  
**Hometown:** Honolulu, Hawaii  
**Previous Paralympic Experience:** Rio 2016  
**Tokyo Result:** Round of 16 (singles), Quarterfinals (doubles)



JOE DELAGRAVE

**Sport:** Wheelchair rugby  
**Age:** 36  
**Disability:** C6-7 SCI  
**Hometown:** Prairie du Chien, Wisconsin  
**Previous Paralympic Experience:** Bronze medal, London 2012  
**Tokyo Result:** Silver medal



ALICIA DANA

**Sport:** Handcycling  
**Age:** 52  
**Disability:** T9 SCI  
**Hometown:** Putney, Vermont  
**Previous Paralympic Experience:** London 2012; silver medal, Rio 2016  
**Tokyo Result:** Bronze medal, road race; bronze medal, team relay; sixth place, time trial



SUSAN SEIPEL

**Sport:** Canoe and kayak  
**Age:** 35  
**Disability:** Arthrogryposis multiplex  
**Hometown:** Ipswich, Queensland, Australia  
**Previous Paralympic Experience:** Bronze medal, Rio 2016  
**Tokyo Result:** Silver medal, canoe sprint; seventh place, kayak sprint



CHUCK AOKI

**Sport:** Wheelchair rugby  
**Age:** 30  
**Disability:** Hereditary sensory and autonomic neuropathies, type II  
**Hometown:** Minneapolis, Minnesota  
**Previous Paralympic Experience:** Bronze medal, London 2012; silver medal, Rio 2016  
**Tokyo Result:** Silver medal

## WAITING FOR TOKYO



**Shelby Baron:** I was playing some of the worst tennis of my life when the pandemic hit. I graduated from college and put off working so I could train, but I really questioned what I wanted to do. I put a lot of stress on myself, and my game was suffering. In 2020, when the word came down from the U.S. Tennis Association that we had to stop playing because of COVID-19, it actually came at a really good time for me. I needed a mental break.



**Joe Delagrave:** When the Paralympics were delayed, I took a pause to figure out what it meant. It meant that instead of five months of training left, we've now got 17 months ... oh crap. That was a big deal. I just had to let those emotions come through and feel them, and then go, "OK, let's make a plan for what that looks like for me as an individual and for my family."



**Susan Seipel:** Australia had extensive restrictions and many lockdowns leading up to the games. Fortunately, due to its solo nature, paddling was declared a low-risk outdoor activity, and I was able to take my Oru kayak out for exercise. While boat sheds were closed, the portability of the lightweight, folding kayak made it easy for me to throw it in my trunk and independently practice on any waterway when social gatherings were banned. It was great to maintain my fitness and keep a positive mindset, giving me a sense of freedom during the toughest lockdowns.

**Delagrave:** There was also the Team dynamic with wheelchair rugby. We had to figure out how to keep our chemistry and camaraderie together when we couldn't be together for what ended up being 10 and a half months. Some of the guys were pretty isolated and alone. So, in addition to Zoom workouts and film sessions, we'd

have some calls where we just had a beer or a drink or whatever and talked and hung out.

**Baron:** To stay sane, I got a little whiteboard and every evening I'd write out my schedule for the next day. Having little goals in my life helped me stay on track and productive. I went on walks with my coach, did workouts and got into cooking. With the time away from the court I focused on other things including my mental health. I started seeing a sports psychologist for the first time and once I got back on the court, I began to enjoy tennis again.

## 2021, HOPEFULLY



**Alicia Dana:** At 52 years old, I had looked to these games as my final hurrah and was eager and determined to bring home gold in at least one of my races.

Recent developments in the Paralympic movement [see sidebar, page 24] made me hang in there — the U.S. Olympic committee was now the



TOKYO 2020



Shelby Baron poses in the Paralympic stadium.

Paralympic Games



# Now Live from Tokyo — the Paralympics

BY SETH MCBRIDE

**“W**heeler! Why are you reaching?!” This was probably the most surreal moment of my Tokyo Paralympics television experience. Mark Zupan — a former Paralympic teammate of mine, a guy who among many others helped teach me the game of wheelchair rugby — was providing color commentary for the NBC television broadcast of wheelchair rugby, and he saw what I saw: U.S. athlete Josh Wheeler reaching for the ball late in the clock, getting called for a foul when, if he’d kept his hands on his wheels, the U.S. likely would have forced a turnover. I yelled the same thing as Zupan at the same time, only I was sitting in my living room, and he was being beamed into homes across America.

I laughed, and I marveled at how far the Paralympics had come. Back in Beijing 2008, at my first Paralympics and Zupan’s last, anyone who didn’t make the trek to China had to navigate a byzantine website system to, hopefully, find a balky stream of our games. Some sports you couldn’t find at all. The only way for an American who wasn’t already interested in Paralympic sport to happen upon it was via a 90-minute documentary or one of a few highlights shows broadcast months after the games. NBC clearly didn’t think there was much of an audience.

But times have slowly changed, and in March of this year, NBC announced that it would be airing the Paralympics on prime-time television for the first time ever, alongside 1,200 hours of total television coverage. What’s more, they invested in their Tokyo coverage. Alongside Zupan, you had retired Paralympic athletes like Chris Waddell, Alana Nichols, Paul Schulte and Scout Basset, among others, providing commentary and sideline reporting. Before the games, NBC had sent out job postings to current and former Paralympic athletes for a slew of temporary roles helping the network broadcast the game, everything from on-camera broadcasting to behind-the-scenes research.

When I first saw the postings, I thought it was pretty cool. But watching the games, I realized how big it really was: This had likely been the largest training program for people with disabilities in U.S. television broadcasting history. Add the onscreen broadcasting talent to the athletes themselves, and the Tokyo Paralympics were certainly the most visible that disability has ever been on U.S. television.

Perhaps the craziest thing about this increased coverage and increased investment in the Paralympics is how it came about: Advertisers demanded it.

According to Gary Zenkel, the president of NBC Olympics, it started with Toyota. “They said, ‘The Paralympics is as important to us, if not more important, than the Olympics.’ And they

wanted to know that we were going to stand behind that interest with more and more coverage,” Zenkel told the magazine *Amplitude* in May 2021.

Toyota — along with other major corporations including Nike, Eli Lilly, Comcast, United Healthcare, Peloton and Deloitte, to name just a few — realized years ago that disabled athletes make for good advertising. Watching a lot of the media coverage of the run-up to the Tokyo Games, I’d bet that Tatyana McFadden and Jessica Long were as visible and recognizable as any nondisabled athlete not named Simone Biles. It was these advertisers that gave NBC the resources to finally invest in their Paralympic



Joshua Wheeler of the United States in action during a training session at Yoyogi National Stadium ahead of the Tokyo 2020 Paralympic Games.

coverage in a way that countries like Great Britain and Australia have for a decade now.

And what’s more, people watched. According to NBC’s data, a total of 14.1 million viewers tuned into their television coverage, an 81% increase over Rio 2016, and the first-ever prime-time coverage of the Paralympics on August 29 attracted 2.1 million viewers. That’s still a fraction of what the Olympics draws, but the Olympics lost significant ground since the last games — with 16.8 million viewers a night for its Tokyo prime-time coverage compared to 25.8 million for Rio.

The numbers are good enough that Tokyo is likely just the tipping point toward a world where the Paralympics are mainstream. NBC certainly thinks so. “Los Angeles will be hosting the Paralympics in 2028, and that is the moment we are building toward,” said Zenkel. “For the event, for the sports, and for these athletes, that will be the watershed moment, and I really look forward to it.”

# Big, Welcome Changes for the Paralympics

A sea change is surging through the U.S. Olympic & Paralympic Committee — and it brings welcome news for elite disabled athletes. One new development is that Paralympic medalists now receive the same amount of money for their achievements as Olympians. How did this come about? Will Paralympians now enjoy the same institutional support by the USOPC as their Olympic counterparts?

We talked with Dr. Cheri Blauwet, a legendary wheelchair racer who won numerous marathons in New York City, Boston and Los Angeles and who medaled in three Paralympics games, all between 2000-2008. Today she's a sports doctor for Spaulding and Harvard Medical School and serves on the board of the USOPC.

**NEW MOBILITY:** We hear you have good news to share about the current direction of the Paralympics.

**Dr. CHERI BLAUWET:** We're in an era of very open-minded attitudes among the executive leadership and board of the USOPC. That's made the difference in progress for the Paralympic movement in the U.S. Although there is still a lot of work to do, there's now a better collective understanding that if we support the Paralympic movement, then all boats rise, to use that metaphor.

**NM:** Medal parity is an excellent example of a positive change by the USOPC. Previously a Paralympian gold medalist received \$7,500 compared to an Olympian's \$37,500. But Paralympians in the 2020 Tokyo Games got the same amount of money for their medals as Olympians, and 2018's Paralympic medalists received a retroactive payout. How did this come about?

**CB:** The Operation Gold program rewards medal payments to Paralympic and Olympic athletes, and there was a difference in the amounts for quite some time. After the 2016 Rio games, there was a percentage increase in the payments, however this created a further disparity. For example, picking numbers at random, say a Paralympian makes \$1,000 per medal and an Olympian makes \$2,500, and they each get 10% more. You've increased the percentage, but you've also widened the gap as the Paralympian would receive \$100 more, but the Olympian would receive \$250 more.

When that change was made, athletes rightfully started to speak up, and ultimately, the discussion made it to the board level. At the board, the discussion was very positive. It was clear that the ongoing disparity was not a tenable situation because not only was it unequitable, it also undermined athlete confidence in the movement.

Medal parity was unanimously approved by the board in September 2018.

I joined the USOPC board in 2017. As a Paralympian, it was meaningful to see that cultural change happen before my eyes. Medal parity transformed from a difficult to an easy conversation. It goes back to all those principles of change culture and creating relationships, as we had more Paralympians with a seat at the table. That's also what led to the name change in 2019 when Paralympic was added to U.S. Olympic

Cheri Blauwet crosses the finish line and wins the gold during the 2004 Paralympic Games in Athens, Greece.



Photo by Brian Bahr/Getty Images

& Paralympic Committee. I thought there would be lots of resistance, but there was very little. It goes back to the idea of a tipping point — it reached that tipping point.

**NM:** Despite the positive changes that have occurred, there's an enduring sense that our Paralympians don't always receive the same resources and support as Olympians. How is this changing?

**CB:** Sports medicine, athlete safety, career mentoring — all those things should be equitable to all athletes.

The sea change is that we added

well-being to the USOPC mission, which is now "Empower Team USA Athletes to achieve sustained competitive excellence and well-being." Our focus is still elite sports, but we do everything we can for those who become part of the elite system to enhance their performance while also protecting their well-being.

The resources accessed by Paralympians vary a lot from sport to sport and athlete to athlete. Part of that is because organizations that promote elite sports often use a funding model that inherently rewards good performance. If you have a well-performing sport, then more resources are allocated. The same thing is true on the Olympic side. The resources given to a sport like swimming — where we typically win many medals — are more than those given to athletes in a sport where medals are not typically won.

If you look at Paralympic resources, some areas like sports performance, high-performing training support, and direct funding to athletes, vary based on how the athlete and sport perform. But the well-being support and the core things needed to compete safely — such as sports medicine services — are equally afforded to all athletes once you reach the elite level, regardless of your podium potential.

**NM:** What are the barriers athletes face to reach that level?

**CB:** One challenge we have in the U.S. is our pipeline. In terms of athlete support, for the Olympics, the whole collegiate system exists. That's much spottier for the Paralympics, although there are some phenomenal programs in places like the University of Illinois and the University of Arizona.

One of our biggest challenges is we don't have that same National Collegiate Athletic Association infrastructure to support their journey to becoming elite. Paralympic athletes have to seek out their sport, then find where to train, practice and get the equipment. Often with nondisabled athletes, the sport finds them. You just join a team and give it a try. With Paralympics, you have to look around and ask, "What programs are in my area? How do I get the equipment?" It's just a lot of work.

**NM:** Despite these lingering challenges, it sounds like the Paralympics are better supported and respected by the USOPC than ever before. There's so much good news!

**CB:** It's not like it happened overnight, but now the culture and attitudes are in the right place. Although there is a lot more work to do, it predicts very good things for the future. Now we're growing together rather than the Paralympics being seen as an afterthought.

It's a pleasure to be part of it, and there's more to come!



U.S. Olympic & Paralympic Committee, and the pay scale for us Paralympic athletes had at last reached parity with our Olympic counterparts. As a single mother with no other significant source of income and my daughter nearing college age, this was a golden opportunity — pun intended — to provide some means for her education. Armed with over 10 years of experience in the sport, a record of success at the highest level, and the motivation and grit of an “older” Mama Bear, I was ready to get the job done.



**Delagrave:** When we started having training camps again in 2021, the biggest mental piece for me wasn't the fear of getting sick or dying from COVID, as our team ended up being fully vaccinated, but just the fear of a positive or a false positive COVID test. You're training your butt off, working toward a goal, and then day before the championship game or even at the airport you could test positive, and it would all be over.



**Baron:** I was not confident that the Paralympics were going to happen — not when I got the call that I qualified, and not even while the Olympics were going on. They canceled fans and kept saying worrisome things that made me think it was truly up in the air. Still, I made sure that I wasn't going out with anybody because I needed to stay healthy and COVID-free.



**Seipel:** We needed three negative PCR tests taken 14 days, 72 hours, and 24 hours before our flight. For PCR testing, a health care worker took a nasopharyngeal swab, which is not the most pleasant procedure. We also had to limit movements two weeks before leaving to avoid becoming a community close-contact and were discouraged to check in at public places like shopping centers and restaurants. Sadly, there were no celebrations with friends and family before we left.

**Delagrave:** We have 12 guys on our roster and one coach who uses a chair. With competition chairs that equals 26 wheelchairs in total. Our home base, where we had our last training camp, is in Birmingham, Alabama. The first leg of our flight to Japan was on a small, regional jet from Birmingham to Chicago. Our competition chairs and wheel bags flew the day before to make room for all of us and our wheelchairs. It made for much easier logistics and alleviated some stress for the long day of travel to Tokyo.

**Baron:** Our team went to Florida to train before flying to Japan together. Even the plane ride was nerve-wracking. Our flight was pretty empty because there were no tourists, but we all stayed away from each other knowing that if one person tested positive on the plane we would have to quarantine at the airport. Other than that stress, it was a good flight — I had a whole row to myself. Once we stepped foot in the village after a long travel day, I let out a huge breath of relief.

**Delagrave:** We spent three hours going through COVID protocols upon arrival at Haneda Airport in Tokyo. It was a critical game of hurry up and wait. The last step was waiting for the test results to come back — the final hurdle to gain access to accreditation and a bus ride to the village. The Tokyo 2020 official came up and said we were all good to go except for one person whose test results were inconclusive. The lady said the four numbers that identified the player and we all looked to see if it was ours. Of course, it was mine, so we waited some more. It was terrifying, to say the least.

Fortunately, 45 minutes later we had good news: My second test came back negative. Away we went to the village.

## OPENING CEREMONY



**Chuck Aoki:** We all knew the Tokyo Games would be different and that having no fans in the stands and arenas would lead to

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a quieter experience. But the process of preparing for the Opening Ceremony was still thrilling as we got fitted for our outfits — dressed up fancier than most of us had been in a long time — and rode the buses to the stadium. And we still felt the energy from our fellow Team USA athletes and the rest of the world.

This opening ceremony was extra special for me, as I was honored to be chosen as one of our two flagbearers, alongside Melissa Stockwell, to lead our delegation into the stadium. It is hard to express what an honor it was. Team USA has so many incredible athletes, and for them to choose me as one of our representatives is something I'll never forget. I felt a surge of emotions as we headed down the tunnel into the stadium, accompanied by over a hundred of our athletes chanting "USA! USA! USA!" at full volume. It was the kind of moment you read about in books or see in movies, not something you live yourself. I can't thank my fellow athletes enough for giving me this once-in-a-lifetime moment.



Chuck Aoki passes the ball during the gold medal wheelchair rugby match.

As we entered the stadium, a gigantic American flag was placed into my wheelchair's specially designed flag holder — hint: it involved many zip ties. Melissa walked beside me as we proudly led our delegation. It was certainly different from the London or Rio Games, where tens of thousands of cheering fans greeted us. It was almost

eerily quiet, given the size of the space. I couldn't help but feel a little sad, as I do not doubt that in a non-pandemic world, a roaring, packed crowd would have welcomed us.

While the absence of stands overflowing with spectators hurt some, it was still a special moment.

## GETTING INTO THE GROOVE



**Baron:** Village life was different from what I experienced in Rio. When we weren't playing or practicing, we basically went to the cafeteria and then back to our building. There was a resource center called "the ARC," and an international center, where you could go shopping or get your nails done or haircut, but that was it.



**Seipel:** COVID restrictions for our team within the village included not being allowed to enter the dining hall or gym or other buildings (there was a canteen and gym in our accommodation building). We could not spectate at other sports due to crowd limits. We had to wear masks at all times and maintain social distancing. On top of that, the Australian team did not attend the opening or closing ceremonies.

**Dana:** I didn't exactly hit the ground running. Jet lag, the interminable CO-



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VID processing through Narita airport, the worry over not having achieved an ideal upper body and head position or suitable hands-free hydration system on my handcycle, plus intense performance pressure, all combined to create few nights of decent sleep and resulting days of uncomfortable emotions.

**Baron:** Other than not being able to leave the village, the biggest difference was in Tokyo, we couldn't go support our teammates in other sports. I watched so many sports I had never seen in Rio, and I missed that in Tokyo. Team USA athletes could watch different competitions at the ARC, but it wasn't the same.

On the positive side, the lack of options helped me focus. It's always good to just be able to isolate yourself from others to focus on your own preparation. At the same time there was more stress knowing that I needed to stay away from people. Every day, before eating or drinking anything, we had to submit a vial of spit for COVID testing.

**Seipel:** Despite all the limitations, I loved village life and there was a great vibe within the Australia Team. There were televisions placed around our building so we could support our teammates virtually. The village is like a community of diversity and acceptance. No one stares at a person eating using their feet or at mobility devices because it's the majority. Everywhere is accessible and difference is normalized. It's a wonderful place. I wish the real world was more like the Paralympic village.

**Dana:** The closer it got to race day, the more panicked I felt at not having my body and mind rested and tuned or my equipment 100% dialed. It began to feel like a race before the race — to reach a point of “finality” with my preparation, at which point I felt I could relax and focus entirely on the race. Fortunately, I got help from a teammate on my equipment issues and opened to two of my coaches about my mental stress and they were able to help me deal with it.

## FINALLY, COMPETITION

**Dana:** I awoke race day morning feeling pumped. Nervous, but the kind of nervous that mainly was excitement. I felt good. Ready.

**Baron:** For all the talk of what it would be like to not have fans in the stands, honestly, there aren't a lot of people watching at most wheelchair tennis competitions, so it wasn't that weird. It's good we had the opening ceremonies as they distinguished the event and made it feel a little bit more prestigious. As one of my teammates said, without the opening ceremonies it really would have been just like any other tournament.



**Delagrave:** The lead up and the warmups didn't have the same allure as London or Rio, with the huge, cheering crowds. But competition-wise, we've played in front of three people at a random public gym how many times? This was the most competitive pool wheelchair rugby has ever had at

the Paralympics, and once the ball was tipped, the intensity was absolutely the same level as previous games.

**Seipel:** The lack of a crowd didn't affect my racing. I pulled my blade through the water, propelling the boat forward into the start bucket. I looked down my lane toward the beautiful Tokyo Gate Bridge and took another deep breath. The starter called, “Hold your boats, ready, set.” The bucket dropped beneath the water, and that's all I remember ... the race was a blur.

**Dana:** At the countdown, I was off like a demon. The whole first lap went like butter. Suddenly [on the second lap], my chain came off, getting jammed on the inside of the ring. [A coach who arrived told me] I was 40 seconds ahead of the competition. She struggled. I waited. Then the second staff person joined us. The two of them fumbled some more while I sat there, feeling the seconds turn to minutes, the golden dream becoming a nightmare.

Nearly five minutes passed while riders I had passed came by me. Finally,

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the chain was re-positioned, and I was able to start moving again. Lactate that pooled in my muscles made it feel like riding through mud, but I forced my arms to turn the cranks around, knowing the pain was temporary. I pushed like my life depended on it, but inside, I knew that it would never be enough, could not possibly be enough, to make up those excruciating lost minutes.

**Baron:** I lost my last match pretty late in the day. In general, it wasn't the result I

wanted ... I felt like I probably could have gone further under different circumstances. I had one day to figure out my flights, and then I left the next morning. It felt like punishment — you lost, now go home.

**Seipel:** As I watched the replay of the race, my memories flooded back. I recalled changing my paddle from my left hand to my right to steer the boat and some powerful strokes to pull away from the field at the finish line. Out of the corner of my left eye, I saw my oppo-



nent in front of me. I felt extreme happiness and relief — I knew I had the silver.

The medal ceremony took place about an hour after the race. We were given a lot of instructions before the ceremony around COVID protocols. Traditionally the medals are handed to the winners by dignitaries, but this time the athletes had to collect them from a tray. I was slightly overwhelmed by the occasion and completely stuffed this up by instinctively reaching for the medal in the middle — the gold — and was hastily corrected. The gold medalist asked if she could present my medal to me. Breaking all COVID protocols, she did, along with a big hug. I was honored and bursting with pride.



**Delagrave:** The medal ceremony was tough for me. Right after we lost the final, I found and congratulated Jim Roberts, one of GB's players

who was a teammate of mine in our league in the U.S. They whisked us off the court, and a doping control officer came over to me. Oh great — I was it for peeing in a cup. He followed me around everywhere and I had dysreflexia during the ceremony so there were a lot of distractions.

What brought it all home, though, was afterward — you pick up your phone and hear from everyone and their grandma, all watching at home on NBC-SN. They're all just proud to see you out there representing your country. That was really cool.



**Baron:** I didn't feel great the day after losing, but I knew that a lot of people had already exited the village by that point. Within 36 hours of stepping off the court I was gone.

When I got back to the States, I was jet lagged and upset. But then I talked with my sports psychologist, and he asked, "Were you actually happy with how you played?" I realized I was, and I came to terms with everything pretty quickly. After five years of training and living my life around tennis, suddenly I was free again. I'm not sure what's next. I got my master's degree in speech therapy. Now I need to find a job.

MM

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# PUTTING DISABILITY CENTER STAGE

Wheelchair Sports Camp's  
Kalyn Heffernan plays the  
Cheshire Cat in Phamaly's *Alice  
in Wonderland*.

BY GREG MOOMJY

For many of us who live with disabilities, seeing Ali Stroker become the first actor with a disability to win a Tony for a featured role on Broadway in 2019 was a flashbulb moment. Her speech, which received a standing ovation, made it clear that the gravity of the moment was not lost on her. In a pithy remark, she said, “This award is for anyone with a physical disability or limitation who wants to see themselves represented in this arena. You are.”

However, because the stage had no ramp access from the audience, Stroker spent the evening prior to her historic win sitting backstage rather than enjoying the show with her peers, just so she could roll on-stage to receive her award — if she won.

Stroker's Tony experience perfectly encapsulates the difficulties faced by disabled performers all across the country. Not only was there a lack of physical access to the stage, but there was also a lack of awareness about what full inclusion for disabled performers really means.

Thankfully, several organizations throughout the United States are dedicated to finding and nurturing actors with disabilities, giving them a chance to hone their craft in an accessible environment, allowing them to express their creativity and find their voices. If they have their way, Stroker's win won't be the last.

## Accommodating Disabled Actors

“The entertainment industry is one of ‘beautiful people,’ so anyone who doesn't fit that ideal is often overlooked,” says Ann Marie Morelli, an actor with multiple sclerosis and a long-time company member of Theater Breaking Through Barriers in New York City. The main difficulty facing actors with disabilities today is one of fear, she says, and this fear goes both ways. Since disability encompasses many limitations, theatre administrators and professionals are hesitant to audition actors with disabilities. Similarly, disabled actors are often reluctant to audition due to a lack of accommodations.

Initially founded in 1979, TBTB was first known as Theatre by the Blind but changed its name to be more inclusive to actors with a range of disabilities. Today it is the only off-Broadway theater company dedicated to advancing people with disabilities at all production levels.

“We want to be able to meet as many artists as possible so we can continue expanding our circle and create more opportunities for all,” says Tucker Burroughs Salovaara, a power wheelchair user who interns on the business side of TBTB. Accommodations are expected and may include large print or Braille scripts, American Sign Language interpreters, or extra spacious audition rooms to accommodate wheelchairs. “We also open our auditions to designers, stage crew and





TBBT's actors are compensated for their work, says Ann Marie Morelli. She's the wheelchair user in this photo.

## Pandemic Possibilities

The Covid pandemic has yielded some unexpected advantages for disabled actors, which have been a boon for equity and inclusion in the performing arts. Tucker Burroughs Salovaara, a business and administration intern at Theater Breaking Through Barriers, points out that TBBT has held both performances and auditions virtually during the pandemic. This has several benefits. Productions staged online or over Zoom immediately preclude any problems of accessibility as far as getting actors literally on stage. Also, since the camera only shows the individual from the chest up, this levels the playing field because audience members or casting directors are not as readily able to see if the person is in a wheelchair or not.

even to a tech guy like myself," adds Salovaara.

Members of TBBT's company are professionals. "From the beginning, artists have always been compensated for their work whether it is a main stage contract or a small honorarium for play readings," Morelli says. "Many performers have had the opportunity to earn their Actors' Equity card." An equity card for the stage actors' union is an effective way to get auditions, and she says that many of TBBT's performers have gone on to other companies and into film and television roles.

## Theater for All

Showcasing actors with disabilities on stage is of utter importance. At the same time, it is also crucial to ensure that theaters' repertoires include stories that reflect a variety of disabled experiences. There are several programs dedicated to cultivating disabled voices. Among these are Theatre for All in New York, Phamaly in Denver and an online course for playwrights designed by the Dramatists Guild.

Theatre for All is an initiative of Queens Theatre in New York City established in 2018 to showcase and cultivate disabled talent in all aspects of theater, including acting, playwriting and directing. Today the program has grown to include well-known disabled actors in its administration, including Gregg Mozgala, an actor with cerebral palsy who has appeared in music videos and documentaries.

Actors who join this intensive program receive instruction in voice training and scene study. Participants also attend

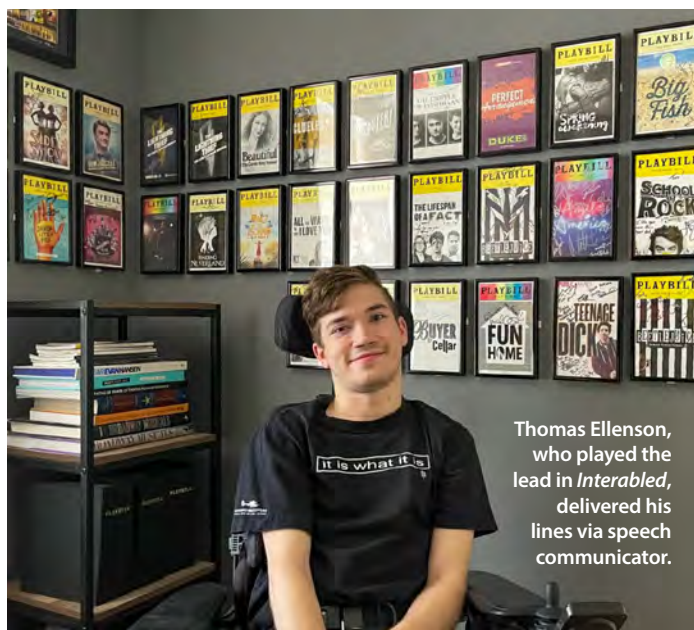
workshops on theater and video acting, commercials, movement, auditioning and improv. The program culminates in a performance of plays written by disabled playwrights or featuring disability themes.

One such play, *Interabled*, was written by Marianna Mott Newirth (full disclosure: it is a play based on my life as a 20-something-year-old wheelchair user with cerebral palsy). It starred Thomas Ellenson, a 24-year-old actor with CP.

Mott Newirth specified that the lead needed to be played

by someone with CP. But she hadn't considered how an actor like Ellenson, who is non-verbal and uses a speech-generating device via an iPad to communicate, would deliver the character's lines. She learned to adjust to the cadence of his lines to allow him time to input them into his communication device. "I had to tailor my message to the capacity that my actor had to deliver it, which inherently shifts the eye, the way the piece lands and enriches it. Tom brought an energy to the piece I could never have even thought of."

Other programs that seek to elevate disabled voices in the theater include a Dramatists Guild class taught by Anita Hollander, a disabled actor and playwright. For 10 weeks, using John Selef's "At the Intersection of Disability & Drama: A Critical Anthology of New Plays," attendees discuss the role of disability in theater from several angles, including allyship, accessibility, medical models, identity and more. Guest speakers include Mozgala



Thomas Ellenson, who played the lead in *Interabled*, delivered his lines via speech communicator.



and Monique Holt, the co-director of MAP Deaf Theatre Festival, and the class costs \$400.

Additionally, TBTB recently restarted its playwriting group, which aims to give disabled artists a safe space to create original work that may or may not feature disability as a storyline.

## A New Take on Disability

Efforts to better integrate the disabled perspective to the theater world are not limited to New York. Colorado-based Phamaly has been providing opportunities and challenging norms since 1990. Phamaly, an acronym for Physically Handicapped Actors and Musical Artists' League, performs a wide range of shows, from musicals like *Guys and Dolls*, plays like *Romeo and Juliet* and challenging new productions like the world premiere of *Alice in Wonderland*, which featured music composed by the hip-hop group, Wheelchair Sports Camp.

The actor Regan Linton, a paraplegic and manual wheelchair user, made her mark on Phamaly as its first artistic director with a disability. Linton points out that both disabled and nondisabled individuals comprise the company's administration. The hope is that they will take what they have learned about inclusion to other companies once they leave.

There are a few glaring omissions from Phamaly's long history, such as a *Christmas Carol*, *Of Mice and Men*, and *The Secret Garden*. According to Linton, as canonical as they may be, these works do not depict the true disabled experience in all of its variety and complexity.

When Phamaly does tackle problematic classics, it uses disabled talent to cast the stories in a new light. Such was the case with the recent performance of *Side Show*. The musical takes place at a carnival sideshow and tells the real-life story of conjoined twins who were vaudeville performers. It opens with the song, "Come look at the freaks," immediately establishing the show's intent to explore the tension between the private lives of

the sideshow attractions and their public persona. "The show took on a completely different energy and spirit by having people who have actually experienced being treated like freaks out in the wider world singing those lyrics," says Linton.

"The musical has its flaws and was not originally performed — or intended to be performed — by actors with disabilities," says Linton. But for Phamaly's actors, "It was an opportunity

for us to throw our experience right in people's faces, and be like 'Look, this is who we are.'"

Phamaly's *Side Show* production gained acclaim among the Denver press and public, in part because of the way the company was able to present the subject matter. "When it was on Broadway, the two actresses who played the twins were not joined in any way — they just walked next to each other," says Linton. "In our production, one twin — me — couldn't walk, and one could. But we used a big bariatric wheelchair. We sat next to each other, and one of us would wheel one side while the other one pushed the other side. It meant that we actually had to work together to move. The interdependence was so much more authentically present."



Actor and writer Regan Linton is also Phamaly's first disabled artistic director.

## Moving Beyond Representation

A recent article in the *New York Times Magazine* mirrors Linton's perspective by illustrating what a disabled actor can bring to the role of a character with disabilities. The article dealt with portrayals of blindness and visual impairment on TV. The writer noted that when sighted actors play characters with visual impairments, they usually look off to the side when talking to other characters. However, a blind or visually impaired person can train themselves to recognize the direction from which sound waves are coming to make eye contact.

Life with a disability is a nuanced experience encompassing a wide range of both capabilities and limitations. Fortunately, some in the entertainment industry are finally starting to understand the value of casting disabled actors to play disabled characters. But many disabled performers want to move beyond simple representation to full inclusion. "As performers ... we want to be able to play any role," says Morelli. "In theater, we create the reality. Disability only matters as much as we want it to."

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Ali Stroker is the first wheelchair user to win a Tony Award.

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# 5 STEPS TO FINDING THE RIGHT DISABILITY LAWYER



BY KELLEY BROOKS SIMONEAUX

Six months after my spinal cord injury, I sat in my new manual wheelchair in the living room of my grandparents' house, surrounded by a room full of lawyers and engineers who had flown in from around the country to discuss my injury and whether the car manufacturer was liable. The car I was a passenger in when I became paralyzed had been purchased by the lawyers and was being stored in the barn outside.

After a great deal of discussion and measuring, the lawyers explained I had a “textbook lap-belt injury” — I was a low-level paraple-

gic because I only had access in the center rear seat to a two-point restraint instead of a three-point restraint seatbelt. The lawyers told us that car manufacturers had known the two-point restraint lap belts allowed in the center rear seat at the time could cut into a person's lower abdomen and damage the spinal cord, but still decided it was easier to pay paralyzed victims than to fix the flawed restraint system.

Even as a 16-year-old, this information angered me. Car manufacturers were not addressing the safety of the passengers. I could see it

would take more cases being filed in court along with a push for policy changes to right this wrong. It would take lawyers who wanted to go against these giant companies to help bring about this change. I decided then I would be one of those lawyers.

I went on to graduate high school, college and law school. I decided to devote my career to helping those with spinal cord injuries and disabilities navigate the legal world. Between my experience as a client and over a decade as a lawyer, I have seen how difficult this can be for people with disabilities and how valuable the right help is.

After the living room meeting, the lawyers put together their argument that the lap belt was the reason I was now paralyzed and what that paralysis would cost in my future. The goal was to get some type of settlement before my case could be completely thrown out. Had they not been proactive, educated and competent in this complicated area of law, I could have recovered nothing.

The need for good legal representation is not limited to how someone sustains a spinal cord injury. It also includes navigating Social Security, housing, wills, estate planning, special needs trusts, civil rights law, employment, work injury, divorce,

child custody and more. These are complex issues and adding a spinal cord injury or other disability can make the need of retaining a qualified lawyer even more important.

Knowing where to begin when you believe you have a situation that requires legal assistance can be overwhelming. However, if you believe that you need to engage a lawyer, here are five steps to ensure you get the best outcome.

## 1. Decide What Type of Attorney you Need

Each area of law brings its own set of laws, challenges, and specific guidelines. Not every lawyer is qualified to help in every legal situation. While there are plenty of attorneys that may be willing to look at your potential case, unless they have specific background, knowledge, and experience in that area of law, they will not be able to best serve your interests. Just as you would not go to a neurologist for bad allergies, it is important to seek out a lawyer with expertise in the area of law that your concern involves.

Several years ago, I met Sarah. She became a quadriplegic when the car she was a passenger in flipped over and the roof crushed her head. She called me frustrated with all she had going on in life. She was trying to establish herself amid a post-injury divorce while working on qualifying for government benefits. She was scared a settlement could affect her ability to maintain services she needed to survive. Who was the right lawyer for Sarah? The answer was three different lawyers.

She needed a lawyer to help advance a complicated product liability case. She also needed a family law attorney to assist with her divorce and make sure her custody rights were protected. Finally, she needed an attorney that could assist in setting up a special needs trust to protect her government benefits if she received a personal injury settlement.

I helped connect Sarah to the different lawyers she needed. Importantly, these three lawyers also needed to coordinate with each other so that her various issues could be addressed with the other issues in mind. Months later, I checked in with her. “Things are still hard, but now I have a plan,” she says. “Most importantly, I have advocates helping me so that I can focus on my physical health and emotional recovery. I am getting stronger and more independent day by day.”

## 2. Do Not Delay in Engaging an Attorney

Time is not on your side when faced with a legal matter — do not delay in engaging an attorney. The more time goes by, the more difficult it becomes to preserve evidence, protect the statute of limitation (the time you have to bring a claim in court) and prevent the unnecessary delay of a resolution. I often talk to people with valid legal claims but too much time has passed, and there is nothing that can be done.

In my case, it was imperative for the lawyers to buy the wrecked car and store it at my grandparents’ farm to be reviewed by experts. Had we waited to retain an attorney, the vehicle would have likely been sent to a junk yard and I would have lost my opportunity to bring a claim. In other types of cases, such as child custody, a delay in time could mean seri-

## QUESTIONS TO FIND THE RIGHT LAWYER

You’ll likely want to interview more than one lawyer before deciding to sign a representation agreement. If a lawyer isn’t willing to take the time to talk through your concerns and questions, that should be a red flag that the lawyer is not going to work for your best interests. Approach your first interaction with the lawyer as an interview and do not be afraid to ask questions. Here are five to get you started.

1. Have you helped a person with a spinal cord injury or disability in the past?
2. What was the outcome of those cases?
3. What information do you need from me to best represent my interests?
4. What is the anticipated timeline to resolve my legal issue?
5. Is there anything that can be done immediately to help with my legal issue?



ous consequences to your ability to keep or fight for custody of children. Or in a Social Security claim, benefits you are entitled to could be unnecessarily withheld.

### 3. Find a Lawyer That Understands Your Disability

If your lawyer does not have a deep understanding of your disability, they will ultimately be unable to fully advocate on your behalf and get the resolution you deserve. For example, if your case involves a personal injury claim, part of the damages is the future care you will need. A spinal cord injury is a lifelong, expensive injury, and every aspect of your future care — housing, personal care assistance, urological supplies and more should be considered when calculating damages. A lawyer who does not understand the medical complexities of a spinal cord injury may undervalue your needs.

In other situations, having a lawyer who understands your disability is important because they will be better prepared to fight for your rights. If you have been discriminated at work because you require certain reasonable accommodations like an adjusted work schedule or an accessible workstation, having a good lawyer can ensure that all your needs are being addressed in a claim.

Unfortunately, there are predatory lawyers who see a client in a wheelchair as a quick payday. Rather than fighting for the best outcome, they work towards a quick resolution that may discount your actual damages.

### 4. Find a Lawyer That is Accessible

Your lawyer should be accessible physically, remotely and in terms of communication. At a minimum, the lawyer should have an office or virtual set up that is accessible to you based on your disability. If you are meeting online, any accommodations you need should be provided. In today's world, where many people work in remote settings, having direct access to your lawyer via cellphone may be necessary, as is knowing they will respond to phone calls and emails.

While lawyers are ethically obligated to maintain contact with clients, every lawyer does not take this obligation equally. What many lawyers fail to appreciate is that this is your life and your only case. They may forget how scary the legal world can be if you are navigating it alone. Find a lawyer that is open, communicative, responsive and willing to take time to explain what is going on in your case. It will ultimately save you anxiety and frustration.

### 5. Know the Fee Structure Before You Hire an Attorney

You should never feel unclear on what legal services will cost in your case. There are different types of fee structures for legal services, and some are more commonly used for certain types of cases. For example, in a personal injury claim, it is most common to have a case on a contingency fee structure. This means that you pay nothing at the outset of the case and the attorney

will receive a percentage of the recovery at the end as compensation for their work. This typically ranges from 25% to 40% of the total recovery, depending on the type and complexity of the case. Things to consider in this type of fee structure is whether you must pay for any of the experts or costs of the litigation upfront and if the attorney will require you to pay any fees if there is no recovery or a small recovery.

In estate planning or setting up a trust, a lawyer may work for a flat fee. This means that you pay a certain price for the services regardless of the amount of time it takes or the recovery. The other common fee structure is hourly rate services. This means that you pay the attorney an agreed-upon hourly rate for the work performed. The hourly rate of an attorney can vary based on the attorney's experience, geographic location, and years of practice. Be sure you understand not only what the hourly rate of the attorney is, but also the rates of any associate attorneys, paralegals or staff. You want to ensure that the attorney has a system in place to be transparent about what work they are performing and what they are billing.

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## HOW TO AFFORD LEGAL HELP

For many people, the cost of an attorney may prevent them from hiring one. Add in spinal cord injuries or other disability and a fixed income, and it may seem impossible to retain an attorney. Depending on the legal issue, different resources are available that can provide low or no cost legal services. Each state has a protection and advocacy agency created through the Administration of Community Living to help people with disabilities. In some cases, P&A may help provide services to help you advocate for yourself or provide no cost legal representation. Also, most law schools have legal clinics that provide no-cost legal services to people who have a qualifying low income. Each law school has clinics that specialize in different areas of law that could include wills, landlord/tenant and disability law. If you are unable to use the resources of a P&A or law school clinic, it is still possible in some situations to engage a lawyer on a contingency basis or a reduced hourly rate.



# DAILY DILEMMAS

By Sheri Denkensohn-Trott

## TO INFORM OR NOT TO INFORM? THAT IS THE QUESTION

**Q.** *I am a low-level quadriplegic who needs assistance in certain activities that require upper body strength. Recently, my family took a trip to Florida, where we saw an advertisement for a local snorkeling outfit. My wife, our two teenage children and I drove to the shop at the time listed for the afternoon trip.*

*When we arrived, other people were purchasing tickets and getting their gear. Some were already on the boat. My wife went to the counter to buy our tickets, and the attendant immediately called the boat captain. He told us we could not go out that day and said we should have called in advance about my disability. I assured him my family knew how to handle my spinal cord injury without special treatment. He called his boss and then gruffly repeated that we had to come back another time and must call in advance. It was humiliating to have this loud discussion while others were present. I was outraged because my family knows how to assist me. Additionally, since all patrons sign a waiver of liability before going out on the boat, why was I singled out?*

*How should I have addressed this situation in the moment? And is legal recourse appropriate because I was excluded based on my SCI?*

**T**hat's discrimination," says Cody Unser, founder of the Cody Unser First Step Foundation, and one of the leading advocates for accessible scuba diving. "It's not surprising, but it really should not

have happened at all."

While certain water sports, like scuba diving, have rigorous requirements for certification for all participants regardless of disability, snorkeling, which is much simpler and less dangerous, generally does not. If you wanted to go snorkeling on your own, you could roll down to Walmart, buy some gear and get started.

The operators may have been leery of taking you out because of unique, complicating factors, but that doesn't excuse their behavior. "This happens a lot in scuba diving, too," says Unser. Some scuba operators can be intimidated when someone with a disability comes into their shop, "but there's usually a way to figure it out."

As many businesses that offer snorkeling also offer scuba, Unser recommends checking the operator's certifications and reporting their behavior to the appropriate governing bodies. The leading certifiers are Scuba Schools Interactive, Professional Association of Diving Instructors and National Association of Underwater Instructors.

Reporting them may not help you in the moment, but it might prevent someone else from being discriminated against. The best advice for avoiding the situation in the future is to call ahead and inquire about any special requirements for people with disabilities. Ideally, such action should not be necessary — and one could argue it is discriminatory to single

*"If you want to go snorkeling on your own, you can roll down to Walmart, buy some gear and get started."*

out individuals with disabilities — but proactive notice can prevent them from being caught off-guard. There might also be logistical reasons for advance notice to the company. In your situation, the outfitter may want to ensure sufficient space for your entire family to snorkel together in the same outing.

If you call and are assured there are no special procedures for individuals with disabilities (and nothing written exists), but upon arrival are told that you cannot participate, make sure to get the names of the employee who barred you from participating. Then, if possible, file a complaint with the higher-ups.

When considering legal action, remember the time and cost of such an endeavor. Only you can decide if pursuing what is likely to be a small settlement at best is worth it. As an alternative, consider sharing an account of your incident on social media and online reviews. Sunlight, as they say, is the best disinfectant.





# REFRAMED

by Reveca Torres

## ODE TO A PARALYZED CHICKEN

Arriving to your new home in a cardboard box  
A woman on wheels welcoming something to care for  
Surrounded by your sisters all looking the same, but not you  
You, adventurous chicken, had to stand out  
A jump out of the box, ceramic impact on tiny fragile bones  
a new life of paralysis

How lucky you are baby chicken that I know what it's like  
I know when you close your eyes you're in pain  
I see how frustrating it is to try and move and go nowhere  
I understand sitting in your own shit is no fun  
I get you can't play with your sisters but still you want to be  
near all the action  
I will give you the best chicken life

Little bird, do you know x-rays and pain meds and vet bills  
were worth it?  
Hand-made slings, swings and walkers  
Your own personal physical therapist, a graduate of chicken  
anatomy from Google  
Hydration and feeding in between Zoom calls  
Social visits with the Silkie sisters  
Your first time on grass and learning to forage

Pollita it was an honor to care for you  
Is this a bit like my mother felt when I was so small  
and broken?  
Helping you was not a burden but a joy  
Is it possible that I too can be joy

Resilient modern-day dinosaur, you were here  
You were broken but never worthless  
You belong to a kingdom where wheels and splints are pillars of power  
Where we move our own way and it's beautiful  
Where our ancestors fought and we fight to claim our existence  
Where one day our castles will have access and we can live as kings and queens if we chose

*\*Megan The Chicken lived from March-June 2021*



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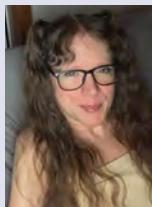
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## Meet New Member Cathleen Morgan

Age 52, from Middletown, New York  
C4 incomplete spinal cord injury  
Student and advocate



**Why I joined United Spinal:** I was blessed to have found NEW MOBILITY magazine right after my spinal cord injury. It introduced me to beautiful and positive disabled people, and it gave me hope.

**What is the one disability-related product you couldn't live without?** My hospital bed because it makes me feel safe. In it, I am able to do all the exercises I need to do to improve my spasticity.

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## THERE'S SOMETHING ABOUT DAN MURPHY

A generation before Ali Stroker became the first wheelchair user to win a Tony, there were other brilliant actors with disabilities laying the groundwork for her. One of these was Dan Murphy.

Best known for playing parts in Farrelly Brothers movies like *There's Something About Mary*, he explained how he got his break in New Mobility's May 2001 story "Dan Murphy, Actor." His life-long friend, Peter Farrelly, asked what he thought of *Dumb and Dumber*. "Peter, I didn't see anybody in a wheelchair in that movie," Murphy teased. Farrelly responded by offering Murphy a part in *Kingpin*, a comedy about an Amish bowling sensation.

"Before I knew it," he says, "I was in the Amish country of Pennsylvania with Woody Harrelson, Randy Quaid and Bill Murray. What a trip! It was weird watching guys I grew up with tell Harrelson and Murray what to do." He passed in 2014 and his absence is still felt. Read the whole story here: [newmobility.com/dan-murphy-actor](http://newmobility.com/dan-murphy-actor).

SPINOUTS



## NM LIVE VIDEO SERIES with Teal Sherer

Teal Sherer's NM Live video interview series will be moving to a truly live format this month on Instagram Live.

### NOVEMBER GUEST: DANI IZZIE, CREATOR OF THE DOCUMENTARY DANI'S TWINS

Dani Izzie is one of the few quadriplegics ever to give birth to twins, and she is sharing her pregnancy and early parenting journey in the documentary *Dani's Twins*. "My ability to be a mother doesn't depend on my ability to walk," she says in the film's trailer.

Sherer and Izzie will discuss parenting with a disability, the documentary and more. Follow us on Instagram @newmobilitymag for more information on the date and time.

*Dani's Twins* premieres in 2022. You can learn more at [danistwinsfilm.com](http://danistwinsfilm.com).

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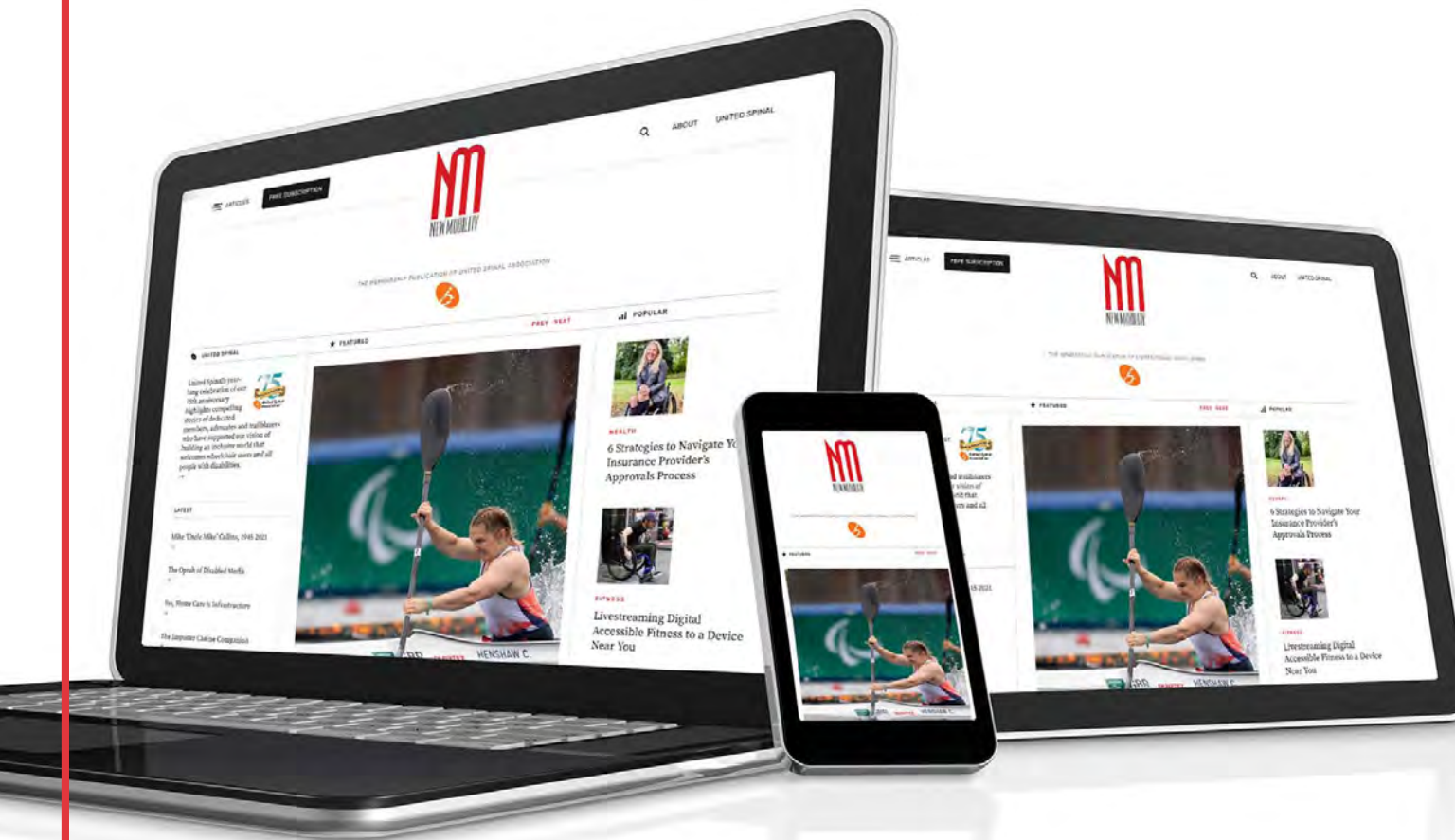
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