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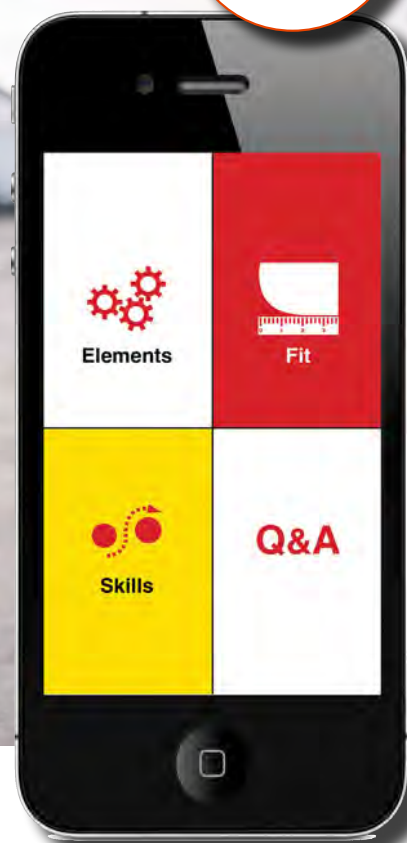
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— Tanya L., Physical Therapist/
Assistive Technology Provider



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[HTTPS://UNITEDSPINAL.ORG/MY-WHEELCHAIR-GUIDE/](https://unitedspinal.org/my-wheelchair-guide/)

COVER STORY

THE EXPAT LIFE

What is it like to give up the people and places you have known and start anew in a foreign land with different ideas on disability and access? MARTIN HENG talked with wheelchair users who have moved abroad to see how things are going and what their experiences have taught them.

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FEATURES

12 SELF-WORTH, SHAME AND SCI

Rediscovering a sense of self-worth can be an uphill battle after spinal cord injury. This collection of short essays looks at how different people adjust and find their place post-SCI.

22 FIGHTING INSURANCE ALI INGERSOLL shares her experience and talks with other wheelchair users to give you the tools and tactics to get the medical equipment you need, even when insurance denies your requests.

25 ACCESSIBLE FITNESS APPS Online adaptive fitness apps and videos are booming as disabled people look to shed the "COVID 15." JOHN LOEPPKY surveys the options and reports on what you can expect.

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**PRESIDENT & CEO: VINCENZO PISCOPO
VP OF PUBLICATIONS: JEAN DOBBS**

EDITORIAL

**PUBLISHER: JEAN DOBBS
EXECUTIVE EDITOR: JOSIE BYZEK
EDITOR: IAN RUDER
ASSOCIATE EDITOR: SETH MCBRIDE
SOCIAL MEDIA MANAGER: TEAL SHERER
EDITOR EMERITUS: TIM GILMER
SENIOR CORRESPONDENT: BOB VOGEL
CORRESPONDENT: AARON BROVERMAN**

CUSTOMER SERVICE

Toll-free 800/404-2898, ext. 7203

ADVERTISING SALES

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MANAGER, CORPORATE RELATIONS:
MEGAN LEE, EXT. 7253
ACCOUNT EXECUTIVE
ERIC HALL, EXT. 7185
AD MATERIALS: DEANNA FIKE, EXT. 7250

PRODUCTION

PRODUCTION MANAGER: DEANNA FIKE

CIRCULATION

CIRCULATION MANAGER:
BEVERLY SMITH

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BULLY PULPIT

By Ian Ruder

MIKE 'UNCLE MIKE' COLLINS, 1945-2021

One of the best parts of being the editor of *NEW MOBILITY* is building relationships with all of our readers and contributors. I look forward to the semi-regular emails and phone calls with our diverse crew, and I feel privileged to soak up their insights and wisdom and share them in the print and webpages of *NEW MOBILITY*.

If I had to list the contributors I have enjoyed corresponding with the most, Mike Collins would be very near the top of the list. He was an editor's dream, equally capable of writing about adaptive driving and accessible vehicles and tackling complex legal and advocacy issues. Every time we talked or emailed, he had interesting story ideas and seemingly had contacts in every field and every locale.

You need a source for a story on airboats? Mike's got a guy. How about someone knowledgeable in filing ADA claims in Idaho? Mike knows someone.

I met Mike when he was a source for one of the first stories I ever wrote for *NEW MOBILITY*. He told me about a rogue caregiver he'd employed who had rendezvoused with a secret lover in his house when he was on vacation. His advice for hiring caregivers: Avoid "shack up situations." The anecdote made my story and helped establish Mike as someone I knew I could count on.

As an editor, I always ask writers to show readers what they are writing about instead of telling them. Instead of listing all the examples and reasons why something is true and asking them to believe you, bombard readers with colorful anecdotes, characters and quotes that leave readers no other choice than to believe you.

Mike did this instinctively. He told stories in a way that highlighted exactly what *NEW MOBILITY* was about: living life to its fullest regardless of your ability. I never questioned how he developed this talent but reading his lovely obituary it becomes

obvious: Writing that way was natural for him because that's how he lived his life.

Mike and I only hung out once in person, a few years ago at a shopping mall Chinese restaurant, but we slowly became friends over phone and email. He'd update me on his latest accomplishments and struggles, and I'd do the same.



In the months before COVID, most of his updates focused on fighting insurance for approval of a series of surgeries he hoped would help him get back to living his life the way he wanted. A syrinx in his spinal cord had been slowly robbing him of the precious function he had always maximized.

Thanks to the same tenacity and savvy readers came to expect from him, he finally had everything lined up in the winter of 2020, then the pandemic hit. With hospitals postponing elective surgeries, Mike found himself back in a holding pattern.

That holding pattern came to an end June 14. As a lifelong advocate for the importance of living independently, it is fitting that Mike remained at home and spent his final hours surrounded by his daughters and sisters.

His legacy will live on, not only in the archives of *NEW MOBILITY*, but in the broader disability community to which he was so passionately dedicated and the many lives he personally touched.



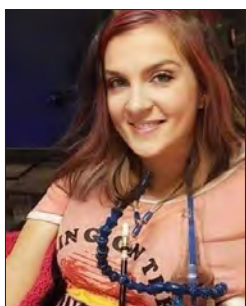
BEHIND THE STORIES

With Ian Ruder

As an expat himself, **Martin Heng** was the perfect person to tackle this month's story on living in an adopted country. He left England in 1987 and lived, worked and traveled around the world before settling in Australia in 1997. He hasn't looked back. "I actually believe I moved to the best country in the world to raise a family," he says. "It also happens to be a pretty good place to live for a person with a disability." As the former accessible travel manager for Lonely Planet, Heng brings a wealth of global knowledge and contacts and an astute eye for cultural differences. He shared his Big Ideas for the future of accessible travel in our July issue last year, and it's great to have him back in the fold.



Cassandra Brandt's essay popped into my inbox as one of those unexpected, pleasant surprises. After reading it and checking out more of her writing at mysoquadlifeblog.wordpress.com, I added her memoir *Iron Girl: Tomboy, Tradeswoman, Tetraplegic* to my reading list. The book jumps between her pre-injury life as a commercial ironworker and the difficult adaptation to life as a quadriplegic. "My hope for this book was to just be very real and raw and discuss how lives and perspectives can change," she says. Brandt is currently in grad school to teach high school English and working on a self-help manual for new quads called *So Now You're a Quadriplegic*.



We've received a number of pitches for articles on adaptive fitness apps over the last few years, but **John Loeppky's** stood out. Perhaps that's because in addition to a passion for journalism, Loeppky played wheelchair basketball and rugby at a high level and enjoys covering sports. In addition to writing for sites like fivethirtyeight.com, he currently works as the lead programmer and administrative assistant at Listen to Dis Community Arts Organization, a Canadian nonprofit. He says he got the idea for the story from a Tweet during the pandemic. "Halfway through the pandemic, I realized my body was not at all that happy with the lack of movement," he says. "Reporting this sparked my interest in how I can stay active."



Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org



COLUMNISTS

MAT BARTON • JOSH BASILE
SHERI DENKENSOHN-TROTT
MIKE FRANZ • BROOK MCCALL
TEAL SHERER • TODD STABELFELDT
REVECA TORRES • KATE WILLETTE
KARY WRIGHT

CONTRIBUTORS

KIM ANDERSON • CHRISTIAAN BAILEY
LAWRENCE CARTER-LONG
RORY COOPER • DEBORAH DAVIS
JENNIFER FRENCH • ALEX GHENIS
RICHARD HOLICKY • GARY KARP
PAULA LARSON • CORY LEE
REGAN LINTON • LILLY LONGSHORE
KATE MATELAN • BEN MATTLIN
ASHLEY LYN OLSON • KENNY SALVINI
ERIC STAMPFLI • MITCH TEPPER
ANTHONY TUSLER • KIRK WILLIAMS
LOREN WORTHINGTON

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Find fantastic accessible destinations and resources at Ashley Lyn Olson's long-running website, Wheelchairtraveling.com. Created in 2006, the site works to empower people with limited mobility to experience the world of accessible leisure and adventure travel.



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JUNE 2021

Building a Better Rehab

It Takes a Community: It's great to see the collaboration that was done during the construction process.

Dave Velguth

Newmobility.com

The People Make the Place: Good story, but as a 1985 Craig Hospital SCI alumnus, I never thought it was dark or lacked any features that limited its mission. The culture exceeds any lighting, architecture features, etc.

Loren Worthington (@azrollingphotog)

Instagram

Service Dog Photo Contest

Not to be a Wet Blanket: We must remember service dogs are dogs first and the service is second. Dogs are domesticated social animals that thrive around others and attention. I have seen, and gotten into fights, with service dog owners who forget their dog's needs don't end simply because they are forced into serving a human. Service dogs, as helpful as they can be, never choose to be in service and must be treated as dogs first.

Kevin Kirby

Newmobility.com

Gear Hacks: Hacking a Home, Part 3

A Little Automation and a Lot of

Awe: I came across your article in NM and if I was not sitting already I would have fallen on my butt!

We are in our second house but did

"It's great to see the collaboration that was done during the construction process."

not do anything on our own. I have very few skills (like really not a lot), but I have a lot of sitting experience! I am 43 years post-injury C6 (my only claim to fame). From what I can see, you know everything already in your short life (and then some) that I know in my long one. Stay well my friend. You made my day!

P.S.: We have a little home automation to help me a bit (it is also fun): Alexa and a couple Sonos speakers, C switches, Wi-Fi doorbell and locks, a couple Foscam IP cams, a Nest thermostat, a few Hue lights from Philips, and the wife (the boss actually) had a 22kw Generac generator installed a year and a half ago. It is very expensive, but the winter before we went almost 48 hours without power, and I had nowhere to go.

Pierre Thibodeau

Via email

Accidents Happen – So Give Us Better Bed Pads

You Just Made a Sale: After I finish laughing, I want to hug you! I have a neuromuscular condition that has progressed to the equivalent of a bladder/bowel situation of someone who is paralyzed. Thank you! I am off to Etsy [to buy the bed pads mentioned in the story].

Emily Averette

Newmobility.com

Shifting Sands: Life with an Incomplete Injury

I Feel Seen: This story was wonderful. It was a warm blanket to me. I have struggled with numerous labels since three rare neurosurgeries, two in 1983 and one in 1994. In 2005 my world drastically

changed in a six month loss of neurological function that was recently reclassified as SCI. Richard Holicky put into words and presented the drastically diverse impact this damage can have.

Lois West

Via email

From Isolation to Empowerment: A Nightmare Hospital Stay that Led to Change

You Are Not Alone: The same thing happened to me back in April 2020. Trached for the very first time during a pandemic on the same floor with COVID patients, I realize I'm extremely lucky. This experience changed my life, and I never want someone else to go through this! It took everything I had to get through.

Scott Chretien

Facebook

Hybrid-Drive Power Wheelchair Designed for Indoor and Outdoor Performance

More Like This, Please: Great to see another rear-wheel drive wheelchair available. Very similar to the Amy Systems R3 Hybrid chair I bought a few years ago. When you need a low floor-to-seat height to get under the steering wheel of your minivan, it is a great bonus.

Norm

Newmobility.com



VIRTUAL ROLL A VERIFIED SUCCESS

United Spinal Association and approximately 200 advocates from across the country gathered virtually June 14-16 for the 2021 Roll on Capitol Hill, meeting with their representatives in Congress to ensure that people with spinal cord injuries and disorders are included in shaping disability policies.

Roll on Capitol Hill provides United Spinal members a platform to amplify our voices on issues that impact our health and independence, share our experiences as wheelchair users, and be proactive in advocating for disability rights at state and national levels.

"We need events like Roll on Capitol Hill more than ever," says Vincenzo Piscopo, United Spinal's president and CEO. "The stories we tell about being able to land our dream job, move to our dream cities and live truly independent lives, or proudly roll across the stage at graduation, continue to be matched by those who remain underserved by our society. There's so much work to be done."

This year, with 200 virtual Congressional office visits completed in one day, Roll on



Capitol Hill attendees advocated for issues critical to the disability community, including transportation, broadband access, telehealth, veterans' health, SCI model systems funding, and home and community based services funding.

Davita Carter, an advocate from Illinois, was one of many first-time

Roll on Capitol Hill attendees who came away energized and motivated to get more involved. "Thank you for letting me know my voice matters," she says. "This is such a cool organization, and I hope this is just the first of many years that I can be a part of Roll on Capitol Hill. I'm excited."

On the afternoon of June 16, United Spinal hosted its Congressional and Corporate Advisory Council Reception to recognize individuals dedicated to strengthening disability rights and inclusion. Awardees included:

- Natalie Barnhard — 2021 Finn Bullers Advocate of the Year Award
- U.S. Senator Jerry Moran of Kansas — 2021 James J. Peters Distinguished Veterans Legislator Award
- U.S. Representative Dina Titus of Nevada — 2021 United Spinal Outstanding Congressional Leadership Award

"This award is such an honor because I'm able to bring awareness to the changes I am working hard to make here in my community," said Barnhard. "As an advocate, I hope to make lasting changes for people who live with SCI/D with their physical recovery and create a better quality of life for everyone through physical rehabilitation, accessibility, care and support."

The reception also commemorated United Spinal's 75th Anniversary and its mission to build an inclusive world that empowers all people with disabilities. United Spinal highlighted the impact of its programs and services and recognized the vital support of its corporate partners, which make a substantial difference in the lives of individuals with disabilities, their families, friends and caregivers.

MEMBER BENEFITS

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United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

BENEFITS INCLUDE:

Personalized Advice and Guidance

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Advocacy and Public Policy

Veterans Benefits Counseling

Accessibility Advocacy

Local Chapters

New Mobility magazine

Informative and Educational Publications

Ongoing Educational Webinars

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Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

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.



By Josie Byzek

YES, HOME CARE IS INFRASTRUCTURE

Home care being reframed as infrastructure is the most revolutionary development in personal assistance since ADAPT bullied the bully Newt Gingrich, then speaker of the U.S. House, into supporting Our Homes Not Nursing Homes back in '97.

I was with ADAPT that day. We'd heckled Gingrich from Atlanta to Washington, D.C., until he agreed in writing, on a cocktail napkin, to the outline of what eventually became a slate of policy changes over the next decade. This was two years before the landmark 1999 Olmstead Supreme Court decision that found people with disabilities have a right to live in the least restrictive settings — again, Our Homes Not Nursing Homes — and eight years before Money Follows the Person became a thing.

Since then, the disability community has put its collective shoulder to the policy wheel to redirect funds that stream to nursing facilities and other institutions into people's own homes instead. Most states have Medicaid waivers now that keep that fund diversion flowing.

Our community has been so successful that home care is in high demand across our nation. Unfortunately that demand can't be met the way those programs are structured right now. People are reporting terrible problems finding workers to fill their hours, for one thing.

It's the Economy, Sweetheart

T.K. Small is director of policy at Concepts of Independence, Inc. He's also a wheelchair user with spinal muscular atrophy who uses personal assistance and has put thought into the worker shortage.

"It's partly the added unemployment benefits and other pandemic relief things," he says. "Here in New York City they suspended all landlord-tenant proceedings. With the added unemployment and not being under the gun to pay your rent, you can probably survive."

Also, New York State tweaked its minimum wage to help the lowest earners, which is great, but may have suppressed the labor market for home care positions. "Before that rule change, home care work was paid at roughly 150% of the minimum wage rate and at that rate we were either equal to or above fast food workers," says Small. "Then they put in the new rule the following year to change the rate of home care workers but not all at once. It's spread out over a three-year period. Now my workers start at \$16 during the week but they're paid about the same rate as fast food workers, so basically it's a minimum wage job. There are lots of employers who pay more than that — at Amazon, very few jobs start out at \$16 in New York City — so it's rough."

That hourly wage wildly fluctuates depending upon regions. In Texas, the average rate is \$10.45 and in Pennsylvania it's \$12.75, but this difference usually also reflects cost of living and other factors. Nationally the average hourly rate for a home care worker is \$13.02, which is comparable to many other entry-level jobs and certainly explains the massive churn in the industry — the 2019 turnover rate was 64%. Who can afford to stay at an entry-level wage their entire career?

Often participants supplement their workers' salaries. "The Consumer Directed Personal Assistance Association of New York State did a survey in 2020 and 26% of

"My workers are paid about the same rate as fast food workers, so basically it's a minimum wage job. So it's rough."

folks are adding to the wages even though that's technically illegal," says Small. "But the vast majority of people who rely on home-based care and services can't supplement the wages."

Also, frets Small, what happens if the programs keep expanding? "It feels like we're putting more and more people into the boat and at some point the boat may sink. I don't know that I completely trust the politicians to make the right decision about who gets put into the boat," he says. "Is it possible that the boat may go down? Unless you rebuild the boat immediately on the ocean they have to be very careful about how they do that."

Politicians of all stripes are famous for not being careful. But something must change or the progress we've made in people leaving nursing homes for their own homes may be undone.

Pandemic-Driven Changes

The pandemic taught us that as a nation we're collectively a bunch of classist fools since it took not knowing if we'd be able to buy groceries to realize that grocery store workers are essential to our food supply. And the list of who's essential most definitely includes those who provide personal assistance for people with disabilities. America sees that now. Without home care, jobs are lost and unbearable pressure may be put on families. But we've never

paid it much attention as a society, any more than we might the person bagging our groceries.

That may be about to change as President Biden is using his podium to educate America on the importance of understanding home care as part of what he calls “human infrastructure.”

“The American Jobs Plan is going to help in big ways,” said Biden during a March 31 speech on infrastructure. “It’s going to extend access to quality, affordable home or community-based care. ... Think of home care workers going into homes of seniors and people with disabilities, cooking meals, helping them get around their homes and helping them be able to live more independently.”

Biden needs 60 votes for his plan to pass and avoid a filibuster. Although Republican senators are balking at expanding “human infrastructure” — home care, child care, Medicare expansion, etc. — it looks like enough of them will back brick-and-mortar infrastructure for that part to pass on its own. Rather than abandon human infrastructure in return for roads and bridges, Biden plans to package it into a filibuster-proof budget reconciliation bill.

Let’s hope it goes according to plan. Even if it doesn’t, Biden’s reframing home care as infrastructure — as crucial to our national well-being as bridges and roads — has changed the conversation. The question is no longer, “How can we get policymakers to recognize the importance of home care?” Now it’s, “How can we get policymakers to pony up enough funds to keep our home care system afloat and make it better?”

Listen to how advocates are starting to talk:

“Right now, we don’t have the infrastructure for aging services that we need, and the systems that we do have are crumbling,” said Katie Smith Sloan, president and CEO of LeadingAge, during Biden’s news conference. “The COVID-19 pandemic made clear the tragic human consequences that can happen when our systems are weak from significant shortages of staff to provide care to chronic underfunding of all kinds of services. But make no mistake, the need to renew and revitalize our aging services infrastructure existed even before the horrific last year.”

And Rep. Steve Horford used the language of infrastructure in an article he wrote for The Hill to make the case for inclusion of home care in Biden’s job bill:

“This isn’t just a family or private issue — our lack of care infrastructure hurts our entire economy,” he wrote. “Investing in home care workers and our care infrastructure is critical to recovering from the COVID-19 pandemic and charting a safer and brighter future for our families. By 2028, our country will need to fill 4.7 million home care jobs to meet rising demand, but we cannot do that sustainably or ethically when one in six home care workers live in poverty. Investing in those who care for us is a huge step to create an inclusive, equitable economy that works for everyone — where all working people have a fair shot at opportunity, with no exceptions.”

We’re Going to Win

We no longer have to prove the merits of Our Homes Not Nursing Homes, like we did in the ’90s. Back then we protested for Medicaid waivers and petitioned the Supreme Court to recognize our constitutional right to live where we wanted. Now we’re fighting for funds to improve the home care infrastructure, which is part of the essential grid of systems that keep our nation competitive.

And we’re going to win this fight.

Consider that despite the best efforts of our community’s advocates we never actually got a law passed that requires states to provide home care. But we changed the conversation in such a big way that now there’s a plethora of waivers and programs in most states. And we still may get that law, as on March 16, Rep. Debbie Dingell and Senators Maggie Hassan, Bob Casey and Sherrod Brown released draft legislation, the HCBS Act, to mandate that Medicaid provide personal assistance as a right, not a waiver.

Such a law is necessary to ensure every American has access to personal assistance no matter what state they live in. Yet regardless of whether we get a law passed, we no longer need to prove the value of home-based care — there’s widespread societal agreement on that. Now we have an infrastructure to protect and improve, and the language to make that case.

Did You KNOW...



United Spinal Association produces more than 30 brochures and pamphlets on subjects like *Disability Etiquette*, *Fire Safety for Wheelchair Users at Work and Home* and *Understanding the ADA*. You can download them for FREE or order printed copies on our website at www.unitedspinal.org

EMPLOYMENT ADVOCATE

Elaine Stefanowicz



Elaine Stefanowicz struggled academically, jumped from job to job and declared bankruptcy. But the University Place, Washington, resident has battled back from all of that to help others with disabilities as an employee of the Washington State Governor's Committee on Disability Issues and Employment.

Battling Back

If you're one of those people who believe government employees have no idea what you're going through, you've never met Elaine Stefanowicz.

The 56-year-old, T7 paraplegic had horrible math and test anxiety, to the point where it took her 17 years to get her associate degree, one class at a time, before going back to school to get her bachelor's. In the meantime, she went to vocational college to become a travel agent, hoping to "revolutionize the travel industry for people with disabilities."

That proved hard to do while earning minimum wage and not receiving any benefits, so she filled her time doing

several secretarial and administration jobs. Everything changed when she won the Ms. Wheelchair America title in 1997 and earned a full-ride college scholarship. After traveling the country, she went back to school, looking to wipe the slate



President Bill Clinton is one of many policy makers Stefanowicz has crossed paths with.

BEST DATING STORY: My partner is also a wheelchair user and an outdoors guy. He built a tent and a commode so I wouldn't have to use a public bathroom going camping. He's amazing.

MOST ACCESSIBLE PLACE YOU'VE BEEN: Oahu in Hawaii. They had a free, accessible transit system that would take you anywhere on the island — that was wonderful.



A native of Alaska, Stefanowicz enjoys winter sports.

clean and overcome her academic struggles.

"I took a class called Overcoming Math Anxiety at Tacoma Community College, and it changed my whole life. I finished my eventual master's degree with a 4.0 because of that class," says Stefanowicz. "It just changed the way I think, gave me confidence and helped me realize that school is turning in your work on time and asking for help if you need it. I thought it was some magic IQ number you're born with."

Though she was able to tackle her academic insecurity, she still found herself in a precarious financial situation. "I nearly lost my home and had to declare bankruptcy in the last couple of years because Social Security Disability said they overpaid me eight years ago. They garnished my wages to the tune of \$440 a month and kept my tax refunds for two years. It was painful, and I almost lost my condo over it," says Stefanowicz.

This month, she'll finally get her full paycheck with no garnished wages. "But I'm used to not having that money now," she says, "so I guess I'll just pretend I'm still being garnished and save that money as part of deferred compensation because I still have 11 years left until I can retire."

Even after all that, Stefanowicz still believes in the



value of work. She got her master's degree at age 40 in human resources because she was disturbed by the high unemployment rate among Americans with disabilities.

"It's so maddening. I believe in the value of work, but I understand why people get stuck and they don't want to work because they don't want to lose their benefits. Social Security Disability is something they can count on every month," says Stefanowicz.

Now, she works as a program coordinator for the Governor's Committee on Disability Issues and Employment to address these problems. She does this in a supporting role, working with subcommittees, coordinating legislative work groups and most importantly, encouraging people to engage with their state representatives.

"When I see people chain themselves to buses in protest, that stuff excites me, but you don't have to be militant — you just have to vote and get other people to vote. Drive your friends to the polling places and help them cast their ballot because even though people think their vote doesn't count, I've seen firsthand that it certainly does."

Hide and Seek

Stefanowicz talks about what it was like raising her now 22-year-old son, Michael, first in a household where both parents had disabilities, and then later as a divorced single mother.

“His dad is a blind musician, and we joked that at 6 months old our baby was the most nondisabled person in the house. We knew one day he would test that, and sure enough he messed with us. One day he hid under a table. I had to call my in-laws and go, ‘Michael’s been under the table for 45 minutes — you may need to come over.’ But I think I eventually lured him out with a cookie. Around his dad he’d get very quiet. He’d test us all the time. But he and I are very close because it was just the two of us for a long time. It always used to bother me when I would see parents walk holding their kids’ hands because I couldn’t do that. I talked to him about it and he just said, ‘Yeah, but I had your lap. No other kid had their parents’ lap.’”



WHAT WOULD YOU SAY TO YOUR YOUNGER SELF? I'd say, "You're going to be OK, don't be afraid to take chances and embrace the fire inside to be and do more. Drink more water and take care of your skin!"

WHY I JOINED UNITED SPINAL: I just really believe in that camaraderie of sharing your experience with other people with disabilities. We can't do this alone, especially with the self-isolation during the pandemic.

SELF-WORTH, SHAME & SPINAL CORD INJURY

BY CASSANDRA BRANDT

I was raised with the example of a hard-working, blue-collar father, and I went into the trades at 21. As I welded my way up the West Coast, young daughter in tow, I adopted this perspective that over-working oneself to death was an admirable way to go. My self-worth felt determined by how much I was contributing and participating. This applied to both my then-career in commercial iron and my anticipated career as a writer.

I never imagined the former would be cut so brutally short. I sustained a life-altering injury at age 32, when I was the passenger in a car accident. My C4 vertebra was crushed, and I'm now paralyzed from the chest down.

ENTER SHAME

Trading my hard hat and steel toes for a bulky power wheelchair was a blow I'm still reeling from six years later. Trading my overtime ironworker paychecks for a disability check further assaulted my pride.

Grasping for a shred of dignity, I was determined to make sure people knew I was still a valuable contributor to society. My ego insisted on convincing others of this. I cringed to imagine anyone might assume I spent my time idle, a burden.

I also hated the way my disabled body looked and the space my wheelchair took up, and oh, if it malfunctioned in public, I felt I could just die.

Why did I feel this shame regarding my disability?

My pride was so wounded. I'd really internalized the idea that my worth had diminished; I felt like I was a burden now, unworthy of love, belonging, joy or nurture.

When I'm treated like a burden, my



shame is particularly intense. I'm embarrassed that I'm seen as unlovable. Inside I seethe with self-hatred and desperately grab for dignity by hiding behind an entitled attitude to avoid a torrent of tears I can't wipe away.

My shame tells me I am less of a person because I need help — that, like a baby, I just occupy space and the time of others.

The damage to my self-efficacy is also staggering — self-efficacy to dress myself and put a spoon to my mouth and financially support myself.

WE ARE MORE IMPORTANT THAN A JOB

Those of us living with disabilities often have the poverty stigma on top of the stigma of being disabled. Performing skilled labor for a paycheck didn't make me any more worthy than I am now of the space I occupy, but society's attitude doesn't reflect that.

Society assumes that I can't "do my part" and resents me because they assume I need taxpayer help. That's not necessarily even true. Many people with disabilities choose to work even

though it's difficult because Social Security pays so little. They put their health and lives in danger pushing their bodies to the limit.

Others would seek work but need basic care needs met first. Our care would be a worthy investment for the government to make. It would create jobs for caregivers too. But giving assistance to people with disabilities is seen as a waste of resources on someone who allegedly can't perform productive labor in return. I am supposed to sell my labor in order to earn my bread; that's how it works.

Our society's industrial mentality facilitates the perspective of disability as a shameful thing.

When meeting for the first time, people often ask each other what they do because of this ever implicit assumption that employment is how we provide value to society. People don't ask what I do anymore. I'm disabled, so they assume I'm probably not gainfully employed or making a contribution anymore.

It's insulting, but at the same time it's also ignorant to assume our career contributions are what give us worth anyway. Our value as human beings shouldn't be tied to our net worth or our capacity to work.

My pride makes me push back against the presumption that my life is of lower value, my ability to contribute is minimal or nonexistent, or my needs far outweigh what I have to offer.

I want to be accepted as I am, but I'm not concerned with being palatable or pitied or being a feel-good-story. I don't want you to look at my wheelchair, but

not because I'm ashamed of how I get around, but because it doesn't have much to do with who I am at all. Ask me what I do. My disability isn't my occupation or my job. I'm just as proud of my work as a writer as I was of my work as a welder. In fact, my contributions feel more significant now.

Granted, there's meager money starting out in freelance, and I've needed Social Security to survive. Accepting SSDI can feel defeating, an acknowledgment of your inability to maintain a job.

I used to keep my SSDI recipient status a secret and now, when I share it, it's usually while discussing marginalized demographics or how broken the social welfare system is. I don't mind being an example.

Still, I find myself quickly listing my current contributions, regardless of the reality that my humanity alone makes

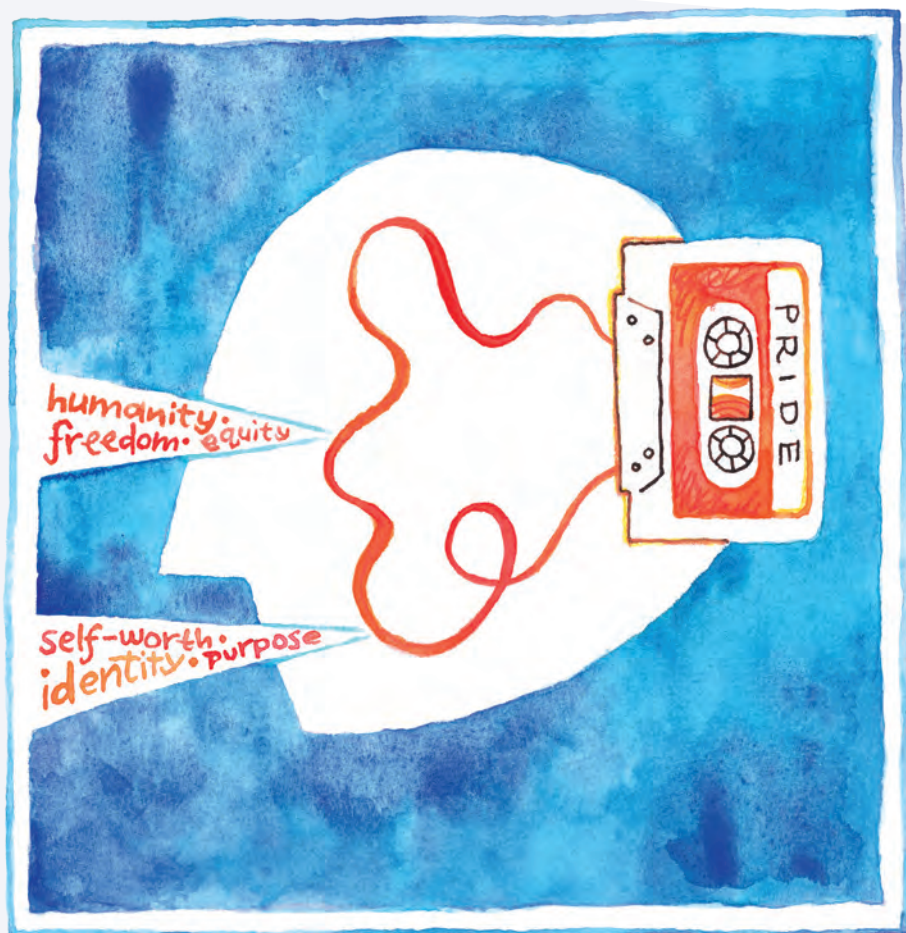
me worthwhile and worth protecting. How deeply ingrained is the bootstrap rhetoric that we are ashamed when we can't pull ourselves up.

Poverty happens to people due to any variety of challenges in life and is often unavoidable in this economy. Getting help from the government is nothing to be ashamed of. Being disabled is nothing to be ashamed of. The shame should belong to those unwill-

**"MY PRIDE MAKES ME
PUSH BACK AGAINST THE
PRESUMPTION THAT MY LIFE
IS OF LOWER VALUE."**

ing although capable of alleviating the financial burden of people with disabilities who are struggling.

In between fighting stigma, pity, toxic positivity and ableism, we don't have time to fight shame too. I'm over it.



Illustrations by Erin Barker

SEE MY POTENTIAL

BY RANDALL DUCHESNEAU

I work because it gives me purpose and something to be proud of. As a quadriplegic, I know how life-altering a spinal cord injury is. It strikes at the core of your identity because a lot of who you are, how you see yourself and how you describe yourself to others is by saying what you do — and when you can no longer do the things you used to do, who are you?

What you do for work says a lot about you. It's a way for people to get to know you but can also be a way for society to fit you into a box. What do you think when someone says they're a doctor, elementary school teacher or social media influencer? People have stereotypes in their mind of the people that have those jobs.

Unfortunately, people also have prejudices about "the unemployed" and "the disabled." Society has codified these stigmas into law, and instituted policies that trap people with disabilities in poverty and discourage work. Even just to qualify for SSDI, people who have be-

come disabled spend so long convincing the government they can't work that these stigmas often get internalized — they don't see that it's possible to work, only the insurmountable barriers.

I was a senior in college, months away from a career in finance, when a C5-6 spinal cord injury left me incapable of doing many of the things I identified with. Yet, I returned to school still holding on to the belief that my mind was intact and, even though I could no longer play violin, breakdance or ski, I could still pursue the career and dreams that I had.

This motivation kept me going for so long, until I was face to face with rejection and discrimination. Employers looked at me and saw a minority "in" a wheelchair, who couldn't hold a pen or shake a hand. Lumbering into an interview with a motorized wheelchair and needing assistance with the door didn't help. Employment discrimination is not something new — women, people of color, religious minorities and the

LGBTQ+ community are still fighting against discrimination in hiring.

While most employers are smart enough to not blatantly discriminate against people with disabilities because of the ADA, it still happens. And once in a while I've heard someone let slip what they really think — that I can't possibly work. I even heard this from a doctor, someone who I thought would be more understanding and encouraging.

So I sought out people and organizations that could see my potential. I volunteered at nonprofits and did freelance work to gain experience and applied to hundreds of jobs in a variety of industries. Getting a job was a struggle, but it was worth it: better health insurance, identity, purpose, socialization, improved physical and mental health and, of course, an income. Now, my work gives me a reason to start the day early and a feeling of excitement to see what challenges the day may bring. I can't wait for tomorrow.

RACISM, ABLEISM & FREEDOM

BY LUTICHA DOUCETTE

You have to work twice as hard to get half as much.

This is a common mantra told to Black children. However, being disabled I was always told that I needed to work three times as hard. Throughout my life I have always been that individual that was a hard worker but didn't see much success financially.

Growing up I always knew that I was Black, but I also always knew that I was Disabled. Inaccessible playgrounds, inability to go to other people's houses and always having everything centered around physical therapists doing painful therapy and going to see doctors, I was always reminded that I didn't fit in. I never really saw positive images of dis-

abled people and never knew that there was anything outside of constantly being told, either implicitly or explicitly, that I was a problem.

My parents tried to instill a sense of pride in me, especially as a young Black girl, but I always felt this sense of shame and disconnect from my own body. It wasn't until I saw my first Picasso and Frida Kahlo paintings that I began to think that there could be something more to just whatever *this* was.

I was in my 20s when I was gifted a trip to Costa Rica along with other disabled individuals. At the peak of Mount Poás I looked into the bubbling magma, and I realized that I too could be something more, and that holding on to all of

that hurt and anger meant nothing. I had done something that nobody in my family had done and that none of my friends could ever say they had done. This was an accomplishment, and not just about who I was as a disabled individual. I was fully seeing myself for the first time.

Now that I am an adult working in the field of equity, I understand that ableism is deeply rooted in this country. I'm also of the tradition that knowing history matters. You cannot dismantle what you do not fully understand. So let me be brief:

The major requirement for the enslaved to be freed was proof of value of the labor that they gave to slaveholders, not their inherent humanity but

what they could produce. So therefore, if you were disabled you had no value and could not get free unless you escaped with family or friends. Recently, Juneteenth has become widely popular, especially with being ratified as a national holiday. However, many do not know the fact that disabled children and young adults were signed away back to slaveholders and lived in bondage until they died. So, these ideas of who is seen as valuable, whose labor is seen as important and that “working hard” leads to freedom can be myths. Fun fact: enslaved folk worked extremely hard and yet their hard work did not translate into financial freedom.

Enslaved women and femmes were often those who took care of white children and cleaned the houses; after slavery ended this labor was still outsourced

by white households who could afford to do so — a practice that is still done to this day. The idea of women taking on household chores and them being relegated as “simple women’s work” is a vestige of patriarchy. Whole cam-

“THESE IDEAS OF WHO IS SEEN AS VALUABLE, WHOSE LABOR IS SEEN AS IMPORTANT AND THAT ‘WORKING HARD’ LEADS TO FREEDOM CAN BE MYTHS.”

paigns such as home economics classes were really patriarchal indoctrination to keep white women from economic freedom. So focusing on whose labor is valued, of course we see the continuance of underpaid home health aides and other care workers whose work is often deemed as “unskilled.”

A longstanding question remains

unanswered: What is the worth of a human being?

During COVID we have to radically shift our thoughts on labor and care, but do we have the collective willingness to do so?

Even now I’m doing the emotional labor of internalized ableism; it’s still a very difficult process. I still have self-doubt. I have literally worked myself into sickness, and now as an entrepreneur

I am redefining what my worth is. One of the principles of disability justice teaches us to recognize the wholeness of individuals. We are more than just a job or some sort of cog in a giant wheel; we are human beings. And the work of equity is to get back to what is human about us. And to create a society that acknowledges, honors and supports the humanity of everybody. ❧



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EXPATS: BUILDING AN *Accessible* LIFE ABROAD

BY MARTIN HENG

In a world where simply traveling abroad with a disability can seem daunting, the prospect of moving to a foreign country might seem overwhelming. How will people treat me? What access obstacles will I face? Can I get the medical services and resources I need? And that's not even considering the fact you are likely abandoning your entire support system and moving somewhere you know no one.

We reached out to people with disabilities who are succeeding after moving away from their native countries to find out their keys to success and suggestions for others.

Tony Boatright left the United States for Panama nine years ago — almost 40 years after sustaining a C5-6 spinal cord injury. His only regret is not moving there sooner. Mitch St. Pierre has been living in Cambodia for the last six years after growing up in Canada as a wheelchair user. He says he feels totally accepted as a disabled person and has relished the move: “I love adventures.” Power wheelchair user Josh Grisdale also left Canada and became a naturalized Japanese citizen five years ago. Rhonda Raven Neuhaus

had been visiting Costa Rica for 25 years before she finally decided to move there in 2019. An amputee who uses prosthetic legs, Neuhaus says, “It’s beautiful to live in a country that prioritizes the natural environment and its people. Costa Rica is a beautiful nation rich with biodiversity — and the people are amazing.”

All of these people shared a passion for adventure and a desire to experience something new. Boatright acknowledges that living abroad isn’t for everyone but doesn’t want anyone to give up on that dream because of a disability. His advice? “If you are ready for adventure, prepared to face unexpected difficulties and have an open mind, try it.”

“If you are ready for adventure, prepared to face unexpected difficulties and have an open mind, try it.”

Tony Boatright added a 50-foot long, 12-foot wide porch on the back of his home. He sits on a cliff overlooking the Rio Zarati in Panama.

MAKE NEW FRIENDS

Near the top of many people’s lists of concerns about moving abroad is the fear of leaving behind friends, family and support networks. While you may not be able to replace the support provided by existing family and friends, all the people we spoke with suggested that over time new friends can fill these roles. “As I’ve been coming to Costa Rica for 25 years, I have people who are my family here and I’ve made a large circle of friends,” says Neu-



haus. “I am also blessed to have a wide circle of expats from all over the world near where I live. This mix is perfect for me.”

Boatright and St. Pierre both report how easy it is to make friends — both locals and expats — in their adopted countries. “The Panamanian people are very kind and welcoming,” says Boatright.

“It’s very easy to meet people here, especially in the local bars,” adds St. Pierre.

Additionally, the pandemic has taught us that we can sustain meaningful relationships — not to mention employment — via FaceTime, Zoom, Skype and so on. Although getting physical support via the internet isn’t possible, the advice and emotional support available can help with stress and homesickness.

Formal supports are easier to replace with forethought and planning — you know best what your needs are, so careful research should tell you whether they can be met in the country you’re planning to emigrate to. Everyone we interviewed for this article stressed the importance of two things: finding out as much as you can about the destination and testing the waters by frequent and,



Mitch St. Pierre gave up Canada and gained Angkor Wat.



The sidecar St. Pierre rides in would never pass inspection in Canada. Good thing he’s in Cambodia.

WHAT ABOUT MY BENEFITS?

If an important reason to move abroad is affordability, it's vital to understand whether your disability benefits are still payable if you're not resident in the U.S. And the good news is that in general they are, which means that your standard of living may be much higher than it would be stateside, even though it may not be exactly luxurious.

Supplemental Security Income and Social Security Disability Insurance are two of the most common programs from the Social Security Administration. U.S. citizens who are eligible for SSDI can receive benefits even if they live overseas, although there are some countries — notably North Korea and Cuba — to which the SSA cannot mail benefit checks under any circumstances. The full list of countries to which the SSA cannot send benefit payments can be found on the SSA's website. But there are dozens of permitted countries for SSDI across the world from Latin and South American countries to Southeast Asia and Europe where your dollar is worth a lot more.

Note that the SSA considers any stay outside the U.S. or its protectorates (American Samoa, Guam, Puerto Rico, the U.S. Virgin Islands and Northern Mariana Islands) that lasts longer than 30 days to be residence outside the U.S. rather than just a visit. Therefore, any stay lasting 30 days or more requires you to report your status change to the SSA, including submitting change of address information. Similarly, SSI and Medicare benefits are not payable to non-residents; that is, people who are staying longer than 30 days outside the country.

The situation with regard to the approximately 28,000 disabled veterans who live outside the US is more complicated. A group of laws known as "Title 38" originally authorized the US Department of Veteran Affairs to provide healthcare only to veterans with service-related disabilities (regardless of where they lived). This general restriction was modified in 1996 to provide non-service disability health care for veterans living in the US but not for veterans living outside the US. Section 1724 of Title 38 specifically prohibits the VA from providing non-service disability healthcare to expat veterans.

Boatright's only regret is not moving to Panama sooner.



if possible, extended visits.

"I would recommend visiting many times before moving," says Neuhaus. "I would ask a lot of questions, find local disability organizations and meet other people in the community. I would also be sure to find any accessible housing or other needs prior to arrival."

That approach worked for Grisdale. "I visited Japan numerous times and wanted to try living here," he says. Both he and St. Pierre recommend making friends in the local disability community to get expert advice when navigating the welfare and disability systems and to make connections. "You'll need and maybe even rely on them," says St. Pierre.

ACCESS & AFFORDABILITY

Quite possibly the primary reason people with disabilities choose to move abroad is affordability. Lower costs for labor, resources and property may allow you to buy or build the accessible dream home you couldn't afford in the United States. Boatright wasn't able to find suitable modified accommodations, so he simply bought and modified his home — something he would have been unlikely to be able to afford stateside.

St. Pierre takes full advantage of the flexibility that comes with lower construction costs. "The apartment I

live in in Cambodia is actually easier for me than back home," he says. "My bathroom is bigger, and if things need to be changed it is very cheap and easy to have something built."

On the downside, more affordable countries often lack the economic means and political structures that facilitate disability access and support. Without relevant legislation, like the Americans with Disabilities Act, or the means to enforce it, getting around can be difficult.

Both Boatright and St. Pierre acknowledge that their adopted countries lack the resources not only for the upkeep of infrastructure, but also for the enforcement of building codes. Boatright says that Panama has "accessibility laws, but no standards." He says he encounters lots of ramps, but many are too steep or impractical.

St. Pierre describes Cambodia in bleaker terms, saying, "There is no infrastructure for disabled people in Cambodia." But both added that a lack of infrastructure is made up for by people power and a willingness to help. "Getting around Cambodia can sometimes be difficult, but everyone is so helpful — carrying me into a car or tuk-tuk," says St. Pierre. Neuhaus lives near the first independent living center in Costa Rica, Centro Morph. "They, and other organizations like them, have done a

What about health insurance?

It's worth making your own investigations, starting with long-term health insurance designed specifically for expats. One option is TRICARE, the comprehensive healthcare program for uniformed service members, retirees and their families around the world. Most TRICARE health plans meet the requirements for minimum essential coverage under the Affordable Care Act.

lot toward passing legislation, educating the public, providing assistance services and advocacy toward inclusion," she says. "That said, there is much needed here for full inclusion and access."

St. Pierre notes that the lack of regulation leaves ample room for innovation, highlighting the sidecar he designed and built for his then-partner's motorbike. It would be illegal in Canada but has been a boon for getting around in Cambodia. "I basically showed a picture of a sidecar to the local welder who took the measurements of my chair and built me a sidecar that attaches to my girlfriend's motorbike," he says.

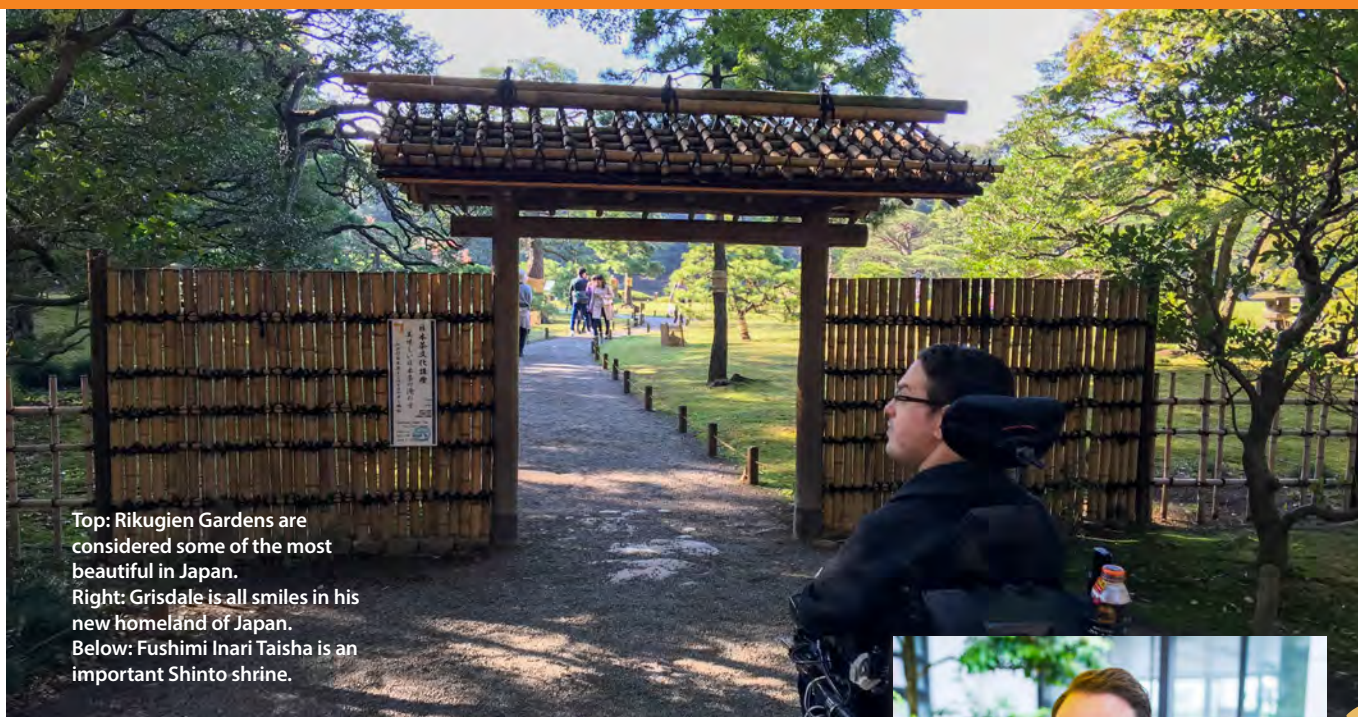
CARE DOESN'T HAVE TO BE COSTLY

Living with a disability often means that you need to be more mindful of the quality and cost of healthcare. There's no doubt that the U.S. medical care system is among the best in the world — first-rate doctors, clean and modern facilities, and top-quality care — but it's also without doubt the most expensive, and largely unaffordable without health insurance, which itself can be prohibitively costly.

Almost anywhere you move is sure to have cheaper medical care, but ensuring that it is competent and accessible remains important. Thankfully, the rise in medical tourism and the growing global economy have increased the number of countries offering solid services. Our interviewees reported mixed levels of satisfaction,



Josh Grisdale checks out the new ramp at Meiji Jingu.



Top: Rikugien Gardens are considered some of the most beautiful in Japan.
Right: Grisdale is all smiles in his new homeland of Japan.
Below: Fushimi Inari Taisha is an important Shinto shrine.



but good experiences overall.

In Japan, which is very much a first-world country with prices to match, Grisdale makes do with a combination of national healthcare and his company healthcare plan. He admits that navigating the welfare system was one of the biggest challenges he faced once living in Japan. He relied heavily on local friends in the disability community for help and advice.

As a legal resident of Costa Rica — ranked No. 3 in affordable healthcare by *International Living* magazine — Neuhaus is able to take full advantage of the country's highly-regarded universal

healthcare system. Her experiences emphasize that challenges are inevitable, even in a good situation. "As an amputee, the biggest challenge is that my closest prosthetist is three to four hours away in the capital, San Jose," she says. "When my leg broke, there was nobody local to fix it. When I had a new set of legs made, I had to constantly make trips back to San Jose."

Panama may not be the country that jumps to mind when you think of healthcare, but Boatright reports that it is "good and cheap." He noted that therapy can cost as little as

\$1.50 per hour. "The prices there are so affordable I have never bothered with buying insurance," he says.

St. Pierre's experience in Cambodia has been more mixed. "Cambodia is a developing nation, and its medical standards are nowhere near those of Canada," he says. While hospital care can be costly, medication is highly affordable. Despite the uneven offerings, he says, "I would

only return home if I had some kind of serious medical issue."

EMPLOYMENT EVERYWHERE

Even within developed economies, disability representation in the workplace is much lower than the average, while people with disabilities represent a minuscule proportion of the international workforce. As with building codes, although the legislation may be in place, in some countries it is rarely enforced. Modified or adaptive equipment may also be unavailable or difficult to access in some countries.

As a writer, Boatright can carry on his trade from anywhere there is electricity and an internet connection.

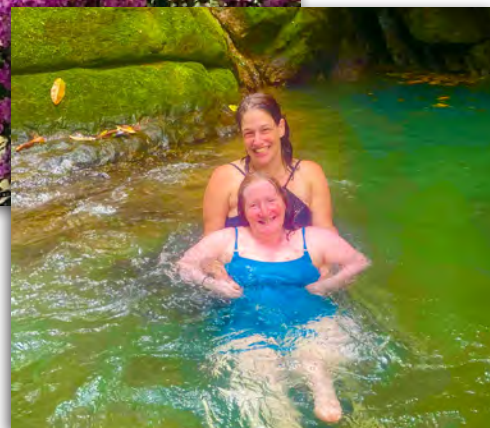


Neuhaus, similarly, is an entrepreneur who works from home, making it immaterial where she is based. “As a consultant in disability rights and as an intuitive healer, I feel very blessed that I am able to live where I desire,” she says. “I very much appreciate having a disability community in my area that has welcomed me into its heart, with the love and the same passion for inclusion that I carry.”

St. Pierre believes he’s been “pretty fortunate” to find employment. While Grisdale found it much more difficult than back home to find a job, he now



From flowers to waterfall pools, Rhonda Neuhaus loves Costa Rica’s beauty.



Safety Concerns

If you’re worried about safety, consider this: the United States has the second-highest number of gun deaths per year, behind only Brazil. Grisdale’s new home of Japan consistently ranks as one of the world’s safest countries, while both Boatright and Neuhaus report feeling as safe in Central America as they did in the U.S. Even St. Pierre says he finds Cambodia “pretty safe,” saying, “I’ve been robbed physically two times in my home city and four more times in other countries.”

feels well-supported and secure in his role as a webmaster. He set up the website Accessible Japan and the social media platform Tabifolk because, “I believe strongly in giving back to society, and I love to use technology to improve the lives of people with unique needs and challenges.”

HOME IS WHERE THE HEART IS

There’s nothing easy about giving up the world you are familiar with for a new world riddled with new challenges and unforeseen obstacles. But if that task sounds slightly familiar, it’s because many of us have already faced some-

thing similar with our disabilities. The same skills and attitudes developed living with a disability often prove invaluable in making the move to a new country.

At the end of the day, though, home ends up being where the heart is. Everyone we spoke to settled in the country they fell in love with. St. Pierre first laid eyes on Cambodia while filming a documentary for Canadian television. “During the filming of our documentary, I fell in love with this beautiful country,” he says. For Neuhaus, that process happened slowly over 25 years of visits, but the end was never in doubt. “I always thought that I would retire in Costa Rica,” she says, “but made my move 20 years earlier than anticipated. Truly, this is a second home for me and I felt called to make this move ... I feel very at peace here.”

Boatright moved to Panama with a plan to live there for a year. He got hooked: “After 10 months, I bought a car and started looking for a home.” Grisdale visited Japan numerous times before moving there 14 years ago and felt so at home that five years ago he renounced his Canadian citizenship and became naturalized. Tellingly, no one has plans to move back to their country of origin.

MM

SEVEN STEPS TO LIVING ABROAD WITH A DISABILITY

1. Do your research: Find out as much as you can about accessibility in countries you’re interested in before you visit.
2. Identify and make contact with local disability organizations; they can provide you with invaluable resources and specific information as well as local contacts.
3. Search out trailblazers: It’s likely that you won’t be the first person to be emigrating to your chosen country, so seek advice from someone who has already done it.
4. Try before you buy: Visit the country you’re interested in migrating to for an extended period — at least a month and preferably three.
5. Equipment check: Make sure your equipment is in good condition before you leave.
6. Find a source: Locate a reliable local supplier of equipment, spare parts or medication you need.
7. Champion the cause: Emigrating is not a one-way process: you can help change attitudes by the way you act and how you cope, which will not only encourage people to help you, it will also help pave the way for others with similar disabilities.

6

STRATEGIES TO NAVIGATE YOUR INSURANCE PROVIDER'S APPROVALS PROCESS

BY ALI INGERSOLL

As a C6 quadriplegic, I've spent the last decade perfecting strategies to improve my odds of success in getting the durable medical equipment, prosthetics, orthotics and supplies I need from my health insurance provider. A few key pieces of equipment I have successfully obtained include a specialized shower chair, pressure-relieving mattress, hospital bed, FES bike, and seat elevator for my power wheelchair.

I'm not the only wheelchair user who's figured out effective strategies for every step of the process, from prior authorization to putting together effective appeals if denied. I interviewed others who use wheelchairs, including two staff members of the United Spinal Resource Center team, to present you with the best strategies for obtaining the medically necessary DMEPOS you need to not only survive but thrive in life.

01 CAREFULLY CRAFT YOUR LETTERS OF MEDICAL NECESSITY

When Bruce Stultz' initial requests for a SmartDrive were denied, he realized his letters of medical necessity needed to be more carefully crafted. When he collaborated with his physical therapist to craft a LMN that specifically stated a SmartDrive would reduce his back injuries and improve weakness in his shoulders from pushing his wheelchair due to his getting older and living with spina bifida, his request was approved.

Now he has this advice for others struggling to obtain necessary DME: "You need to work with your medical professionals to tweak the language in your LMN with keywords and phrases to include:

- Improving quality of life
- Medical necessity of a piece of equipment
- Improving activities of daily living
- Elaborating on the cost benefit analysis to the insurance company. This means showing how a health insurance provider not approving a piece of equipment could lead to secondary complications that would be more costly in the long run.
- Elaborating on specific secondary complications that would arise without the use of a specific piece of equipment."

Stultz says to be very specific in the language you use, do your own research, and work with your medical professionals to ensure the LMN is written in medical insurance language.

United Spinal Resource Center Director Bill Fertig adds, "As a manual wheelchair user, I have also found success in advocating for my own ultra-light wheelchair components by having

good communication with my psychiatrist, which, in turn, led to a quality LMN for so-called 'accessories,' such as my pressure-relieving cushion and Natural Fit handrims, which prevent trigger-finger injuries."

The Resource Center recommends backing up your LMN with peer-reviewed journal articles and fact sheets to make your case stronger. Especially explain any secondary complications that would arise without a specific piece of equipment you're trying to have approved by insurance.

02 LEARN YOUR INSURANCE RIGHTS

Regardless of whether it's private insurance or Medicaid/Medicare, each system has several steps to follow. To learn these steps, and your rights, read your insurance policy documents. In general, expect a prior authorization phase and several levels of appeals. Beyond that, you have the right to an ex-



Bruce Stultz

ternal appeal, whether it be through the Department of Insurance for your state or in front of an advocate judge.

“The appeals process is complicated, and there are mountains of paperwork involved,” says Lee James, a C5-6 quadriplegic who has navigated the winding appeals process road to approval with success. “Even if you know your rights, it’s absolutely essential to call your insurance provider to find a human representative and build a relationship with them. Tell them your story and humanize yourself.”



Lee James

This is so important because you are generally just a number in a file to these insurance providers. You have to foster a relationship with a human being who will advocate for your case.

James fought to have enough catheters approved when his insurance company told him he could only go to the bathroom a certain number of times a day. He worked with a representative within Medicare to help facilitate collaboration and education between his physical therapist and general practitioner. Together, this collaboration pointed his insurance provider in

understand each level of appeals. Also, if you have a responsive vendor, PT, OT, or physician that has your interests at heart, you should utilize their clinical expertise when available. Further, make sure to read your formal denial so that you know specifically what is being denied and why in order to create a stronger appeals case.

03 BE A PERSISTENT ADVOCATE FOR YOURSELF

Jonathan Merchant, a C5-6 quadriplegic, fought vigorously for the approval of his manual wheelchair and all the necessary components. This was time-consuming because he and his PT had to justify everything from a specialized backrest and wheelchair cushion to push handles, rims, and armrests. Each piece needed its own justification for Merchant’s level of disability.

Merchant returned to his PT each time he was denied a component of his wheelchair, and often more than once per denied component. “Make sure to add every single element of the wheelchair you are asking for upfront, so you don’t have to keep going back to your medical professionals, which can result in constant delays and approvals for each component of your wheelchair,” he says.

It’s important to stay on top of your DME provider, physical therapist and general practitioner. “You have to be persistent to understand where you are in the approval, denial, or appeals process,” he says, adding that it’s also important to compromise. “You may not get everything you ask for, but ask for everything you think you need. It’s a lot more challenging and time-consuming to keep going back to your PT for added elements of your wheelchair than asking for the moon and stars upfront.”

Castagnino stresses it’s important to, “remember the squeaky wheel gets the grease. So keep at it, and record who you talked to, when, and what they said.” It’s worthwhile to keep a careful record of contacts made, dates, and times throughout the entire insurance

approval process in order to keep track of where you are over the many months it can take to get the proper approvals.

04 WORK CLOSELY WITH YOUR DME PROVIDER

Karen Roy, a T10 paraplegic, has a unique perspective, as she is a wheelchair user who works for a major complex rehabilitation technology company. “In general, your doctor is not going to be as knowledgeable as your PT, who knows the specific requirements for your disability, and your CRT provider will usually facilitate the process with your insurance company for the approval,” she says. “But you have to get involved in the process.”

Roy points out that there are layers of paperwork involved in the insurance process and many things get lost in translation between medical professionals with respect to medical coding, current procedural terminology codes, medical justifications, and so on. The CRT company she works for has online portals to show people precisely where they are in the approval process, but even so, she strongly feels it goes more smoothly when the wheelchair user is engaged.

She says you can’t expect your medical professionals to justify why you need every piece of equipment without your help because you are the one that knows why you need a piece of equipment the best, and exactly how you are going to use it. She stresses this takes team collaboration.



Daniela Castagnino

“GOOD COMMUNICATION WITH MY PHYSIATRIST LEADS TO QUALITY LMNS.”

the right direction. “The appeals process is not a one-man game but involves collaboration of many medical professionals. There is a higher probability of resulting success if we get all parties involved to fight on our behalf,” he says.

Daniela Castagnino, a quadriplegic on staff at United Spinal’s Resource Center, says, “Don’t be afraid to appeal your initial denial. It’s important to know your rights and exercise them.” The Resource Center advises that you

05 SEEK OUT-OF-NETWORK PROVIDER APPROVAL SOLUTIONS

While fighting for a pressure-relieving mattress, shower chair and fully-electric hospital bedframe, I had a problem: My insurance approved the requested equipment — but at an out-of-network

rate. This is extremely costly for many of us because we are left paying the difference between the in-network rate and the out-of-network rate within our insurance plan.

I learned, however, that I can ask for an in-network gap exception so insurance can pay 100% of the billable amount — it's a little secret insurance companies don't want to give up.



Jonathan Merchant

If there is not a provider of a piece of equipment within a reasonable geographical radius of your plan, your insurance company has the ability to make this exception for you. Whether you have private insurance,

Medicare or Medicaid, you have the right to ask for an out-of-network exception. Here's a great article that goes a little bit more in depth about how these exceptions work: verywellhealth.com/network-gap-exception-what-it-is-how-it-works-1738418

The worst an insurance provider can do is say no. However, if you don't try you're definitely going to be left holding a hefty financial bill because many specialized DME providers are out-of-network.

06 BUILD RELATIONSHIPS WITH MEDICAL PROFESSIONALS THROUGH EDUCATION AND INVOLVEMENT

Every single one of the wheelchair users interviewed in this article agrees the most important aspect in getting any piece of medically-necessary DMEPOS approved requires wheelchair users to advocate for ourselves. We simply have to be our own advocate in our life and have the ability to facilitate education and communication among our medical professionals.

It's important to note that your PT, OT or physician will be among your biggest advocates because after you, they are the ones who understand your disability best. They can help educate your other medical professionals involved in the process as to your specific needs.

When you don't know the answer to a question or how to frame the justification properly for a piece of equipment, that's OK. You just need to:

- know the right people to ask and how they can help you
- make sure to understand what your rights are by reading your health insurance plan

- stay actively involved by being persistent
- consistently follow up to see where your case is in the prior authorization or the appeals process.



Karen Roy

The overarching message Merchant conveyed is that you are your own best advocate and if you don't know the answer to a question, to "Find other advocates to help you find the answers you're looking for." There are tens of thousands of other wheelchair users within our community who have been through what you are going through. Merchant points out that, "many of these folks are fabulous resources, so

"WE HAVE TO FACILITATE EDUCATION AND COMMUNICATION AMONG OUR MEDICAL PROFESSIONALS."

don't reinvent the wheel if you don't have to."

The insurance system should not be this challenging or immensely frustrating. Unfortunately, we need to learn, as advocates, how to work within the current system as it stands today.

However, not every insurance battle will always end in success. The United Spinal Resource Center advises that if you are unsuccessful in getting equipment approved by your insurance provider, there are additional outlets such as fundraising with Help Hope Live, writing grants, and working with United Spinal to find additional funding options.

Please contact the United Spinal Resource Center for additional help if you need it: 800/962-9629; unitedspinal.org/ask-us

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CHECK AND DOUBLE-CHECK YOUR PAPERWORK

In general, your DME provider will collect all of the paperwork from your PT and other medical professionals to submit to your health insurance company. It's a common mistake to let your DME provider submit this paperwork on your behalf without you first double checking all of it. Many of these companies have hundreds of clients, and it's not uncommon for things to slip through the cracks, such as wrong diagnosis codes (ask your physician to explain each diagnosis code), a missing signature, an incorrectly written letter of medical necessity for your level of injury, and so on. This can cost you time and time means waiting for what you need to become more independent in your life.

LIVESTREAMING DIGITAL ACCESSIBLE FITNESS TO A DEVICE NEAR YOU

BY JOHN LOEPKY

Ben Clark didn't expect to find himself stuck at home with nothing but a broom handle, a few resistance bands, and some puny weights to stay in shape. However, that's exactly the predicament he found himself in as a wheelchair user during the pandemic.

Clark runs Adapt to Perform, a YouTube channel dedicated to fitness for those with disabilities. The United Kingdom-based former professional swimmer goes live to his 12,000-plus subscribers twice a week

and says he enjoys finding ways to make routines accessible for those with all kinds of access needs.

"What I really like about the live stuff is the interaction between me and the audience, having that feedback immediately, and being able to help people," says Clark. "Also, I like the sense of community it creates. I go on the YouTube chat, start recognizing the same people and get to know them a little bit better." Clark started the livestreams at the beginning of the pandemic as a way to build community, lessen isolation, and provide one hour a day where people could be together on their respective fitness journeys.

GYMS DON'T CARE

Clark's focus on digital accessible fitness solutions came from his own experience as a wheelchair user. Before a 2010 spinal cord injury, he had been a high-level athlete — hopeful to land a spot on the Great Britain swimming team for the 2012 Olympics. But when he tried to get back to fitness after his accident, he found the options lacking.

Clark isn't alone. Statistics show that disabled people are far less likely to engage in regular physical activity. The Centers for Disease Control acknowledges several factors that contribute to a lower rate of physical activity for those with disabilities, including a lack of access to facilities and trained professionals that can provide proper support.

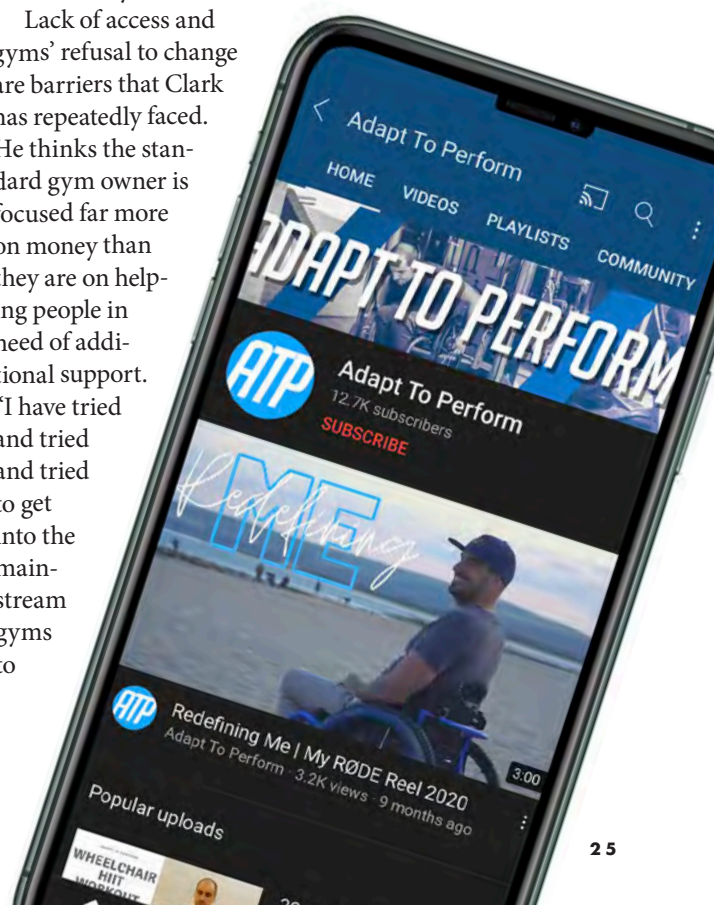
This often leaves disabled people looking for options outside of the gym environment. Dannie Ocasio, who has CP, is one of those people. When he put on weight during the pandemic, a combination of dieting,

workout videos from Beachbody, and a CrossFit routine with a trainer brought him back on track. Ocasio chose the gym he did because of ease of access from his house. He kept adaptability front of mind and says he chooses his trainers based on how they approach his disability from the start.

"I always ask the trainer, 'Hey, what do you mainly focus on?' If it's just to have me lift bigger weights, then we're a no go and I'm very upfront about that," says Ocasio. "I care more about proper form than I do about the heaviest weight. The last thing I need to do is to pull a leg or arm muscle or hurt my back, because it takes me just that much longer to heal compared to everybody else."

The extra barriers to exercise faced by people with mobility disabilities led many to simply stop trying. According to the CDC, almost 50% of American adults with disabilities go without aerobic physical activity. More concerning, its data suggests that disabled people are three times more likely to have heart disease, stroke, diabetes or cancer than adults without disabilities. If the data is representative, that means approximately 9.4 million disabled adults in the U.S. don't exercise daily.

Lack of access and gyms' refusal to change are barriers that Clark has repeatedly faced. He thinks the standard gym owner is focused far more on money than they are on helping people in need of additional support. "I have tried and tried and tried to get into the mainstream gyms to



OUR RESIDENT CURMUDGEON TRIES SOME ONLINE FITNESS OFFERINGS

BY SETH MCBRIDE

Let me start by saying that I am not a fitness class kind of guy. Don't get me wrong, I love working out — but I find chipper instructors shouting encouragement at me grating at best. But I also have a brand-new baby and I recently moved to the country where there's no gym close by. In order to stave off the dreaded dad bod, I decided to open my mind and give an Adapt to Perform video and a Kakana class a go.

BROOM HANDLE THROWDOWN

On the Adapt to Perform YouTube channel, I chose a video titled “Tough Wheelchair Cardio // At Home!” because the image showed Clark holding a broom handle, and I was intrigued. The video starts with a montage of a few of the moves you're going to be doing, which is nice when you're trying to quickly discern whether you have the function to be able to complete a workout. The good video and audio production quality is immediately noticeable. Clark then hops on and gives a brief explanation of the workout and what you'll need — in this case it's just the broom handle, which he dubs the “cardio pole.”

The workout itself is five different movements including a paddling motion, a series of karate chops, a push out and then up and a couple of twisting maneuvers, all of which I could complete in my everyday wheelchair with no straps or core function. Each move is done for one minute, with no rest in between. At the end of the set there's a one-minute rest before repeating for a total of five sets. It took approximately 20 seconds before my shoulders started burning, which made me feel bad about myself.

Midway through the first set, my heart rate was up and I was breathing hard, and I have to admit that if I was doing this workout without a video, I probably would have snuck a few quick rests in. But having Clark there doing it — complete with a quad belly and looking kind of fit, but certainly not in-your-face muscley — was motivating in a way I hadn't expected.

Through the workout Clark is encouraging and relatable, saying things like “Just do the best you can do ... don't worry about everybody else or what I'm doing, which is getting tired pretty quickly ...” while fighting through muscle spasms and finicky brakes on his wheelchair and apologizing to his plant, Clive, for

whacking it with his broomstick. By the end of the workout, I was whooped, my arms felt noodly and I didn't want to punch Clark in the face.

Verdict: Definite win.

KAKANA CROSS CYCLE

Kakana is a subscription-based service that costs \$14.99, but they offer a seven-day free trial that doesn't require a credit card to enroll, so you don't have to worry about getting charged if you don't like it but forget to cancel. They offer live classes throughout the week and have a range of previously held classes archived online. I was curious about their “Cross Cycle” classes, as they're arm-ergometer-based, and I was shocked to find that you can buy a desktop ergometer for as little as \$30 on Amazon. I ordered a \$60 version that looked like it would work better for me, and two days later I had it at home. Assembly took maybe 15 minutes, even with quad hands. I was ready.

Firing up a previously held class with a wheelchair-using instructor, Adrien Burnett, I immediately noticed that the production quality wasn't as high as on the Adapt to Perform videos — more like a webcam inside of Burnett's home. Nevertheless, whether guiding you through a warmup or high-tempo intervals, Burnett was a solid instructor. There was upbeat music that made it feel like a spin class, which wasn't a good thing for me but might be for some people.

The biggest problem I had was with the ergometer. I'm used to using the multi-thousand-dollar ones you find at a gym, and this was definitely not that. The resistance mechanism was stiff and jumpy and the crank arms were short, which made me feel like a Tyrannosaurus. Plus, when I upped the RPMs, the whole unit started to wander around the table. I found myself more focused on the equipment than the actual workout. But even with my wandering ergometer, by the end of the workout I was flushed and gulping air, and I suppose that's the whole goal.

Verdict: Somewhat annoying, but still got a good workout.

change their opinions and convince them of why it's important for them to make their spaces more accessible,” he says.

Frustrated with the options available, Clark began experimenting with his own home fitness routine. He found that a gym wasn't necessary to create a quality fitness routine as a wheelchair user. All he really needed was a little creativity and a few pieces of inexpensive equipment.

He started his “Adapt to Perform” YouTube in 2017 to help other wheelchair users along on their fitness journeys, and he's now looking to take the concept further. Clark will soon be launching what he calls “Netflix for adaptive fitness,” a website dedicated to on-demand accessible fitness. “We're bringing it to people's homes so they don't need to have a car to get to the gym, they don't need to have a gym that has a ramp or an accessible toilet or the right equipment,” he says. “They can just be in their own home, doing it by themselves

sort of thing, but still getting that community feel and enjoyment from it.”

He isn't the only one working in that space.

DIGITAL ACCESSIBLE FITNESS FILLS A NEED

Matt Ney got involved with the adaptive fitness scene after seeing how people with disabilities were left on the sidelines when he worked for a company that created fitness videos for teachers and students.

“Students didn't want to do it, or they weren't able to do it and it had nothing to do with them, or the teacher — it was my fault,” says Ney. “I created the content that was inaccessible. So, I went home and just started researching the terms ‘adaptive fitness’, ‘accessibility and



fitness’, and ‘inclusive exercise’ and I found nothing.”

Ney self-funded his company, Kakana, mid-pandemic, in October 2020 after a beta run during that previous summer. Its instructors are trained in the mold of SoulCycle or Peloton trainers but, instead of requiring an expensive membership or a large piece of equipment, the cost is a \$14.99 membership and a hand ergometer, available for as little as \$30 on online retailers. Kakana offers courses in yoga, strength, crosscycle, meditation, stretching and cardio. Ten adaptive fitness instructors — including five wheelchair users, an arm amputee, a below the knee amputee, a little person, and one with chronic pain — offer classes across the week, with on-demand options also available to subscribers.

Ney, who is not disabled, reiterates that for him, this wasn’t a charity case. He saw a need and wanted to fill it. He also acknowledges that the economics of the move made sense. As many have pointed out in recent times, the collective spending power of disabled people is both underappreciated and underexplored.

“It really started with identifying that at best I was naive and at worst I was an ass,” he says, laughing. “And realizing that what I had created previously was just only for 70% of the population, and that wasn’t good enough.”

Ney believes that the future of digital accessible fitness is bright. In addition to Kakana and Clark’s offerings, a number of disability organizations have begun offering their own online fitness classes

covering everything from strength to cardio to yoga to dance and more [see sidebar].

On the corporate side of things, Ney points to the success of adapted Tommy Hilfiger clothing as an example of what happens when human-centered marketing meets the market realities of businesses such as his own in a positive way. “The disability community can wield serious power. And when that is realized, the bigger companies out there that are not accessible will see that is a reason, not just a feel-good reason, but an economic reason, to make their products accessible early.”

Dom Kelly, a former dance teacher and Kakana subscriber, was drawn to the platform by the adapted exercises. “I wanted to be able to have exercise options that would be understanding of the fact that some things are not acces-

sible,” says Kelly, who has cerebral palsy. He points to dance classes that teachers adapted for him as a child and says that a similar level of care feels lost to him now in most gyms. “As an adult, most fitness instructors don’t know how to adapt to folks with disabilities. My experience has been that I don’t feel as comfortable in an environment now where I’m with other people in a class because it’s oftentimes not as easy for me to participate.”

Online classes and other digital offerings can provide a valuable service for people like Kelly who don’t have access to a quality adaptive instructor or for anyone else who struggles getting to a live class or accessible gym. When asked what he tells someone who is contemplating digital accessible fitness but isn’t quite ready to take the plunge, Clark says, “I totally understand that fitness isn’t for everyone, in terms of wanting to do it, but fitness is definitely for everybody in terms of what you can benefit from it. That doesn’t necessarily mean that you have to become a Paralympian. You don’t have to be doing all these crazy heavy weights or loads of distance.”

To reap the health benefits of a fitness regimen, all you need these days is a computer, an instructor who knows what they’re doing and maybe that old broom handle in your closet. NM



Seth McBride tests Kakana cross cycle classes.

OTHER ONLINE ADAPTIVE FITNESS OPTIONS

A number of disability organizations, some spurred by COVID precautions, have begun to offer online adaptive fitness classes. Options include:

- **DPI Adaptive Fitness:** Affiliated with Medstar National Rehabilitation Hospital, DPI offers a variety of live online adaptive fitness classes, including strength, boxing, high intensity interval training, a class specifically for people with multiple sclerosis and more. Cost: free to \$15 per class. Visit: dpiadaptivefitness.co/dpi-class-sign-up.html
- **The Axis Project:** This New York City-based disability org has been offering in person adaptive fitness classes for years and since the pandemic they’ve begun hosting free, live adaptive workouts — including strength, stretching and even seated Zumba — on their Facebook Page. Cost: free. Visit: facebook.com/TheAxisProject/
- **Bay Area Outreach & Recreation Program:** The Oakland-based program now offers online adaptive fitness classes to everyone. Weekly classes include dance, functional strength training, Rumba, Tai Chi, yoga and more. Cost: free. Visit: borp.org/borp-online-fitness-studio/
- **Yoga Anytime:** This online yoga studio features a high-level, in depth yoga program for wheelchair users hosted by Quinn Brett, a para. Cost: \$18 monthly, 15-day free trial available. Visit: yogaanytime.com

For the most comprehensive list of online fitness classes and resources we can find, please visit: borp.org/online-fitness-options/



DAILY DILEMMAS

By Sheri Denkensohn-Trott

THE IMPOSTER CANINE COMPANION

Q. About seven years ago, I was trained by Canine Companions for Independence and received my dog, Derby, from them. I am a high-level quadriplegic, and the decision to get a CCI dog was not made lightly. The application process is daunting, and the ongoing care is expensive and time consuming.

I talked it over with my family, and everyone was on board. My application was accepted, and I attended training. The training was arduous but so worth it! At the end when I was paired with Derby, I knew right away we were pals for life.

Derby helps me pick up items off the floor, puts things in the garbage pail, grabs my mug with his teeth and — most importantly — barks when I need help. He knows to just lie down and be quiet when I am out in a coffee shop or a restaurant. He wears a vest indicating that he is certified so I can bring him into establishments and on trips. I don't know what I ever did without him.

Recently, though, I have been having difficulty with my friend Jane. She and her dog, Juicy, have not gone through training. Juicy is a large, rambunctious black Labrador. Though she's friendly, she jumps up and scares people and other dogs, including Derby.

I have asked Jane to tell Juicy to behave, but Jane ignores my comments. Recently, Jane started putting a blue CCI vest on Juicy and bringing her into stores

and restaurants. True to form, Juicy runs all over and does not behave.

This makes it more difficult for individuals like me with a trained dog to enter an establishment without being questioned. Plus, I know all the work involved in getting trained with a CCI dog. Jane is short-circuiting the system and acting like she has a CCI dog. What should I do? Do I avoid the topic and stay angry? Should I initiate a conversation and risk her getting angry and defensive? I want to maintain our friendship, but I can't get past Jane's use of Juicy as a certified CCI companion dog.

There are specific guidelines and procedures that everyone must follow to get a CCI dog. With this certification comes responsibility. And the owners and dogs must comply with rules and training when they are working. What Jane is doing violates the rules and, as you suggest, Juicy's behavior makes it appear to others that a certified dog with a blue vest is not under control.

You have some options to consider. One approach is a very low-key conversation with Jane stating that you enjoy spending time with her, but that her use of Juicy as a trained CCI dog is misleading and is not fair to those who have gone through the expense and time of being trained.

Hopefully, Jane will agree and refrain from using the vest and stop

“Jane is short-circuiting the system and acting like she has a CCI dog. What should I do? Do I avoid the topic and stay angry?”

bringing Juicy into establishments. If Jane gets angry, you can try to further explain your reasoning for bringing this up: that you are concerned it will make it harder for trained dogs like Derby to enter establishments without pushback; and that the action she is taking with her “imposter” CCI dog may well create an adverse impact on your ability to have your dog assist you when needed.

If Jane still refuses to comply, you may have to resort to being blunt and say, “Apply to CCI for a training slot, or I won't be spending time with you when you have Juicy.” While tricky, this sends Jane a clear message. In the long run, your relationship with Derby must be primary, and integrity of the system of having a recognized support animal must be held to a high standard so that it is understood by the public and not abused.



REFRAMED

by Reveca Torres

IN MY OWN TIME

I was in my sophomore year in high school, and everyone was taking driver's ed. I enrolled as a requirement but there were no adapted vehicles for me to take the driving portion. I was embarrassed to take the class. *Would everyone wonder: Why is she even here?*

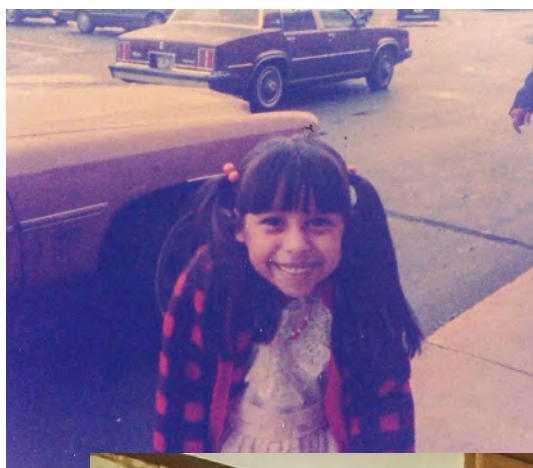
I didn't actually get a driving evaluation and lessons until I was 19 years old. I drove for the first time at 21.

I didn't get my first job until I graduated from college and was recruited to do a summer program at the hospital where I used to be a patient.

I didn't go on a real date until well into my 20s because I was so afraid of being rejected for being disabled.

I feel like I have gone through a big part of my life measuring and comparing my life's milestones to other people's — especially my nondisabled peers — and feeling inadequate or falling behind. Unfortunately, I have also spent a lot of time comparing myself to others with a spinal cord injury like mine. Am I doing enough? How come they have more function than I? They have a job. They are traveling. They are married. They have children. It's been over 25 years since my injury, and it can still be difficult to not compare myself to others.

However, I've been able to flip a switch in my mind and realize that growing up as a disabled woman, I move my own way and get to where I am supposed to be when my time is right. In fact, sometimes having this extra time has allowed me to observe others and make better choices and decisions. I appreciate what I learn from others and celebrate their milestones rather than feeling like there are greener grasses elsewhere.





PRODUCTS

By Michael Franz

THE QUADSTICK FPS

The video game industry is massive, with an estimated value between \$160 billion and 180 billion. Thankfully, developers are finally working to make games more accessible, and new devices like Microsoft's Xbox Adaptive Controller are allowing gamers with any level of function to play.

But before Microsoft and other companies focused on adaptive gaming, there was the QuadStick. Since 2014, the QuadStick has been the premier mouth-operated controller. The QuadStick FPS is one of three hands-free gaming devices in the QuadStick family. The controller works with all types of games but got its name from, and was designed especially for, first-person shooters. The QuadStick FPS is operated entirely by the user's mouth and is appropriate for those with limited or no arm and hand function. As a C5-6 quadriplegic, I am not the target audience for a hands-free device, but I wanted to try the unit out to show what is possible for other gamers.

The QuadStick FPS is made up of a joystick, four sip-and-puff sensors, and a lip button. Each component can be customized to execute a different function on the computer or gaming console being used. For example, the joystick can be programmed to work as a mouse on a computer or as a joystick or D-pad on a video game controller. Similarly, the sip-and-puff sensors and lip button can be assigned so that a puff on the middle sensor works as the



Mike Franz demonstrates the sip-and-puff functions of the QuadStick.

B button, or a sip on the right sensor engages the right trigger. While playing, the user can switch between modes to use the different joysticks and D-pad on the fly.

The QuadStick FPS can be attached to a mounting kit that can be connected to a wheelchair, desk, or bedside table. My demo unit came with the Flexible Mounting Arm Kit that is available on QuadStick.com for \$105. I attached the kit to a bedside table and was able to move the table and adjust the height so that I could use the QuadStick FPS without a problem. Other mounting kits are available from QuadStick.com, or a customized mounting kit can be built with components found online.

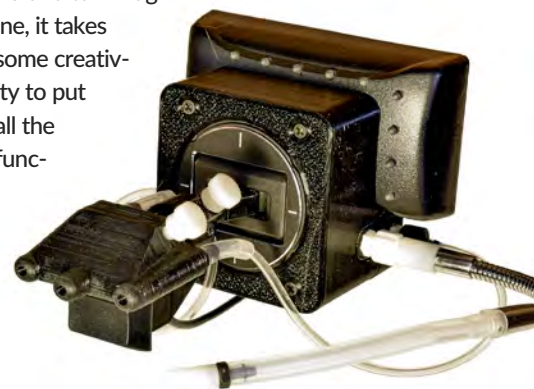
During my time with the QuadStick FPS, I tested it with the Nintendo Switch and Xbox Series X. The controller works out of the box with the

Switch, PS3 and PS4, Mac and Windows computers, Android, and iOS 13+, but needs an adapter to work with newer systems like the Series X and PS5. I used the Brook Super Converter for testing with the Series X.

The QuadStick FPS works very well and I did not encounter any significant glitches while using it, but there is a learning curve. The sensors always registered my sips and puffs, but it took a while for me to learn the difference between a soft sip and a hard sip, and a soft puff and a hard puff. As any gamer would know, pressing the wrong button can be the difference between clearing a level and

dying, so it is important to be accurate when you are playing. None of this was the fault of the controller or the software, but don't expect to be a gaming god after a few sips and puffs.

The most difficult aspect of using the QuadStick FPS for me was remembering how to actually play a game with it. As one can imagine, it takes some creativity to put all the func-



QuadStick FPS



Flexible Mounting
Arm Kit

tions of a standard game controller into a device with one joystick, four sip-and-puff sensors, and a lip button. For example, the Xbox Series X controller has 11 buttons, two joysticks, and one D-pad. The fact that the creators of the QuadStick FPS can make this work is quite remarkable. However, memorizing how to make the buttons work was difficult, and I never got the hang of it completely. Fortunately, there are cheat sheets available that lay out the various commands for individual buttons. There were many times when I would have to pause a game just so I could look at the cheat sheet and plan my next move. As with anything new, it takes time and practice to learn. With more practice I am sure I would have become more proficient.

One of the best features of the QuadStick FPS made learning the sip-and-puff commands more difficult, but at the same time made games easier to play. The QuadStick Management Program is a Windows app that allows the user to customize their controller. Joystick sensitivity and the sip and puff threshold can be adjusted, firmware can be updated, and custom game profiles can be uploaded. The QuadStick FPS has a flash drive that can store 10 custom game profiles.

While I was testing the QuadStick FPS, I was able to download profiles for *Breath of the Wild* for the Nintendo Switch, as well as *Assassin's Creed: Valhalla* and *Cyberpunk 2077* for the Xbox Series X. These profiles, and many

others, can be found and downloaded from the QuadStick forums. Once downloaded, the user can customize the profiles further, or load them directly to the QuadStick FPS. Custom profiles can also be built completely from scratch to suit the specific needs required of individual games. Learning different commands for every game is difficult, but it is worth it as it makes the games easier and more fun to play.

The QuadStick FPS is an excellent

hands-free gaming controller for those with limited or no arm and hand function. It works with all of the major gaming consoles, Windows and Mac computers, and most current Android and iOS devices. It does take a lot of practice to get used to playing with the QuadStick FPS, but it is worth the effort as it opens a world of opportunities for long-time gamers and those looking to get into the hobby. The QuadStick FPS is available for \$549.99 at QuadStick.com.

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IN THE MEDIA

By Teal Sherer

THE OPRAH OF DISABLED MEDIA

In the May 22nd episode of Andrew Gurza's *Disability After Dark* podcast, Ryan O'Connell says that he wants to be like the "disabled Oprah." "You get a job, you get a job, you get a job," he tells Gurza. O'Connell is referring to the way he hired disabled actors in the second and final season of *Special*, a Netflix show he writes, stars in and executive produces. "I don't know how long I will be in the position to give people jobs and so while I am in that position, I want to give all the jobs ... because I know that's the only way people accrue opportunity and gain power in this society."

Special is based on O'Connell's 2015 memoir, *I'm Special: And Other Lies We Tell Ourselves*, about his life as a gay man with cerebral palsy. The first season, which is made up of eight short-form 15-minute(ish) episodes, premiered

on Netflix in 2019 and received three Emmy nominations. In season 2, which was released in May, the episodes are "a luxurious, sexy, full 30 minutes," says O'Connell on *Disability After Dark*.

Special explores the complexities of being disabled with honesty, humor and heart. Early in the series, the character Ryan is hit by a car. When his boss assumes his limp and poor hand dexterity is from the accident, Ryan doesn't correct her. He keeps his cerebral palsy, which is way less accepted in our ableist society, a secret.

Special is also celebrated for its authentic portrayal of gay sex. In the third episode of season 1, Ryan hires a sex worker to lose his virginity. The scene is raw and tender and captures a reality that, like disability, is rarely represented on TV and film.

After Ryan comes clean about having cerebral palsy at the end of season 1, he embraces his disability in season 2. He finds community through a disability support group called the Crips — who are planning their upcoming event Crip Prom. Nicole Lynn Evans, who has roles on NBC's *Superstore* and Freeform's *Good Trouble*, plays Natalie, one of the Crips. "When I booked the job, it was such a huge moment for me," says Evans, who has osteogenesis imperfecta, a brittle bone disorder. She is also a



Ryan O'Connell and the Crips film season 2 of *Special*. (From left to right: Buck Andrews, Nicole Lynn Evans, Ryan O'Connell, Danielle Perez)

little person. "I see so much of myself reflected in Ryan's character, like his journey of learning to accept and love his disability."

Though it was shot during the COVID-19 pandemic in 2020, filming Crip Prom was a highlight for O'Connell. "It was so amazing not to be the minority in a room for once," he tells Gurza. Evans agrees. "We were all dressed up and had so much fun. It was great to be on set working with so many talented actors with disabilities," she says. "Everyone was tested for COVID and had PPE. I felt safe."

While Netflix has no plans to make more episodes of *Special*, there is no denying the impact it has had on expanding disability representation.



Nicole Lynn Evans and Danielle Perez pose in their masks between takes.

"Ryan pushes the envelope so much but even pushed it again when he said I am going to have people of different ethnicities and disabilities in the second season, and I want them to be celebrated," says Andy Arias, who has cerebral palsy and is an actor. Arias also works on national policy for people with disabilities and facilitates United Spinal Association's Rolling with PRIDE LGBT+ monthly discussion group. "Special is opening a door for people like me, who are Latinx, disabled and gay." Arias' favorite scene in season 2 is when Ryan hooks up with a guy that fetishizes his disability. "I love how they handled that storyline. Devotees are something we talk about within the disability community, but we never see it represented in entertainment."

O'Connell tells Gurza that he hopes *Special* motivates other disabled people, if they are creative, to work on their own projects and know that their voice has value. "I hope, I hope, I hope that the



The *Special* episode "Prom Queens" featured many disabled actors who took part in a Crip Prom.

conversations around disability continue to deepen and people continue to see us as multifaceted, complicated, amazing people. And give us fucking jobs," he says.

In the meantime, O'Connell has no plans to slow down in his quest to bring disability to the mainstream. He sold a show to HBO Max called *Accessible* about group of disabled teenagers

at boarding school. If it gets made, it would feature a mostly disabled cast. O'Connell also wrote a novel during quarantine, *Just by Looking at Him*, about a gay disabled television writer who falls down a rabbit hole of sex worker addiction. It is being adapted into a movie that O'Connell would star in.

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www.unitedspinal.org/pathways-to-employment/

Meet New Member Peggie Avers

Age 52, from Elmore, Ohio
T11 and L3 incomplete spinal cord injury
Owns a lawn care business; Director,
Ottawa County Agricultural Society



Why I joined United Spinal: I joined to learn about new or different disability products. I was excited to find a group of people with various disability or mobility issues who I could talk to and get advice from.

What is the one product you couldn't live without?

My grabber – to reach things on shelves when I am getting dressed and when I am cooking and need ingredients.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?

Accessible/usable parking places and restrooms, easy to navigate store aisles, better access to in-store electric carts and automatic doors would all make a big difference to wheelchair users.

Meet other members or join United Spinal at unitedspinal.org



Photo by Léa-Kim Châteauneuf/Wikipedia Creative Commons

WHAT'S NEW WITH CANADIAN WHEELCHAIR RACING STAR CHANTAL PETITCLERC?

When we named Chantal Petitclerc our 2007 Person of the Year, she had already won nine Paralympic gold medals and was considered the fastest racer in the world. In addition to chronicling her many successes, our profile wondered where she'd shine next? Maybe we could've predicted the five gold medals she added to her tally in 2008, but it would've taken true vision to guess Canada's prime minister would appoint her to the Senate in 2016. She has since served as an outspoken disability advocate. "I'm always trying to bring a person-with-a-disability lens so I can be that voice. I make sure that I speak out and that we are taken into consideration," she told Paralympic.org.



NM LIVE VIDEO SERIES with Teal Sherer

AUGUST GUEST: PARALYMPIC ATHLETE CHUCK AOKI

Team USA Wheelchair Rugby athlete Chuck Aoki is getting ready to head to Tokyo to compete in his third Paralympic Games. After winning the bronze medal in London, and a silver in Rio, Aoki and his teammates are going for gold.

In our interview, Aoki talks about the Paralympic experience and how he physically and mentally prepares to compete. He also shares what the pandemic taught him, the COVID-19 precautions Paralympic athletes must take and how we can help grow the adaptive sports movement.

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