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ARCHITECT, BUSINESSWOMAN AND POLICY-SHAPE KAREN BRAITMAYER

Karen Braitmayer has excelled at making accessibility cool since before the ADA even existed. With an approach and understanding that is molded by a life using a wheelchair, Braitmayer’s commitment to elevating the discussion around architecture and access transcends professional boundaries: For her, it’s personal. Her impact goes far beyond her Seattle home, and earned her the American Institute of Architects 2019 Whitney M. Young Award for Social Responsibility. For these reasons and many more, we are honored to present Braitmayer as our 2019 Person of the Year.

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48 LAST WORD
Last June I used this space to recap all the changes and additions to New Mobility in my first year as editor. In retrospect, I wish I had waited until this issue because the pace of change has only accelerated since then and is about to speed up even more in the new year.

I guess that’s why they say hindsight is 20/20. Bad humor aside, 2020 is shaping up to look like a great year for New Mobility. We have an exciting slate of stories lined up and we’ve enlisted some new voices that I think you are really going to enjoy. A couple of those new voices — Todd Stabelfeldt and Josh Basile — make their debut later in this issue.

Also look for expanded monthly coverage of United Spinal Association and a new quarterly feature focusing on sharing insights from community leaders and visionaries. We’re calling it “Big Ideas” as an homage to September 2019’s Big Ideas Issue.

If I had to pick a highlight from 2019, that issue would be my choice. It was a ton of work, but it pushed our editorial team to think outside the box in terms of content and design, and I genuinely believe the final product will stand the test of time as an invaluable resource for our community. It also educated us about some hot-button issues we now plan to cover more in the future.

“Big Ideas” will build on the excitement and momentum the issue generated by featuring a Q&A with a different thought leader or innovator every quarter. Executive Editor Josie Byzek kicks it off in style this month with an interview of famed disability advocate Judy Heumann.

While our content evolves at a break-neck pace (my New Year’s resolution is to give up humor — I swear), we are doing our best to keep up with the changing worlds of publishing and online distribution.

As the official membership magazine of United Spinal Association, New Mobility is seen every month by over 100,000 people, either electronically or in print. Thirty years ago, that level of distribution would have been more than enough to entice a king’s ransom of advertisers and fund an all-encompassing staff to cover every aspect of life on wheels.

“If I had to pick a highlight from 2019, the Big Ideas issue would be my choice.”

Today a publication’s online readership and social media metrics are just as — if not more — important than print circulation. Despite the explosion of web content on all topics, we believe that New Mobility fills a niche of authentic, curated content for wheelchair users better than anyone else on the internet, and we are committed to ensuring that content reaches as wide an audience as possible. To that end, we are working behind the scenes on a number of ideas and projects that I will reveal to you in the near future.

In the meantime, I hope you enjoy our first issue of the ‘20s. With your help, I am confident we will make this New Mobility’s best decade yet. And who knows? Maybe scientists will have discovered an all-encompassing cure for SCI/D by the time 2030 rolls around.

Just to be clear, that wasn’t a joke.
Todd Stabelfeldt isn’t looking for the limelight, but because of the way he lives his life to the fullest, it keeps finding him. Whether it is Permobil or Apple featuring him in national campaigns, or an annoying editor from New Mobility pestering him to write a technology column, Stabelfeldt is beginning to adjust to being in demand. “I’ve been living this wheelchair life for over 30 years now,” he says, “and I figure if I have some experience and knowledge that can be of benefit to others, it’s on me to pay that forward.” As the aforementioned annoying editor, I can’t wait to see how he channels his learned wisdom into “Todd Against the Machine.”

When I first discussed the idea of a regular employment column with Josh Basile, I told him to take some time and put together a list of topics he thought would be of interest to New Mobility readers. I often ask interested contributors to do something similar, and usually they get back to me in a week or two. Basile sent me a detailed two-page list within 24 hours. Despite diverse interests that include everything from advocacy to slingshot golf, Basile’s true passion has always been obvious: helping people with disabilities find employment. He does this every day as an employment lawyer and will now be doing it quarterly in his “Work Works” column for New Mobility.

For the past six years, mealtime has been a little bit tastier and more interesting thanks to “Eat Well” author Joanne Smith. Smith came to New Mobility as a coauthor of “Eat Well, Live Well,” which she wrote along with Kylie James for years before we split the column in two. As the sole author of “Eat Well,” she has found a way to make nutrition and SCI fun and accessible on a bimonthly basis — no small feat. While this will be Smith’s final issue at the helm of “Eat Well,” we hope she will continue to contribute and share her knowledge in our pages.

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

That’s the problem with any equipment to help people with disabilities be more active: It’s so expensive they can’t afford it (“Product Roundup,” November 2019). Medicare option is great, but not everyone in a wheelchair is old enough to have it — not to mention the fight you’d go through to get it approved even if you do.

Anita Sharp Wood
Via Facebook

Editor’s Note: Regardless of your age, if you are eligible for Social Security Disability Insurance benefits, then you are also eligible for Medicare coverage. However, there is a 24-month waiting period between when you start receiving SSDI until you may receive Medicare benefits. You also may be eligible to enroll in your state’s Medicaid program to receive health insurance during this waiting period.

Get it Done

Some people would probably cringe at the stuff I’ve rigged up (“Gear Hacks: Spatula Solutions,” November 2019) to assist me in doing nondisabled activities such as getting up in a tree stand or things I’ve done in my wood shop to make certain cuts. But hey, get shit done any way you can is my motto.

Kevin Kunz
Via Facebook

After Ian Ruder’s Bully Pulpit (“A Table With Tales to Tell,” November 2019) outlining the strange emotional attachment he has to his adjustable-height table, readers responded with their “can’t live without” pieces of equipment:

Tea Time

My electric tea kettle. It minimizes making a cup of tea, as it goes everywhere and isn’t too big or heavy. I got burned too many times using the stovetop kettle.

Allison Lansberry
Via Facebook

Easy Access Cutting

Mine are the slide-in cutting boards built into my lower kitchen cabinets so I can roll my lap under while I cut vegetables or prep other foods without hiking my shoulders. One is placed next to my oven where I can place hot items. The other, which is a bit higher, is next to the refrigerator and cooktop.

Madonna Logosz
Via Facebook
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Get Off the Boat With Ease

Disabled cruise enthusiasts tired of missing out on inaccessible shore excursions have a slew of new reasons to be excited thanks to MSC Cruises. The Switzerland-based cruise giant announced a series of custom, accessible excursions designed specifically for people with mobility-related disabilities.

“This program is unique because for the first time we offer accessible tours available in both popular cruise regions of the Caribbean and the Mediterranean,” says Jean-Pierre Joubert, MSC Cruises’ head of shore excursions. “By joining these tours, all guests will have the care-free opportunity of enjoying the best of every excursion.”

The new excursions will include 11 ports in the Caribbean and nine in the Mediterranean. John Sage, the CEO and founder of Accessible Travel Solutions, says the offerings will make booking easier and more affordable for travelers with disabilities. “This is going to be great for disabled travelers since they can now book their accessible shore excursions through this cruise line and split the cost of the accessible van with other guests,” he says.

Resource: Facing Disability’s Voices of Experience Series

Anyone looking for answers or new to SCI/D will benefit from FacingDisability.com’s new Voices of Experience series. In each of the 10-15 minute-long videos, long-time wheelers share their answers to a common post-SCI question. A focus group of SCI team members at the Shirley Ryan AbilityLab reviewed and refined the final list of questions. The series was created for distribution on the in-hospital TV networks of the Spinal Cord Injury Model Systems hospitals and online. Watch these 10 new videos at facingdisability.com/voices-of-experience-videos.
**ICYMI: TravelAbility Summit**

Over 100 representatives from across the travel industry and the world of disability met at the Hotel Kabuki in San Francisco November 11-13 for the TravelAbility Summit, a first-of-its-kind conference dedicated to improving travel experiences for people with disabilities. The three-day event kicked off with a Monday session highlighting accessibility-related travel products and services, and finished with two full days of presentations, panels and breakout sessions covering everything from specific destinations to accessibility training.

"While I felt that connecting assistive technology and tourism professions with thought leaders in the disability travel community would create a unique synergy, I was surprised that so many of them were inspired to spring into action so soon after the event and spread the word among their peers in other destinations that they had discovered a growing niche that added a new and meaningful purpose to their jobs," says founder Jake Steinman. Next year's Summit will take place in Orlando. For details visit, travelabilitysummit.com.

**WANT**

**LINCOLN RHYME: HUNT FOR THE BONE COLLECTOR**

ON JANUARY 10, NBC ROLLS OUT THE LATEST TAKE ON JEFFERY DEAVER'S 1997 NOVEL THE BONE COLLECTOR, FEATURING ACE DETECTIVE LINCOLN RHYME TRYING TO CATCH THE EPONYMOUS VILLAIN WHILE COPING WITH HIS NEW LIFE AS A QUADRIPLEGIC. RUSSELL HORNBSY (FROM THE TV SERIES GRIMM) TRIES TO FILL THE WHEELS (AND BED) DENZEL WASHINGTON INHABITED IN THE 1999 FILM.

**Affordable All-Terrain Access**

Ben Huntzinger has been driven by a simple goal since he was paralyzed in 2009. "Everybody should be able to go and buy a good all-terrain wheelchair just like you can go buy a mountain bike," says the 33-year-old college student.

An outdoor enthusiast, Huntzinger, a T4 paraplegic, wanted to be able to take his dog to the river and not have to sit idly on the banks. He wanted the ability to barrel over gravel and rocks and get out in the water in his chair. This May, his dream became a reality when he started selling the Spartan Wheel Chariot — a rugged all-terrain chair he designed, manufactures and sells for the remarkably low price of $500.

Huntzinger taught himself to weld and bend conduit on the tailgate of his truck and eventually went back to school to learn the skills he needed to transform his dream into a business and a reality. Over the course of eight years, his design evolved from an old wheelchair with a downhill skateboard axle mounted under the footplate to an award-winning conduit frame with four-link rear suspension, 10-by-3-inch front tires and Spinergy rear wheels with knobby Kenda Nevegal tires.

He used the prize money from an innovation contest sponsored by the Georgia Chamber of Commerce to buy the parts in bulk and keep the cost down. Affordability was always at the fore. "Think about the difference we can make in the spinal cord community when everybody has a chair that they can use just for the outdoors," he says. Order or find out more at spartanwheelchariots.com.

**Reclaiming Disability Imagery**

Disabled and Here is a collection of photos and interviews made by and featuring disabled people from underrepresented communities aimed at changing the narrative around disability and creating representation from within. The photos are free for public use and accompanied by insightful interviews with many of the people featured. Check out the photos and find out more at affecttheverb.com/disabledandhere.
REFUSING TO DIE: THE CHRIS DUNN STORY

On July 7, 2018, Chris Dunn survived a freak diving accident that left him paralyzed, on a ventilator and mostly blind only to face an even more hellish reality: a year living in a Maine ICU fighting for his right to go to rehab and get back to living his life.

Other than a short-lived attempt to return home a few months after the accident, Dunn, 44, did not leave the ICU for over a year. There were no local rehab centers that could accommodate his needs, and after initial efforts to find an out-of-state rehab failed, he found himself stuck.

Unable to see, eat, breathe or move on his own, with little to no access to therapy, Dunn, a father and concrete worker, spent day after day lying in bed listening to the History Channel and hoping for a chance — just a chance — to show he could do more. After hearing Dunn describe his stay, perhaps the best way to describe what he went through is a living nightmare. “I’m pretty sure they just wanted to kill me,” he says. “I wasn’t too happy. It sucked.”

The notion of a hospital wanting to kill a patient may seem far-fetched, but when you factor in that administrators repeatedly urged Dunn’s mom, Carol, to consider putting him in hospice, the nightmare becomes much more real.

“I cried and felt so desperate. I was scared to death every day and didn’t want to wake up because I knew there would be a fight,” says Carol. “I’d go into a room and I was outnumbered by doctors, nurses and case workers, and as it went on, more and more came in. They thought if they increased the numbers, I would give in. But you don’t give in for your child. You don’t give in for somebody who wants to live. And Chris told me, ‘Mom, I can do this.’ He wanted to live.”

‘We Need Help’

Carol refused to give up. After seven months of reaching out to hospitals and rehab centers all over the country and receiving nothing but rejections, in February 2019 she filled out the online form to join United Spinal Association. In the space on the form where applicants can ask a question, she explained Chris’s situation and wrote, “We are desperate…we need help please.”

Carol’s application and plea landed in the mailbox of Jane Wierbicky. Wierbicky, a longtime nurse, is one of six members of United Spinal Association’s Resource Center team. Every month the team receives between 200-300 new member applications, and every application gets assigned, read and, if needed, responded to. Wierbicky emailed Carol the next day, beginning a partnership between the Dunns and United Spinal that would eventually turn the tides and get Chris back to living his life.

As Carol explained what had been going on since Chris’s injury, Wierbicky and Resource Center Director Bill Fertig developed a fuller picture of the problem. By all accounts, Chris had a complicated medical condition — because he had a lot of rehabs facilities willing to consider him, but his injury had also left him mostly blind and necessitated the installation of a pacemaker and feeding tube.

“Carol felt like he had originally been denied from some rehabs because of his medical condition — because he had a lot going on,” says Wierbicky. “She thought they’d be able to revisit things and get him into rehab when he was more stable.”

When Carol kept getting rejected and hospital staff and administrators started suggesting alternatives and that she consider hospice, she grew frustrated. “People kept shutting the door without even trying, without even giving us a chance,” she says. “That’s unacceptable to me.”

Wierbicky agreed. “It’s always shock-...
Far from dying, Chris Dunn found renewed life once he made it to a world-class rehab. The Dunns said they were met at Shepherd with hugs and words of welcome.

it wasn’t an option because of Chris's insurance, but after much wrangling they came to an agreement.

“I said, you know, if we go to Shepherd and they can’t do anything we’re still OK because I know that the best people in the world at least had a chance to look at Chris,” she says.

Return to Living
The Dunns’ dream came true, and July 16 they boarded a plane for Atlanta. Chris was ecstatic, but after so many false starts, Carol remained on edge until they rolled into the hospital.

“There were people literally waiting there to hug us and say, “We’re glad you’re here. We’ve been waiting for you,”’ she says. “And for the first time in over a year I felt a calmness, and I was able to take my first deep breath.”

As one of the nation’s premier SCI rehab centers, Shepherd Center was perfectly positioned to address Chris’s needs. “We were able to give him a lot other facilities wouldn’t have been able to,” says Tammy Arnold, the case manager for the SCI Unit who oversaw Chris’s case.

“Shepherd Center has the full breadth of services for catastrophic patients,” says Chet Bhasin, Shepherd’s chief strategy officer. “Starting with a 10-bed ICU all the way through to outpatient clinics, we can provide the appropriate level of care at the right time for any brain injury or spinal cord patient.”

“We’ve got great people here and great teams to support him: therapists, psychologists, nursing, assistive technology, even a neuro-optometrist to look at some of the visual changes he had with the anoxic brain injuries that we suspected,” says Dr. Wesley Chay, the doctor who coordinated Chris’s care. “We had an interdisciplinary approach to get Chris — and his mom and girlfriend — back to living.”

Respiratory therapists went to work trying to wean Chris off the ventilator and strengthen his voice, while physical and occupational therapists tried to undo the damage a year of lying in the ICU had done to his body, including extreme rigidity and extensive neck extension that prohibited him from eating.

“They were a godsend,” says Chris. “They loosened me up and got me back lots of range of motion.”

The team helped Chris build up the lung capacity to only need the vent at night. “That makes a huge difference,” he says. Chay says Chris had always believed he could wean himself, but he needed someone to believe him who knew how to support his efforts.

“It wasn’t so much a surprise, but kind of a confirmation of, ‘Hey, you know what, Chris was aware of some things that he really thought he could do,’” says Chay. “At Shepherd, we’re really trying to just find where people are at, and you know, find the things that they’re passionate about.”

High atop Chris’s list was getting back outdoors after a year under florescent hospital lighting. Rehab therapists helped him check off his list by taking him fishing. “I caught a fish!” he says. “He was just a little fellow, but we caught a damn fish!”

After over four months at Shepherd, Chris and Carol headed back to Maine. While Chris was in rehab, Carol found an accessible apartment and worked with the team of advocates she had assembled to set up the things Chris would need to live independently.

They returned home on his birthday and settled in to enjoy Thanksgiving together with his girlfriend at home. They are still fighting to get the caregiving, equipment and benefits Chris needs, and they still hold weekly calls with the United Spinal Resource Center team, Disability Rights Maine and others, but things are improving. “It’s going to be slow and we have to be very safe,” says Carol, “but even if there was no further improvement, I am happy.”

Thinking back on the days before Chris finally went to Shepherd, she recalls a rare moment of doubt where she wondered if she was advocating in Chris’ best interests when she fought the hospital’s push to send him to hospice.

“I don’t know that I would have been able to make things happen without the United Spinal Association,” she says. “I was getting tired. I wasn’t going to give up. But they came in and propped me up and gave me some courage and some encouragement to keep going. They pointed me in some right directions and stood behind me, and that’s all I needed to cross that finish line.”

Chris is off the vent all day and only uses it for a few hours a night, hanging out with friends he hasn’t seen in ages, and following his beloved New England Patriots as they try to make it back to the Super Bowl. He is eager to keep improving and plans to start his own United Spinal chapter to help others like him.

United Spinal’s Resource Center can be reached at unitedspinal.org or 800/962-9629.
NM: The ADA turns 30 this year. Did you think we’d be further along by now, and where do you think we’ll be when the ADA turns, say, 50?

JH: Quite frankly in the beginning I wasn’t thinking that far into the future. I didn’t think there would be this much advancement in this period of time because it felt like we were so far behind other movements in so many different ways. We were looking at the need to create organizations and develop principles like cross-disability, intergenerational, independent living, community integration … those were issues I thought about most prominently, not where we would be in 10, 20, 30 years.

Looking at that question today, I have a number of thoughts.

First, change takes a long time. On some level that’s kind of a trite thought, but when I think about the amount of work that has been done in my lifetime to advance the movement, we've made important progress but are still very far behind other movements. In part this is because other movements by and large don’t see us as a part of their movements.

We’ve seen progress, not excellent, but good to very good, in physical access. But then you see New York City building subway stations that are not accessible and airline travel becoming more difficult, not less difficult.

Disabled students receiving quality education in integrated settings so they can participate in their community and not be marginalized is, in my view, pivotal. And employment is another critical issue. We need to ensure that people get the education they need to work in the work force of today and tomorrow.

It’s not just about today. If we’re not part of discussions about the future, we will lag behind. When you think of autonomous vehicles, if not for the fact we started getting involved early, I doubt there would even be a discussion about our issues, and we’re still not where we need to be.

We must be part of discussions about global warming so we can play a more meaningful role in the policies and practices that are being developed. It’s also important that disabled people be running for office in greater numbers.

NM: That is quite a comprehensive list of issues, and they’re all vital to our continued success. But if you were forced to pick one, where should we put our focus?

JH: Organizing. Expanding the movement. Getting people who don’t identify as disabled to understand that they have a disability and why it’s important for them to identify. Giving people the tools they need to effectively work with elected representatives and influence policy.

It’s important to allow disabled people opportunities to work with other people so they can grow a network that is fighting for equality. And not with just any one group, but to be able to fight for the rights of people across the board.

And we need to ask our own organizations, “Are you truly reflective of the breadth of people with disabilities from all backgrounds? How are you working collaboratively with other groups on the issues that are most important to you? Like a report card, how reflective is your board of directors and your staff of those you work with?”

We must work across disability, and being part of broader movements is so important. What’s important for nondisabled people is important for disabled people. We need to talk more effectively for others to see us supportive of the broader agenda of equality for all, and also demand that others see us as part of their movement.

Since she was born in 1947, Judy Heumann has defined what it is to be a disability rights advocate. She contracted polio at 18 months, and her mother fought for her to go to school. When she grew up, Heumann fought to be allowed to teach and won a groundbreaking lawsuit to do so. Then she fought for Section 504 regulations by taking part in the famous 1977 sit-in. She co-founded the World Institute on Disability, did a stint with the World Bank, served in two presidential administrations and recently wrote a must-read memoir, Being Heumann, that we will publish an excerpt of in the near future. She’s also our inaugural interview for our new “Big Ideas In” column, where we ask leaders to share their Big Ideas for our community.
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Welcome to Todd Against the Machine. I'm the author and namesake Todd Stabelfeldt and like all of you, I'm in a fight.

We all have a machine that whirs around us and a life that sometimes grinds us down. It might be a flat tire on Tuesday, a fall that lands you in urgent care on Wednesday, a job, or the bills ... we all face the fight. Since I became a C4 quadriplegic in 1987, I've fought for my independence and to present myself as Todd: the human and not just Todd: the quadriplegic.

Some of the road has been harsh. The core of my existence as a child was being reminded that I had to do what I was told and that the chair didn't make me special. I was going to go out and get a job and put food on the table like everyone else. Quadriplegia didn't exempt me. I was told that I would leave the house by age 20, and that I should be grateful for the two-year grace period. In fact, I left home at 16.

It's been tough, but I've been lucky. I am the founder and CEO of C4 Consulting, I'm married to a retired U.S. naval commander, and I have a home my friends have dubbed the "quadthedral." I have a pretty dope life, and I'm doing some pretty dope things.

The decades in a chair have taught me that we can prevail against the machine because we own our reactions to its always-changing ways. We have a choice in how we respond. I've learned that with grace, prayer, some help and a little luck, we can make the choice to
say, "Screw it. I'm going to make it."

In this column, I will focus on what I know best: technology, and how it can help us beat the machine. Technological advancement has enabled many new and improved solutions for independence that have provided restoration, dignity and respect.

There are a lot of ways to explore and discuss technologies for wheelchair users. For me, those that simplify basic tasks have been the best, including those that help me do the following:

1. Get in and out of my own home
2. Use the phone in both the wheelchair and bed
3. Use the computer in both the wheelchair and bed

Today there are a lot of viable, affordable door automation solutions that allow you to get in and out of the house independently, but that wasn't always the case. Years ago, one solution cost me over $5,000 — for one door! This solution had automation technology in the door itself, and then required more technology as part of the home automation system. Now I use the Apple ecosystem for home automation, and the Apple Home Kit app integrates the door opening function. So, in my case, I no longer need a specific button hardwired to my chair.

Likewise I used to have to yell through the house for the nurse. Now I just push a button on my phone app (or tell Siri to do it), which silently signals the nurse’s station. It's easier, more dignified, and I can do it when I'm sitting in my chair or lying in bed.

In bed, my iPhone is connected wirelessly to the Mac, which lets me make calls or answer the phone. Back in the '90s, I had to use a different headset at night that only worked with a customized phone, connecting through modems and employing voice software packages. A nightmare. Today, the continuity and portability in the Apple ecosystem lets me maintain my independence everywhere.

The third critical need is access to computing power whether in the wheelchair or in bed. For this, I blend the home-based Apple system with my Windows-based work environment. In my bedroom there's an arm mounted to the wall holding a monitor, along with a mouse that I run with my mouth. With these tools, I have access to and control of both my home and work computing/connectivity environments when lying down, just as I do when sitting in my chair, which means freedom to connect anytime and anywhere for anything.

The nondisabled may appreciate these independence technologies, but to them, they're conveniences. To me, they're the difference between functionality and dysfunction, between dependence and independence, between the machine winning and having the choice to take some control.

I know that sharing information can help transform lives. I did a lot of research and explored a lot of technologies to assemble solutions that worked for me, and they've made a huge difference. Through this column, I hope I can help you identify solutions to maximize your independence, improve your lives and stare down that machine.

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I’ve had the pleasure of being the nutrition columnist for New Mobility for the past six years, and now it is time to wish you all a final bon appétit.

Over these years, I’ve covered a wide range of topics from digestive dysfunction to unbalanced sex hormones, and explained how specific nutrients, foods and supplements can address a multitude of health conditions in-between. I hope the material I have shared with you has provided a greater understanding of how important it is to eat well to help reduce the risk of developing many common disability-related secondary health complications, as well as helped demonstrate the powerful relationship between nutrition and optimal health.

In this, my last column, I’d like to leave you with the greatest lesson I have learned as a nutritionist and share some final food for thought.

I’ve had the incredible fortune of meeting and working with thousands of people who live with disabilities and/or work in the disability community across North America. Through all of my experiences, conversations and interactions with clients, consumers and health care providers, it never ceases to amaze me what a profound impact food has on everything we do, every day.

Food has the immense power to bring joy, give comfort, form connections, build relationships, spark conversation and creativity, set the rhythm of our days, be the center of celebration and, obviously, satiate our hunger. The connection between food and our identity is also deeply ingrained in our cultures and traditions. And of course, food has the amazing ability to help us heal, both physically and emotionally.

This is particularly evident in the clients I work with who have newly acquired injuries or health conditions. In these situations, when people have lost control over certain parts of their body or their ability to function independently, food often becomes a focus. During these stressful times, food can be one of the few things we maintain control of, while simultaneously providing us with nourishment and pleasure.

What I’ve come to understand very clearly through the process of working with individuals from all demographics is that food is extremely personal. It means vastly different things to different people. These differences are often reflected in the unique and diverse ways in which we grocery shop or prepare, cook and eat our food. These are habits that have developed over our lifetime and most often have emotional ties. It is these last two factors that make long-term dietary changes difficult. This is why providing nutritious and delicious meal plans, recipes and supplement schedules sometimes isn’t enough to help people transition to, and maintain, healthier diets.

As a nutritionist, I’ve learned that the keys to making successful dietary changes is to identify why you want to make healthy changes and to explore what food means to you and understand how it motivates you.

So, here is my last recipe — a strategic plan of four steps to help you achieve your future nutrition goals:
NEW YEAR, NEW START, NEW ENERGY

As a child, I looked ahead to the year 2020 and thought it was so far away. I envisioned a futuristic world with advances in technology, medicine, cars and robots. The future is now, and we do in fact have those incredible advances — robot vacuums, self-driving vehicles, medical breakthroughs, and free Wi-Fi everywhere! Technology has become such an extension of us.

That same kid never saw disability as part of my future. It was not even on my radar. I never imagined that when 2020 arrived I would be thinking about the anniversary of the Americans with Disabilities Act or what’s new in spinal cord injury research.

Disability became part of my identity in 1995. I was thankful there was a law that protected my rights as a person with a disability, and I was hopeful because I was told a cure was only five years away.

In the past 25 years, I have seen positive changes such as more access to buildings or transportation, more representation in media, and some promising therapies and research that could one day improve function and quality of life for people with SCI. However, on a global scale I witness the societal, physical and institutional barriers to our community that still remain.

The wheels need to turn faster and leave this stagnation in the dust. Today I am hopeful because a new year always feels like a fresh start with renewed energy. Our community has strong disability advocates and activists, it is an election year, and technology is opening up new pathways to accessibility in homes, communities and social interactions!

I am an adult now, and looking forward, I can see 2020 as a year of change and a year to celebrate the contributions people with disabilities have made (and will make) in our communities.

Four Steps to Help You Achieve Your Future Nutrition Goals

1. Set Clear Goals: Having well defined objectives will help you stay focused and on track.

2. Explore Why These Goals Are Important to You: This is a vital step. The more you understand why you want to make changes and why these changes are important to you, the more likely you will succeed. This is harder than it sounds. People often tell me that they want to “be healthier,” but don’t have a clear answer why or what it involves.

Eating well includes not just introducing new foods but giving up old ones. This might sound obvious, but I’m frequently asked, “Can I still eat McDonalds, chips and/or candy bars?” Giving up old food habits is difficult because it involves emotion and discomfort. This is where I see people get stuck or give up. So this is where you need to dig deep and analyze your relationship to food and why you might be unwilling to give up foods that aren’t good for you.

3. Choose a Good Time to Start: Dietary changes involve lifestyle changes, and this takes time and effort. It’s not realistic to expect that you can transform your diet overnight. Choose a time in your schedule when you can focus your attention on learning new recipes and cooking methods.

4. Enjoy Your Food: Food is meant to be enjoyed! Eating well does not mean eating boring, bland food. There are delicious, healthy alternatives to every meal and thousands of free recipes online. So be adventurous, try new foods, eat well and live well!
These days, Barb Zablotney’s friends call her the Rolling Rainbow because of her positive attitude and the bright colors that adorn her body and chair — but the nickname wouldn’t have worked a few years ago. Before she was a fierce disability advocate, Zablotney waged a 10-year-long battle with depression.

There was a time when Zablotney, 33, thought wheelchair users were full of crap. The T10 paraplegic from outside Johnstown, Pennsylvania, believed there was no way any wheelchair user could be happy. Her grandfather had a spinal cord injury and was a grumpy old man — and Zablotney herself didn’t have much reason for joy either. Only a year after the car accident that caused her SCI, her mother died. Then, soon after, she separated from her fiancé.

“‘In doing that, I was giving up my life in Scranton, knowing I’d have to move back home, four hours away. I probably wouldn’t see my friends. I wouldn’t be able to finish school there. And I would have to leave my job. So severing that tie wasn’t just severing the tie of that relationship, but severing the tie of my life there,” says Zablotney.

That realization hit hard and spurred on the depression that saw her put on 100 pounds and had her praying to die. The turning point came when doctors informed her that she was too heavy for surgery to fix her ongoing bladder and bowel issues. They set her up with a food addiction counsellor and a trainer who would adapt a workout to her abilities. It took three years, but eventually she lost the extra weight.

“I was so depressed that I didn’t realize I was depressed. It was just everyday life and I was probably depressed even before my injury. I didn’t realize that’s what it was until one day [it lifted and] I was like, ‘Wow is this how a normal person feels?’” she says.

ADVICE YOU’D GIVE YOURSELF IMMEDIATELY POST-INJURY:
Don’t focus on the magical cure of walking again. Realize there’s more to life with an injury, and talk to other wheelchair users.

HOW TO BEAT STRESS:
Doing my make-up always helps. I look at it as an art form. I’m an affiliate for Notoriously Morbid Cosmetics, and I like to try out looks for them.
Before, she didn’t plan for the future because she didn’t see the point. But as she lost weight and got more involved in her community, she started seeing a path forward for herself. Still, as she went out in public again, she dealt with people saying the most ignorant things about her disability.

“I thought, man, I wish I had a platform where I could have my voice heard louder, but all I have is a Facebook page and an Instagram account, so I don’t know what to do,” she remembers.

Then a family friend recommended she compete for Miss Wheelchair Pennsylvania, and on March 3, 2018, this tattooed pageant contestant was crowned. Winning gave her the advocacy platform she sought, and she’s still running with it to this day.

“For some reason, when you have a sparkly thing on your head and a sash over your shoulder, people listen to you all of the sudden,” says Zablotney. “It literally changed my life, giving me direction, purpose and a community I never thought I needed.”

She’s appeared in Johnstown’s paper, The Tribune-Democrat, countless times. Last October, the paper ran a featured article about the day she convinced the mayor and city planners to use wheelchairs for a downtown excursion. With actions like these, she showcases wheelchair users as regular people of all shapes, sizes and ages — and this leads to real improvements to accessibility in her region.

A former teacher invited her to present to classrooms about driving safety and the impact of not wearing her seat belt. In her hands, it became a lesson in perseverance.

“I think these teens see me and go, ‘It’s OK if I have depression. It doesn’t mean there’s anything wrong with me,’ and I think it’s helping them realize depression should be lifted. Lots of people struggle with it — it makes you human and it’s OK to talk about it, because if you need help, you should look for help.”

Reading the Rainbow

Zablotney’s signature look is dominated by her bright and colorful tattoos. The ink was a motivator and helped her realize there were brighter days ahead.

“"My tattoos are how I got through the worst part of my life. Tattoos were how I coped with that period of depression.

I have a full-sleeve of Lisa Frank designs on my right arm done by a fourth-place finisher on the show Ink Master, and my left arm has a half-sleeve of meaningful things in my life. It has a memorial for my mom, a memorial for her best friend who is like a second mother to me, and the date of my accident along with the mile marker and a dead tree signifying the tree that I hit. Then I had to get tattoos commemorating my family still living, and I added the Ms. Wheelchair Pennsylvania crown.

The Lisa Frank sleeve is full of bright, colorful and cute things, so how can you look at your arm and not smile when you see something that cute and colorful looking back at you?

When you have depression, you feel so numb sometimes that you just want to feel something, which is why a lot of people who have depression get tattoos. Mine tell a story of where I was in my life at that time.

I think of them as art and not something people should judge instantly when they see someone who has them. In a weird way, my Lisa Frank sleeve started helping me get out of depression because I wanted my attitude to match my sleeve and there were no colorful clothes out there for fat people. That was a huge motivation to lose weight. My brother said that as soon as I could fit into pants that were colorful and fun, he saw a noticeable change in my demeanor.”

KEY TO COPING WITH DEPRESSION:
Remaining active, confiding in people and being present in my community really helped me realize my issues aren’t so bad.

WHY I JOINED UNITED SPINAL: I wanted to be more involved in my community. Karen Roy, then the reigning Miss Wheelchair America 2019, encouraged me to start my own chapter in South Central Pennsylvania.
A hobby is a great way to have fun, learn and geek out on a subject of interest. Hobbies also lead to cool social interactions with others who enjoy the same pastime. Arguably the best part of a hobby is when a person becomes so immersed, they enter a state that psychologists refer to as being “in the zone” — a hyper-focused, almost spiritual frame of mind where the only thing that exists is the here and now of the activity. Here’s a look at three hobbyists, and the adaptations they’ve made to get the most out of their passions.

**Pinball Wizard**
Darren Brehm fell in love with pinball as a kid playing with his dad. He kept the hobby alive through high school and college and even integrated it when he fell in love again. “My wife and I played pinball when we were dating,” says Brehm, 47. A United Spinal board member, he refused to let a C4-5 spinal cord injury 26 years ago end his relationship with the game. “In my early days of SCI, it was challenging to find something to do that wasn’t patronizing, something that was normal. For me that was pinball.”

When Brehm came home from SCI rehab, his wife suggested he buy a pinball machine to help get him out of his “new SCI funk,” and a friend helped him adapt it. Since Brehm doesn’t have hand, wrist or finger movement, they attached two pieces of line to the leaf switches inside the machine that operate the right and left flippers. Brehm then attached each line to a carpal tunnel glove, enabling him to operate the flippers with bicep and shoulder movement. “I was back playing pinball, doing something normal!” he says.

“To take the next step, my dad and I created a ‘version 2.0 controller’ that has the switch controller wires routed to electronics in a box that sits on my lap so I could operate the flipper switches by hitting two red discs,” says Brehm.

“Everything about it, the look of the game, the sounds, the lights, even the unique smell of pinball machines brings me back to my childhood and young adulthood,” says Brehm. “And it is something I can do as well as I could before my injury. Also, it is a great thing to do with my kids — twin 8-year-olds — and with friends. It’s a perfect equalizer.”

“IT enjoys pinball so much I bought a second game, and a third, and now I have 10 machines,” says Brehm. Each machine has a different theme, including Twilight Zone, Monster Bash and Metallica, and each offers a different audio-visual experience. “They combine nostalgia and pop culture with the fun of a game.”

Brehm says pinball machines go for around $6,000. However, there are a lot of enthusiasts, and if you buy one and want to trade or sell it, you can usually break even or possibly make money on the deal because there is a healthy market for them.

There are pinball shows all over the country and social media has made it very easy to geek out with other people that are into the hobby. “Pinball fanatics are a bit nerdy, which is cool,” says Brehm. “They are a fun group to hang with, playing pinball, drinking beer and socializing. When they find out I’m in a chair, they are super supportive.”

This includes the person who designed Brehm’s current adaptive controller, version 3.0. A wiring harness installed on all of his machines enables him to plug his controller box into the machine he wants to play, while his friends can still use the standard flipper buttons as player two. Also, there is a pinball manufacturer called Jersey Jack that makes machines with an interface that allows a computer mouse to operate the flippers. This is something that should easily hook up to any type of switch controller, like sip-and-puff or chin control.

For good players, pinball is a game of skill that requires practice, superior coordination and split-second timing. “Every time the ball comes down to a flipper you have the opportunity to put the ball where you want, somewhere that creates points and/or desired effects. This requires coordination and timing similar to a major league home run hitter,” says Brehm.

A skilled player can, more often than not, push the flipper at precisely the right time to make the ball go where they choose — this is known as “having the ball in control.” The more controlled shots, the longer you are in play and the more points you accumulate.

“In addition to the social aspect of pinball, it’s good brainwork,” says Brehm. “When I’m playing, I’m so focused on the game, nothing else exists — I’m 100% in the here and now.”
Total Control with Remote Control
Cameron Shaw-Doran has been racing remote-controlled cars since he was in the fourth grade. As soon as he got home from rehab following a C6-7 injury 22 years ago, he bought a new RC car. “It was cool because being in a wheelchair had nothing to do with it. Whether I was working on the car or driving, I was just Cameron, not ‘Cameron, quadriplegic,’” says Shaw-Doran, now 40. “Nothing else existed while I was into my RC. It was also a great way to hang with friends and do fun things like ride on a dirt road in the passenger seat of my friend’s car while driving my RC in front of their car.”

Shaw-Doran’s next RC interest was featherweight helicopters. They are easy to fly, fit in the palm of your hand and you can fly them in your house. “They have two main rotator blades that rotate in opposite directions, which makes them easy to fly. And they can be purchased for as little as $40,” he says. He and his friends flew them around and through the house. “It was fun and easy to learn. Then I advanced into higher performance, more difficult to fly, blade helicopters, and I had a great time flying them.”

The current hobby that has Shaw-Doran’s full focus is drones. “My first drone didn’t have a camera, but it was and is easy to fly,” he says. “I was hooked.” What he really likes about drones is the easy learning curve. “I would fly it through my yard, through the trees, in and around the swing set and have a blast.”

As with many hobbyists, Shaw-Doran’s passion for drones led to better, more advanced models. Last year he purchased a DJI Mavic 2 Pro Drone that has a high-quality, built-in camera and can be flown by viewing the video feed on a smart phone or tablet. It has a range of 11 miles and can fly at over 30 miles an hour.

“One of the first things I did was fly it down a riverbed — a place that had been inaccessible to me,” he says. “It was so cool to be able to fly through this area and see it in real time on my cell phone. It was like a flight dream: I was wondering ‘What’s over there?’Oh yeah, I can fly over there and check it out! It is surreal and completely addicting. When I’m flying the drone, I’m fully focused on what I’m seeing during the flight as well as what I want to see and where I want to go.”

Shaw-Doran is so hooked on drones he is working on getting his FAA certification, starting a commercial drone business and making enough that he can get off SSDI. “It has gone from something that is super fun and a passion, to something that hopefully will be a successful business.”

With his drones, Cameron Shaw-Doran can explore places previously inaccessible to him.

Bashing with Brehm
When Darren Brehm isn’t honing his pinball skills, there’s a good chance he’s driving one of his remote-controlled vehicles. “RC cars are addicting and crazy fast — they will do 70 miles an hour,” says Brehm. There are RC versions of most full-size competitive cars and trucks, from street racers, to off-roaders, to “bashers” that simply drive around and bash through dirt and mud. “I’m a basher driver,” says Brehm. “I like going out in a field or housing development and just bashing like crazy. In addition to driving RCs with my kids, it’s something I enjoy doing with my adult friends. It is a fun way to be outside and be social and/or have my buddies come over and work on them.”

A high-quality RC car can be purchased, complete with remote controller, for around $170. RC cars usually come with a pistol grip/twist knob controller. Brehm adapted his by purchasing a controller for an RC plane, which has two joysticks for control, and putting goalpost handgrips on the joysticks. An inexpensive way to get custom joystick extensions is to have them 3D printed (see resources).

Darren Brehm owns 10 pinball machines that he plays using an adaptive controller.
Dashing Through the Desert

Andy Blood didn’t know he loved driving 900 horsepower trophy trucks at speeds over 100 miles per hour in off-road desert races until he started a nonprofit to help get other people with disabilities back on the road. In 2012, eight years after becoming a T12 paraplegic, Blood and his wife started Blood Brothers Foundation, a nonprofit organization to fund adaptive vehicle modifications for those who needed them (see sidebar).

When he started Blood Brothers, Blood became so involved in hand controls that he decided to have a set installed in a Polaris RZR 2-seater, a utility task vehicle. “I was hooked. For me it was better than anything I’d tried — faster, more fun — it was my introduction to off-roading,” he says. “I drove it and pushed it as far as I could.”

In 2015, he decided to try to race against the best in the world and moved into trophy trucks — the unlimited class of off-road desert racing. He put together a professional off-road racing team called Runnit Racing, complete with shop and desert test track on his property near Grand Junction, Colorado, and went to work building and testing two trophy trucks. Blood, 39, was injured while working as a lineman and used some of the money he had received in a settlement to cover the expensive endeavor.

Blood and his team designed a unique right-hand control that has a twist throttle, push brake and a push-button actuation.
tor for shifting. All of his team vehicles — trophy trucks, several RZRs and a pair of Class 1 race buggies — are equipped with hand controls. The team uses the race buggies to pre-run every racecourse and take notes on every bump, twist and turn of the course to compile information his co-pilot will read to him during the race.

As Blood drives, he relies on his co-pilot to call out target speeds, upcoming turns and rough sections gleaned from the pre-run course notes, as well as monitor all the gauges. It is a team effort. “Your adrenaline is maxed, especially going 100 mph in thick dust where a momentary lapse in concentration could mean hitting an obstacle that will flip the truck. It is such a rush that after the finish line I don’t want to get out of the truck.”

Over the past few years Blood has competed in many iconic desert races, including the Mint 400 — where he rolled his truck — and the NORRA 1000 in Baja Mexico. “Our team spends countless hours preparing the truck, practicing at the track and pre-running courses,” he says. “As soon as I’m at the starting line of a race I’m in the zone — nothing else exists, just the here and now of racing. On the course, I have to be 100% focused every second.”

Now that Blood has achieved his goal of racing at the ultimate level, he plans on retiring from trophy trucks and returning to UTV Polaris RZR class racing, which has seen an explosion of new racers. “I also want to put more time and effort into helping people out — in the end, helping people feels better than wasting a bunch of money for a plastic trophy.”

Resources:

- Adaptive pinball or RC controller info, dcbpinball@yahoo.com
- Blood Brothers Foundation, bloodbrothersfoundation.org
- Jersey Jack Pinball Machines, jerseyjackpinball.com
- Runnit Racing, runnitracing.com

![Andy Blood poses in front of one of his race team's Class 1 buggies.](image)
Karen Braitmayer is a certified architect, a wheelchair user with osteogenesis imperfecta and the founder of the Seattle-based accessibility consulting firm Studio Pacifica. She is well known within the world of Seattle architecture, and her clients, some of the largest companies in the world, include Amazon, Nike, Starbucks and Microsoft, among others. Additionally, she consults with other award-winning architects as they complete projects that will shape the character of her city for decades to come.

In addition to her day job, she’s also involved nationally with public policy and education. President Obama appointed her to the U.S. Access Board, which helps define the nation’s accessibility standards, and she travels the country to moderate panels and educate architecture professionals on inclusive design.

In recognition of her impact and accomplishments, in 2019, the American Institute of Architects awarded her its Whitney M. Young Award for Social Responsibility. Tom Kundig, one of the most revered architects in the country, whose firm worked with Braitmayer to renovate Seattle’s iconic Space Needle, wrote a letter supporting her nomination for the prize. It was emphatic and detailed, and it contained a line that sums up the feelings of most everyone who has had a chance to work with Braitmayer: “Karen represents the best that our field can offer.”

We agree. There’s no hyperbole in saying that Braitmayer has as much positive impact on making our built environment more accessible and inclusive as anyone working in the United States today. We are proud to name Braitmayer the 2019 New Mobility Person of the Year.
“Karen’s work is influenced by a deep commitment to diversity and inclusiveness. It is exactly this type of work that we need most in our communities, now more than ever.”

Tom Kundig
Mainstreamed

Braitmayer grew up in Darien, Connecticut, a place she describes as “a very well-to-do, suburban New York City community.” Her father was a business executive and her mother a stay-at-home mom. Braitmayer was the oldest, and her parents didn’t even know she had a disability until she was diagnosed around the age of 6. They noticed that their daughter was small and that she did some clumsy things and broke bones, but they were first-time parents and didn’t have much to compare her to. “It wasn’t until my sister came along that they even thought, ‘she’s really small.’”

When she was finally diagnosed with osteogenesis imperfecta, the doctor told her parents that things were going to be different, and more difficult. A lifetime later, Braitmayer still chuckles at her parents’ response, which was typical of their attitude toward her disability: “Well, I don’t know, she seems fine to me.”

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In 1960s pre-ADA America, when Braitmayer began to use a wheelchair in elementary school, public space accessibility didn’t really exist. “There were no curb cuts, no accessible parking spaces, nowhere to sit in the movie theater. I was a fire hazard for years,” she jokes. But still, she describes her childhood as a typical one. “I was mainstreamed, so I went to a neighborhood school, same one my brother and sister went to.” Around home, Braitmayer and her siblings were held to the same set of high expectations — they were expected to do chores, do well in school, and go to college. “In my family, they expected that I would be able to do whatever I wanted to do, with some obvious limitations, like walking up stairs,” she says.

When people tried to push her away from an opportunity because of her disability, she simply refused to accept the premise of the rejection. She recalls applying for a job in high school at a gift shop with stairs at the entrance. The manager called her and told her he was sorry, but they couldn’t offer her the job because they didn’t have an accessible entrance. Braitmayer responded that her family could help her up the stairs. Well, the manager said, he didn’t think their bathroom was accessible either. “Oh, I can use just about anything,” she responded. “I’ll come take a look and let you know if it’ll work.” Braitmayer figures they really didn’t want to offer her the job, but every time they offered a disability-based excuse, she offered a solution.

She got the job. Her mom had to pull her up the stairs into the building for every shift, and the bathroom was terrible, but Braitmayer made it work. “If he had said, ‘We don’t have a job for you,’ I might have accepted it. … But I wasn’t going to let them say no because I was in a wheelchair.”

Braitmayer started undergrad at Houston’s Rice University in 1977, and like many young people, she didn’t really know what she wanted to do with her life. She wound up with a degree in behavioral sciences and got a job in sociological research. She lasted three months before deciding that research was definitely not the career for her.

At the suggestion of her father, she took an aptitude test. It listed medicine, engineering and architecture as the careers most matched to her interests and talents. Medicine and engineering were non-starters, but architecture was intriguing. “As a kid, I did a lot of crafts. I used a lot of paper and glue and cardboard and fabric. I liked to make stuff,” she says. “Ar-
An Architect at Home
In 1996, Karen Braitmayer and her husband, David Erskine, bought a mid-century style ranch home in the hills of Seattle’s Magnolia neighborhood. The home was already a single level, so it didn’t take much more than a ramp through the garage to make it work. They added another family member, and another wheelchair user, in 2000, when they adopted their daughter, Anita.

The family made the space work, but there were always annoyances — oddly sized and out of proportion spaces, and a kitchen that was nearly impossible for two wheelchair users to occupy simultaneously. Braitmayer partnered with Carol Sundstrom to remodel the house. The two architects decided to drill deep into how the various members of the family would use different parts of the house and how to make daily life easier for everyone. “We took it as an opportunity for her home to be a laboratory of ideas that really take things a step further in terms of ease and comfort,” says Sundstrom.

The remodeled kitchen features a long island of two different heights. The lowest section is open underneath with space for two wheelchairs to roll under. It’s directly across from the fridge so that food can be transferred to the island where it’s easiest for Braitmayer and her daughter to prep food. The sink was installed with faucet and controls at the side and an open bottom so that Braitmayer could make the most of her limited reach. The pièce de résistance, for Braitmayer at least, is a cabinet that pops open and reveals a shelf with a Kitchen Aid mixer that can easily be pulled out over a lap. Braitmayer loves baking cookies, and over a decade after the remodel was completed, this feature still makes her giddy.

The effect of this level of customization and thoughtful planning is a home that resembles a well-fitted wheelchair: optimized for their bodies and their lives. “One of the things Karen and I implore is: Let your home be where things are easy,” Sundstrom told the Seattle Times. “There are enough obstacles out there. Save your energy for when you go out.”

Braitmayer pores over plans with an associate at her business, Studio Pacifica.

Shifting Perspective
After graduating with her master’s degree in architecture, Braitmayer had little desire to put accessibility at the center of her career. In 1985, she got an internship at Ray Bailey, a large architecture firm based in Houston, doing mainstream architecture in a state that had few building codes. But the work and the culture weren’t a good fit for her, and when economic pressures caused the bottom to drop out of the Houston building market, she packed up and moved cross-country again, this time to Seattle.

In Seattle, a respected local architect suggested that she go into “handicap” architecture. “I was almost insulted,” she says. She didn’t have anything against making buildings accessible, just a suspicion that this man only saw her disability, not her talent as an architect.

After landing at a mainstream Seattle architecture firm, however, Braitmayer found that she couldn’t help but notice when colleagues were drafting needlessly inaccessible features into their plans. “You don’t want to do that!” she’d think, and couldn’t help but offer advice, even if it was unsolicited. “I kept sticking my nose in where it probably didn’t belong,” she says.

At the same time, Braitmayer began hanging out with other people with disabilities — she joined an adaptive sailing club and made disabled friends. The experience started to change her perspective and showed her that her struggles with an inaccessible environment weren’t hers alone. She met a graphic designer named Barbara Allan who was involved with Easter Seals and had helped develop an illustrated guide for accessibility principles. “She met me and went,
‘ooh, architect and a wheelchair user!’ says Braitmayer. “So she kind of took me under her wing.”

Allan helped get Braitmayer a seat on the Washington State Building Code Council representing people with disabilities. That was the first experience that really gave her a mindset that she had a role to play in the broader movement for access. “It was probably a 10-year process of shifting my mindset from ‘What am I going to do?’ to ‘What can I help with?’” she says. “A lot of that, I think, is a growing up process.”

That shift helped her realize that as both an architect and a wheelchair user, she had a unique perspective. In 1994, she left her job to open Studio Pacifica, and transitioned from working as a generalist architect to a consultant. In her new role she advised other architects on the nuts and bolts of accessibility code, how design decisions affect people with varying mobility needs, where problems may arise and potential solutions that account for the needs of all users. “I’ve been the guy trying to build this thing on budget and in time for a client. So I understand their pressures. And I also know that I want to get in the door, and I want my family to be able to get in the door, so I’m trying to find a way to make those two things come together,” she says.

Thinking Beyond Code
A big part of Braitmayer’s success comes from her perspective and creative talents. “She comes at it as a professional and as a community member. She doesn’t come at it as a vigilante. There’s nothing overreaching about her approach at all,” says Carol Sundstrom, a residential architect who has been a friend and colleague of Braitmayer’s for decades. “She comes at it with a very deep understanding of what you’re being asked to do in the code, and also, why did that even end up in the code?”

For Braitmayer, accessibility code isn’t just a prescription to be applied, it’s a framework within which good design can flourish. Architects always work around constraints — budget, climate conditions, site topography, building materials, seismic requirements or any number of others — and those constraints are often the impetus for creative inspiration. Accessibility doesn’t have to be a burden, “I think of it as an extra place to shine, an extra place to really make a project special,” says Sundstrom.

Within the field of architecture, though, accessibility isn’t often thought of in those terms. In architecture school, it’s taught alongside plumbing and electrical codes. Glanced over is a kind way of putting it. Accessibility is often interpreted as a set of features, like grab bars and lowered urinals, that are plunked onto a design at the end of the process. Code sets a uniform standard, a baseline of access requirements, but good design is about anticipating how the built environment influences the experiences of the people using it and making that environment work for the broadest range of people as possible.

“So many times, disability-centered design just feels so sterile and so functional,” says Rebecca Cokley, who served in the Obama administration and was part of the team that appointed Braitmayer to the Access Board. What Braitmayer brings to accessible design is “a different sort of creative flair that I feel like is missing,” Cokley says.

Architecture’s Other Diversity Problem
The biggest problem with Karen Braitmayer is that there’s only one of her. Just as the practice of architecture has long excluded those with physical disabilities from the built environment, so too has the profession excluded people with disabilities from its ranks. These phenomena are not unrelated. Braitmayer, a certified architect and a woman who uses a wheelchair, is a bit of a unicorn.

In June 2019, when Braitmayer rolled onto the stage at the American Institute of Architects’ national conference in Las Vegas to accept the Whitney M. Young Award, she was the first architect in the 40-plus-year history of the prize whose work focused on accessibility. She was also only the fourth woman to receive the award.

The profession has a long-documented and ongoing problem with diversity: as of 2017, only 19% of certified architects were women, and in 2018, only 15% of newly certified architects identified as non-white or Latino. As bad as those numbers may look, the statistics for people with disabilities don’t even exist. The Nation-
The Council of Architectural Registration Boards produces an annual “By the Numbers” report that looks at the industry’s demographics, but it doesn’t include disability alongside its gender and ethnic data.

It’s both shocking and baffling to Braitmayer that there are people within the field, even those interested in diversity and inclusion, who don’t make the connection that people with disabilities should be treated just as any other underrepresented group until they happen to hear her speak on the issue. “I had no idea!” one earnest young woman exclaimed after hearing Braitmayer talk about access and disability as part of a diversity panel.

For decades, the AIA has been trying to chip away at its diversity problem by offering scholarships to members of underrepresented groups, as well as hosting events and programs that reach out to the same communities. These efforts have had an impact, with gender and POC disparities slowly improving, but until recently, the AIA didn’t include disability in any of these diversity efforts.

Last July, the same month that she accepted the Whitney M. Young award, Braitmayer called out the gatekeepers of the profession in an article for Architect Magazine: “It’s time we name the real roadblock for students with disabilities considering architecture as a career: academic and professional stereotyping and discrimination, and omission from diversity efforts.”

Seattle’s Space Needle is one of the most iconic buildings in the country. Braitmayer consulted on the recently completed $100 million renovation of the 1962 building. One of the biggest accessibility issues was providing wheelchair access to the outer observation deck at the top of the tower. There was elevator access to the top level, but an unreliable platform lift made stairs the only practical way to get to the outdoor ring that provided the most expansive views of the city. “In all the years I went, it was never functional,” says Braitmayer.

Experiencing the Space Needle is all about the views, and a major part of the renovation was removing as many obstructions to those views as possible. Glass floors were installed on the restaurant level, and enormous panes of glass that lean out precariously over the void were installed on the observation deck to replace unsightly security cages. The new feel would be stripped back and sleek, and standard access lifts simply wouldn’t do. “They were looking for something that blended in with the iconic architecture.”

On a trip to London, Braitmayer and her daughter had seen a wheelchair lift that operates a bit like a magic trick: one minute they are a set of stairs, the next minute it transforms into a platform lift with guardrails — all with the push of a button.

The mission of the renovation was to let visitors see more than they ever had before. Thanks to Braitmayer’s help, wheelchair users can now lean out over the edge and let their stomachs drop alongside everyone else.
programs in the industry.”

Braitmayer followed by calling for a culture shift in architecture to make disabled practitioners more welcomed into the industry. At the same time, she has been pushing for the AIA, architectural organizations and schools to add disability to their diversity programs and as a qualifying criterion for diversity scholarships. She does all this while also traveling the country to educate design professionals about inclusion and access.

At long last, these efforts are gaining institutional backing. In October, AIA published an article that it promoted on the front page of its website calling for a culture change to center access and inclusion from the very start of the design process. That came just months after the award ceremony for the Whitney prize, which served as direct acknowledgement from the AIA that architecture’s much needed diversification has to include disability. “Her selection wasn’t an accident,” says Katie Wilson, who served as the jury chair for this year’s award.

**Change Via Representation**

To give people with different mobility needs an equivalent experience in a space, you have to be able to anticipate how different features will affect different people. If the ADA says you have to have one lower counter at a gym’s check-in desk, are hurried employees going to offer to log out of their computer and onto a different one for a single customer? Is there any reason that you couldn’t rearrange the work area and lower the entire counter so that a wheelchair user doesn’t have an internal battle about whether or not to speak up every time they get to the gym and would really prefer to just workout instead of having a conversation about access? You most likely wouldn’t think about any of this unless you’ve had experience with being the short person at a too-tall check-in counter or know someone who has.

Wheelchair users and people with other disabilities make up a large minority of society but remain glaringly absent from many workplaces. Involving disabled professionals and community members in the design process is a critical component of more inclusive design, but better integrating disabled employees throughout all levels of employment would help drive a more inclusive culture as well. When your employees, colleagues and bosses have disabilities, you can’t help but broaden your perspective and internalize some of the challenges that people with varying mobility needs encoun-
"Designers design for what they know," says Braitmayer.

Three of the five accessibility consultants at Studio Pacifica have a physical disability. There are two wheelchair users and two employees with hearing loss (Braitmayer fits in both categories), and the firm regularly collaborates with an accessibility specialist with low vision/blindness. The data to know what the numbers look like throughout the architecture industry as a whole is still lacking, but it’s safe to say that disabled practitioners are grossly underrepresented. Braitmayer, for one, doesn’t think that architects in general have any particular resistance toward designing more inclusive spaces. She just thinks they’re rather unaware of the ways in which features they may view as trivial can affect people with disabilities. “I just don’t think they understand that putting a grab bar in the wrong place, or making a door too heavy, can just stop someone in their tracks,” Braitmayer says. “Simple changes might make it possible for people to feel confident enough that they could continue with their education, or get a job, or give back to their communities … whatever it is they want to do.”

Sundstrom, who doesn’t have a disability, began working with the disability community while working alongside Braitmayer in a shared office space. She says that she finds the additional layer of problem solving necessary in inclusive design to be rewarding both personally and creatively. The thing about inclusive design, is that if you do it right, it isn’t just about accommodating disabilities, it works better for everyone.

She’ll sometimes visit a mall in Auburn, a suburb of Seattle, and watch how people use the space. “They’ve blended stairs and ramps throughout the mall, and I find it interesting how few people use the stairs. In that particular design, the ramps are in the middle, not stuck off to the side where you have to go find them, so everybody just uses the ramps. When it’s designed well, and its design-integrated, then we all benefit — we don’t even think about it.”

Architects still love stairs — they’re a feature that can make buildings look really cool. But if you work and live alongside people without perfect mobility, it’s pretty easy to see that when a ramp is done right, nobody misses the stairs.

**A Deep Dive Into Good Design**

In the basement underneath the Spheres — Amazon’s 90-foot-high conservatories of hexagonal glass that house 40,000 plants, in addition to serving as an employee workspace and lounge — sits a small bar called the Deep Dive. It’s a moody place of dim lights, dark curving wood and overstuffed furniture. Amazon brought Braitmayer on early in the design process, and usually when that’s the case, providing access is not an issue, because you have control of all of the design elements.

But Deep Dive was a leftover space in the basement of a building that the architects were tasked with turning into a public bar. In terms of spaces, “it was the worst of the worst,” says Braitmayer. There was a street-level entrance door, a lower floor slab that would have to serve as the bar’s main seating area and an intermediate level floor slab at the back of the space. Working with Braitmayer, the architects designed an elegant solution: a ramp that descends from the door, wraps around to access the main level and then ascends to the higher rear floor in a single, sweeping curve. The bar top is a consistent-height slab of wood that bridges both levels. At the raised rear end, there’s enough space for two wheelchair users, or you and a date, to sit with the bar top just over your knees, eye-level with the bartender and the patrons on the main level.

Good design doesn’t have to be grand, elevated, or even bold. But it does have to be thoughtful. Good design is accessible, Braitmayer likes to say. Good design lets you in the door and makes you feel welcome to sit down for a drink.
The United Cerebral Palsy Foundation’s YouTube miniseries, “Accessibility is Beautiful,” follows designer and HGTV host John Gidding as he explores architect-designed homes that showcase the principles of universal design. NEW MOBILITY Person of the Year Karen Braitmayer’s home is featured, along with that of Leslie Haynes and Randy Earle, and the two-segment finale showcases Casa Cabo Pulmo, owned by Pat Wright and Deb Zeyen.

Designed by House + House Architects, Casa Cabo Pulmo is proof that a home can be designed to be green, accessible and stunningly beautiful. It’s located hours away from the nearest town in an area so remote that architect Cathi House says, “It’s not only off the grid — there is no grid.” All of its appliances are run completely on solar power, and “all the materials we built the house out of are local. The floors are concrete with natural materials, detailed with stones picked up off the beach, and even the posts that are holding up the roof of the terraces are actual tree trunks with vines that had already fallen,” says House, who is proud that the home showcases the beauty of Mexico.

Such beauty and function are usually costly, but Cathi House says that’s not so in this case. “It’s not a very expensive home,” she says. “It’s built simply with simple materials. Its cost would be equal to a regular house in, say, Blacksburg, Virginia.”
“I have never not lived in an accessible home. I can’t imagine doing work asking the Congress and the world to end second class citizenship for people with disabilities and not practicing the theory in my own private life,” says Pat Wright, a lawyer with a visual impairment whose leadership in getting the Americans with Disabilities Act passed earned her the nickname “The General.” She owns the home with her partner, Debra Zeyen.

Designed to be wheelchair accessible, the house features a 162-foot-long ramp to its second floor. It’s a work of art with its switchbacks designed to showcase planters and vistas of the land and sea. “Regardless of their degree of mobility, guests normally choose to walk up the ramp because the views are so beautiful and the journey such a joy,” says architect Steven House.
Over the course of our 30 years, New Mobility writers have interviewed hundreds of wheelchair users to unearth secrets to one of the most difficult disability-related tasks: hiring good caregivers. The thinking behind the majority of the stories was simple: Who knows what works better than the people doing the hiring?

The answer always seemed obvious until I found myself in a conversation with a friend’s caregiver this summer. She has worked for my friend for many years, and it became clear that she hasn’t stuck with the job out of need. She puts up with the early morning wake-ups and last-minute calls because working with my friend means something to her.

I realize that caregivers are like snowflakes, in that each one is unique, but I got to wondering what we could learn by talking to some who have been in successful long-term situations. What matters to them? What makes a good employer? How do they like to be managed?

With these and other questions in hand, I set out to talk with a diverse group of five caregivers, united by the fact that each has worked at least five years for a single client. I figured if you stay with someone for five years or more, something about that relationship is working.

I ended up speaking with four women and one man whose situations ran the gamut. They worked with one client from between six and 35 years. Three of them were paid by an agency or with Medicaid or state funds while two received private pay. All but one worked the equivalent of full-time; the other worked as a live-in.

THREE KEY WORDS

A number of common themes came up throughout the interviews, the most universal one being the importance of respect. “Mutual respect is a big thing,” says one. “We both understand that we’re both humans, and we’re gonna make mistakes. Everyone has bad days, and when they do, it’s important to remember that it’s just a bad day.”

“It works because my client and I respect each other,” says another. “I know I have responsibilities with my job, but she has responsibilities as my boss, too, and she has to be as respectful of those as I do of mine.”

For four of the five caregivers, that respect made them feel more like family than merely an employee. “His mom started talking to me right when I first started, and she said, ‘Anyone that stays with us should become family. You’re in our lives, you’re in our house, you’re at all of our dinner tables — why treat you like a stranger?’” recalls one caregiver.

“If ‘respect’ and ‘family’ were the two most commonly uttered words, ‘communication’ was probably the third. Every caregiver I spoke with emphasized how essential being able to talk with their employer is. “I get a lot of anxiety and stressed out, and I feel like I’m overwhelmed a lot,” says one caregiver. “My client doesn’t necessarily feel it or she doesn’t feel it about the same things. So I’ll tell her, I need you to listen and let me talk this through. She will, and usually I’ll feel better just by having talked through all the steps.”

“We’re generally pretty good, as far as understanding each other,” says another about her client, “but he makes sure we have a formal sit-
down every six months to air any problems or needs. It sounds awkward, but it’s been really helpful and led to a number of good talks and changes.”

All three themes — respect, family and communication — remind me of a comment one caregiver made about why so many caregiving relationships fail.

“I know a few people who have gone through caregiver after caregiver. I think it’s because they don’t treat their caregivers like people.”

TROUBLESHOOTING

Spending inordinate amounts of time working together was the most cited way to develop those understandings, but too much time together can also lead to rifts. The important thing is knowing how to work through those tensions.

“If you’re mad with me, tell me why you are mad,” says one. “Then I can understand. But if you’re mad with me and you’re lashing out at me for nothing, that is a little hard.”

“I can tell when he is in a bad mood,” says another caregiver of her boss. “I’ll say, ‘Hey, do you need some time to yourself?’ And I’ll give him some privacy. Likewise, he’s pretty good about saying, ‘Hey, I’m gonna meditate and have some time to myself’.”

That same caregiver related the story of what she deemed the most difficult period of her employment, when her employer started dating another of his caregivers. The two eventually married, and all three are now close friends, but initially things weren’t easy. She credits him with going out of his way to talk through the situation with her and his other caregiver.

“He actually took us to dinner and talked to us to find out what we wanted...
to see and what we were willing to do and not do,” she says. “It helped us figure out a new dynamic and move forward.”

Sometimes the table is flipped, and changes to the caregiver’s life are responsible for helping or hurting the employee/employer bond. One caregiver mentioned how the end of a long-term relationship left him in a funk and short on resources. After weeks of what he later realized was probably perceived as moping, his boss pulled him aside and asked what was wrong and what he could do. A new schedule with more hours helped relieve the financial crunch and improve his attitude.

The story also shows how critical it is to be observant and pay attention to your hires’ wellbeing. A simple thank you or acknowledgment of a caregiver’s work can go a long way.

“He’s really appreciative, which is a big thing in my book,” says one caregiver. “When I leave, he’ll ask if I need anything from him. He’s always the first one to tell you that he appreciates everything that you do, and he goes above and beyond with birthdays and holidays. He makes a point to know his people.”

“He is constantly apologizing for asking me to do what are often really simple things. I appreciate the sentiment but I try to let him know I get it — this is a job,” says another. “Still, I’m glad he cares and doesn’t want to overburden me.”

A GREAT OPPORTUNITY

All of these insights will hopefully give you a foot up on hiring and working with future caregivers, but as many interviewees pointed out, there is only so much you can do if you aren’t compatible with someone. One caregiver suggested prioritizing compatibility above all else when hiring.

“Skills can be learned and skills can be taught,” she says. “I would want to find somebody I could have fun with, not because I’m looking for a friend but because you’re going to spend so much time with this person and you want to be able to enjoy your company and not hate life.”

“I’ve had so many crazy experiences thanks to this job. I’ve learned new skills, tried new foods and been places I never would have gone on my own. Honestly, when I think about everything that’s happened over the years, the stuff people think of as ‘caregiving’ is such a small, small part of the job.”

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Also, it’s important to think beyond your own needs and consider what your caregiver is getting out of the relationship. “At the beginning I thought I’d just do it for a year, because that was what was asked of me,”

ARE YOU ELIGIBLE FOR AN ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) SAVINGS ACCOUNT?

If your disability occurred before your 26th birthday, you may be eligible to open a tax-exempt savings account that won’t affect your eligibility for federally-funded benefits such as Medicaid and SSI.

Funds saved in an ABLE account can be spent on qualified disability expenses such as housing, transportation, personal support services, assistive technology, education, health care, and employment training and support.

To learn more about how to open an ABLE account, visit ablenrc.org/get-started.
says the same caregiver. “And then it really worked out. I got to do a lot of things I hadn’t done before, like drive across country and travel, and I was completely responsible for myself and another person. I think it was really good for me.”

“I’ve had so many crazy experiences thanks to this job,” says another. “And then it really worked out. I got to do a lot of things I hadn’t done before, like drive across country and travel, and I was completely responsible for myself and another person. I think it was really good for me.”

“On Helping New Employees: “A new hire will come in for two or three morning shifts and watch our morning routine before we let them work a shift by themselves. We call it shadowing. We give them the rundown and show them what to do. That way, if you don’t remember it all the first time, it’s not a big deal because somebody else will be there to help you.

Bonding Over a Pet: “We got a dog within the first two weeks of knowing each other and we definitely bonded over the dog.”

Write It Down: “Having my daily responsibilities written down was really helpful. I got a step-by-step list detailing how to do everything when I started. After eight years, I don’t need that anymore, but we started a white board where he can write random tasks and jobs, and that has been great.”

Money Matters: “She has always been really clear about how much I will make, and she has let me know when there are changes because of state policy or something. I can handle uncertainty with other topics, but not with money.”

Random Tips From the Other Side

Below are a few comments and ideas the caregivers shared in their interviews.

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ABLE ACCOUNTS HELP YOU SAVE MONEY WITHOUT LOSING BENEFITS. HOW CAN WE MAKE THEM BETTER?

United Spinal supports the ABLE Age Adjustment Act, which would expand eligibility for ABLE accounts to allow people whose disability occurred before their 46th birthday to sign up for these life-changing savings plans. This would allow another 6 million Americans the opportunity to open an ABLE account.

To contact your members of Congress, please visit unitedspinal.org/save-the-able-act. To learn more about ABLE accounts, visit ablenrc.org/get-started.
On March 12 [1990], we gathered in front of the White House at noon. Over 1,000 strong, most in wheelchairs but including people who are deaf or blind, we marched down Pennsylvania Avenue, the 17 blocks to the U.S. Capitol. We carried signs and chanted “ADA Now!” Mike Auberger, from ADAPT, closed with a stirring speech. “We are Americans,” he said, “and we want the same rights as everyone else.” After the speeches, many abandoned their wheelchairs and climbed the 83 steps on the west front of the Capitol, as a symbolic gesture dramatizing the barriers that the disabled still face. … It’s too early to tell whether our goals have been reached, but there was a feeling of solidarity, and of a successful crusade on behalf of equal rights for disabled people in employment, transportation, housing, places of public accommodation — every aspect of American life. That, indeed, is the purpose of the Americans with Disabilities Act.

— Richard Treanor, Spring 1990 issue

When the ADA was passed, there was this euphoric feeling that we had reached the mountain peak and that it was all downhill from there. But it is only another step in a progression of steps that has been ongoing since the ’50s. You go back in the early ’80s, and what we were looking at was curb cuts. Nobody had gotten around yet to this idea of rights and full access to the community. … There’s been plenty of phase-in time to get the word out about this bill — that’s one of its strengths. But it’s still going to take my going to the barber shop and seeing that I can’t get a haircut and talking to the barber about it before things will start turning around. It’s going to be a long, slow battle, but it’s a good struggle, and we’ve got the right tools.

— Speed Davis, Winter 1992 issue
We have ADA now. We can talk about careers, not just jobs. We’re not objects of charity, we’re people with rights. Our status is changing. Our mental attitudes have to change, too. We’re still begging, aren’t we? Still got that old attitude. Thinking it’s a privilege to work and earn our own livings. ... There are lots of ways to resist. It has to come from inside us, doesn’t it? It has to come from our belief that we have a right to be in the society, the community. That we have a right to be there and do what we want to do. If the community’s not ready for us, they’d better stand back. We’re coming. We’re already here. We’ve already made some changes and we’re going to raise more and more hell until the real change has come.

— Ed Roberts, May-June 1994 issue

1995: HAPPY BIRTHDAY, ADA
What NM Readers Said Five Years After Passage

“It hasn’t made a difference in my life yet, but it’s given me hope. Maybe we’ll end up with just a couple more curb cuts on Main Street and a couple more ramps to public buildings and nothing else. But you’ve got to give it a good-faith effort. You’ve got to work with them.”

— Larry Quintana, C4-6, retired urban planner

“The ADA has done a couple of things for me. It has enriched my life because it is an affirmation of our identity as a community. It has let me dream that the disabled will be included as equal partners who can speak for ourselves, us saying what we need. It’s also frustrated my life because we’ve got so far to go to make the dream a reality.”

— Anthony Tussler, L1-2, disability services director

“Structurally, the ADA has changed things for the better, but is it going to change attitudes? It’s going to take a while. But I still have my goals and dreams, and I’m going to chase them whether society believes I can or not.”

— David Barron, CMT, business communications graduate

“Legal protection is really important. It’s scary to be at the mercy of people’s good will. I had to be dependent on luck for people to accommodate me before the ADA.”

— Anne Keehnen, T9, special education counselor

“The ADA is a big, beautiful promise.”

— Lucy Gwin
THREE MOLECULES AND A MOM

This month’s column is about three molecules, a mom, a tenacious father-in-law and a biotech breakthrough with huge possible implications for people with spinal cord injuries. The story starts with the mom. Her name is Codi Darnell, and she lives with her husband and three kids in Vancouver, British Columbia. In March 2016, Darnell and her husband were renovating their house when she stepped into a 10-foot hole where a staircase would one day be. That fall was enough to cause a break at T11 and make her a paraplegic.

Darnell happens to be married to a man whose father is the sort who doesn’t take “no” for an answer. Here’s how she tells what happened next on her blog, HelpCodiHeal:

“We all know people who are fixers — people that see a problem and need to find a solution. My father-in-law, Dr. Harold Punnett, DMD (more affectionately known to me as Grandpa or HP), is one of those people. When he started sifting through the internet in search of a cure, we believed he was fighting an impossible battle, but we let him be. He would occasionally bring up things he found, but my focus wasn’t on a cure — it was on getting strong, getting home and learning to make the most out of my life. However, he was not deterred and one day found something really interesting.”

Sticky Walls and How to Get Around Them

The one thing most people “know” about the spinal cord is that once it’s been damaged or broken, it does not grow back. It’s not like skin. It doesn’t repair itself and function again. It doesn’t regenerate. The cord is, in part, made of impossibly tender bundles of fibers — called axons — that are supposed to be protected by the flexible bone structure of the spine.

When that bone structure takes a hard enough hit, the bones shatter and the bands of fragile axons are ripped apart. Each individual axon in the bundles is a gossamer thread projecting from a single neuron; each one is the carrier of information from brain to body, or body to brain. Each axon’s job is to form the permanent connections with other cells that allow us to feel, breathe and move. The tip of a healthy axon is always the point of a permanent connection.

The massive, intricate networks of firing connections in healthy brains and spinal cords allow us to wake up every morning knowing who we are. They’re why we know how to get out of bed and what our favorite cereal is. We want those connections to be permanent, which is why we’re grateful
for molecule number one: chondroitin sulfate proteoglycan. In healthy spinal cords, CSPGs form tiny traps that protect all those connections. They’re great, but after an injury they really get in the way of recovery.

In Don’t Call It a Miracle, I described what happens at the site of an injury as being sort of like what happened at Chicago O’Hare Airport on the morning of 9/11. The authorities didn’t know what was happening yet. Planes were being taken and flown into buildings. They had to try to protect the airport but no idea what to protect against, and their best idea was to put up some kind of barricade. They got their giant snowplows out of storage and arranged them, blades out, around the control tower.

That’s a bit like what happens after an injury — CSPG molecules that usually protect established connections are recruited instead to form a protective structure around the lesion. The very same mechanism that makes the connections reliable is what prevents post-injury broken axons from growing back.

Those CSPGs fill up the injury site and sit there, ready to fend off invaders while simultaneously helping to limit the spread of damage inside the cord. Unlike the airport authorities, though, we can’t just put the metaphorical snowplows away; we can’t get rid of the protective wall. When axons get over the shock of being abruptly severed, they start trying to re-grow and get back to sending information up and down the cord, but instead something terrible happens. They encounter that wall of CSPGs. Even worse, they get stuck in it, struggling helplessly like flies on flypaper.

Why? Because of molecule number two: protein tyrosine phosphatase sigma. Without going too crazy on the chemistry, we can think about PTPσ as a sort of Lego that appears on the seeking end of an axon. The Lego molecule causes those axons to find CSPGs and get stuck on them.

If you’re still following along, you see the problem. We have axons that want to grow, but the interaction between molecule number one and molecule number two makes that impossible. The goal would then be to interrupt that interaction — to either get rid of the CSPGs, or to fool the PTPσ molecules into not seeing them.

As it turns out, it’s hard to get rid of that wall of CSPGs, which makes sense. It should be hard. These are molecules we need and want in our brains and spinal cords; we just don’t want them filling up the injury site.

Enter molecule number three: intracellular sigma peptide. This one was custom-designed a few years back in the lab of Dr. Jerry Silver, a neuroscientist and professor at Case Western Reserve University. ISP is a cool molecule. Here’s what Silver said about it in an article published last spring:

“We developed a molecule that negates the [PTPσ] signal, allowing the regenerating axons to ignore and bypass CSPGs. When the molecule was administered noninvasively via injections under the skin, it interfered with … the signaling … allowing for robust axon regrowth resulting in greatly improved bladder function and improved locomotion in animal models of spinal cord injury.”

In plain English, he’s saying that they used a regular small needle — the kind they use for flu shots — to give paralyzed rats a dose of ISP, and then watched while the rats recovered the ability to pee and walk and climb tiny ladders. Molecule number three works, at least in rats.

By now you may have guessed that the “really interesting thing” that Darnell’s father-in-law found was a report about Silver’s work with molecule number three. Once he saw that commercialization of the molecule might lead to healing for Darnell, Punnett went to work.

What’s Next
By March 2019, almost exactly three years after Darnell’s injury, a whole lot of things were in place.

Punnett helped found a biotech company called NervGen. That company acquired a license to Dr. Silver’s molecule, ISP, and renamed it NVG-291. The company had a $10 million IPO, and its officers rang the opening bell on the Toronto Exchange last May.

At Working 2 Walk in Cleveland last October, Silver and NervGen’s director of research, Dr. Marc DePaul, said they are currently on track to conduct a safety study using healthy volunteers during the first quarter. The study is intended to show that injecting the molecule does no damage to healthy nervous systems. Immediately following that, during the second half of 2020, they are planning a safety trial for people with spinal cord injuries. At some point, if all goes well, the mom who lives today with axons that won’t grow will be able to get that injection.

Resources
• Codi’s website, helpcodiheal.com
• Codi’s post about Dr. Punnett, helpcodiheal.com/ng/#more-1688
• Dr. Silver and Dr. DePaul’s presentations at Working 2 Walk, wirestream.tv/customer/unite2fightparalysis/2019/10-04/#
• “Emerging Treatments for Spinal Cord Injury” by Dr. Jerry Silver, static.wixstatic.com/udg/a58383_3c8ed15beb794c1db8289a4d583531f.pdf
• Interview with Dr. Punnett, usabusinessradio.com/t-11-paraplegic-inspires-canadian-father-in-law-to-find-fund-cure
• NervGen, nervgen.com
I happened the summer after my freshman year of college. An innocent family vacation became life-changing when a large wave picked me up and dropped me, leaving me paralyzed below the shoulders. On August 1, 2004, I became a C4-5 quadriplegic. And at 18 years old, I had no idea what my future would look like.

Being paralyzed didn’t change my dreams. I still wanted to graduate from college. I still wanted to work. I wanted a good job, a good house, a good future. But newly paralyzed at 18, I had no clue how I would even begin to accomplish these dreams. How would I be able to finish college? How could I hold a job someday? Would I lose my caregiving if I earned an income? I was afraid of these unanswered questions, and I was afraid to start my employment journey because it could end in heartbreak.

This changed by the summer of 2005, when I started getting my college wheels wet thanks to my state’s vocational rehabilitation program. Vocational rehab, which is available in every state, helped pay for school and provided me with assistive technology to get the most out of my education. I started at community college, then transferred to a bachelor’s degree program. And after that, I went to law school, joining the small group of lawyers to graduate without ever flipping a single page.

Throughout my schooling, I received SSDI monthly cash benefits that helped me get by. I also utilized Medicaid, which helped me receive community long-term care supports such as caregiving. All was well, until my initial fears of making an income became a reality.

**Priority One: No Nursing Home**

In law school, I was offered a paid internship. I was so afraid to take the offer, even though it was a great opportunity, because I thought earning money could potentially jeopardize my caregiving. As a C4-5 quadriplegic, losing my caregiving would force me to move into a nursing home to get the supports I need to survive. As such, I will always, always choose my health care over my work. But luckily, I learned it was possible to have both.

My vocational rehab counselor recommended that I accept the summer internship and enroll in Social Security’s Ticket to Work program. The Ticket to Work program provides free benefits counseling, which helped me learn all of my options regarding income, assets and maintaining eligibility for federal programs like Medicare. Through Ticket to Work, I tested out the working world and maintained my Medicaid benefits for nine trial months. The experience helped me realize that I can do a job that I love and keep the benefits I need.

After the nine months ended, I enrolled in my state’s Medicaid buy-in program, which I still use to this day. This buy-in program allows me to keep my Medicaid eligibility despite my earnings. Keeping my Medicaid helps me in so many ways — it’s given me the chance to maintain my caregiving and receive a new power wheelchair every five years. Medicaid buy-in and other federal programs are available across the country, and there are different options for keeping health care benefits while holding a job depending on where you live.

Today I work as a medical malpractice attorney, fighting for people who have been catastrophically injured. I also work with United Spinal’s Pathways to Employment Program, and I provide free one-on-one job mentoring through SPINALpedia.com and willingtoworkusa.com.

I wish I could tell 18-year-old me not to be afraid. I wish I could show my newly-injured self the full life I lead today. Most of all, I wish I could tell the old me, “You will not be alone during your disability employment journey.”

I can’t speak to 18-year-old me, but I can speak to you. I am energized to let New Mobility readers know that work is possible after a spinal cord injury or disorder. It’s all about understanding that there is a system in place to help you to get to work, and then maintain a job without fear of losing your benefits. There are many resources out there that help people with disabilities find and keep employment. You, too, can follow your dreams. You do not have to be alone on your employment journey.

This is my first disability employment column of many. I’m looking forward to sharing stories, tips and tricks, and all things disability employment-related. In the meantime, if you would like to receive free one-on-one job mentoring or information on free benefits counseling, please email me at josh.basile@gmail.com.

And remember, work works!
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There are some cripples who can easily get away with appearing not to be crippled at all, at least for a little while. But in the long run, this is always a futile proposition. Your crippledness will manifest itself sooner or later. Like for instance, someone may have epilepsy and strut around looking normal, but sooner or later they’ll have a seizure and their cover will be blown.

I have a name for that moment when your crippledness puts itself out there for all the world to see. I call it the big reveal. When it comes to the big reveal, you can run but you can’t hide.

I know how it is. I may look crippled as hell, but believe it or not, there are still times when I can pass for a vert (short for vertical, which is what I call people who can walk).

I’m one of those cripples whose voice doesn’t sound crippled. So when my first contact with someone is on the phone, if I don’t say anything about being crippled, I can lead them to believe I’m perfectly normal. And believe me, I tried to use that to my advantage a lot back in the days when I was still hunting for jobs and dates. I would try to answer help wanted ads or personal ads by phone so I could state my qualifications with my resonant voice. If it was a personal ad, I’d try to sound extra manly.

My strategy was to amp the intimidation factor way, way up. I was trying to get the other person all enthused about meeting me. So that way, after the big reveal came when they finally met me in person, they would feel extra pressure not to reject me for fear of looking and feeling like a real cripophobic jerk. But most of the time it was just delaying the inevitable. Most people figured out that the easiest way for them to get off the hook with me was to try hard to keep a poker face and then say something like, "I’ll get back to you soon" and then never do it.

I always wondered how those poor saps who both look and sound crippled handled big reveal situations like these. These are the cripples who speak with a thick cerebral palsy accent or in a thin and gaspy quad voice or a droopy post-stroke voice or something like that. Those people have nowhere to hide. It’s nearly impossible for them to delay the big reveal.

My friend Larry is one such cripple. He talks a lot by using one of those Stephen Hawking talking boxes with a robot voice. I always wondered if, when answering a help wanted or personal ad, he’d maybe set up an elaborate, Cyrano de Bergerac type of ruse. He’s a good writer, so I thought maybe he’d write out some eloquent, poetic prose and then have some vert (or someone like me who sounds like a vert) read it to the person on the other end of the phone hoping to get them mesmerized. Because in this case, how else would somebody using a Stephen Hawking talking box stand a chance of getting an audience, even if he put the robot voice on the extra manly setting?

But I doubt Larry ever went to all that trouble. If he ever bothered to answer a personal ad, he probably just went ahead and did it with his Stephen Hawking talking box. There’s a lot to be said about having no choice but to wear your crippledness on your sleeve like that and come right out of the box with it. It cuts through all the BS. It tells you a lot up front about who’s who. If someone is freaked out by a little thing like a Stephen Hawking talking box, then it’s their loss. But if you answer a personal ad and the person who placed the ad is turned on by the robot voice of a Stephen Hawking talking box, then you hit the jackpot! Quality wins out over quantity.

I’m glad I’m no longer hunting for jobs and dates. I don’t feel the pressure to fool anybody anymore by trying to pass myself off as a vert. I can just relax and be crippled.
Our Research Center of Excellence, housed at the University of Miami Miller School of Medicine, is dedicated to finding effective treatments, improving the quality of life of individuals with spinal cord injuries, and ultimately, finding a cure for paralysis.

To be considered for current and future research studies, please visit our website:

http://www.themiamiproject.org
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or
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**EMPLOYMENT OPPORTUNITY**

**Job Title:** Americans with Disabilities Act (ADA) Coordinator (Part-Time)

**Description:** The Americans with Disabilities Act (ADA) Coordinator will build upon and administer the ADA accommodation program from start to finish. The position will also be involved in the Light Duty/Return-to-Work program. Other duties include but are not limited to the following: Identifies and performs outreach to employees possibly requiring accommodations; educates management and employees on the rights and duties under the ADA; coordinates with management and employees to develop and provide employees effective and reasonable accommodations; develops written materials and other informational pieces regarding the ADA program; develops and maintains internal measures to track ADA status and compliance and maintains and documents records of all disability and accommodation issues ensures compliance with applicable laws, regulations, and policies; assures that workers with disabilities are provided effective and reasonable accommodations allowing them to work productively and safely; assure Township-Sponsored activities, Township Facilities and events address accessibility and accommodation concerns.

**Requirements:** Bachelor’s degree in social sciences, human resource management, business administration or related field and two years of personnel administration experience are required (or a combination of education and/or training and/or experience which provides an equivalent background required to perform the work of the class); a minimum of eighteen (18) months of experience in a position that involved evaluating and administering reasonable accommodation issues subject to the ADA or §504 and completion of a course on barrier-free design or ADA accessibility guidelines which was sponsored or approved by the New Jersey Department of Community Affairs or a department which oversees the Uniform Construction Code in any other State, the American Institute of Architects, the Paralyzed Veterans Association, or the United Spinal Association, within twelve (12) months of hire.

**Salary:** DOQ

**Hours:** Part-Time, three days weekly (not to exceed twenty one hours per week).

**Apply:** Send resume or application to: Ms. Braedon Gregory, HRIS Coordinator, Human Resources Department, Township of Montclair, 205 Clarendon Avenue, Montclair, New Jersey 07042 or email: bggregory@montclairnjusa.org

**Closing Date:** Job posting will remain open until position is filled.

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Meet New Member Jason Swarbrick
Age 46, from Stratford, Connecticut
Spina Bifida

Why I joined United Spinal: I was referred to United Spinal Association when I needed help selling a vehicle. I like reading New Mobility to learn about new products and services available to wheelchair users. Even if I can’t afford the product, I still like to know what’s available to wheelchair users.

Can’t live without: Besides my wheelchair, the two products that are particularly important to me are my adapted Dodge Grand Caravan and my Acorn Stairlift.

What I would change: The quality of life for wheelchair users would be greatly improved if more things like doctor’s offices and restaurants were accessible.

Meet other members or join United Spinal at unitedspinal.org
Because of the circumstances, I had no say on what was packed for the months I spent at an out-of-state rehab. Thinking it was practical, my mom packed me every roomy, deep V-neck T-shirt I owned. She said, “These will be easy for us to put on and get over your neck brace.”

Being suspicious, I commented, “OK, but I would usually wear a tank top under most of these,” and followed up with, “What bras did you bring?”

“Oh honey, bras are a pain, you don’t need to wear one!”. I knew better but had yet to start any therapy out of bed at that point and had done all of that immodestly in my hospital gown and things seemed to go OK (or the drugs lessened my concern about it).

It didn’t take long to test her theory. Once I got out of bed, started getting transferred, then stretched and pulled back and forth every which way in the therapy gym, it was clear that I needed more coverage. More than once, my female therapists added an extra maneuver to covertly re-cover the boob peeking out from my top. I made sure my very first outing was to the mall to purchase some needed reinforcements.

Anita Brah
Our Mission
VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

Our History
As a program of United Spinal Association, VetsFirst has a long and illustrious history assisting and representing veterans and their eligible family members. United Spinal—a VA recognized veterans service organization—strives to ensure the organization remains an instrument for veterans.

About VetsFirst
VetsFirst brings to bear seventy years of expertise in helping America’s veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, timely news and information and valuable self-help guides.

VetsFirst advocates nationally for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. Our advocacy efforts go far beyond offering words of support and encouragement. We take this fight to Capitol Hill to bring attention to issues that matter most to the men and women who proudly served our country.

Timely Support
We connect with thousands of veterans and active military servicemen and women annually through our call center and online help desk, Ask VetsFirst. Our staff takes the time to address each inquiry, offering guidance with questions on military separation, claims appeals, and state benefits. Visit http://helpdesk.vetsfirst.org/ to submit your questions and receive quick response from our knowledgeable staff.

Valuable Resources
In addition to providing individual support and counseling services, VetsFirst offers timely news and information across the spectrum of issues presently impacting the veterans community, including state benefits, separating from the military, as well as exclusive feature stories on military health care and VA funding and compensation.

Our Core Beliefs
VetsFirst’s priorities are based on three core principles that will improve the lives of veterans with disabilities.

Community Integration and Independence— We support policies that help veterans with disabilities reintegrate into their communities and achieve independence.

Timely Access to Quality VA Health Care and Benefits— We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

Rights of Veterans with Disabilities— We believe that discrimination against disabled veterans that produces barriers to housing, employment, transportation, health care, and other programs and services must be eliminated.

www.vetsfirst.org
Once his initial rehab was over, Thomas, 26, was determined to get out and about and meet friends. The only issue was his injury meant a caregiver, friend, or relative had to help him catheterize. He explains: “I couldn’t be spontaneous – it was like an anchor keeping me down.”

From the start, Thomas preferred intermittent catheters and felt they offered more control than an indwelling product. But the problem was finding one he could open himself. He adds: “My occupational therapist suggested SpeediCath Compact Set, but I couldn’t open it at first. But I tried with the Dycem gripper and I could do it. It was exciting – to actually have it work and to know that I could do it made me happy.”

Thomas got his driver’s license around the same time as he started using SpeediCath Compact Set and he identifies that as the time things started to turn around for him on a personal level. He continues: “Now I don’t have to ask my friends or family to take time out of their day to come and help me. I feel more like I did before – an independent 26-year-old man.”

It’s now the only product he uses when catheterizing himself and Thomas is particularly happy about its discreet size and the hydrophilic coating, which makes the catheter pre-lubricated. He goes on: “The reason it’s so much easier is there are so few steps involved – you don’t have to lubricate it, or push through the bag. The catheter’s already out so you just put it right in and you’re good to go.”

“It’s easier to keep more of them in a bag, and they’re easier to handle and use. It goes into the bladder easier and with less resistance, and the handles on the bag are useful.”

For Thomas, just 15 months after his injury, his focus is still firmly on his rehab. He’s taking part in the Activity-Based Locomotor Exercise (ABLE) program close to his home in Minnesota and is beginning to think about looking for his own apartment. And with SpeediCath Compact Set, he has found a product that is playing a key role in improving his quality of life. He concludes: “Now I can do things on my own and take care of myself, which is a good feeling.”

“I feel more like I did before my accident – an independent 26-year-old man” Thomas*, catheter user

After his accident, Thomas had to rely on other people to help him catheterize. With SpeediCath® Compact Set, he’s gotten back his independence.

About SpeediCath Compact Set
SpeediCath Compact Set is an all-in-one catheter and bag solution. Rated easy to use by 88% of users1, SpeediCath Compact Set is designed for everyday use both in and out of the home.

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SpeediCath Compact Set is available by prescription only.

1 Product evaluation of SpeediCath® Compact Set, response from 70 HCPs and 550 end-users, Feb. to April 2013.
*Thomas is a SpeediCath® Compact Set user who has received compensation from Coloplast to provide this information.
** Individual results may vary.