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**CONTENTS**

**GO FARTHER, BETTER**
Long gone are the days of depending solely on giant, leaky batteries to power chairs and cycles. BOB VOGEL has the scoop on how new and improved battery technology is helping users get the most out of their devices.

**READY TO LEAD, READY TO ROLL**
Rear Admiral Kyle Cozad had done a little bit of everything over his three-decade career in the Navy, and as SETH MCBRIDE reports, a 2018 SCI didn’t keep him from serving our country.

**THE PRIMARY CARE PROBLEM**
A primary care provider is supposed to help manage your complex care needs, but finding one who understands SCI/D and actually helps can be surprisingly difficult. BOB VOGEL examines what’s behind the difficulties and shares advice so you can make sure your next PCP doesn’t let you down.

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**THE ADA AT 30**
Thirty years ago the Americans with Disabilities Act was stuck in Congress. MIKE ERVIN talks with the activists who crawled up the Capitol steps and shook it loose. JOSIE BYZEK interviews advocates about how our civil rights law has performed since it passed, and where it needs to go next. And STEVE WRIGHT introduces us to people whose job it is to ensure the ADA works for everyone with a disability, whether they live in the country, our biggest city or somewhere in between.

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Cover and Contents Photos by Tom Olin
By Ian Ruder

On the list of “terrible things about flying as a wheelchair user,” being referred to as “an ADA” by inconsiderate airline staff probably ranks somewhere between having your wheelchair damaged and waiting for everyone to deplane before getting off. It’s dehumanizing, embarrassing and, honestly, just rude.

It’s bad enough having to be strapped into the world’s least comfortable chair and delivered to the seat like a slab of meat on a dolly. But hearing another human reduce your existence to an acronym for a piece of legislation — often while refusing to make eye contact — is the final step in complete objectification.

It’s a legacy Justin Dart and the other disability leaders who fought for the Americans with Disabilities Act over 30 years ago surely didn’t envision, and probably wouldn’t have been thrilled about. But as ugly as it may be, I think there is a good argument that the use of “an ADA” is actually evidence of one of the law’s most meaningful impacts: giving Americans a framework and a vocabulary (however limited) to openly discuss disability rights and see them as civil rights.

Outspoken disability activists and advocates long ago understood that disability rights are civil rights, but prior to the passage of the ADA, I don’t think most Americans understood what they meant. The ADA has become what no previous disability legislation managed: an animating embodiment of the belief that disabled people should enjoy the same civil rights as everyone else.

The airline employee who calls me “an ADA” has probably never heard of Section 504, and probably doesn’t know that it’s actually the Air Carrier Access Act that protects my equal rights as an airline passenger, but he does know that I am entitled to equal rights, and he associates that with the ADA.

Would I rather have him thoughtfully engage me on the merits of in-home support services and why a broader application of the Olmstead decision makes a lot of sense? Of course I would. And in no way am I trying to excuse his total lack of people skills and compassion. But it’s progress.

Now you can definitely argue that’s a small step for 30 years, and you’re 100% right, but there are plenty of examples of bigger steps surrounding us everywhere we look, from public transit to architecture, employment and beyond. I chose this example because it speaks to the law’s impact on the collective consciousness — that dark corner of society that can be so hard to light up.

“IT SPEAKS TO THE LAW’S IMPACT ON THE COLLECTIVE CONSCIOUSNESS — THAT DARK CORNER OF SOCIETY THAT CAN BE SO HARD TO LIGHT UP.”
When our editorial team started discussing the idea of an oral history of the Capitol Crawl, my mind instantly leapt to Mike Ervin as the person for the job. He was there for the Crawl, he knows lots of the other people who were there, and he’s a heckuva writer; what better qualifications could I hope to find? When I pitched the story to him, he told me he thought he could find a few people to interview and pull together 1,200 words. Well, he ended up with almost twice that many words and a collection of voices that makes for a colorful and valuable piece of history. “Fortunately, everyone I spoke with was pretty eloquent in their recollections,” says Ervin.

Photographer Tom Olin had a feeling March 12, 1990, was going to be a great day to take photos so he lugged a gigantic 500 mm lens with him when he set off to cover the disability rights action planned for the U.S. Capitol. He was right. The photos he shot of what became known as the Capitol Crawl helped galvanize Congress to pass the ADA and turned the nation’s eye to the civil rights of disabled people. Still, Olin plays down his reputation as one of the preeminent chroniclers of the disability rights movement. “I was never really a good technical person,” he says. “I think of myself more as being there and being able to take the right picture at the right time and the right place.”

This issue wouldn’t be a New Mobility ADA anniversary celebration without a memorable contribution from our own executive editor, Josie Byzek. Since I arrived on staff nine years ago, she has been my go-to source for history, perspective and analysis when it comes to the disability rights movement, and she has been anchoring our ADA coverage for longer than that. Her personal history as an activist, a journalist and now an elected official, combine to give her the 3D vision needed to see complicated issues like this clearly. Oh, and did I mention I enjoy watching her get excited and geek out as she thinks about whom to interview and what to focus on? Well, I do.

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

Responses to New Mobility’s May cover package, “Life in the Time of COVID-19,” from Newmobility.com:

I just want to thank you all for all the great stories. It’s nice to read something and no longer feel alone. I’m a T4 paraplegic, and I’ve been hospitalized three times during this COVID-19 pandemic, which was one of my biggest fears. There was sort of this relief or calming feeling, as I read each story and found a connection in some form or fashion. Y’all are awesome.

Sean Martinez

What a blessing to have people share their personal stories. I felt a sense of connectivity with all your stories. Because of our individual situations in learning acceptance, patience, adapting to the new, etc., I strongly believe we have a better understanding of what the world is going through. We have an abundance of resources and online services compared to 31 years ago when I became a T7 paraplegic and a mother of a gorgeous baby boy. Life is different right now, but I know we all have a powerful strength within ourselves that will help us fight through this. Keep safe everyone, and enjoy life one day at a time.

Sylvia Luna

I think back 30 years ago, and this incident would have been devastating to me and a lot of people in the Women’s Wheelchair network. Today it is difficult, but advice, resources and support abound. This helped me out today. I was feeling a little low.

Louisa Coughlan

These people, who are probably the tip of the iceberg, are an inspiration to us all. All the very best for your continuing journey and health.

Julia Carson

I have such respect for the writers and the people written about in this excellent article. Wishing you all “medical establishment” improvements, new joys and necessary supports as we move beyond the current impacts of COVID-19.

Nan Abernathy Moss

OMG! These are all remarkable works — technically and thematically (“Art in the Time of COVID-19,” May 2020). As a writer, I am not usually at a loss for words, but I am now. I am going to have to come back and sit with them and hope I find the right words to express my feelings.

Candy Parton

Complicated Care

It isn’t easy to care for someone at home under the best of circumstances (“Caring for Your Parents From a Wheelchair,” May 2020). The doc sent my mom home with me after treating her for a fall (no broken bones) at the ER. Then, I had to find a way to get her into the house. Not easy to do when the caregiver (me) is someone in a wheelchair and her best friend is a tiny woman. Then, we took care of her until a UTI sent her back to the hospital ... followed by rehab admittance three days later (Medicare rules). I was exhausted and sad that I couldn’t help her at home. She died a few months later from pneumonia. I am just glad she isn’t here now dying from coronavirus. I did the very best I could, as have others ... being a caregiver is never an easy thing.

Jann Hartman

Newmobility.com

Hospital Hell

Just came from the hospital for a non-COVID-19 related pressure sore issue. It truly was a nightmare, and you described well the situation with doctors and nurses coming from treating COVID-19 patients standing over me breathing, talking, etc. (“Should I Stay Or Should I Go?” May 2020). Many of the nurses seem to be backups.

Hospitalizations are times when it becomes necessary to tune out and feel numb. I had the distinct experience of spending four days in this zone, then being sent home and called back for another five days due to an infection I probably acquired at the hospital.

Coping with such a lack of control is challenging. I don’t want to dwell on the helplessness but, psychologically, I fear not dealing with it could be harmful.

Paul Bowers

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<th>Model</th>
<th>Weight capacity</th>
<th>Base width</th>
<th>Seat width*</th>
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<tr>
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<td>300-450 lb</td>
<td>25.5&quot;</td>
<td>Up to 26&quot;</td>
</tr>
<tr>
<td>Alltrack R3 (HD)</td>
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<tr>
<td>Alltrack HD3</td>
<td>Up to 550 lb</td>
<td>27.5&quot;</td>
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* Wider seat sizes are available as custom modifications.
There are a thousand surveys detailing the most minute aspects of how Americans feel and behave in response to the coronavirus pandemic. But, as usual, disability-specific information is hard to come by. So we sent out our own survey. So far, we’ve received 225 responses. It’s not enough for a scientific data set, but it’s enough to get a better feel for how the pandemic has been affecting our community. Five individual respondents report having COVID-19 themselves and 47 (21%) know a close friend, family member or caregiver who has been infected. In addition, an overwhelming majority (almost 70%) feel that the pandemic has had an increased impact on their lives because of their disability. Many people took the time to describe how the pandemic has altered all aspects of life — see selected responses at right. We hope you find the results as interesting as we do.

“Had to finish freshman year of college online. My mom is now my primary caregiver. Unfortunately, I may not return to campus this fall due to increased exposure and have to continue courses online.”

“I am paralyzed from T6-7 and have Type 1 diabetes and multiple other underlying health conditions. I was sick from March 3-10. I quarantined myself for one and a half months. I beat this virus in seven days. I live in a building with other people with illness — by March 6, we got notices that people had tested positive in the building, and multiple others were sick here. They tested two people with the worst symptoms, and both were hospitalized and returned home, but only one supposedly tested positive for COVID-19, when we all know everyone must have had it.”

“I use oxygen daily and knowing that COVID-19 is a respiratory disease makes me very anxious. I know if I get it, it will kill me.”

“COVID-19 has completely taken over my small town. I’ve never felt so lonely and trapped in my life. It’s really brought even more stress on to my already stressed life. Can’t wait for this virus to go away!”

“I contracted COVID-19 and was hospitalized. I participated in a Remdesivir study and had good results. I continued to improve, and I am doing well.”

Tyler Stosich, a power chair user, came up with an effective way to route his sip-and-puff control tubing through an N95 mask. Stosich has been self-isolating with his live-in girlfriend as much as possible but says he uses the mask setup “whenever I have to go to the grocery store or any public place.” He says he’ll be getting a new shipment of N95 masks soon, and he’s happy to convert and ship to anyone who needs one (email us at smcbride@unitedspinal.org).

Given the increased risk factors for transmission and development of severe symptoms that the SCI/D community faces, it’s not surprising that our survey respondents tend to be more careful with their behaviors than the general public. In a May Gallup survey, only 36% of Americans say they wear a mask whenever they’re in public and a full 31% say they never wear one. Among our respondents, 50% wear a mask whenever in public, and only 5% never wear one. When it comes to travel, 34% of our respondents say they’ll be willing to resume travel only when a vaccine is available, whereas one recent survey (bit.ly/2NjF7IB) showed that only 16% of the general public plans to wait for a vaccine or cure before resuming travel. One similarity between the SCI/D community and the general public is that we all think it will be a while before life returns to something resembling normal. A Marist poll found that two-thirds of Americans say a return to normal will take six months or more. Our survey found that 70% thought a return to normal would happen either in 2021 or when a vaccine is available. Maybe we are all in this together, after all.
Other Impacts:
- Not able to go to the gym to exercise.
- Unable to have routine doctor appointments/medical procedures due to the shutdown.
- Depression.
- Inability to protest with everyone.
- Poor access to quality foods and disinfecting products.
- Unable to go to church.
- Homeschooling my son.

“Curbside delivery of food from restaurants has been wonderful with not needing to get my chair out of the car to get food.”

“Unable to go to the hospital for pressure sore issues. That has been very difficult. Also, my caregiver is no longer working, so my 60-year-old parents are doing everything.”

“I've lost my income for the rest of the year, as my employer has decided not to reopen this year.”

“I had family call me a murderer for going out. Drove two hours to eat inside a restaurant today. Felt great and no mask.”

“I enjoy solitude, but I miss seeing friends and family, socializing, human touch. I am an active volunteer, and I miss that involvement. Normally, I would be taking part in the ongoing protests, but I won’t put my health more at risk. A close friend died from COVID-19, and those of us who loved him can’t be together to support each other and celebrate his life.”

“Zoom has actually improved my connection with others in the disability community.”

“This COVID-19 situation was a whole new level of isolation. It was depressing to have more limits put into my life than ‘just’ my quadriplegia.”

“At first I was irritated and couldn’t wait to get back to life. But now I’ve accepted it, and this is a new way of life — like when we were injured, we had to adjust how we did things.”
United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

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

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.

**MEMBER BENEFITS**

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Gabrielle Broder is one of roughly 300 people across the United States who received $500 COVID-19 relief grants from United Spinal Association this spring. The grants were made possible by a $1 million grant from the Craig H. Neilsen Foundation, which has also allowed United Spinal to add to its chapter peer support efforts, fund personal protective equipment shipments, provide disability-specific COVID-19 information and more.

Broder, 43, shared her harrowing COVID-19 story and how she used the money.

“I am very grateful to United Spinal for being there for me in a tough situation. I am a C5 quadriplegic who relies on home care 24/7, and I live with my elderly mother. When the pandemic struck New York, one of my aides came down with a bad case of COVID-19 that nearly killed her. She was hospitalized for nine days, and six of her family members also fell ill, two of whom sadly didn’t survive.

Before she developed symptoms, she exposed me and my household. The following week, two more aides developed a cough, and I and another aide developed a fever.

It was very frightening because I cannot survive even a day without home care. I rely on it for every basic need. And yet, everyone had to quarantine. My 78-year-old mother cannot perform most of the tasks I need help with, and I was fearful of exposing her. And replacements? I don’t have a traditional agency that can send subs. I am in the self-directed program so am responsible for all staffing: recruiting, training, hiring and firing.

In any case, even when my insurance company gave me special emergency permission to use a traditional agency, they were unable to staff some shifts because so many aides were unavailable to work. I did have more aides, but they were afraid to come in for their own safety. I literally had no one left to turn to. In addition to all that, I lost all my income because the gym where I work part-time was obviously closed.

With the check I received from United Spinal, I was able to pay privately for a few hours of home care to tide me over for a couple shifts I was unable to fill. It was difficult to find people, but it helped that I could pay cash and not require them to go through hoops to sign up with the agency. The check also helped me purchase immune-boosting nutritional supplements, along with some resistance bands and other light exercise equipment, so I could work out at home, and finally, basic items like groceries and cleaning supplies.

Fortunately, all my aides recovered and most of them are back at work. I am thankful for the support I got that helped me get through this tough time.”

**NEWS FROM UNITED SPINAL**

**HELPING PEOPLE SURVIVE THE NIGHTMARE**

Gabrielle Broder used her relief grant to pay for home care when her usual aides became ill with COVID-19.
There’s been a lot of talk about “accessible tourism” lately, but is this the right term to use? As a wheelchair user, if somewhere—a cool bar, a significant monument, a beautiful view—is accessible only via steps or rugged terrain, I can’t go there. Yet people with a vision, hearing or cognitive impairment, or those living with chronic illness, may be perfectly capable of visiting such places. I would argue that using the term “accessible tourism” limits not only the discussion, but also our chances of participation in cultural life, recreation, leisure and sport.

While access is vital, it’s true inclusion we should be striving for. By emphasizing access, with its reliance on legislation, the stress is immediately put on compliance, not inclusion. To borrow an analogy from a thought-providing article by Lee Young called, “Understanding the key differences between Accessible Design and Inclusive Design,” imagine an established members-only men’s club that installs ramps, an accessible toilet, an elevator and hearing loops to meet legislative requirements. These renovations might make the facility more accessible, but by disallowing female members and requiring high fees or an invitation to join, the club remains exclusive rather than inclusive.

This is where—in both the built and online environments—inclusive design has rightly come to supersede accessible design and barrier-free design. In her article, “Inclusive Design and Accessibility,” Josephine Miller writes, “Accessibility is an attribute of Inclusive design, and while Inclusive design is about designing for diversity, it is more than meeting a set of standards.”

Microsoft’s definition of the two are: Accessibility: the qualities that make an experience open to all; inclusive design: a design methodology that enables and draws on the full range of human diversity.

To paraphrase Young, inclusive design is less logical and objective, and more emotional and subjective: It requires much higher levels of understanding and empathy.

So why is this important in the context of “accessible tourism,” as it’s most commonly known? Yes, it’s great that accessible tourism has become an area of study to which researchers can contribute. Likewise, accessible tourism has become an area of policymaking and government funding that a few progressive destination management organizations are embracing. It also identifies a market segment that can be quantified and targeted. In a world driven by economic rather than social principles, this has been useful to convince policymakers and the tourism industry that accessible tourism offers an economic opportunity by tapping into a market that is neither niche nor small.

But the concept of “accessible tourism” has only gotten us so far: Change is slow and piecemeal. If this travel segment were described as “inclusive tourism,” it would put the focus on making sure travel experiences are able to be enjoyed by as many people as possible (inclusion) rather than on the costly business of installing elevators, ramps and accessible toilets (access). The message we need to get across is that disability—or rather a lack of functional ability—affects us all at some point in our lives.

We need to look beyond touting a market segment made up of people with disabilities and an aging but affluent demographic, and instead encourage the tourism industry to adopt an inclusive mindset that prioritizes customers who have infinitely diverse desires and needs. It’s not about creating tourism product that caters to a market segment, but about catering for the entirety of the market. That’s not only a compelling business case, but also simply the right thing to do.

Further Reading:
- Article 30, United Nations Convention on the Rights of People with Disabilities: tinyurl.com/yb8fgg19
- “Understanding the Key Differences Between Accessible Design and Inclusive Design,” tinyurl.com/y747dgb6
- “Inclusive Design and Accessibility,” tinyurl.com/ybdqxc8q
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Both my grandmothers had flowers and plants all over their homes. Their gardening timeline followed moon cycles and other acquired knowledge I didn’t have much interest for. However, I did admire the pretty flowers and enjoyed the lemons and juicy peaches from the trees in their gardens.

A few years ago, my dad gave me a small tree, and I struggled to keep it alive. He took it back to save it. I became frustrated, thinking if I wanted to have plants, it would be just one more thing I would need to ask a caregiver to assist me with. Surely, plants and gardening were not for quadriplegics.

One day, when I was down a Google rabbit hole, I read and researched microgreens, about the ease of growing them and their nutritional value. With curiosity, I found some takeout containers I had saved, bought seeds and started my own microgreens garden. Soon there were tiny sprouts, and I felt the familiar excitement I had in seventh grade science class from growing bean sprouts in a Styrofoam cup. This was a small garden I could set on a table, and I could use a cup or spray bottle to hydrate the plants. Through trial and error, I eventually made it accessible to me and was able to watch my plants grow.

Fast forward a year, and I’ve asked my brother to build me a raised bed for an outdoor garden and a table for my indoor plants. Checking on them has become something I look forward to. There is joy in caring for something and helping it thrive. I have slightly remodeled my living room to be my own little oasis of green that saves my mental health during grey winter months or isolating pandemics.

It’s possible I’m becoming my grandmother. I look forward to it.
Besieged by medical problems and a declining quality of life, Keith Smith couldn’t picture a positive future for himself for years after sustaining a C4 spinal cord injury in a 2009 motorcycle accident. A fortuitous phone call and an epidural stimulator changed everything.

When Keith Smith started applying to every SCI medical trial he could find in 2013, it wasn’t about trying to walk again; it was about trying to live again.

Sure, that sounds cliché, but at the time, he thought anything would be better than the hell he’d been living since his injury in 2009. Unable to regulate his blood pressure, his heart frequently went into atrial fibrillation; being rushed to the hospital became an almost daily occurrence. He was constantly sick and battling infections that couldn’t be controlled without heavy doses of hospital-grade antibiotics.

Aside from his personal care, all he focused on was getting into clinical trials. But after years of trying, he gave up. “I thought I was done. I wasn’t getting into anything, and I wasn’t getting better,” he says. “It was weird, but the moment I gave up and stopped trying to get into trials, I got a call from The University of Louisville.”

That call was from Dr. Susan Harkema, rehabilitation research director at the University of Louisville’s Kentucky Spinal Cord Injury Center and leader of The Christopher and Dana Reeve Foundation’s epidural stimulation research initiative, The Big Idea. “They wanted me to come in for a screening,” says Smith. “I was blown away. Even though I’d never been on a plane before, I thought this could be my last shot to get in a trial.”

An epidural stimulator is a device implanted on the spine that sends electrical signals at various frequencies to reinvigorate the spinal cord. Harkema’s study has received international media attention, including in New Mobility, and has researchers rethinking many things they once held true.

“I’m not walking around, but just having the stimulator turned on, my body feels warm. It’s humming and I can smell, taste food and smile again,” he says. “My heart beats normally now. Of course, I’m still paralyzed, and I hope I will keep progressively getting better, but even if I stayed exactly how I am right now, I would take it.”

Smith uses his stimulator from the time he wakes up to when he goes to bed. He uses a special configuration to help him regulate his blood pressure, activate voluntary

**EPIDURAL STIMULATION ADVOCATE**

**Keith Smith**

Besieged by medical problems and a declining quality of life, Keith Smith couldn’t picture a positive future for himself for years after sustaining a C4 spinal cord injury in a 2009 motorcycle accident. A fortuitous phone call and an epidural stimulator changed everything.

**The Big Idea**

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Smith uses his stimulator from the time he wakes up to when he goes to bed. He uses a special configuration to help him regulate his blood pressure, activate voluntary

**BEST DATE NIGHT SUGGESTION:**

My girl and I get into my van and kick back at the drive-in or grab fish and chips at the beach.

**MOST ACCESSIBLE PLACE I’VE BEEN:** Port San Luis in Avila Beach, California. There’s a pier I can drive my car on and my kids can drop their fishing poles right off the edge.
It’s definitely challenging being a parent in a wheelchair. It’s possible and it’s doable, but it’s more difficult because you have all these struggles. You have things you have to deal with that your kids don’t quite understand, like catheter changes, infections and blood pressure issues. My kids kind of get it now, but it took years of bad experiences for them to realize, ‘Oh man, my dad’s in a pretty jacked up spot.’

I know my situation has cost them a lot, but what they’ve gained is I’m around all the time. Before my injury, I was working two full-time jobs just to get by. Now, I’m around to guide them. I teach them how to cook, grow plants and barbecue. They’re kind of little adults now because they have to be more mature and independent since I’m not there to do everything. If the house catches on fire, they better grab that fire hose.

movement of his core and ankles and even to help with his spasticity. He says the stimulator has improved his bowel and sexual function.

Being a part of epidural stimulation research has changed Smith’s life so dramatically that he now evangelizes the procedure to anyone who will listen. He is starring in the soon-to-be released documentary Rise Up, which chronicles his journey through the clinical trials at the University of Louisville.

Thanks to the stimulator, Smith is finally able to truly live life as wheelchair user. He recently founded the Central Coast of California chapter of United Spinal Association. He hopes to open up an activity-based rehabilitation center for wheelchair users who can’t afford traditional rehabilitation in the state.

“Now that I’ve gotten to go through this trial, I’ve learned quite a bit about recovery and SCI and intend on having one of the most kick-ass rehab centers out here — that’s my goal.”
No matter what type of mobility device you use, the allure of being able to go farther and faster with less effort and toll on your body is always appealing. If you use a power chair or assist, the limiting factor is battery life. Thankfully, advances in battery technology are extending the range of wheelchairs, allowing their users more freedom to explore than ever before.

Switched On
Ian Mackay has completed two 300-mile border-to-border crossings of Washington state in his wheelchair, first going north to south and then east to west. Although lengthy adventures like these are nothing new for him, his journeys have a twist.

A C2 quad, Mackay tackles the terrain, which includes long climbs and descents over steep passes, in his 3-year-old Invacare TDX. Remarkably, he averages 40 miles a day without stopping to recharge. The secret to his long-distance success is that he supplements his lead-acid batteries with a lithium-ion one mounted on a tray behind his chair. A friend custom-built a wiring harness that allows Mackay to toggle between the two types with the flip of a switch.

Mackay’s long-distance trips double as fundraisers for Ian’s Ride, his nonprofit foundation dedicated to increasing outdoor accessibility. They also provide a perfect illustration of the differences between lithium-ion and lead-acid batteries. His two group 24 sealed lead-acid batteries are identical to what most power chair users rely on. Thanks in part to his chair’s gearless, brushless motors, Mackay estimates he gets 30 miles on one charge, which is about the same distance he expects from his supplemental 24-volt, 75-amp-hour, lithium-ion marine battery — but the similarities stop there. The lithium-ion one weighs 70% less than its lead acid counterparts. Additionally, the two power sources deliver their charges very differently.

Lithium-ion batteries maintain max power output until they are depleted, whereas lead-acids put out less power as they near empty, resulting in a noticeable slowing of the chair. “In my experience, the lithium-ion battery gives me the same range as lead-acid. But because it puts out full power until it quits, it gives me an average of 1 mile per hour extra speed over a course of 20 miles,” says Mackay.

Everyone who uses a power chair probably isn’t going to need the ability to go up to 50 or 60 miles without recharging like Mackay, but having more options is always a good thing.
and bodes well for the future. "My setup gives me the flexibility to explore the outdoors as much as I want for as long as I want, and that flexibility is something we should all have," he says.

**The Lowdown on Lithium**

Lithium batteries aren’t exactly new, but they are powering a growing number of power-assists that are improving the lives of their users. Although there are several types of lithium batteries, the type used in most mobility devices, as well as power tools and approximately 90% of electronic-assist bikes, is lithium-ion. These batteries consist of individual cells, such as the 18650, which looks like a slightly-bigger AA battery. Larger lithium-ion batteries consist of multiple cells in a management system known as a battery pack. These can range in size from small for an e-bike to large enough for a Tesla car.

Christian Bagg took advantage of the ability to customize the size of the pack while designing the Bowhead Reach adaptive adventure cycle. “When we started Bowhead, we would get our lithium-ions by taking apart packs from crashed Tesla cars that had 2,000 cells in them,” says Bagg, a T8 para. “In a Bowhead Reach we use two battery packs with 50 cells in each.”

Lithium-ion’s blend of power and reduced size and weight, combined with more efficient motors, also helped to enable the development of devices like the SmartDrive, Yamaha NAVIONE, Twion wheels and the steerable Firefly.

The primary disadvantage of lithium-ion batteries for standard power chair design use is that they are significantly more expensive than lead-acid and require a complicated charger that controls how much and for how long it charges. Also, because of concerns about lithium-based batteries catching fire, you have to get a FAA waiver, or the battery has to be below a certain size, to take it on an airplane.

Mackay was initially hesitant about lithium-ion batteries because of reports that they could get hot enough to catch fire. Howard Kramer and Topher Downham ride NUKE off-road mountain handcycles with power assist on a trail above Boulder, Colorado.

### COMPARISON OF PRODUCTS MENTIONED IN THIS ARTICLE:

<table>
<thead>
<tr>
<th>Devices Powered with Unique Lithium Batteries</th>
<th>RANGE</th>
<th>MAX SPEED (MPH)</th>
<th>WEIGHT (LBS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBOT</td>
<td>17.4 MILES</td>
<td>6.7</td>
<td>4.4 LBS X 4 BATTERY PACKS = 17.6</td>
</tr>
<tr>
<td>FIREFLY</td>
<td>15 MILES</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>BOWHEAD REACH (80 VOLT)</td>
<td>15-20 MILES</td>
<td>20</td>
<td>13</td>
</tr>
</tbody>
</table>
fire. He researched and found that was more of a problem with earlier ones, and that if there was any danger it would be during charging, not when it is sitting or in use. Also, the fire problem was primarily limited to one type of cellphone that didn’t have very good chargers.

If you’re wondering why more power chairs don’t switch to lithium-ion, experts say it’s simple: lead-acid batteries work well. And, the bulkier, heavier size of lead-acid batteries gives power chairs a low center of gravity, which can be desirable for stability.

On the flip side, the desire to shed pounds led the designers of the new iBOT to ditch the nickel cadmium used in the original. “Switching from ni-cad to lithium-ion provides a significant weight reduction,” says Luke Merrow, CEO of Mobius Mobility. “Because the iBOT is a dynamic chair, weight is a very big issue. The lighter the machine is, the more responsive it is to the human.”

The iBOT uses four lithium-ion battery packs, which lasts for about 17.4 miles. Users can add two more packs for an expanded range, and the iBOT is still within the size and wattage limits for commercial airlines.

**Power Assist: Taking Back the Trails**

Beyond wheelchairs, lithium-ion batteries and improvements in motors are also upgrading adaptive recreation. Their smaller

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**COMPARISON OF POWER CHAIR BATTERIES MENTIONED IN THIS ARTICLE:**

<table>
<thead>
<tr>
<th>Batteries</th>
<th>Range</th>
<th>Max Speed (MPH)</th>
<th>Weight (LBS)</th>
<th>Approx. Retail</th>
<th>Fun Fact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GROUP 24</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LEAD-ACID</td>
<td>21 MILES</td>
<td>7.5</td>
<td>52 LBS X 2 BATTERIES = 104</td>
<td>$305 PER BATTERY X 2 = $610</td>
<td>Weight keeps center of gravity low, helping with stability. Chair performance slows when charge is run down to a certain level.</td>
</tr>
<tr>
<td>LITHIUM-ION</td>
<td>21 MILES</td>
<td>7.5</td>
<td>31</td>
<td>$1,400</td>
<td>Delivers full power until completely empty then quits. This results in approximately 1mph extra speed over a full 21 miles compared to lead-acid.</td>
</tr>
</tbody>
</table>

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size and the ability to add packs for more power makes them perfectly suited for the needs of outdoor enthusiasts looking to tackle increasingly-tougher terrain.

The outdoors opened up for Topher Downham when he added an E-BikeKit power assist unit with a lithium-ion battery to his handcycle. Downham, the outreach coordinator for Boulder, Colorado’s Open Space and Mountain Parks, is in his 25th year as C6-7 complete quad. He has a Freedom Ryder that he purchased used for $500. “I rode it for years and enjoyed it, but I was much slower than my nondisabled friends, and couldn’t go anywhere near the distance they did. Plus, after a ride I’d be wiped out.”

The E-BikeKit he later added has a range of 42 miles and top speed of 20 mph. “With the E-BikeKit, I can keep up with my nondisabled friends on long rides and still have energy to go have a beer afterward,” he says. “Also, it’s safer. With my level injury I don’t sweat, and if I’m riding way out there and start overheating, I can just hit the thumb throttle to go fast enough for a cooling breeze and make it home safely.”

Open Space and Mountain Parks bought three NUKE off-road handcycles and later converted two of them to power assist. “Prior to power assist, it was tough to get new SCIs interested in the off-road handcycles because it’s difficult unless you are in good shape,” says Downham. “With power assist, it is a different ballgame. People who haven’t been on a bike path or trail since their injury start off kind of tentative. By the end of the day they are doing river crossings, and they have these shit-eating grins on their faces that say, ‘Yeah, I’m back, my life isn’t over!’ That makes it for me — reaching one more person and showing them the possibilities.”

“With power assist, instead of having to ride a chair lift up a mountain bike resort to enjoy riding down single track, or struggling to peddle a mile and calling it quits, I can hop on, go biking with my friends, and get a great workout,” he adds.

Speaking from experience, I can attest that power-assist add-ons are amazing for paraplegics as well. I rode off-road handcycles for well over a decade, and it was a blast, but even on mild uphills my speed was reduced to a walk, and a long ride wiped me out. Now I use a Bafang e-bike kit on my Reactive Adaptations Bomber handcycle. Not only does it enable me to ride with my nondisabled friends, but it also lets me take Killy, my German shepherd, on the 2-mile, 1,000-foot descent to, and climb back up from, our favorite swimming hole on the American River. It provides a serious workout without putting undue strain on my aging shoulders.

While lead-acid batteries remain an excellent and more affordable energy source for most power chairs, it is exciting to see the innovation inspired by lithium-ion batteries. Hopefully they will continue to make it easier to go farther and faster for a long time to come.

Many thanks to Rory Cooper, founder and director of the Human Engineering Research Laboratories at the University of Pittsburgh, for his input and expertise on power sources for mobility devices.
I didn’t think the Capitol Crawl would be an historic event and wasn’t even sure it was a good idea at the time. I’m glad I was wrong.

It was March 12, 1990, but the temperature in Washington, D.C., was in the mid-80s, and it was sunny. I was part of the Chicago ADAPT contingent meeting up with ADAPTers from other cities for our spring action. At the time, ADAPT stood for American Disabled for Accessible Public Transit, and our reason for being was to ensure that all public transit vehicles and facilities were accessible for people with mobility disabilities. There was no federal access mandate, so in some cities lift-equipped buses were commonplace, but in others they were scarce. In Chicago, there wasn’t a single accessible bus.

ADAPT held actions every spring and fall in either D.C. or another strategically-selected city to push this agenda. And we did so ADAPT-style, by committing nonviolent acts of civil disobedience that often resulted in arrest.

The timing was perfect for this particular action. The Americans with Disabilities Act had passed overwhelmingly through the Senate but was stalled in the House. ADAPT was there to knock it loose.

We marched through the streets of D.C. and held a rally with other disability groups outside the U.S. Capitol Building. Various speakers waxed eloquent about the importance of the ADA. I remember feeling restless and a bit bored. After all the speechifying, masses of ADAPTers moved over to the foot of the giant staircase outside of the Capitol Building, and I followed even though I didn’t know why. That’s how it is at ADAPT actions — only a few leaders know the target, and the rest of us just follow and trust. Since the success of an action often relies on the element of surprise, the fewer people who know about where the march is going, the lower the odds are that the police, who are always nearby, will overheat something and tip off the target.

I remember ADAPT leader Mike Auberger, a quadriplegic who spoke at the rally, telling me people were getting out of their wheelchairs and crawling up the steps as a vivid, symbolic demonstration of what the struggle to pass the ADA was all about. Congress was smugly ensconced in its ivory tower, trying to pretend that we didn’t exist. But we weren’t going to let them ignore us.

I wondered if the image of the crawl might project the opposite image. Disabled people crawling around might conjure images of sad, powerless beggars rather than strong, determined activists. But, then again, maybe not, I mused. It might intimidate those in Congress who were being obstructionists. What the hell, then. It was worth a try.

But there was no way I could get out of my wheelchair and crawl up steps. I suppose if I had insisted, somebody would’ve flung me over their shoulder and carried me up. Instead I took the accessible route to the plaza at the top of the stairs and joined those cheering the crawlers on and greeting them as they arrived.

I spoke with other ADAPTers who took part in the Capitol Crawl to see what they remember and have to say about it today. They are Bob Kafka and Stephanie Thomas from Austin, Larry Biondi from Chicago, Robin Stevens from Denver, Julie Farrar from Colonie, New York, and Anita Cameron from Rochester, New York.
**STEPHANIE THOMAS:** At that time, Bob and I were national organizers for ADAPT and we helped design the plan. During the rally, I got a group of people together who could crawl and were willing to get arrested, and we made our way over to the base of the stairs. When Bob gave us our cue, we dropped from our chairs and started to crawl. Though I was the first to drop to the ground, I was quickly overtaken by the other crawlers.

**BOB KAFKA:** I was further back but crawled also. At the time, we were both in manual chairs and more mobile than today.

**THOMAS:** Thank God someone brought our wheelchairs to the top.

**KAFKA:** The system people [disability advocacy lobbyists] were stalled. The ADA had gotten stuck in the House of Representatives, and they were not able to get it moving again. We wanted to show that “access is a civil right” is more than just words, that we were willing to take action. We wanted to make sure the statement we made was symbolic and visual.

**ANITA CAMERON:** I was living in Colorado Springs, and back then those of us from out west rode in caravans across the nation. Colorado chapters met up in Denver, and sometimes Utah and Texas would join us, or we’d meet along the way, picking up more folks as we went through Kansas and other states. I often rode in [ADAPT founder] Wade Blank’s van on these trips, so I got to hear a lot of brainstorming and planning.

I knew once the rally was over that the crawl would happen, and I thought it was a great idea. I felt that ADAPT needed to really highlight what it was like to live as second-class citizens and what the Americans with Disabilities Act would mean to us.

**JULIE FARRAR:** By the time of the crawl, I was about 19. I was pretty tiny and much more mobile. I was known for being able to crawl around, through, up, down, over police barriers, stairs and so on.

We were watching Bob Kafka and waiting for the signal to start crawling up the stairs. The feeling of camaraderie was palpable — the excitement on our march there, the staging. I don’t remember the speeches. I just remember feeling so proud in a very sacred communal way of being a part of it all.

**LARRY BIONDI:** It was extremely hot for March and when we reached the Capitol Building, we stopped in front of the steps. I had no inkling what the plan was and then a couple of people asked me if I wanted to crawl up the steps. A burst of energy came over me, so I said, “Why not?”

Ron, my personal assistant from college, assisted me crawling up the steps by putting his hands behind my feet so I could have leverage. When I made it to the top, I was exhausted and my elbows and knees were bleeding. Wade poured water on my face while I lay on my back.

I didn’t know that 30 years later what we did would evolve into an historical moment. Climbing those steps was symbolic of how badly the disability community wanted the ADA to get passed.

**CAMERON:** I was in line with my friend...
Frank McCollmb, who had been in a nursing home for 43 years before being moved into his own place by Wade. When we got to the site, Frank’s attendants helped him to the stairs, and I took his manual wheelchair and pulled it up backwards beside him. It was a bit awkward because I had my white tactile cane as well, and Frank’s chair was heavy.

Halfway up, I became exhausted and gave Frank’s chair to his attendants and scooted backwards up the rest of the way. I went slowly and stopped to chat with a few folks to make sure they were OK.

I was excited, honored and humbled that I was helping to get a message across, and I’m not surprised that it was so historic. I felt that we were crawling our way into the history books.

**ROBIN STEPHENS:** It was hot as hell, especially when we were exerting ourselves, and there was no water until later at the top. I had been hanging with a blind friend and her new dog, and I asked her if she wanted to do the stairs with me. She said yes, so I parked my power wheelchair at the left side of the staircase and we slowly made our way up the steps to the landing, taking rests, making sure everyone was OK, offering help … and I crashed at the top, feeling totally dead, and helpless without my wheelchair. We finally got water and eventually my wheelchair.

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**ALL THE WAY TO THE TOP**

How One Girl’s Fight for Americans with Disabilities Changed Everything

**THE LITTLEST ACTIVIST**

All the Way to the Top is a children’s book that tells the story of Jennifer Keelan, the little girl with CP who climbed the Capitol Building stairs with other ADAPT activists. In ways children can understand, the book shows how Keelan was left out of class activities and unable to roll down the sidewalk because of her disability. Even though she was so young, she was part of the crew that helped make the ADA a reality. The book can be found in all the usual places, including Amazon.

Jennifer Keelan’s mom gives her a hug as she reaches the top of the Capitol steps.

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**ROLL ON 30!**

July 26th, 2020 marks the 30th Anniversary of the Americans with Disabilities Act (ADA), the landmark civil rights law that protects our members and other people with disabilities from discrimination.

United Spinal is proud to be a part of the legacy of the ADA. Throughout our history, we have used the ADA to fight for inclusion of wheelchair users in all aspects of our society.

But there is still important work to do!

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Learn how you can help fulfill the vision of the ADA, by visiting www.unitedspinal.org/roll-on-30

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THOMAS: It was hotter than hell, and I was soon soaked. Other folks were passing me by. I couldn’t go fast, but it wasn’t a race. Every step, I pulled myself up, adjusted my feet and pulled again. I was soon using the railing to pull myself with.

I saw so many people getting up those steps in so many ways, some moved rather easily, some with more difficulty. Some were being cheered on or crawling in groups, others by themselves. Some were being carried. It became a bit of a free for all, and that seemed to be so very appropriate. I was so glad to see all the people at the top. It was like a big hug from my peeps!

STEPHENS: Then the rotunda action took place the next day, along with our arrests, and our court appearances were the following day after that. I wrote a heart-felt speech for the judge, and when my turn came in court, I read it, got sentenced and rushed to the airport for my flight, which I missed. I returned to the hotel and listened to emotional discussion from fellow ADAPTers about what the demonstrations meant to everyone.

I’ve always felt the demonstration in the Capitol Building rotunda was much more effective than the crawl in knocking the ADA loose in the House. We gathered in the rotunda and our chanting reverberated like galloping horses. We demanded that House leadership come meet with us, and both the Speaker of the House, Tom Foley, and House Minority Leader Robert Michel soon complied. They told us some BS about how we all had to be patient and then left to a resounding chorus of boos. The chanting resumed, and soon the police moved in to arrest and remove over 100 of us.

But it’s the Capitol Crawl that’s considered by many to be the pivotal event that led to the passage of the ADA. In an interview with the Indiana Disability History Project, former U.S. Senator Tom Harkin, who introduced and championed the ADA, said of the Capitol Crawl, “When that hit the evening news all over America, we got the bill out of the House 30 days later.”

Since then, the Capitol Crawl has taken on an air of mythology. When Marca Bristo, president of Access Living, Chicago’s center for independent living, died last September, U.S. Senator Tammy Duckworth, a wheelchair user, said, “Because she crawled up the steps of the Capitol to pass the ADA, I get to roll through its corridors to cast my votes in the U.S. Senate.”

I really don’t recall Marca being present for the Capitol Crawl, but it doesn’t matter. In the light of history, the event is seen as such an important political action that it’s assumed that everybody who was involved in the disability rights movement at the time must have been there, front and center.

Many ADAPT activists say this demonstration in the Capitol Rotunda was more effective than the Crawl.
At 30 years old, is the Americans with Disabilities Act a grand achievement to be celebrated, or does the lack of uniform enforcement water it down too much? Has it met the lofty expectations of President George H.W. Bush, who upon signing it proclaimed, “Let the shameful walls of exclusion come tumbling down,” or are those barriers still holding people back?

To find answers, we consulted Lex Frieden, from Houston, Texas, who’s widely known as a chief architect of the ADA; Ola Ojewumi, an exciting young leader who hails from the Washington, D.C., area; Shannon Moore-Cardoso, a mapmaker who’s lived all over the United States; and Terri O’Hare, creator of the Facebook page Ramps from Hell and a constant challenger of the ADA’s boundaries in Albuquerque, New Mexico, and beyond.

**HAS THE ADA MET EXPECTATIONS?**

“I would say yes,” says Lex Frieden, 71, a quad who is a professor at The University of Texas Health Science Center at Houston and director of the Independent Living Research Utilization Program. He headed up the National Council on Disability back when the Americans with Disabilities Act was just an idea, and it’s no exaggeration to say there might not be an ADA if not for him. “There’s been a sea change in the way people in the public view those of us with disabilities, at least those of us who are active and participating in the community.”

Today, many Americans take curb cuts, disabled parking, and reserved seats in stadiums and theaters for granted. Younger people might even think...
these architectural features always existed. "Like on a bus, the seats that fold up, many of them believe, 'that's nice, look what they've done.' But it wasn't nice," says Frieden. "It was done because the law required them to. There has been a significant impact by the ADA."

Albuquerque advocate Terri O'Hare isn't as positive as Frieden. "If cities, governments and private business would actually follow the ADA, the U.S. would be far more inclusive and accessible," says the creator of the sarcastic Facebook page Ramps From Hell. She's responsible for local venues, such as trails, being made accessible and, although she's a wheelchair user with muscular dystrophy, her most recent fight has been about making her city's public "One Albuquerque" artwork accessible for people with visual impairments.

The 17,000-pound sculpture of the phrase "One Albuquerque" has the A, L and B letters sticking out at exactly the right height to bop some innocent blind pedestrian in the head. The city tried to resolve this by putting ropes around the typographical monolith, but a white cane could easily slip underneath. Anyway, the plaza's not stiff enough to hold that much weight, and officials are trying to figure out where it should go instead.

O'Hare, 62, resents having to keep fighting discrimination. "If so many of us didn't have to haggle with city officials and employers about rights that were passed as federal law 30 years ago, we'd be able to focus on the more exciting aspects of disability and access culture," she says. "But we're still having to write emails and call city planning directors and CEOs about obvious failures to meet compliance."

**GROWING UP WITH THE ADA**

Shannon Moore-Cardoso, who has rheumatoid arthritis, was 13 when the ADA passed and says that for her whole life most places in America have been at least somewhat accessible. Her wife is from Portugal, and together they have lived in Europe, on the West Coast and now in Gulfport, Florida. When she thinks about whether the ADA has met expectations, she mentally flips through the maps of places she's lived. Access in San Francisco constantly puts East Coast efforts to shame, and Florida is OK. Despite being friendly and charming, Portugal — which is not bound by American laws — was challenging access-wise.

"Over there, sometimes the only place you can go to the bathroom is a gas station or something crazy like that, so you really have to plan ahead," says Moore-Cardoso. Even American joints like McDonald's don't follow the ADA in Portugal. "The only place that does is Hard Rock Cafe, because it's a photocopy of the ones here in America."

It was Portugal's spotty access that led Moore-Cardoso and her wife, Joana, to create their company's product, Effortless City sidewalk pocket maps. Their inspiration came from a meeting with a paralyzed cousin of Joana's. "He was super-depressed, so I went to meet him and give him a wheelchair person pep talk because nothing there was accepting and open for him," says Moore-Cardoso. "But even in Portugal, if you really try to figure it out and determine a route, you can go to this place and you can go to that place. So we thought, we need to make maps of accessible routes, so people know they can have a life." Their cousin ended up coming out to California, and his life did turn around.

Ola Ojewumi was born the year the ADA was passed and says, "It's a monumental, pivotal law. Without it I would not have the rights that I have. I've used it to advocate for myself as an employee and student in public school and college. But it can be improved upon, particularly for children with disabilities. The work is not over — it's not done."

When she was 11, Ojewumi survived a heart and kidney transplant. "Three years later, I'm in high school and they refused to give me an elevator key, and they wouldn't put my classes on the same floor. I passed out twice trying to get to classes, and I got lower grades because I was late to class. I knew if I was a 15-year-old white girl, none of that would have happened — I would have been treated as a hero for surviving two transplants. But to my school and the white administrators, I was a nuisance," she says.

The Individuals with Disabilities in Education Act covers the right of students with disabilities to receive a free and appropriate public education, and the ADA requires school buildings to be accessible. If they're not, then reasonable accommodations — like those Ojewumi requested — must be permitted.

Ojewumi's government teacher en-
courted by Rep. Nancy Pelosi and Sen. Chuck Schumer because I couldn’t get a ride.”

Then, when she learned what the ADA was and that she could use it to get that key, she says, “It was game over. I started fighting for myself and other students with disabilities, and the school board appointed me to the Disability Inclusion Advisory Board for over 150,000 students in my county.”

Frieden concurs with Ojewumi, referring to ridesharing’s scofflaw attitude to be most qualified, regardless of the facts, and it’s very difficult to question that kind of judgment,” he says. Employers certainly have a right to choose who they believe will move them closer to their goals, “but when you look at the whole big picture, you see it results in discrimination. I’m at a loss to know how to legislate that.

O’Hare focuses on public accommodation violations. “Today I drove by a new dining and entertainment complex with shipping containers as its design core. It opened a week ago,” she says. The parking lot is done all wrong because the architect and site planner ignored the ADA, which the city didn’t catch when it gave the business a certificate of occupancy. Once a complaint is filed, the pathway to the restaurant will have to be leveled out, and more accessible parking spots are going to have to be designated.

“There is no excuse for this 30 years after ADA,” she says. “If I took my city’s violations of ADA, which are in the thousands, and multiplied them by other cities, we’re looking at so much ignored physical access compliance that it’s maddening.”

And then there are the programmatic issues, as all the cultural events and venues of a thriving city — such as plays and zoos and parks and libraries and museums — must be accessible. “They groan when reminded, and even when they say they’ll involve the disability community ‘the next time’ in the planning, they tend not to,” says O’Hare. “I think until folks stop seeing disability as an ‘othering’ thing, but as something that can and will happen to them, their kids, and their parents, there’s little incentive to get engaged and excited about what it can mean.”

Moore-Cardoso grew up in New Jersey, where her mother fought for her to get an education. "My school didn't want to provide me with a wheelchair bus," she recalls. "They said, 'We don't have to do that,' and she'd say, 'Yes you do,' and she'd go to our congressman to enforce it. But even here in Florida, where I live, there are three pools nearby, and not one has a lift. That's a tough thing about the ADA. In some places it's awesome, and in other places they don't really care." She says her apart-

IN WHAT WAYS IS THE ADA LAGGING?

There have been great strides in the area of transportation, as buses, trains, planes, and — in some places, anyway — subways have become accessible. But then along came ride-sharing companies like Uber with their goofy argument that because they use a phone app to connect drivers with riders, they’re somehow not transportation providers.

This argument wreaks havoc in Ojewumi’s budding public policy career, and she is one of several witnesses testifying against Uber in an accessibility lawsuit. "It takes me an hour to get a WAV, and a nondisabled person gets picked up in two minutes,” she says. “I’ve missed speaking engagements, including opportunities to speak alongside of Rep. Nancy Pelosi and Sen. Chuck Schumer because I couldn’t get a ride.”

Disabled people are a huge customer base, and any transportation company that understands this stands to do quite well for itself. Instead, “They’d rather spend money fighting us than making money. We have a base and a major law that we can use to advocate for equal transportation, but we still have to fight these corporations for accessibility,” says Ojewumi. "I shouldn’t have to convince you of my humanity. I am a disabled person, and together we are a major market, so why are you fighting us?"

He’s also disappointed in how stubbornly the area of employment has resisted compliance with the law. "In some respects, I believe the awareness of employment discrimination has been significant, as employers are more aware of discrimination than they were before the ADA,” he says. “My concern is that they, whether by intent or not, practice a kind of subtle type of bias that you can only see by looking at disparities.”

Let’s say three highly-qualified people have all made it to the top of an HR pile and all are called in for interviews, but one has an obvious disability. “I think there’s a high likelihood that one without disabilities will be determined
Joana and Shannon Moore-Cardoso

ment complex even made her pay for a little baby ramp to put over her apartment door's threshold. "State by state, when it comes to accommodations, you're really gambling."

WHAT COMES NEXT FOR THE ADA?

Moore-Cardoso hopes that ADA compliance becomes uniform across the United States, and even overseas, as more nations adopt American-style access. "I've lived in a lot of different places: New York, New Jersey, Ohio, California, Florida ... California was amazing. But everything is about awareness," she says. "We need to compare, state to state, and have a place to talk about the differences. Why can some have an amazing light rail system, and in New York City you can't even use the subway? It doesn't make any sense."

Frieden wants a focus on inequities in the health care system. "The pandemic experience has unmasked a lot of gaps in the ADA to the extent that there has been evidence of discrimination in regards to health care," he says. "I believe it's now more clear than ever that the ADA should include a title on non-discrimination in health care."

He suggests that title should speak more clearly about alternatives to institutionalization. "When you look at the numbers of people in nursing homes who have died, the major difference between the two groups is disability," he says. "You might say it was both disability and age, but we have data that points to disability."

Ojewumi says an end to subminimum wages would be great, as would an end to Medicaid work requirements. But her heart is with our future: students with disabilities. "I'd like to see accommodations made so part-time students aren't penalized," she says. "That was a problem for me because I was hospitalized three times my final semester of college, and it affected everything. Being forced to be full time to keep my scholarship, it stressed me out. Meet students where they are, so they don't fall through the cracks."

Also, she wants to see an end to racism and its associated ableism in public policies, especially health care. "We see with COVID-19, how many more black people have died because of medical racism. I want race issues on the forefront," she says. "If racism wasn't so prevalent, then the government wouldn't think disabled people could live on $780 a month on SSDI. All of this is because of anti-black 'welfare queen' public policy."

O'Hare wants to see disability arts strengthened, as they are a potent way to influence our broader culture. "I am heartened by the many disabled artists, writers, performers and movement voices I see who are pushing ADA and access beyond ramps and moving disability inclusion into cultural areas," she says. She cites high-quality memoirs being published, such as Corbett O'Toole's Fading Scars and Alice Wong's anthology, Disability Visibility, and films like Crip Camp, which broke through into the mainstream. "This is where the riches lie. The creative output and examination occurring in our movement is so powerful. This is how we will connect to a larger public and also create space for those coming up or going deeper into their current experience of disability."

Predicting the Future of the ADA

BY JAMES WEISMAN

"By the year 2000, after 25 years of every school system in the United States complying with the Education for All Handicapped Children's Act (now known as the Individuals with Disabilities Education Act), people with disabilities will be completely assimilated into the population at large. They will be fully employed. They will be university presidents, romantic leads, politicians and office workers."

Certain that mainstreaming children with disabilities into public schools in the most integrated setting appropriate to their needs would dismantle disability discrimination forever, I gave the above prediction as a new lawyer 43 years ago. By 1990, it was clear that despite 15 years of IDEA, and well over 30 states having adopted anti-discrimination laws protecting those with disabilities, we still needed the ADA.

Correctly predicting the future of ADA advocacy is probably more about coincidence than foresight. But it is safe to say that, either directly because of litigation or the expectation of access and inclusion that's been created by the law, the overwhelming majority of places, things, jobs, and organizations will become accessible and inclusive. There is no logical argument that supports discrimination on the basis of disability.

We always win access battles. Some of them, like the taxi issue in New York, take 20 years. But with effective advocacy, inaccessibility and exclusion always yield to accessibility and inclusion. Employment, housing, public transportation, and the education system will look different 30 years from now, but it will all work for people with disabilities because of the ADA.

Perhaps the ADA’s greatest accomplishment is raising the expectation levels of everyone about people with disabilities’ potential for satisfaction and achievement. So, as these questions are asked — Will rideshares and autonomous vehicles be accessible? Will space travel be accessible? Will people with disabilities be captains of industry? — keep answering yes to everything. Because eventually, you will be right.

James Weisman is the CEO of United Spinal Association, of which New Mobility is the membership publication.
The ADA makes me grieve for my grandpa who died in 1977. He used a wheelchair all the years I knew him. Fast forward 13 years as the ADA arrived exactly when I needed it: It was signed when I was in the hospital for the first time due to MS. For my entire adult life, I’ve benefited from this great civil rights legislation. Because of it, it’s not often that I feel the bitter sting of exclusion. But when I do, I think of my Opa, who rarely got to sit beneath the open sky, had no adaptive technology and lived constantly with that bitter sting. My Opa makes me more grateful for the ADA and even hotter to fight those who are chiseling away at it.

JOHN MOHLER
Bolingbrook, Illinois

I have been a T8-9 para since 1975 and believe me the changes have been like night and day. Before the ADA, going to a washroom in a large establishment, like a shopping mall, was a challenge and small restaurants were a joke. Being able to get on a bus or public train was a dream. Curb cuts and public buildings with doors I could go through were luxuries. While there still needs to be more done, life’s much easier since the ADA was passed.

BRUCE HAGAN
Huntley, Illinois

I am a C6 quadriplegic, and I use a power chair. My accident was in 1994, so I don’t know how life for disabled people was before the ADA. It might have been a lot worse. I just know from my experience that the ADA should have been made stronger and fully enforced by now. It is the only civil rights legislation that I know of that after 30 years is still
not fully enacted and enforced.

My wife and I were in a financial bind, and we were going to lose our fully-modified wheelchair-livable home. There are no apartment complexes in my city that have wheelchair-livable apartments. Not even the ones where you have to be old or disabled. Shouldn’t these things be covered under the ADA?

When the Arby’s in town was remodeled, they completely put in a new sidewalk that does not have curb cuts! If the ADA had teeth and was enforceable, this would not happen. There have been several other buildings in town with new owners. They all remodeled, but have no ramps to get into their stores. The ones I have gone to will put up a portable ramp. This would have been perfectly acceptable when the ADA was just passed, but 30 years later, they should put in a permanent ramp.

I’m not all negative about the ADA. It made a big difference for people with disabilities — it just fell way short of what it could have been.

CRAIG A. BRADBURN
Muncie, Indiana

In 1995, when I was walking on crutches (from polio in 1945), and working for a community college, I fell on the job. The job non-renewed my contract, stating they thought I’d fall again, even though I used a wheelchair from the accident. I sued, and in the course of the lawsuit, there was a ruling from the Supreme Court that found you could not sue a state agency for an ADA violation [Board of Trustees of the University of Alabama v. Garrett, 2001]. We continued with the lawsuit in the state court system and I won, but it took 10 long years to get to that win.

The change in the ADA really crippled my case, and my win left me exhausted. The defense made every attempt to malign me and engaged in endless delays. The college was compelled to offer me another position, but with my reputation ruined where all this had taken place, I had no intention of returning to accept the position.

EMILY LADAU
Editor, Rooted In Rights

Upon retiring in 2013, I moved with my partner from California to Pennsylvania and then Florida. I discovered in this process that the level of ADA enforcement is directly related to the values held about disability independence by a community. In California, I had the expectation of 80% wheelchair accessibility. I never had to think much about going to restaurants, bars, shows, stores, etc. My assumption was that
they would be accessible. If I discovered a rare facility that was not, I had not only California law and ADA, but the community’s value of disability independence working with me to rectify an intolerable situation.

Very soon in Pennsylvania, I discovered that you can maybe expect 40% accessibility and no sense of accountability. Not only are places inaccessible to wheelchair users, but also the folks who run them have no clue that they should be. For example, Pam and I wished to go to a bookstore coffeehouse in a little village in Eastern Pennsylvania. Having discovered the “40% rule” of Pennsylvania, I called ahead and asked if their facility was wheelchair accessible. The young woman on the phone said it was, and that there were only six steps up the front. I replied that the ramp must be in the back. “No,” she said. “There are 12 steps in the back.” After talking with her for literally half an hour, I finally got her to concede that the place was not wheelchair accessible. Behind her lack of awareness was the value that wheelchair users should not be independent but always come with a “helper.” Florida is better, but not by much.

Without the political/legal forge that characterizes the independence movement that occurred in California, the Americans with Disabilities Act will not be enforced uniformly.

**RICHARD O. SALSGIVER**

*Professor Emeritus, California State University, Fresno*

ADA is a joke!

First, the federal government exempted itself from having to follow many ADA guidelines. I have experienced so many violations in VA hospitals, VA centers and military hospitals, and there is nothing to do since federal agencies and federal properties are exempt from the ADA.

Secondly, in the civilian world as well, in both public and private businesses, very few places are actually wheelchair accessible. The vast majority of places and businesses think they are ADA compliant by putting up a small blue sticker with a wheelchair on it on their window, but they are not at all ADA compliant!

Finally, reserved accessible parking spots are a total joke too. There is so much abuse! Most of the time, I don’t find any disabled parking spots because they are all taken either by people illegally parked without any placard (usually young people who have no respect for any laws) or by people who fake it and have no mobility disabilities whatsoever and can walk and run without any assistance. I personally don’t care to park near an entrance, but I need the extra space to get in and out of my vehicle and to operate my wheelchair lift. They might as well just eliminate these reserved spots since they are never available for genuine disabled people!

**BERNARD NOEL**

*Honolulu, Hawaii*

I am 76 years old and have been a wheelchair user for nine years. I had no idea how difficult it was to go anywhere in a wheelchair and how many exceptions there were in the ADA.

Six years ago, I moved to Wilmington, Delaware. When I couldn’t get into several new retail locations, I was told that they didn’t own the buildings. I then contacted the building code official, and I was told that the design of the entrances was permitted under ADA rules. When I complained to my bank that I couldn’t handle their front doors, their solution was to put an unmarked bell on the building. I ring the bell and someone comes to open the door.

I find the ADA to be very limiting.

**GEORGE OPPENHEIER**

*Wilmington, Delaware*

I am grateful every day for the ADA and its legal framework. However, I think some aspects of its impact are lagging and long overdue. I am constantly faced with doctors’ offices, stores and schools that are entirely inaccessible. Recently, I have noticed ads for teaching positions and desk jobs, such as grant writer, that state candidates must be able to lift 20 pounds. Why? To keep out qualified candidates who have mobility impairments that have no impact on these jobs? That is a civil rights violation, but when I reached out about this to the ADA National Network, their response was that employers are allowed to post any restrictions they want. I find this very alarming.

**L. MAFFEI**

*Cedarhurst, New York*
The ADA is 30 — that statement conjures thoughts profound and emotional. The anniversary of the groundbreaking federal civil rights legislation is reason for celebration because humankind is better when we remove barriers that prevent people from living their lives to the fullest.

But those barriers didn’t bring themselves down. That took sustained advocacy by many dedicated people with disabilities. We reached out to a group of them and asked them to share their thoughts and advocacy accomplishments.

DAVID CAPOZZI
Executive Director, U.S. Access Board

David Capozzi has been the executive director of the U.S. Access Board since 2008 and a staff member since 1992. “I can remember before the ADA was passed,” says the T7 para. “In the early ’80s, you would have to call movie theaters, restaurants, any place, to see if it was accessible. Now I assume it’s accessible.”

The ADA’s effect on public transportation, especially on buses, is one of the biggest successes of the ADA. Fewer than 5% of public buses were wheelchair accessible prior to the ADA’s adoption in 1990. “Now, 100% of fixed-route buses are accessible, and generally they are low-floor buses with ramps, so there isn’t a cumbersome lift to break,” he says. “You don’t have to wait for every other bus to come along and hope the lift isn’t broken.”

In addition to transportation being improved, Capozzi says recreation opportunities have increased infinitely, thanks to the ADA. “Before the ADA, playgrounds were not accessible for adults or children with disabilities. In the 1990s, we wrote regulations, and now you see more poured-in-place rubber surfaces, and the equipment is more accessible than it was before,” he says. Also, now there are more beach access routes, beach chairs, and accessible stadiums and arenas. “Before the ADA, you were lucky to have a stadium where you could find a wheelchair accessible seat at all. Now, we address sightline over standing spectators, and accessible seating dispersed throughout the facility — because of the ADA.”

ROSEMARY CIOTTI
Disability Health Care Consultant

Twenty-five years ago, nurse practitioner Rosemary Ciotti was pregnant with her second child when an inflammatory disease similar to MS gave her stroke-like
Rosemary Ciotti

KELLEY SIMONEAUX
Founder, Spinal Cord Injury Law Firm

Kelley Simoneaux, a T12 para, lives in Washington, D.C., where she was denied a ride by an Uber driver. “That catapulted me into starting my own law firm,” says Simoneaux, who sued the rideshare company.

She is concerned that the gig economy, which was not in existence when the ADA was adopted, is going to erase many gains made under the ADA, because app-based companies aggressively claim they are exempt from it. “Like micromobility — the sidewalks are littered with scooters that create barriers,” she says. “And Airbnb is largely inaccessible. We are going to have to look at regulations that speak to how people with disabilities fit into the tech-based world. We all need to commit during the next 30 years to making sure technology improves the lives of people and is not a barrier.”

BILLY ALTOM
Executive Director, Association of Programs for Rural Independent Living

Effective advocacy is different once you get outside the city, says Billy Altom, a T1 para based in Little Rock, Arkansas. “There is a huge difference in how you enforce the ADA in rural areas versus urban,” says Altom. “In an urban setting, if I go to a store and it’s not accessible, I can file a complaint, or I can go 10 blocks down the street and get what I need at a place that’s accessible. If I’m in rural America and I need to buy pig feed and there’s only one place in the county to buy that and it’s not accessible — I may need to build a relationship with the owner and negotiate a way of making things accessible.”

Altom says he never goes to explain accessibility modifications to a business owner without a copy of the Americans with Disabilities Act Accessibility Guidelines in hand. “I want to work with the person. Maybe they always wanted to build a new door, and now they can understand how to make it compliant, and maybe they can even use it as a tax write-off,” he says. “My mindset is to give the person the tools to help them, to let them make modifications that are cost-effective, so they see me and the ADAAG as an asset.”
VICTOR CALISE
Commissioner, New York City Mayor’s Office for People with Disabilities

Victor Calise, a para, has served under two administrations as the Commissioner for the New York Mayor’s Office for People with Disabilities. “As we approach the 30th anniversary of the signing of the ADA, I am proud that we have made great strides to increase accessibility and to prioritize disability rights in the City’s policy agenda,” he says. Among his office’s accomplishments are:

- A city building code that goes above and beyond the mandates set forth in the ADA.
- The Taxi and Limousine Commission has steadily increased the number of wheelchair accessible taxis. Also, it passed regulations to mandate wheelchair accessibility in all for-hire vehicle bases, including ride-hailing app companies.
- An increase in accessible and affordable housing units by ensuring that a percentage of units in new affordable housing developments are set aside for people with disabilities. All units in new construction are adaptable, should a disabled tenant require reasonable accommodations.
- The NYC: ATWORK initiative that connects a talent pool of PWD to living-wage jobs and internships that meet their qualifications.

HEIDI JOHNSON-WRIGHT
ADA Compliance Professional

Heidi Johnson-Wright has used a power wheelchair for mobility for 35 years. She graduated from law school and got married — to this writer — all before the ADA was enacted.

“One of the big challenges is getting people to understand that the ADA is a civil rights law and not a building code. While people are a lot more informed today, there are still those who hear ‘ADA’ and think it consists solely of curb ramps and restroom stalls,” she says. “So, it’s my job to explain how the ADA applies to access to programs and services. For the most part, people want to do the right thing. They sometimes feel awkward around people with disabilities and are looking for guidance.”

Johnson-Wright, who has rheumatoid arthritis, started her first job out of law school when the ADA was brand new. She made a simple written request for a toilet seat riser and door openers for the restroom and the building’s main entrance. Weeks went by with no action, and her state agency employer seemed to have zero understanding of the ADA. That led Johnson-Wright to file a state civil rights complaint.

“When my boss found out, he flipped out and screamed at me,” she recalls. “Ultimately, I got the toilet seat riser, and a security guard was assigned to help me with the building entrance. I never got a door opener for the restroom. Such behavior would be inconceivable in today’s climate.”

Now with 30 years under the ADA, Johnson-Wright says people with disabilities know their rights and are asserting them. “I’m happy to see young folks speaking freely about disability life without shame.”

“I’m happy to see young folks speaking freely about disability life without shame.”
whether flying missions as a P3 anti-submarine aircraft pilot, serving as commander of America’s most controversial military prison in Guantanamo Bay or directing the White House Situation Room, over his 35-year career, Navy Rear Admiral Kyle Cozad has navigated through some of the most stressful and consequential situations that a person could find themselves in. Thanks to those experiences, in 2017 the Navy selected him as the chief of education and training, responsible for bringing newly-minted recruits in from the streets and instilling in them the skills, knowledge and attitude they need to do their jobs as full-fledged sailors.

Cozad was eight months into this assignment when an unlucky fall in his kitchen caused a spinal cord injury at T12-L2. If this accident had occurred in years past, all of Cozad’s experience and skill probably wouldn’t have outweighed the fact that he now needed a wheelchair to get around, and a Navy review board would have medically discharged him. However, thanks to a combination of his own tenacity and stellar record, and the Navy’s push to modernize itself, Cozad has continued on as the Navy’s chief educator. In doing so, he has become one of the few active duty service members to use a wheelchair and a case study for the idea that physical disability shouldn’t automatically disqualify you from the military.

I MIGHT MAKE A CAREER OUT OF IT

Cozad grew up in Las Vegas, and was good enough at basketball that he was recruited by a number of schools, including the United States Naval Academy. He was drawn to the Academy because of a neighbor who was an Air Force pilot, and the idea of becoming a Navy pilot himself appealed to his sense of service and desire for adventure. Basketball turned out to be a means to an end — he played for the junior varsity team while at the Academy in Annapolis, Maryland, and graduated in 1985. Cozad met his wife, Amy, just before his senior year at the Academy, and they were married a year later. After school, he went to his initial flight training and officially became a pilot. At that point, Cozad planned to spend a few years in the Navy before moving on to fly for a commercial airline. But his second assignment landed him as an instructor in Nova Scotia, where he worked with the Canadian Airforce.

“Amy and I both realized how much we really missed being in the United States Navy. We missed our squadron environment and the camaraderie,” he says. “So with that, we kind of made this decision that we’d go one tour at a time and stick in the Navy until it was no longer fun. Thirty-five years later, here we are. Don’t tell her, but I think I’m going to make a career out of it.”

Over the course of that career, Cozad has flown operational missions in his P3 Orion antisubmarine aircraft, and served as a flight instructor and a squadron commander. Cozad’s current boss, Vice Admiral John Nowell, has known him for almost two decades. “What’s always impressed me with Kyle is his ability to form a team and to lead in a positive fashion. No matter what the
challenge, he has approached it with a very even keel, where he gets the job done and gets it done quite well.”

From 2009 to 2011, Cozad served first as deputy director, then as senior director of the White House Situation Room, the fortified bunker in which the president, cabinet and top military brass handle the most high-level threats America faces. He was there when President Obama authorized the raid that killed Osama Bin Laden. Cozad’s duties involved the
behind-the-scenes logistics — monitoring attendance, setting up communications links and disseminating intelligence — for what he describes as “a zero-fail environment.”

Cozad relished his role. “You jump in the Metro there in D.C. or drive yourself home, and you just think about and process the incredible things you contributed to that day,” he says. “There is a huge sense of satisfaction that you’re making a difference at a really high level.”

From the situation room, Cozad moved on to other high-level assignments: studying “undersea warfare and dominance in the future” at the Naval Operations Strategic Studies Group; working on global formations deployment at the Joint Chiefs of Staff; heading the entire Maritime Patrol aviation community as they transitioned from using the P3 aircraft that Cozad trained on to the new P8 Poseidon jet. His highest-profile post was commanding one of the most famous prisons in the world — the detention center at Guantanamo Bay, a mission he describes as “really difficult, challenging and often misunderstood.”

“There is a huge sense of satisfaction that you’re making a difference at a really high level.”

It’s hard to imagine a military career more diverse than Cozad’s — he’s been involved in operations, training, research and support, in roles that range from so low-profile that few outside of the military even know they exist, to a stage manager for one of the most historic moments in recent American history, to a public-facing leader of the most intensely scrutinized and secretive military bases in the U.S. Through it all, the common thread has been a commitment to professionalism and service.

“He’s one of those folks where you just go, ‘Wow, I hope I’m as good as Kyle Cozad is,’” says Nowell. “You hope that you have the kind of respect and admiration that his sailors — as well as his contemporaries — have for him.”

MISSION INTERRUPTED

In 2017, Cozad was tapped to lead the Naval Education and Training Command. The NETC recruits, trains and provides professional development for the more than 400,000 active duty and reserve personnel in the Navy. “It’s a huge responsibility,” says Cozad. “But the coolest thing about the job is I get to spend a lot of time with people who are brand new to the Navy, 18 and 19-year-old sailors who have never seen the ocean before and are just excited to wear a uniform. They’re excited to serve their country, and to get to their first ship squadron or submarine.”
Eight months into this command tour, Cozad was in the kitchen of his on-base house when he slipped and fell. He doesn’t remember it as a particularly hard fall, but somehow the impact injured his spinal cord. The day after his first surgery, the neurosurgeon delivered the news that his paralysis was likely permanent. “I’m not unique — lots of people get news like that, whether it’s a battlefield injury or a serious illness or an injury like mine,” he says. “And at some point you’re faced with that decision that you have to make. You can lie in bed and feel sorry for yourself, and just expect other people to take care of you for the rest of your life, or you can move on and see what you can make of a dark situation.”

Cozad made it through five weeks in rehab at West Florida Rehabilitation Institute by leaning into the skills and habits he’d developed during his 30-plus years in the Navy. “I’d grown up my entire career with incremental goals. You’ve got to set goals for yourself, take things one day at a time, one step at a time. And literally, that became my motto.”

Then he came home. All of those milestones reached hadn’t prepared him for the real world. He was living in a historic, inaccessible house on base. For a few months, he had to live in a small room on the outside of the house. He was still in a clamshell brace and far from independent. His wife became his primary caregiver. “Watching her do all these things, it really gave me some motivation that, hey, I’ve got to get stronger, I’ve got to get better. And the first thing that I realized was how much I missed the Navy, how much I missed my job.”

Cozad participates in the 2019 Navy rowing trials, which give wounded warriors an opportunity to compete for a spot on Team Navy.
A CASE FOR DISABILITY

Cozad was unique in that he had extremely high-level sponsorship willing to facilitate his desire to return to his post. Vice Admiral Robert Burke was his direct supervisor at the time, serving as the Navy’s equivalent of a human resources chief. “He was very accommodating in telling me that, ‘Number one, your health and recovery is your first priority. But number two, take your time and do what you can do as far as getting back to work,’” says Cozad.

Cozad says the Navy has been incredibly accommodating of his disability as he’s returned to full-time work. His staff at the NETC stepped in immediately after his accident. “I’ve always lived under the belief that you’ve got to train the people who work for you to be able to make a difference, and step right in that day that you can’t come to work,” he says. “They ran the organization for me without missing a beat.” Cozad returned part-time at first and then worked his way up to full-time. He still attends physical therapy three afternoons a week, and is allowed to make up for whatever he’s missed at the end of those days by working from home after his appointments.

The Navy was willing to accommodate Cozad’s new body, but this is still rare. Most sailors who develop a significant physical or mental disability have to retire because they no longer meet physical “deployability” requirements (see sidebar page 37). Working around

A MORE ACCOMMODATING MILITARY?

Q&A With Navy Chief of Personnel, Vice Admiral John Nowell

New Mobility: How uncommon it is for someone who has an accident and winds up with a spinal cord injury or other significant disability to continue in active-duty service?

Nowell: It is out of the ordinary. I will share with you that it’s not about Kyle Cozad being a flag officer — it is about the special skill sets that he had. But I should be very frank with you: We, like the other services … pretty much you have to be deployable anywhere in the world at any time to do your job.

In Kyle’s case, he’s not physically qualified now to fly the aircraft that he spent much of his career flying. That’s not what the Navy needs him to do.

I think where I’m going with this is that in the 21st century, as we look at war fighting, it’s very different. It’s about out-thinking our opponents and our adversaries. In many cases, if you’re a cyber warrior, then I may not need you to be able to deploy, let’s say, like a Marine or someone else on a destroyer or a cruiser. We do have cyber warriors who go out on those, but if you have that skill set and I can put you in the right place ashore, in the right center to do your job, and if you have some kind of a medical issue, do we still have a place for you? The answer is, yes, we do. But this is a new way of looking at it.

NM: Just to be clear, you’re saying that in the modern Navy, there’s some rethinking and some need to be flexible in some of these physical deployability requirements to accommodate talents and to allow people to continue to serve. Is that right?

Nowell: I think that’s true. I mean, first of all, we know that for sailors, flexibility and options are very, very important, but then we also know that for the Navy, we need to be able to do it [deploy]. I will again point out that I’m not saying we don’t need the majority of our folks to fit what you and I would recognize as the standard deployability metrics, but it should not be, and cannot be, a cookie cutter approach.

NM: So there is more willingness to look at individual situations and see where their talents and skills might be able to still be deployed?

Nowell: That’s absolutely true.
Cozad’s situation, says Nowell, is “a testimony to the Navy being smart about how we look at someone who could have quite easily have been cashiered out of the service based upon the injury.”

As part of a broader effort to modernize, Nowell says the Navy has started to embrace the idea of “empathetic leadership,” or the ability to see things through a different lens. “I think a lot of times, no one’s better able to do that than someone who’s been through something that’s really hard and challenging. Do I think it’s made Kyle Cozad probably a better leader? He was already a really good one, but yeah, I would say it has.” (See sidebar, page 38.)

“It’s been beneficial for the rest of us as well. … There was a very active dialogue after his accident: ‘Hey, what’s the right thing to do?’ That very quickly shifted from, ‘Well, the right thing to do is to give him enough time to just let it play out a little bit, and then we’ll move him on and get someone else in there,’ to, ‘Holy cow, who could do this job better than Kyle Cozad? If he’s willing to stay, can we make that work?’ Thank goodness we did.”

THE PATH FORWARD

Since his spinal cord injury, Cozad has worked with the Navy Wounded Warriors, which provides assistance with recovery, rehabilitation and reintegration for injured service members. It’s a program that he considers invaluable in his journey back and a continued source of support.

Through his own experience with disability and with Wounded Warriors, Cozad has developed a passion for mentoring and helping others in a similar situation. At the end of this month, he is set to retire after a 35-year-long and fulfilling career. His current goal, though, is to make retirement less an ending and more a transition. Whether through adaptive sports or a nonprofit organization, Cozad says he wants to carry on supporting disabled veterans and others with a spinal cord injury.

Similarly, Nowell sees Cozad’s service as a powerful example for other sailors. “He epitomizes what good leadership looks like. He is doing that so clearly with a disability, and he’s getting the job done. I mean, the reason he has the job that he’s in right now is because he’s more effective than other leaders that we could have put there,” he says. “I think the message it delivers is that if you are willing, first stay positive and look for how you can accomplish whatever job it is that you decide that you want to do. Then see if there is a path for you.”

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Primary care physicians are, as the name suggests, our primary contact for health care. They work with us to keep tabs on our overall health, provide information and guidance, check for potential problems, manage prescriptions and vaccinations, write letters of necessity for equipment and supplies, and provide referrals to specialists. Unfortunately, when you are living with SCI/D, finding a PCP that fits your needs can be a challenge for reasons ranging from the physical accessibility of the office to a doctor’s limited knowledge of your disability.

For information about how to choose a PCP, including what questions to ask, ways to educate them about your disability and how to search for one, we turned to advice from experts and seasoned wheelchair users. Here’s what they had to say.

**CHOOSE A PCP WHO IS EAGER TO LEARN ABOUT YOUR DISABILITY**

It’s not easy finding a PCP who can, or is willing to learn how to, work with someone who has SCI/D. “I know that a lot of primary care docs are intimidated by the prospect of taking care of people with spinal cord injuries because we don’t get a lot of training in how to care for people with disabilities,” says Dr. Michael Stillman, a physician and professor with the Jefferson University Hospitals.

In his 2016 presentation, “Primary Care and Spinal Cord Injury: What You (and Your Provider) Need to Know,” Stillman recommends seeing if you can meet with a primary care physician and their staff for free before signing up with them, to ensure they’re a good fit. He suggests that even if you interview a PCP by phone, it is a good idea to go to their office to check accessibility. Keep in mind that although finding a PCP who has knowledge about SCI/D is ideal, they are quite rare. If you can’t find one with experience working with SCI/D, it is important to get one who is open and interested in learning about your disability.

To find a doc who will listen to you — one who may even do some reading and consult with colleagues in order to meet your needs — it is important to know what questions to ask. Stillman’s presentation and Craig Hospital’s module “Changing or Choosing Your Spinal Cord Injury Doctor” both offer helpful lists of questions and criteria for choosing a PCP (see Resources).

Kim Anderson-Erisman’s criteria for choosing a PCP includes finding one who is good at communicating and eager to learn about her disability. “In my 31 years as a C5 quad, I’ve had quite a few primary care physicians and found that most are open to learning about SCI. I know my body and my disability so I help them learn, and we have developed good doctor/patient relationships,” says Anderson-Erisman, a professor of physical medicine and rehab at Case Western Reserve University. “On the other hand, I’ve fired PCPs who haven’t been interested in learning and found another PCP who is.”

Sometimes working with a doctor who doesn’t have a background in SCI/D works out just fine, says Candace Cable, 65. “None of the three primary care specialists I’ve had over my 45 years as a T10 para knew anything about SCI at the start, but all were willing to learn,” she says. Two years ago, she moved from
Truckee, California, to Los Angeles, and her new PCP didn’t have a lot of knowledge about SCI but expressed interest in finding out more, so she gave him a copy of the Christopher Reeve Foundation’s Paralysis Resource Guide. “He read it and really appreciated it. He said the book was an inspiration to want to know more,” she says.

Stillman says finding a doctor who is humble and curious is critical. “Primary care docs need to be aware of what they do and do not know about the care of people with spinal cord injuries, and they shouldn’t be bashful about admitting that,” he says. “But if they do admit that they have a knowledge gap, then they have to be hungry for that knowledge. They have to be willing to go read and consult with colleagues, to reference the literature. They have to want to learn more about your condition and how to keep you as well as possible.”

**ASK IF THE PCP IS CONNECTED TO A HOSPITAL NETWORK**

It’s important to choose a PCP who is part of a hospital network or has referral privileges with one — and it’s a bonus if they’re affiliated with a system that specializes in SCI/D. “An ideal PCP is part of a large hospital system that has access to specialists like urology, gastroenterology and PM&Rs so they are able to say ‘This is above my pay grade, I’m going to refer you,’” says Anderson-Erisman. PM&R stands for physical medicine and rehab doctor.

Retired ear, nose and throat specialist Jon Arnow, 63, agrees that hospital affiliations are important. He never used a PCP in his adult life until the car crash that caused his L1 incomplete spinal cord injury when he was 45. “I found I needed to get established with a primary care doc after my SCI for things like referrals to specialists such as a urologist,” he says. “My primary care physician is connected to a network of specialists in my area.”

For Paul Knott, 67, a PCP’s referral privileges are as important as their location. Knott has had three PCPs in his 35 years as a C6-7 quad. “Two years ago, I dropped my primary care doc because, although he was close by, he didn’t have admitting privileges at my local hospital or access to nearby specialists,” he says. “I found another primary care guy who has local admitting privileges and who is willing to work with me.”

Unfortunately for people in smaller towns, health care systems and specialists are likely to be in urban areas, but it is still just as important to ask your potential PCP which health care systems they have referral privileges with. Cable lucked out, as her PCPs have all had good referral connections. Even when she was living in the small mountain town of Truckee, her PCP was able to refer her to specialists, although some were one or two hours away.

**MAKE SURE THE PCP’S FACILITIES ARE ACCESSIBLE**

Check to make sure your potential PCP’s office, exam rooms and bathrooms are accessible. It’s a bonus if the office has an accessible exam table, although a study in the March 2013 issue of Annals of Internal Medicine found only nine of 256 health care facilities had height-adjustable tables or patient lifts.

Although basic physical exams can be done with a person in their chair, Stillman explains that a comprehensive physical exam requires the patient to re-
A NOTE ABOUT PM&R DOCTORS

Some people with SCI/D may employ a physical medicine and rehabilitation doctor as their primary physician, and others may have a PCP for basic health needs and referrals but use a PM&R doc to look after their disability related needs. “My current PCP does a good job communicating with me and keeping me healthy,” says Paul Knott. “But now, after 35 years as a C6-7 quad, I’m thinking I should get a referral to see a PM&R for a ‘tune-up’ as well as a possible ongoing relationship to make sure I’m doing everything I should be for aging with SCI.”

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.

move their clothing and lie on a table. But like many people with SCI/D, Anderson-Erisman says that due to the difficulty of changing into a hospital gown and transferring, as well as lack of accessible tables, all of her physicals have been done with her sitting in her chair.

If your PCP’s office doesn’t have an accessible exam table, ask them if they are willing to think creatively. Cable’s PCP has his assistants carefully pick her up and transfer her to an exam table when needed. When Knott’s PCP has to do a skin check on his back side, the standard exam table doesn’t cut it. “I told him there is no way I will be able to use his exam tables because they are too hard and I’m in danger of falling off. I need a hospital bed with rails,” says Knott. “I wasn’t willing to budge on this.” To Knott’s physician’s credit, he orders a bed brought over from the hospital when Knott needs a full exam.

PICK A PCP WHO WILL ADVOCATE FOR YOU

Having a PCP who will go to bat for you when you need insurance to pay for something is a must. Whether it’s a simple prescription refill or a new piece of equipment, the right words and references can go a long way. “My primary care docs have been ‘Johnny on the spot’ with writing letters for work accommodations and DME equipment,” says Knott.

Anderson’s current PCP is also very good at advocating for her. “She is still coming up to speed about SCI, but she is really open to me telling her stuff,” says Anderson. “Last year I got pneumonia and I was trying to get a prescription for a cough assist machine. She didn’t know what it was, so I gave her information on it, and she put the prescription through.”

EMBRACE ELECTRONIC MEDICAL RECORDS TO ENHANCE COMMUNICATION

Electronic medical records apps are becoming a common way of communicating non-urgent questions or needs with your PCP. Using your PCP’s EMR app provides several advantages: It enables clear communication without the need to wait on hold or leave a message with your doctor; it makes it easy for your doctor to clearly respond back; and you can get email reminders when test results
or doctor comments are available, as well as appointment reminders and updates on ongoing issues. EMR also enables you to go back over your medical chart, look at test results and compare them with previous ones. "My PCP is set up with 'My Health Online,' a web portal that is really good at sending me email reminders of visits," says Knott.

A caveat about EMR apps: Like any record-keeping system, they have a potential for preserving inaccuracies that remain indefinitely in your chart. Arnow, a medical consultant for Social Security Disability Determination, has come up with a name for this problem: "cut & paste, carry-forward."

"It is difficult to get accurate information from EMR notes because of 'cut & paste, carry-forward,'" he says. "I recommend asking your doctor for a printed copy of his chart notes following each visit." The notes should include what you and your doctor discussed, any type of test or exam recommendations, suggestions, referrals, and prescriptions. It should also include a list of your current medications and vaccinations. Many practices will hand you printouts of your chart notes at the end of your visit. If they are not offered, you should ask for them. It is important to check the notes to be sure they are accurate.

**ASK OTHERS FOR RECOMMENDATIONS**

The last task is to start looking for your own PCP. Arguably the best place to start is with a recommendation from another person whose SCI/D is similar to yours. Options to do this include asking friends with similar disabilities, querying a local support group, like your local United Spinal Chapter, or posting a question in a relevant online forum or somewhere like Rutgers Care/Cure forums.

When searching for a PCP, keep in mind that not every doctor will meet all of your criteria. Your choice of PCP may come down to availability where you live, whether a particular PCP is taking on new patients, or whether they accept your insurance plan. Choosing will be a balance of which of the above questions are negotiable and which are most important. Hopefully your choice of PCP turns out great. However, if it isn’t a good fit, you always have the option to let them go and choose another one. It is important to remember that the ultimate person in charge of your health care is you.

**Resources**
- Caring for Persons with Spinal Cord Injury, eprimarycare.onf.org/Resources.html
- Craig Hospital: Changing or Choosing Your Spinal Cord Injury Doctor, craighospital.org/resources/Changing-or-choosing-your-doctor
- Primary Care and Spinal Cord Injury: What You (and Your Provider) Need to Know, [PCP info at 16 min]: sci.washington.edu/primary/
- Rutgers CareCure Forums, carecure.net
- SCI Primary Care Flowsheet for physicians, eprimarycare.onf.org/rsc_files/SCI_Primary_Care_Flowsheet.pdf
- United Spinal Chapter Network, uniteddspinal.org/support/chapter-network/

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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.
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- Reading Hospital Rehabilitation at Wyomissing, Wyomissing, PA; 484/628-8000
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TAKING THE ADA ON THE CHIN

When the Americans with Disabilities Act was signed into law 30 years ago, I was there. Yep, somehow, they even let the likes of me in. So, one thing we can say has changed a lot in 30 years is security was a hell of a lot laxer back then.

And when I left the White House grounds that day, nobody frisked me to make sure I wasn’t stealing any silverware. Of course, the whole ceremony was held outdoors on the White House lawn, which was probably a good thing in the long run. If all the crippled riffraff like me who were present had been inside the White House, the festivities would have inevitably devolved into a pie fight. Either that or somebody would have spazzed out and smashed a priceless bust of Lincoln or something like that. Who knows how that might have altered the course of history? I don’t want to think about it.

But one thing that hasn’t changed much over the last three decades is we still live in a world that’s full of chin-high tables. God how I hate those things. You go into a bar or restaurant, and all they have are those tall tables with long-legged chairs. If you sit in a wheelchair, all you can do is rest your chin on the table. I feel like a dork when I sit at one of those tables, and I bet I look like one, too.

You’d think that by now, the ADA would have wiped out all vestiges of places with only chin-high tables. Because that’s how things are supposed to work, at least on paper. Congress passes a law or the Supreme Court issues a ruling and all the law-abiding citizens comply.

But if that’s how things really worked, then as soon as the U.S. Supreme Court handed down the Brown v. Board of Education ruling, all the racist segregationists would have immediately said, “Well, I guess that settles it. We’ll have to integrate all our schools starting tomorrow. Fair is fair.”

No, there will always be a certain number of scofflaws who adopt a “so sue me” attitude. They act like the law doesn’t apply to them. In the case of the ADA, a lot of business proprietors insist that they are “grandfathered in.” They think that, for some reason, Congress carved out an exemption specifically for them: No provision of this law shall be construed to apply to Bob’s Tavern.

What’s a pedestrian cripple like me to do when confronted with scofflaws like these? It would be nice if I could count on the government to vigorously enforce the ADA. It would be great if the governor or president would send in troops to confiscate the chin-high tables, take them out in the alley and chop them into pieces, like how they used to smash barrels of beer during prohibition. That sure would make an example of these arrogant scofflaws and serve as a powerful deterrent for others.

But that won’t happen. I know I have to be the enforcer. I could sue. Before there was an ADA, there was nothing I could do about chin-high tables. The good news is now if I want to take action, I can file a lawsuit in federal court. The bad news is now if I want to take action, I can file a lawsuit in federal court. What a daunting pain in the ass that would be, which is why I’ve never done it.

The main power the ADA gives pedestrian cripples like me is the power of shaming. Over time, sweeping civil rights laws transform cultures. They kick down enough doors until previously-invisible people become visible to the point where they’re noticed if they’re not around. Their presence becomes as much the norm as their absence was before.

So, I guess the problem is cripples haven’t been present enough in bars. The proprietors can put out nothing but chin-high tables, and nobody notices but us.

Thus, I can best assert the power of the ADA by frequently hitting the bars. Then maybe future generations of cripples will no longer be subjected to the indignation of chin-high tables.
Those familiar with this young column know that “the machine” represents the large or small barriers and roadblocks those of us with mobility disabilities have to overcome. As a C4 quadriplegic, I write about fighting the machine that works to keep me dependent and limit my options. I fight the machine to gain as much dignity, independence and self-reliance as possible.

I realized how much one technology had contributed to this fight when I wanted to turn my fireplace on and off, under my own power, either via voice or app. It turned out to be more difficult than I’d expected (that damn machine again). I spent hours on research, and even spoke to a number of home automation consultants I knew.

Then BabyGirl (one of the few approved nicknames I have for my wife, Karen) asked, “Isn’t there some kind of Bluetooth ‘clap on/off’ that pushes the button for you?” A 30-second Amazon search revealed a device called the Switchmate, which costs less than $30 and runs on two AA batteries. It’s a magnetized button that sits on top of a light switch. It accepts voice commands and connects via iOS or an Android app.

That’s when I realized how much I owed to Bluetooth technology. Bluetooth enables devices I use to control my laptop, such as iDevice, Tecla, mouth mouse and phone, which in turn enable the bulk of my independence. And I know that in the disability community, I’m not alone in that.

Originally developed at Ericsson Mobile in Sweden in 1989, the first Bluetooth consumer device, a wireless headset, was launched in 1990. Since then, the technology has become inescapable. Mice, controllers, switches, speakers, printers, keyboards and just about everything technological connects wirelessly via Bluetooth.

For people with disabilities, Bluetooth has opened the doors to levels of independence that wouldn’t have been possible 10 years ago. Companies like Tecla and Level Access specialize in Bluetooth-enabled devices that allow autonomous use of a cell phone from a bed or chair, as well as management of smart home devices.

What these devices enable may seem trivial to abled folks, but not to us. We know these little actions can make all the difference. In my case, there are quality-of-life issues I want as much (or more than) being able to walk. It’s why I spent an embarrassing amount of time trying to figure how to turn my fireplace on and off before I found a solution. This simple act had obviously come to mean a lot to me. I was determined to claw out this extra bit of independence and control. I was intent on putting another round in the chamber in the fight against the machine.

Bluetooth has provided us with a whole new arsenal in this fight. It provides the tools for more control not just of our own bodies, but our environments as well — controls other people take for granted.

Another benefit of Bluetooth is its universality and popularity. Everyone wants voice control and smart home controls, and not many wish to walk over to that light switch or dial that phone. That’s good ... in some ways. It means that the market for Bluetooth-enabled devices is vast and growing, and the same innovations that simplify the lives of the fully mobile are there to benefit us as well. As I have said in the past, convenience for you is independence for me.

Meanwhile, Bluetooth is powering the cutting edge of accessibility. A company called BrainGate specializes in neurotechnology. They developed a brain-computer interface that allows “those with paralysis to directly operate an off-the-shelf tablet device just by thinking about cursor movements and clicks. Brown University reported that three quadriplegic trial participants were able to control an array of apps on a tablet using the investigational BrainGate BCI that records neural activity directly from a small sensor placed in the motor cortex:

“The participants messaged with family, friends, members of the research team and their fellow participants. They surfed the web, checked the weather and shopped online. One participant, a musician, played a snippet of Beethoven’s ‘Ode to Joy’ on a digital piano interface.”

Of course, the implanted sensor communicates with devices via Bluetooth — a technology that continues to open doors. While I’m not signing up for this particular technology any time soon, I admit it will help us win more battles with the machine.

For more on brain-computer interface, read this month’s Research Matters, page 48.
When my daughter was in middle school, I sometimes found myself at talent shows featuring goofy skits. A favorite was called The Dressing Table. A girl sat with a makeshift dressing table in front of her, pretending to face a mirror. Seated Girl wore a very large sweatshirt, but her arms were not in the sleeves. Kneeling behind her, where the audience couldn’t see, was a friend with her head hidden inside the same sweatshirt and her arms thrust through those sleeves, making it look as though Seated Girl had very short arms. Seated Girl announced theatrically, “I think I’ll put on some lipstick!”

The hands of Kneeling Girl scrambled comically around on the table until they landed on a tube of bright red lipstick, which she then applied, very badly, somewhere in the vicinity of Seated Girl’s mouth, before announcing, “Now I’ll do my hair!”

This skit came to mind while I was thinking about the subject of this article: brain computer interface. Seated Girl was, in a sense, paralyzed. Tucked inside the giant sweatshirt, her hands were useless. Kneeling Girl’s job was to compensate — to use her hands to do the task that her friend was naming for the audience.

This is a little like how a BCI system is supposed to work, only without words. When the paralyzed person simply thinks of doing a task, that intention is decoded and translated to machine language. The translated thought is then sent to an actual machine, which carries the intention out seamlessly and instantly, as if the machine were an extension of the body.

But how does “thinking of doing a task” get decoded and translated? With great care, friends.

Decoding the Neurons

Scientists have known for almost a hundred years that our brains generate measurable electrical current. They’ve been working out the implications of that fact for the last half-century and probably will continue to do so for as long as our species survives. Each of our brains has roughly 86 billion individual neurons, the cells that produce measurable electrical current. Every neuron lives in a particular place in the brain and has well-defined sets of connections to other neurons. Collections of individual neurons working in sync to generate tiny currents are thought.

Let me say that again. What we mean by the word, “thought,” in physical terms, is electrical current flowing between nerve cells residing in the brain.

What we experience as intention — I’m going to put that apple on the cutting board — is, in the world of the body, just specifically located groups of neurons passing electrical current in predictable ways. It’s that grouping and those firing patterns that form a translatable code. With the right equipment, the code can be read, translated and delivered to a robot designed to make grabbing an apple and setting it on a plate a trivial task.

Nicho Hatsopoulos, professor of organismal biology and anatomy at the University of Chicago, published some of the early research on BCI work, wherein human subjects attempted to use their thoughts to move computer cursors. “We said, ‘Think about moving your hand to move a computer mouse, so as to move the cursor.’ That helped us build this decoding, so we could take the brain signals and have them move the cursor,” says Hatsopoulos. “But then what happened was, over time, we asked this one subject, in particular, what they were thinking about, and the subject said, ’I’m not thinking about moving my hand anymore. I’m just thinking about moving the cursor. I don’t think about my hand anymore.’”

Anyone who has ever learned to touch-type or play the piano will relate to this kind of experience. At some point, you stop being careful and intentional about each key; it’s as if your brain has created a shortcut. Your fingers and the keyboard have become, in a sense, component parts of a single entity.
Controlling a cursor on a screen with sheer thought is pretty astonishing, but it’s limited in terms of how it can help people with mobility issues. Moving that cursor lets you open email. You can play video games. You can write novels. But you can’t put a ripe apple on a cutting board, pick up a knife, cut off a slice and put it in your mouth. For that sort of thing, you need a version of Kneeling Girl’s hands, which is where robots enter the picture.

The robot currently in use for this kind of learning is at Dr. Michael Boninger’s lab at the University of Pittsburgh Medical Center. Made by the German company KUKA, it’s known as LBR iiwa, which is an acronym for German words meaning “lightweight intelligent industrial work assistant.” It’s a powerful machine. With correct programming, KUKA could build a car all by itself.

One of the end goals of BCI research is to figure out how to make the robot feel like an extension of the body. Professor Hatsopoulos calls this process embodiment, describing how his tennis racket, over time, has become embodied as an extension of his right arm.

Embodiment of the KUKA will have to involve more than thought-driven fine motor control, though, complicated and astonishing as that achievement is. For the robot to feel like an extension of the subject’s body, it will also be necessary for the subject to have a feel for what the robot is touching. How heavy is it? Is the mass equally distributed, or is one end heavier than the other? How hard do you have to squeeze it to get hold of it, and how hard can you squeeze it before you break it? In a word, you need sensation.

Getting the Feel of It

Only a few people in the world are in a position to tell us about progress in that direction. One of them is Nathan Copeland, and with the help of the implants, he has fist-bumped President Obama, fed himself tacos and leveled up in video games like Final Fantasy. Copeland has four implants in his brain: two in the region that directs motion in his right hand and two more in the region that registers sensation when something touches that hand — or would register sensation if he still had a working spinal cord. His was damaged at C5 in a car crash in 2004, and he hasn’t been able to feel or move his hands since. But he has the implants and — in the lab at least — the robot.

Each implant is a 4-by-4-millimeter array, less than half the size of the nail on your pinky finger. Each array has 100 microelectrodes, and each of those is 1.5 millimeters long and about as wide as a grain of sand. They’re tiny. The surgery to get them correctly placed on the surface of the brain is uncomplicated but intense: five or six hours of meticulous work, followed by a week or so of the usual post-operative discomfort. After that, you can’t feel them.

There are leads coming away from the arrays and through the skull to a pair of what the scientists call “pedestals” located on top of Copeland’s head. These pedestals allow the computers to translate thought to action and touch to a version of sensation.

The sensory implants don’t create an exact analog, but they do allow him to recognize various kinds of touch when applied to the KUKA. He can “feel” tapping, pressure and tingles. He’s spent many, many hours patiently helping researchers identify which particular neurons in his brain must be given the tiny burst of electricity that translates, for him, into those feelings. Just as thought is a pattern of electrical activity, so is sensation. The seamless and instantaneous integration of these patterns is what will, eventually, lead to a robot that has genuine embodiment.

In the meantime, Copeland would very much like not to be the only one. Dr. Boninger, in Pittsburgh, and Dr. Hatsopoulos, in Chicago, are looking to enroll four new subjects, two in each location. These people will have to be prepared for an extended time commitment: four hours per session, twice a week, for at least a year. They’ll need the following: to live near one of those two labs, to have almost no function in at least one hand, and, most of all, to foster a sense of adventure and an ability to commit for the long run.

One of the early subjects of the work with cursors called her implants Lewis and Clark, which captures the sort of approach volunteers need to bring. A sense of humor helps, too. Copeland jokes about controlling a sword to play Fruit Ninja in real life. “I was like, we can lab expense a sword, right? And then you can throw fruit and I’ll try and cut it or something,” he says.

You have to admire his style. When asked why he would sign up for something so invasive and in so early a stage of development, he says that because he can, he has to. That’s more than style; that’s character.

Resources

- Copeland’s YouTube: youtube.com/playlist?list=PL-UehttXKgFOyFysBj6yMtmz8X0mwgLhR
- For more info on the clinical trials, or to sign up: scitrials.org/trial/NCT03811301
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Age 28, from Hudson, Florida C4 Complete Quadriplegia

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Echo was my second service dog, a black-and-tan Doberman with a calm nature and a "diva" attitude. She went everywhere with me, and one evening joined me and two friends at an upscale Italian restaurant. As trained, Echo headed under the white tablecloth for a nap. She's quick, so neither the waitress, nor a friend who arrived late, knew she was there.

When the evening wound down, the waitress came up behind my wheelchair to lay the bill on the table. In the process, she nudged Echo squarely in the butt. Startled out of a deep sleep, Echo jumped up and bonked her head on the table. The thunk rattled the dishes and shook the table with such force that my friend jumped to her feet and shrieked at what she thought was some sort of dining room poltergeist under the table. In reaction, the other diners jumped in a domino effect, staring at the bizarre situation at the corner table.

Echo emerged, and calm was quickly restored. As the waitress apologized profusely, Echo just sat wondering what the fuss was about and why her head hurt.
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