Black Lives Matter: Voices from Our Community
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Behind every sign and slogan are the stories that give a movement meaning. We weren’t sure what stories Black wheelchair users would tell about the intersection of race and disability — so we asked. Thirteen people answered the call, sharing both unique perspectives and common themes of wheeling while Black.

Cover Photo by Erin Taylor
Contents Photo Courtesy of the Milwaukee Journal Sentinel

FEATURES

16 SEE THE WORLD, STAY CLOSE TO HOME
If you’re not sure that now is the best time for international travel, LILLY LONGSHORE shares some creative ways you can enjoy the perks of foreign travel without leaving the U.S.

36 WELCOME TO THE GROUP
A long-running SCI support group at Craig Hospital continues to thrive because of its ability to serve the various needs of its ever-changing roster of attendees. RICHARD HOLICKY talks with his fellow group members to better understand the group’s success.
By Ian Ruder

It’s impossible to know how future generations will look back on 2020 and remember it. If I had to single out one issue that has consumed the most of my thoughts, it would be the murder of George Floyd, the subsequent calls for police reform and the strengthening of the Black Lives Matter movement.

As Alex Jackson writes in this issue, on May 25, when officer Derek Chauvin held his knee on Floyd’s neck for eight minutes and 46 seconds, everything changed. As difficult as it had been to adjust to the stay-in-place protocols of COVID-19 and the new post-virus world, responding to and dealing with the coronavirus was simple by comparison. Wash your hands, wear a mask, avoid large groups. In essence, be smart. Not fun, far from ideal, but clear.

When it comes to reforming the police and addressing the deeply-rooted systems that perpetuate inequality in America, Floyd’s death and the ensuing events have reinforced that the need for radical change is equally clear. What isn’t as clear, and what keeps me awake at night thinking, is how we bring about that change.

I wish we could end systemic racism with something as simple as wearing a mask, but if these last three months have shown us anything, it’s that A) nothing is as simple as it seems, and B) the divides in our nation will not be easily healed.

So, when it comes to bringing about that change, what is the role of New Mobility? What can New Mobility do to be part of the solution?

These aren’t new questions, but in light of current events and ongoing conversations around racism, disability and intersectionality, we want you to know they are guiding our editorial process and future planning.

There is no getting around the fact that our editorial staff consists of four white people. Maybe we pass the bar when it comes to diversity of disability, but in terms of diversity of cultural experience, we are lacking. We know this, and we are working on it.

We have made strides in terms of including people of color in our content in the last two years, but we haven’t been as successful in terms of recruiting and employing writers of color. This issue shows we can do better, and it highlights the value of including authentic voices from across the spectrum of diversity.

“We have made strides in terms of including people of color in our content, but we haven’t been as successful in terms of recruiting writers of color. This issue shows we can do better, and it highlights the value of including authentic voices from across the spectrum of diversity.”

New Mobility isn’t going to end racism, or ableism for that matter, but we have a part to play, and we are committed. It’s not going to be easy, and we’re going to need all of your help to guide us, critique us and enlighten us, but it is critical that we make our voices heard in this fight so that when people do read about 2020 in the future, they can say that George Floyd’s death and the movement that it galvanized led to something that made the world a better place.
At some point in the weeks after George Floyd’s death, our editorial team started discussing the possibility of a cover package focused on the impact on Black wheelchair users. The striking photo on the cover of this issue, which came across one of my social media feeds, was one of many images and stories we saw that quickly convinced us to scrap what we had planned for this issue and commit to the BLM package. The image shows first-time protestor Evita Rush at a Portland, Oregon, protest in early June, and was captured by photographer Erin Taylor, a friend of Rush’s. “We as black people have let so many injustices slide. I’ve lost count of how many times I’ve read about some horrific killings of an innocent and/or unarmed black person,” says Rush. Accessibility concerns had kept her away from protests in the past, but this time felt different. The possibility of a cover package focused on the impact on Black wheelchair users. The striking image shows first-time protestor Evita Rush at a Portland, Oregon, protest in early June, and was captured by photographer Erin Taylor, a friend of Rush’s. “We as black people have let so many injustices slide. I’ve lost count of how many times I’ve read about some horrific killings of an innocent and/or unarmed black person,” says Rush. Accessibility concerns had kept her away from protests in the past, but this time felt different. The experience was powerful, but left her aware of how much work needs to be done integrating people with disabilities into broader movements for social justice. “This protest is for equality, but I was wondering if they’re really thinking of everyone.” Read Rush’s perspective on page 33.

Alex Jackson

has written for and been featured in New Mobility several times, and I was thrilled when he agreed to helm the roundtable discussion at the center of this issue. Showing the resolve in the face of adversity I’d like to think characterizes New Mobility, Jackson persevered through abbreviated deadlines and an unexpected, prolonged hospital stay to create what I think will stand as one of the magazine’s most timely pieces. Despite the difficult circumstances, Jackson says the conversations proved enlightening and highly valuable personally. “Getting the chance to hear so many different perspectives really opened my eyes,” he says. “I learned a lot, and they reinforced why what’s happening in our country is so critical.”

Lastly, I’d like to thank the many members of the Black community who took the time to submit their words and thoughts for our Voices compendium, which starts on page 27. The volume and quality of responses we received inspired us to expand the amount of space we had allocated. As you will read, the stories we received are powerful and exactly the kind we need to be sharing and discussing as we as a community, and a nation, reconcile our attitudes and policies around race.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
An Uncertain Future
Having enough caregivers to do your care and making sure that you are safe now with the coronavirus is a big problem ("Spotlight on Vent Users," June 2020). One thing I would recommend is if you cannot breathe on your own try to get a VOCSN vent. You stay on breathing support for everything like cough assist and suctioning, and it helps a lot. I agree with everything that [the people in the article] are saying, and I do not know how [people will] get out now. I went to my medical appointment and they made sure no one was in the waiting room when I went through, and everybody there was wearing masks. This will not be like this forever, but I will always be at high risk of getting any kind of respiratory infection.

Larry Pagel
Newmobility.com

Front-Drive Fun
I’m 50 and a 30-year para. I’ve often thought about traveling around Europe but wondered about how it would be seeing the famous old stuff in a chair ("Paris by Firefly," June 2020). I recently purchased a front drive and was surprised at how well you can travel on one when the small front casters are simply taken out of the equation. The distance easily traveled is amazing.

Tyler Tingle
Newmobility.com

More Vent Solutions
We appreciated your June spotlight on ventilator users, in particular VOCSN ambassador Loa Greisbach. The benefits of integrated respiratory care are now available to all ventilator users. Anyone who is prescribed a ventilator plus one additional therapy (oxygen, cough, suction or nebulizer) may be eligible for a VOCSN Multi-Function ventilator. Under its new Medicare billing code, HCPCS E0467 is billable across Medicare, Medicaid and private insurance. If any prospective user has questions about cost or insurance, we encourage them to visit VentecLife.com/contactkelly. Our team is happy to answer their questions.

Mark SooHoo
VP, Marketing and Communications
Ventec Life Solutions

Wudlick is Wudlikable
Rob Wudlick has tirelessly advocated for the betterment of those living with SCI. It’s no surprise to see that he’s also used his skills as an engineer to help develop this product ("Helping Design a Life-Changing Product," June 2020). As his former caregiver, I know how impactful this will be for his independence.

Liisa Holm
Newmobility.com

About Time
I can’t wait to see the final product ("Helping Design a Life-Changing Product," June 2020). As an SCI OT, I have always been frustrated at the lack of research and development of upper limb orthotics while I see so much time/effort/capital go into lower limb orthotics. “It’s just not fair,” I’ve heard so many of my clients with C1-4 tetraplegia say. “If only I had one hand to do something with, I’d be happy.” I am so hoping that the Abilitec Assist with help meet that goal. I will be holding good thoughts for you and the Abilitec Company!

Theresa Gregorio-Torres
Newmobility.com

Make Masks Meaningful
I would like to see some masks that say something like “I’m doing my part” or “where’s yours?” or “mask=love” ("When It Comes to COVID-19, It’s Not You, It’s We," Blog, May 14). I’m sure someone could come up with something more creative, you get the point. This is no small thing to ask people to do, but I guess way too much for the president to do. He does not care about anyone else but himself.

Kathi Pugh
Newmobility.com

Think About Others
Even if people can go out and then choose to care only about themselves and not about the safety of others, I’ll stay home. But I urge people to care about others. Wear a mask, keep social distance and wash your hands well. You express this so well. We live in communities. Please.

Rose Pacatte
Newmobility.com

Confused & Confounded
I could not agree with you more! I do not understand why so many people are not taking the basic precautions that will help protect their friends, neighbors, family members, and society as a whole.

Ann Woodley
Newmobility.com
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<thead>
<tr>
<th>Model</th>
<th>Weight capacity</th>
<th>Base width</th>
<th>Seat width*</th>
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<tbody>
<tr>
<td>Alltrack M3 (HD)</td>
<td>300-450 lb</td>
<td>25.5&quot;</td>
<td>Up to 26&quot;</td>
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<tr>
<td>Alltrack R3 (HD)</td>
<td>300-400 lb</td>
<td>25.5&quot;</td>
<td>Up to 26&quot;</td>
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<td>Alltrack HD3</td>
<td>Up to 550 lb</td>
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<td>Up to 28&quot;</td>
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* Wider seat sizes are available as custom modifications.
**Best Places to Work**

The 2020 version of the Disability Equality Index is out, revealing the companies with the best practices when it comes to workplace inclusion and accessibility. According to the report, “the DEI continues to see an increase in year-over-year participation, with the number of top-scoring companies more than quadrupling to 205 in 2020 as compared to 43 in 2015.”

Companies were measured in a variety of categories that included culture and leadership, enterprise-wide access, community engagement and employment practices such as recruitment and retention.

Top-scoring corporations come from all industries — tech giants like Microsoft and Google, financial firms like U.S. Bank and Visa, retailers like Lowe's and Walmart, and blue-chip manufacturers like General Motors and Johnson & Johnson.

The DEI makes sure to note that a score of 100 doesn’t equal perfection. It “means that a company adheres to many of the numerous leading disability inclusion practices featured in the DEI, but there’s still room for improvement.” To read the full report, go to: disabilityinx.org/what-we-do/disability-equality-index/

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**This is Not a Wheelchair**

It’s no wonder the off-road adaptive device “The Rig” is seemingly everywhere on social media lately — Zack Nelson, the guy who built it, runs “Jerry Rig Everything,” a YouTube channel with 5.82 million subscribers. His wife, Cambry, has paraplegia and uses a wheelchair, and a couple of years ago he built her a homemade off-road device out of two electric bikes that he fused together and put a seat between. The pair immediately began working on ways to improve the design, and a few iterations later they launched The Rig (youtu.be/vuMg0QwKAGI). "Our whole goal was to design an affordable, capable off-road wheelchair and mass produce them," says Nelson.

The Rig runs mainly off bike parts, has a top speed of 12 mph and a range of 10-20 miles, though you can upgrade to a two-battery system that can take you up to 35 miles. With a full-suspension model going for $4,750, The Rig is significantly less expensive than many other adaptive off-road vehicles. There are some tradeoffs though. On the positive side, it does well enough in dirt, gravel and grass that it would be able to handle whatever most riders need it to. Also, it has space and mounting racks to carry your wheelchair and packs up small enough to fit in a short-bed pickup or even a Subaru Outback. As far as drawbacks, it only has two-wheel drive, struggles with traction in soft sand, and has a fairly high center of gravity. For full details, check out notawheelchair.com.
Why Won’t You Date Me? — ‘Dating With Disability’

Nicole Byer, host of the popular podcast Why Won’t You Date Me?, recently had comedian, wheelchair user and New Mobility cover woman Santina Muha on the show. The hour-long episode covers everything from problems with the ADA to the unique perils of online dating with a disability to including disability in broader diversity discussions. The conversation is fresh, funny and doesn’t hold anything back. Go to bit.ly/2ZABUSD or search for it on your podcast app of choice.

Move SMOOV-ly

When it comes to attachable power assist options for a manual wheelchair, the SmartDrive has a smooth new competitor — correct that, a SMOOV new competitor. The SMOOV one was designed by Alber, a German subsidiary of Invacare, and has been available in Europe for the past year. As of July, you can get it in the States.

The unit looks very similar to the SmartDrive and has similar specs, with a range of 12 miles, 6 mph max speed and a weight of 16 pounds. There are some key differences though. Whereas the SmartDrive is controlled by a Bluetooth connected bracelet, the SMOOV has a controller that mounts on your wheelchair. You tap it to start and stop, and twist a dial to increase or decrease the speed, and the SMOOV’s motor is smart enough that if you grab your pushrim to stop, the unit will automatically shut down propulsion. Similarly, “If I’m doing six miles an hour going straight, and I enter into a turn, it will automatically adjust my speed downward,” says Bill Russel of Alber USA.

With these advanced drive features and app-based customization, the SMOOV one is worth checking out if you’re looking to add some power assist to your arsenal. It retails for $6,895. For more info and their online shop, visit smoov.com/us-en.

Sitting Pretty

Rebekah Taussig — the force behind the popular Instagram account @sitting_pretty — is set to publish her first book, Sitting Pretty: The View from My Ordinary Resilient Disabled Body. She says it “grew from my tenderest memories and most pressing questions attached to living life from this disabled body. It’s a memoir in essay form — each chapter covering a different topic, from romance to work, ableism to feminism, representation to accessibility.” Release is on August 25 from Harper Collins, and you can go to her website for info on how to preorder: rebekahtaussig.com/portfolio/sitting-pretty.

My Wheelchair Guide

Searching for the right manual wheelchair and proper components is hard, but a new mobile application from United Spinal Association and the University of Pittsburgh aims to change that. My Wheelchair Guide includes tools and resources to help consumers navigate through the wheelchair selection, delivery and maintenance process. “There’s a lot of information out there, but much of it is geared towards clinicians,” says Dan Ding, a researcher who helped develop the app as a one-stop shop for quality information in an easy-to-digest format.

She hopes it helps users better advocate for their own needs when working with a seating clinic or DME supplier. The app is available for download from Google Play and Apple app store by searching “MWG Manual.”
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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- Ongoing Educational Webinars

**NEWS FROM UNITED SPINAL**

**CAPSTONE COOPERATION**

United Spinal Association is hosting two graduate students from Mary Baldwin University as they complete their capstone projects for the university’s doctoral program in occupational therapy. While United Spinal often works with occupational therapists in a variety of roles, these capstone placements are a new approach.

The 14-week-long projects are a critical part of the educational process leading to students’ clinical doctorates, and ask them to create something that will contribute to their fields of interest. Working hand-in-hand with a nonprofit allows students to gain a different perspective on their field, while also offering them an array of benefits and connections that might not otherwise be available to them.

“It has definitely impacted how I view everything,” says Brooke Cardwell, one of the two students paired with United Spinal. “I love working with a nonprofit, because obviously everyone’s heart is in the right place, and it’s very meaningful work.”

Cardwell is developing an online employment resource group and a video library for her capstone, and says having access to United Spinal staff and chapters has been invaluable. Sitting in on one chapter support group’s conversation about the value and role of OTs during their early weeks of rehabilitation proved particularly reaffirming.

“That conversation really impacted me because it showed me that being an OT is important, meaningful, and really is helping people,” she says.

Mary Burford, the other MBU student paired with United Spinal, is working with the organization’s Resource Center team to update its knowledge books and improve the way it analyzes and provides resources to United Spinal’s peer-mentoring program.

“We’re really lucky to be here,” she says. “It’s nice to be with an organization that really cares.”

Both Cardwell and Burford hope to continue their relationship with United Spinal after getting their degrees.

The partnership has been equally valuable for United Spinal, says Abby Ross, United Spinal’s chief operating officer.

“We’ve been thrilled to host Brooke and Mary for their capstone projects. We appreciate their insight and the valuable contributions their work will provide to our programs and members. We hope the experience has given them an intimate view into the SCI/D world that stays with them throughout their careers.”

Ross says United Spinal is currently speaking to several schools about future capstone placements and looks forward to expanding and improving these opportunities.

Brooke Cardwell (left) and Mary Burford are working with United Spinal Association as part of their doctoral degree programs in occupational therapy.
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As an earth scientist at NASA, Shannon Franks tackles some of our planet’s most difficult scientific questions. He brings that same approach to his personal life: confronting challenges head-on to find solutions.

Franks, 43, has always lived the most well-rounded life he can. But, the College Park, Maryland, resident’s idea of “well-rounded” might be a little different than most people’s.

After rehabbing his T2 SCI in 1996, he returned to school at Northland College in Northern Wisconsin, one mile from the shores of Lake Superior, despite the region’s harsh weather and lackluster accessibility. But before doing that, he drove across America for a month — alone.

“That was tough, but it gave me the confidence I needed to know I could still be the person I was before my injury,” says Franks. “I’ve never been the type of person who takes the easy way out.” He credits his confidence for his ability to achieve great things.

The New Jersey native still competes in many of the same sports he did before his injury. He is a competitive rower and wheelchair racer who also takes multi-day skiing, kayaking and handcycling trips. And when he’s not outdoors, he’s conducting remote sensing studies for NASA’s Landsat satellite program, which monitors Earth’s environmental changes. And if that’s not enough, he is a successful inventor with numerous adaptive products under his belt, including Wheelchair Buddies — a mechanism for attaching your wheelchair to a handcycle so it can be brought to places like work or a friend’s house, or on a cycling trip.

He’s also a person who can look at a problem and innately realize how to solve it. For example, Franks and his wife built a log cabin in the Appalachian Mountains that had a second floor Franks couldn’t get to. That is, until he applied some old rappelling knowledge.

“I created a pulley system where I could get to the second floor of my cabin using rock climbing equipment. My wife was like, ‘I knew that was going to bother you, and I knew you’d figure it out,’” says Franks. “And I did.”

When it comes to problem solving, Franks always zigs when everyone else zags. He knows of no other way to be.

“I’m a scientist. My job is to solve problems. The stuff that

**NASA SCIENTIST**

**Shannon Franks**

**Franks to the Fullest**

**FAVORITE ADAPTIVE TECHNOLOGY:** Something that lets me easily get on the beach. Beach chairs mean you can’t push yourself, and you must pre-arrange them. They’re kind of ridiculous.

**WHEELCHAIR OF CHOICE AND WHY:** I have a TiLite. I use it because I can beat it to hell and it doesn’t break.
Me being the person I am said, ‘You know what would be cool to do in Fiji? Maybe I’ll go to a small Island off the coast.’ I did this, and I have no idea why. It’s called Robinson Crusoe island and ... it’s all sand!

I don’t know what I was thinking. I got — well, I don’t want to say stuck — but I was on this island for two or three days. I couldn’t get around anywhere. I had to be carried around by these Fijian men who kept giving me these alcoholic drinks, and I slept in a hut. So, I get myself in these situations because I just live my life. It’s gotten me to a lot of places, and it’s gotten me a lot of funny stories too.

I do, there’s generally no set rules on how to do it. That’s what research is — learning how to do things that are not established,” says Franks. “In my daily life, I always have to figure things out. The pulley system wasn’t my first idea. I had to try a few different ways to figure out the best way to do it, but I’m not a quitter.”

The inspiration for Wheelchair Buddies is testament to that approach. Franks needed to figure out how to bring his wheelchair on his handcycle, so he invented a mechanism that allowed him to do that. With that setup, he handcycled through the mountains of both Big Sur and New Zealand. He quickly learned there was a demand for such a product. “I just thought I could teach people how to make it, and then I realized maybe not everybody is as mechanical as I am,” he says. “I grew up in a blue-collar family with a father who was a mechanic, so doing things with my hands is not necessarily a challenge. I just did it.”

WHERE’S THE MOST ACCESSIBLE VACATION SPOT YOU’VE BEEN:
I would say New Zealand. Not only is it accessible infrastructure-wise, but it is one of the most progressive countries, relating to thought.

WHY I JOINED UNITED SPINAL: I belong to many disability organizations, but most of them are athletic. Maybe United Spinal will get me in touch with people who have other like interests.
THE APEX CARBON FROM MOTION COMPOSITES

The original plan for this column was to review two wheelchairs — the Motion Composites Apex Carbon and another that shall remain nameless. Understandably, both companies had significant problems with production and delivery of the wheelchairs due to the pandemic. Despite the challenges, Motion Composites was committed to delivering the Apex, and did so as quickly as possible. The other company was unable to deliver its wheelchair. Therefore, this review will be limited to the Motion Composites Apex Carbon with comparisons being made to my two-year-old ultralight wheelchair made by another leading manufacturer.

I am a big fan of my current chair, and it works well for me. So to get the most accurate comparison possible, we copied the dimensions of my chair when ordering the Apex Carbon. We also used much of the same equipment including my Ride Designs Java cushion, Invacare Matrix Elite back, and Alber E-Motion M-15 power assist wheels. The only significant differences between the two wheelchairs were the frame and the casters. The Apex Carbon has a carbon fiber frame with 4-inch Frog Legs suspension forks and casters while my current chair has a titanium frame with 4-inch LiteSpeed casters with stock suspension forks.

After spending two weeks with the Apex Carbon, I can confidently recommend it to anyone looking for a new manual wheelchair. The Apex Carbon is a rigid-frame wheelchair made of T700 high-tensile strength carbon fiber. The carbon fiber is strong, lightweight and provides shock damping when going over rough terrain. By itself, the standard size 16 x 16 frame weighs in at a svelte 9.8 pounds. The Apex Carbon can be customized to meet the needs of most manual wheelchair users and is compatible with a variety of third-party add-ons.

In my opinion, the two most important things about a manual wheelchair are how quickly I can get around and how smooth the ride is. To test the speed, I took the Apex Carbon for my usual roll through my neighborhood. I am a C5-6 quad with no triceps or hand function to help push. By no means am I a fast pusher, but I can keep up with most walkers, and my dogs do not seem to mind the pace. The route through my neighborhood is about 1.2 miles, downhill on the way out and uphill on the way back. In my chair, I was able to do the trip in about 33 minutes. Two days later in the...
Apex Carbon, I did the same trip in just less than 30 minutes. The weather conditions were the same on both days, and I doubt that my strength improved by 10% over the course of 48 hours, so I think it is safe to attribute the faster time to the better performance of the Apex Carbon.

Even more notable than the increase in speed was the smoothness of the ride. The streets in my neighborhood are smooth and easy to roll on, but in my chair, I feel every little bump. In the Apex Carbon, the bumps are much less noticeable, and it feels like the chair is just gliding along. In my driveway, where there are much larger cracks and bumps, I could still feel the difference. Big bumps felt like small bumps, and they were much less jarring than usual. Typically, when I hit a larger bump or crack, I can feel the impact through my spine. In the Apex Carbon, I could still feel the impact, but it was much reduced. The brick pavers in my backyard that frequently trigger spasms did not do so in the Apex Carbon.

Oftentimes, the biggest obstacle when ordering a new wheelchair is getting insurance to cover it, and that is especially true of the Apex Carbon, which retails for $4,295. Medicare will not pay for the upgrade to carbon fiber. When dealing with Medicare, there is the option to do an unassigned claim. In this scenario, the dealer submits to Medicare to determine the likely coverage amount and the consumer pays the entire cost of the wheelchair upfront. Once Medicare approves the order, the consumer will receive a check reimbursing the cost of the wheelchair minus anything that is not covered.

Many private insurance companies will pay for the upgrade to carbon fiber if it is deemed to be medically necessary. It can be a frustrating process, but by working with the dealer, doctor, therapists, and insurance company, it is possible to get coverage. Some insurance companies will allow the consumer to pay the difference for the upgrade to carbon fiber. Of course, there is always the option to pay the entire cost out-of-pocket. There are companies like CareCredit that offer credit to pay for medical equipment over a period of time. Any time credit is involved, it is important to check the terms to ensure that the interest rates are fair.

The Apex Carbon is a great option for anybody looking for an ultralightweight wheelchair that offers great performance and a nice ride. The Apex Carbon can be adjusted to fit the needs of most wheelchair users, and many customization options are available. The most significant prohibiting factor is the cost and getting insurance to cover it. If funding and insurance coverage are an issue, the Apex Carbon may not be an appropriate option. However, if insurance is willing to cover the cost, the Apex Carbon is worth looking for your next wheelchair.
After being shut in at home for months during the COVID-19 pandemic, I found myself dreaming of taking tantalizing vacations to distant destinations. I want to get back to enjoying recreational travel, but as a wheelchair user with a medically at-risk family, it’s imperative to stay safe and healthy. Traveling internationally is too much of a gamble, but domestic road trips allow me to control my circumstances. As I pondered where to go, I realized that there is a way to simulate some of the joys and experiences of traveling abroad without leaving the lower 48.

During my travels to all 50 of the U.S. states and Puerto Rico, plus 24 different countries, I have noticed similarities between domestic and European destinations. For example, when I was in Bavaria, Germany, going from Rothenburg ob der Tauber to Munich, I kept thinking, wow, this looks just like southern Ohio. And it really did — green rolling hills covered with species of deciduous trees like oaks, maples, chestnuts and birch stretched as far as I could see, just like in Ohio. After thinking about it for a while, I realized I shouldn’t be surprised. Both areas are along similar latitudes, have similar weather, similar seasons and are in the foothills of large mountain ranges — the Appalachians in Ohio and the Alps in Bavaria.

In addition to Bavaria and southern Ohio, other prominent parallels between America and Europe are the Postojna Cave of Slovenia and Mammoth Cave National Park in Kentucky, the tulip fields of the Netherlands and Skagit Valley in Washington, and the Dingle Peninsula in Ireland and the Oregon coast. With these almost-doppelgangers, road trippers can save a lot of money, time and energy by visiting America’s European-ish counterparts, and in a more self-contained manner. One can get a taste of old-world charm without ever leaving the country. Plus, the American versions are often more wheelchair-friendly. These road trips are not the same as traveling abroad, but they’re a lot better than nothing, and right now that sounds divine.

**AMISH AUTHENTICITY**

Ohio Amish Country is a great place to start if you’re looking for a taste of German-Swiss architecture and culture. The Amish originated in what is present-day Switzerland and they brought aspects of their language and culture with them to the New World. Many German-speaking Amish settled in Holmes County, which is now home to one of the world’s largest Amish communities. They also live in neighboring Wayne and Tuscarawas Counties.

The region’s topography and flora remind me of my visits to Germany and Switzerland. German is commonly spoken in the stores, restaurants and streets, and the Swiss architectural influence is obvious in shops like Heini’s Cheese Chalet, and Sugarcreek’s Broad Run Cheesehouse and Swiss Heritage Winery. Sugarcreek has been dubbed “the Little Switzerland of Ohio” and is famous for its huge Ohio Swiss Festival each fall that draws thousands of visitors. Catering to tourists, the area restaurants have excellent and abundant home-style food.

My favorite wheelchair-friendly Amish restaurants are the Farmstead Restaurant in Berlin, Ohio, Der Dutchman in Walnut Creek and the Amish-Door in Wilmot. These are all nicely accessible with level entrances and wide aisles. Among the many shops that provide easy wheeling and great fun are Carlisle Gifts in Walnut Creek, Sol’s Craft Mall in Berlin and Lehman’s General Store in Kidron. Like some other nearby small towns, Berlin has upgraded its streetscape’s accessibility. The new,
wide sidewalks and curb cuts have made access even better. It’s still hilly, but that’s part of the beauty of southern Ohio — and Bavaria.

Elements of German-Swiss culture endure in the quality clock shops and cheese markets found throughout Ohio Amish Country. Sugarcreek shares a claim to the world’s largest cuckoo clock with the town of Schonach im Schwarzwald in Germany. At almost 24 feet tall, Sugarcreek’s clock stands at the city’s entrance in a small, wheelchair-friendly park. On the hour, a band emerges from within the clock and plays a happy tune while two dancers dressed in traditional style spin around. It is a must-see, along with the town’s famous cheese stores.

Over millions of years, both cave systems were carved from limestone by water, primarily the Green River in Kentucky and the Pivka River in Slovenia. This type of geologic activity where water dissolves and carves limestone is known as karst geology. Karst is distinguished by sink holes, swallow holes, underground caverns and solutional caves. This entire area of geologic study is named “karst” after the Karst Plateau in Slovenia where these unique features are extremely prominent. As limestone caves age, beautiful calcite formations can form, such as stalactites, stalagmites, curtains and columns. These formations are often coated with sparkling crystals.

On a 2.2-mile electric train journey, I saw a very old portion of the Postojna cave system. The age means incredible calcite structures are everywhere. They sparkle like glitter under the artfully placed lights distributed throughout the train route. There is no way of sitting in any wheelchair while on the train, so I transferred into my seat at the beginning of my trip, and the tour staff met me at the ride’s end with my manual wheelchair.

At Mammoth Cave, the newer part of the cave system is wheelchair-friendly via an elevator that takes visitors 300 feet below ground. I used my powerchair on this trip. We left the elevator and entered the Snowball Room, which is named that because of the white gypsum deposits all over the ceiling. Picnic tables, a cafeteria line and a kitchen are still in this room from the days when one could have lunch in the bowels of the earth. A wide, easy-to-wheel, dimly-lit half-mile-long path leads visitors from the Snowball Room into the cave. The gypsum deposits are the distinguishing feature here, as this portion of Mammoth Cave is too new for glittering calcite formations.

Both Postojna and Mammoth cave systems are home to bats and other unique critters that live in the dark, wet clime. Postojna is known for an olm, a white unpigmented amphibian, that lives in the cave. Mammoth Cave has eyeless albino fish, crayfish and crickets among its fauna.

Since Mammoth Cave is a national park, it also has wheelchair accessible trails above ground, like the half-mile Heritage Trail. This level trail begins just outside of Mammoth Cave Hotel and is either packed dirt or boardwalk. Meandering through a wooded area, it provides a view of the historic cave entrance and overlooks an old cemetery.

A two-hour drive from Mammoth
Cave takes you to the fabulous, world-class Kentucky Horse Park in Lexington, where many beautiful Derby and Breeders’ Cup race-winning thoroughbreds are retired. It is absolutely worth the drive. The paths are wide, smooth, mostly level and either paved or packed dirt. The barns — if they can be classified as that — are spotless, spacious and very wheelchair-friendly. What a delight it is to watch and pet these elite creatures!

Slovenia has its marvelous horses, too. Only 23 miles from Postojna is Lipica, Slovenia, where their magnificent Lipizzaner horse farm has bred horses for over 400 years. The wide, paved main path lined with chestnut trees is easy to wheel. The outdoor show arena is up a slight hill along a packed dirt road, but it is so worth it to see these gorgeous horses prancing and dancing in competitive shows.

Why caves and horses ended up together like this, I don’t know. But both Slovenia and Kentucky share these similarities that are thrilling to see.

FIELDS OF COLOR
After wandering through the packed gravel paths and firm grassy areas of the Roozengarde Display Garden in Mount Vernon, Washington, my sister and I found ourselves looking out over never-ending tulip fields. “This looks just like the Netherlands,” she said. “Except there are no windmills.” Really, there is at least one big windmill — it was right behind me in the middle of the garden. But not rows of them. Beyond that, though, there are definite similarities.

Tulips flourish in maritime climates that are cool — but not too cool — with pleasant, breezy summers and no freezing winters. They like soil with good drainage. Two places on earth that nicely fit these criteria are the Netherlands and Skagit Valley, Washington.

Every April, Skagit Valley becomes an array of colors when the tulips take over in time for the annual Skagit Valley Tulip Festival. As we drove through the tulip fields, we passed wave after wave of vibrant hues, all offset against the majestic North Cascade Mountains in the distance — a background that rivals the Netherlands’ rows of windmills.

“I was struck by how much the Irish scene reminded me of the central Oregon coast.”

I have been to the Netherlands, but not to their tulip fields. So I called Jeannette DeGoede, who until last year co-owned Tulip Town in Mount Vernon with her husband, Tom, a native of the Netherlands. As a tulip grower, she has been to the Dutch tulip fields dozens of times and has participated in the Skagit Valley Tulip Festival since it began in 1984. She confirmed that the two regions’ similar climates make for world class tulips, while also noting some differences.

“The focus in the Netherlands is more on growing and not tourism,” DeGoede points out. “In Skagit Valley, we try to do all we can to promote inclusive tourism. We have some truly great events during the Tulip Festival, too.” Tulip Town has a wheelchair-friendly indoor area full of flowers, a waterwheel and huge wall murals.

I attended the Kiwanis Salmon BBQ at Hillcrest Lodge in Mount Vernon and stopped by multiple shops. The popular Downtown Mount Vernon Street Fair, normally held each April, is nicely accessible, too. Cindy Verge, executive director of the Skagit Valley Tulip Festival, pointed out a number of events and venues that are wheelchair accessible, including Art in a Pickle Barn, Art Bash, Art in the Schoolhouse and Garage Sale and Antiques and More at the Fairgrounds. “But I would be careful about going into the agricultural fields with mobility aids,” she cautioned. I heeded her advice and stayed out of the mud, but I was awed by what I did see from gardens and roads edging the many blooming fields.

Although the Netherlands’ tulip growers may not focus on wheelchair accessibility, Keukenhof Park and Gardens are wheelchair-friendly. Flat, wide paths, wheelchair-friendly restrooms, a restaurant and exhibition hall all make this attraction available to wheelchair users. Because the Netherlands is a bit farther north, its tulips bloom throughout most of May.

SEA CLIFFS AND MARINE CRITTERS
The view from my tour bus atop the rocky cliffs of Ireland’s Dingle Peninsula was gorgeous. As I leaned toward the seaside window to catch a glimpse of Fungie, the local bottlenose dolphin that inhabits Dingle Bay, I looked at the sudden, rocky drop-off at the edge of the road. I was struck by how much
the scene reminded me of Newport, Oregon, and the central Oregon coast. Although Dingle is on the Atlantic Ocean and Oregon is on the Pacific, the average high and low seawater temperatures are within a few degrees Fahrenheit of each other. This lends itself to supporting the same types of sea creatures, like seals, dolphins, whales and seabirds. Add that to the rocky islands and crags that sea mammals and birds love to hang around and — voila — another twin.

The species vary a bit — grey and common seals in Dingle and northern fur and Pacific harbor seals in Newport — but the similarity is clearly there. On the inland side, Dingle offers beautiful, unusual green hedgerows extending across emerald, rolling fields. Hedgerows developed as natural fences and are unique here. Newport counters with lighthouses, a cobble beach, a wheelchair accessible intertidal beach and a wonderful historic bay front with barking, entertaining sea lions.

Of my favorite wheelchair-friendly places in Newport, I love Yaquina Head Outstanding Natural Area, which is owned by the Bureau of Land Management. Within this one park, there is much to see and do from my wheelchair. I sat above a cobble beach where wave action caused rounded cobbles to clatter against each other. I could spot harbor seals farther out on the nearby rocks. A woman next to me saw an elephant seal, but I wasn’t so lucky. Behind me, the Yaquina lighthouse stood on a tall bluff, and behind it rose wheelchair accessible whale watching platforms, from which I could see a myriad of sea birds like cormorants, murres and gulls — similar to the species that live in Dingle.

On the other side of Yaquina Head, one of the only wheelchair accessible intertidal zones in the world allows access all the way to the edge of the sea. There’s a great visitors center in the park, too. I met a man in its parking lot who was looking through a long, fancy telescope at a cliff. “I’m watching a peregrine falcon,” he told me. Then he lowered the scope to my level, and I saw it, too. The falcon, perched on a cliff, seemed to be looking right back at me.

Another Newport must-see is the Hatfield Marine Science Center. It is part of Oregon State University’s marine research program and is admission-free. It is nicely accessible and provides family fun and educational opportunities, including a wave machine, an octopus display and a marine “touching tank.”

Newport Historic Bayfront offers many wheelchair-friendly shops like Newport Candle Company and Wax Works gift shop. Restaurants include Mo’s Original restaurant and Rogue Ales’ Public House, and there are also wheelchair-friendly boat excursions around the bay with Marine Discovery Tours.

When it comes to seeing some marvelous sights, incredible nature and unique cultures, I really don’t have to go that far. I don’t even have to leave my own country — or my own state — for fabulous adventures. I can take my own vehicle on a road trip, control my circumstances and go as near or as far as I want.
BLACK LIVES MATTER

A ROUNDTABLE DISCUSSION WITH BLACK WHEELCHAIR USERS

FACILITATED BY ALEX JACKSON
The world came to a halt as we witnessed George Floyd struggling to breathe while a police officer knelt on his neck for nearly nine minutes until he died. Now African Americans are voicing their opinions on issues that have been overlooked for centuries, from the after-effects of slavery to police violence.

The protests that are transpiring today are similar to how people with disabilities fought for the passage of the Americans with Disabilities Act of 1990. It took a rallying of people with and without disabilities who performed public demonstrations, like crawling up the U.S. Capitol building steps, to prove the need for accessibility. After such relentless advocacy, lawmakers eventually realized more had to be accomplished to better accommodate people with disabilities.

Similarly, my hope is that our country is finally realizing that police brutality is a systemic problem for African-Americans.

I interviewed Black people with SCI to get their perspective on Black Lives Matter and its intersection with disability.

— Alex Jackson
**BLACK LIVES MATTER**

**ROUND TABLE PARTICIPANTS**

**ALEX JACKSON, PUBLIC RELATIONS PROFESSIONAL:** For this article, we’re asking African Americans with spinal cord injuries to share their perspectives on Black Lives Matter, police brutality and how we can bring together all of our communities into one better society. Now to let you know a little bit about myself, I was injured at about 9 months old in a motor vehicle car accident and I have a C5-6 spinal cord injury. Even with the injury, I’m able to use my right arm and hand to pretty much do everything. Can you tell me a little bit about your injury?

**NAMEL NORRIS, RAPPER AND EDUCATOR:** I’m a T2 para from a gunshot wound. When I was 17, my cousin was playing with a gun and that left me paralyzed from my chest down pretty much. I’ve been paralyzed for more than 20 years, and I’m from New York, New York.

**STEWART TUCKER LUNDY, MEDIA PRODUCER AND CONSULTANT:** I got hurt in a diving accident in — this will make you feel like a baby — in 1982, when I was 14 years old. And it’s C4-5 incomplete quadriplegia. I live in Denver.

**SHANNON MINNICK, INDEPENDENT LIVING SERVICES DIRECTOR:** I was in a car accident. I was with two friends and one of my friends fell asleep. We swerved and hit a tree, and I was in the back seat of the car with no seat belt on. I’m a quadriplegic, C6-7, for 30 years now. I’m in the Silver Spring, Maryland area.

**WES HAMILTON, SPEAKER AND NONPROFIT FOUNDER:** I have a T11-12 incomplete spinal cord injury from multiple gunshot wounds to my abdomen back in 2012. I grew up as a nondisabled Black man in Kansas City, Missouri. The lifestyle that I chose was one that, I believe now, was designed for a Black man in poverty, living in the streets, really not even expecting to make it past 21, and I was 24 at the time I was shot. At that moment, I knew I was going to die and I didn’t have many regrets like, “I wish I would have lived to 80.” My regrets were more personal, about my daughter or something like that. But being shot wasn’t something that I didn’t expect.

**Editor’s Note:** These interviews were conducted and recorded individually by Alex Jackson, who asked all interviewees the same questions. They were combined after the fact to create the “conversation” you see here.

**ALEX JACKSON:** What are your thoughts on the Black Lives Matter movement as a whole and the response to George Floyd’s death?

**NORRIS:** What happened this year has been a perfect storm. The main thing was George Floyd’s death. That video gave people something to use to identify a lot of what’s been happening, as far as the policy brutality and the injustice, the racism. Then it was other things that happened with Ahmaud Arbery, Breonna Taylor, the Karen stuff. [Karen is a term applied to white women who use the police to harass innocent Black people.]

You got all this going on during this pandemic and quarantine. I think collectively what happened this year is that with people not working and being able to do things, recreational things, they have to stop and actually look and not be distracted. What happened to Floyd was so horrible that it made people finally want to listen because they didn’t really have a choice this time.

**MINNICK:** It’s terrifying. Change is going to come, but for a police officer to feel that it’s OK to put his knee on someone’s neck when they’re telling him that they cannot breathe and when they’re calling for their mother … for someone to feel that this is OK is hurtful. It angers me. And to have other officers there and witnessing this and no one helping? Now I understand that one officer tried to step in and say, “Hey, take your knee off of his neck, he can’t breathe,” but you have to do more than that. Right is right, and wrong is wrong.

**LUNDY:** I read a quote from Will Smith, “Racism’s not getting worse; it’s getting filmed.” And I just see the arrogance when people say there is not any racism in the police force. Well, we’ve been talking about this for a long time.

In regards to the deaths, George Floyd’s hit home. I mean, Alex, you’re a Black man. You know what it takes, pride-wise, to make a Black man yell in desperation for his mother. That almost brought me to tears.

When he said, “Mama, mama.” Oh man, I just want to tear up right now because I know those times when I’ve yelled for my mom, I wasn’t in a good place. So my heart went out to him, because I’m like, “Man, this brother about to die and he’s calling out for his mother.”

**JACKSON:** That really struck a nerve for a lot of people. You realize that it could happen to you.

**LUNDY:** I’m glad for the younger generation — the rainbow generation as far as you got mixed kids, white kids, Asian kids, you got everybody into it. And I think that’s ultimately what we need, because we’ve been fighting this battle for a long time by ourselves or with few allies here and there. But they’re coming out in full force now. And I’m so proud of them for being our civil rights activists.
MINNICK: I haven’t done any protests, but I’m the director of Independent Living Services at the CIL in my area, Independence Now. I’ve been talking to my director and saying that we have to do something. At first, I said, “Let’s have a protest outside the office,” but with the pandemic it’s not safe.

Instead, I had a group of 15 youth with disabilities, and we had a conversation about everything that’s going on. It allowed them to talk about their feelings and their fears. That was pretty amazing because they’re male, female, brown and Caucasian. We had a speaker come in to help us explain what’s going on and how they could have their voices heard safely. And they’re actually holding a live protest on Zoom later this month.

JACKSON: Have you experienced police brutality or racism, either before or after your accident?

MINNICK: I’ve been in a car and the police pulled us over and asked me to get out. I told him, “Officer, I can’t get out. I’m quadriplegic, and my chair is not in the car.” Thankfully they understood but if they hadn’t, how do you deal with that?

LUNDY: I was with a friend of mine, we were in Washington, D.C., getting ready to go into Georgetown, and we got pulled over. This was after my accident.

My friend used to pick me up, put me in his car and we’d go ride around. I remember thinking to myself, “If I have a spasm or make a wrong move or something, this joker is going to shoot me in the back of my damn head.” And I got a lot of different things going through my body right now. I was like, I’m scared, I want to shit my pants, literally. I’m telling my friend Jerald, “Let them know I’m in a wheelchair, man. Let them know I’m in a wheelchair.” Because I could see the cop in the mirror, where I was sitting at, coming up along the side of the passenger side, and he had his hand on his gun. It wasn’t drawn yet, but I was like, “Oh my God, what are we getting into?”

And I’m thinking to myself, “This is not going to be good.” I mean, I’m laughing about it now, but I was scared to death.

HAMILTON: I’ve always felt like I’ve experienced racism. I lived in a radius of zip codes that were defined here in Kansas City as high crime areas. And growing up as a kid, we were always harassed by police because they thought we could be criminals.

The history of Kansas City is that [developer] J.C. Nichols created a dividing line that eventually the rest of the country implemented. The model was, “Here’s one block that separates the whites from the Blacks,” and the blocks on the west side of town have it written in their deeds that you cannot sell a home to a person of color. On the east side are all the houses of poverty. So, our city has a huge racial divide.

JACKSON: Do you think there are any differences in discrimination, based on race and disability?

HAMILTON: I think about the resources that I was never given as an African American becoming disabled. Nobody ever even told me I could drive, bro. I didn’t know I could drive until, like, three years later. And so, I started searching

I THINK ABOUT THE RESOURCES THAT I WAS NEVER GIVEN AS AN AFRICAN AMERICAN BECOMING DISABLED. NOBODY EVER EVEN TOLD ME I COULD DRIVE. I DIDN’T KNOW I COULD DRIVE UNTIL, LIKE, THREE YEARS LATER.
and I found some hand controls. Then, I found out that there was a place here that actually did driving classes.

Most of the people that don’t look like me were able to have access to Craig Hospital or some other nice spinal cord injury hospital outside of Kansas City that, when they came back, gave them a little bit more mobility. I meet someone that’s not of color and I ask, “Hey, have you driven?” And they say, “Oh, yeah. We’re just waiting to get our van now.” And I’m like, are you serious? I’ve had people pull up in trucks and stuff and they get their houses remodeled! You see that?

And when I asked all the Black people in our community, have they heard of driving? No. But now that I have my nonprofit, I have people that tell me, “We learned driving while doing rehab.”

It plays a part in everything I do.

LUNDY: When somebody gets injured at a young age, they’re the flavor of the month. And then it kind of dies off after a while, because it’s like, “OK, we helped said person, blah, blah, blah, blah.” And it’s almost like a charity case. But I’ve noticed with a white woman or white kids, they’re just America’s little sweet-hearts. I don’t feel like we get that kind of love, as African Americans, sometimes. And then funding-wise, a lot of stuff that we need is very expensive, and sometimes agencies don’t pay for things, or it’s set up so you can only make so much money. And then when you get out of that, you pay an arm and a leg to pay for it out of pocket. So it’s like dang, come on, this system is set up to not let you get far. And then on top of that, you’re Black, so you’re really not going to get far.

MINNICK: Have you heard of Michael Hickson? He is the 46-year-old Black man who died in Texas. He was a quadriplegic and he was refused healthcare because the doctor said that he had no quality of life. And so he died six days later of starvation. They didn’t feed him. [For more information about Hickson, see tinyurl.com/y2dzjxws.]

I called my director and asked, “Oh my God, have you heard the story?” She said, “Yes.” We talked about it and I said to her, “If I get COVID-19 and go to the hospital are they not going to treat me because I have a disability and they were not going to be able to improve my quality of life?

JACKSON: That’s so inhumane.

MINNICK: I was looking at Red Table Talk with Will and Jada Pinckett Smith, and I came across the recorded conversation of Mr. Hickson’s wife talking to the doctor. It’s one thing when you read a story and think, “Oh my God, this is crazy,” but to actually hear it and see it, that changes how you feel about things.

JACKSON: It’s really sad to hear things like that but it’s good that people are realizing what’s happening.
**JACKSON:** What can the disability community do to help end racism?

**HAMILTON:** Most people have been around someone with a disability of a different race, whether at an Abilities Expo or some seminar. I highly encourage people with disabilities to use their voice and their platform to support those of a different race who are part of their community in whatever they are doing.

Also, say there’s a sports day or ability camp, and it’s in a location that maybe you don’t go to because it’s too far or it might be in a community like mine. Go. Meet some different people. Find a way to network. And start listening to dialogue. It’s hard for me to tell anybody to take more action without understanding first.

**LUNDY:** I think the visibility part is important. It is putting Black folks, and especially Black men, in elevated areas, where we’re more visible, and somebody is able to relate to us. Because sometimes I’ll see pictures of a group of disabled folk, and it’ll be one or two Black folks. It won’t be a lot, but just maybe one or two. And then all of the rest of them will be white.

**MINNICK:** I think that we have to also be open. We have to find a common ground and get together and have these discussions. It doesn’t have to be a bunch of us walking down the street protesting. Some people are doing Black Lives Matter events via Zoom.

**NORRIS:** I get confused with the fight because on one hand, it’s disability. On the other hand, it’s being Black. Those two things go hand-in-hand so much because both sides don’t get the respect.

From the disability side, I feel like the disability community doesn’t get a lot of support and respect from the mainstream media. Then, coming from the Black side, now people don’t even want to acknowledge racism and speak about it.

But look at the landscape and how things trickle down. Then you see who the money goes to, and how programs are implemented. It’s not directly in the hands of Black people. If you’re Black and disabled, you’re getting double the short end of the stick. That hasn’t changed.

**JACKSON:** How can the disability community and society as a whole change the viewpoint that law enforcement has on African Americans?

**MINNICK:** I knew this question would come up. Folks need to be educated on systematic racism. We African Americans are oppressed, and violence accompanies that. If I feel like somebody’s knee is on my neck, I’m going to be angry, and I’m going to want to fight because I’m struggling to live. Police officers, and people, period, need to be educated on that. Not just have to sit down in a classroom and watch videos and hear stories, but they have to understand it, actually feel it.

Sometimes when you learn, it has to come from the heart. And you have to teach people compassion because if they don’t care about life, then they just don’t care about life. And sometimes with these police officers, I think they’ve been doing this for so long that they need to be let go. You’re not going to be able to change their perspective or what they think.

If this is an officer that’s had three strikes, he has to go. If I get three strikes as the African American, I’m going down. So why is the system different for a police officer? Just think about it.

If you look at child molesters, how much time do they usually get? A year? Two years? But if you have marijuana, they trying to get you 10 years. Why? People have to be treated equally across the board.

We have to educate people on history, and once they get educated they will sometimes — not all the time, but sometimes — learn. We’re human, we’re people. It’s hard for me to think that someone can think of me as an animal because of...
the color of my skin. But you know what? Everything comes out in the light. So there’s a lot of people in our lives, even some of our white friends, whose eyes are being opened today. And if not for this whole incident, we would all still be in that same place of thinking that everything is OK when it’s not. So this had to happen. I’m sorry that it happened, but it has awakened people. And enough is enough. We’re tired.

JACKSON: Definitely. Yeah, hopefully, this will be a wake-up call.

MINNICK: I think it is a wake-up call. I pray all the time that it is. People are waking up. We’re seeing it every day because they’re out on the street every day marching.

NORRIS: Well, I don’t think we have to do anything — they have to do it. That’s why I like that Martin Luther King Jr.’s quote, “It may be true that the law cannot make a man love me, but it can keep him from lynching me, and I think that is pretty important, also.” I feel like that’s the key: Having things in place to keep people in order. Then over time, just working through the process of communication and coexisting with each other will help. I don’t think everybody has to feel the same, but everybody has to be respectful.

LUNDY: I think white police officers have a fear that goes back to slave days, like, “Oh, he’s going to come get me, I’ve got to draw first,” that kind of thing. And training is essential, as far as how you approach someone.

I was telling my wife this the other day that I think, when you come out of the police academy, if you arrest somebody, you should know the person you arrest. Like, “Man your aunt, such and such, you know good and well, she wouldn’t want you out here. But I’ve got to take you to jail.”

The police officer would have a better understanding, instead of going on a stereotype that he has in his head. Or the monster that lives in his head. So I think the training would help a lot.

They’ve got a lot on their shoulders. They have to be social workers, they have to be relationship experts, things like that. And I know when I’ve got a lot of stuff on my mind that I’m not going to do too well, so I can only imagine what a police officer feels when he has to go out and deal with someone in the public acting all crazy or whatever. They’re just not trained for it. And some of those guys are really young, they don’t know nothing.

HAMILTON: We’ve got to test the police’s outlook on Black people, especially if they’re a person who’s not of color. Right? Black cops need training, too, because sometimes there’s a code that everyone lives by. So, they fall into that trap.

Everything has to happen at the grassroots. White people, you’ve got to go to Thanksgiving dinner and have that conversation. You know what I mean? You’ve got to see Grandma’s views. Grandma might not even share her views with you, but she instilled them in your mom.

I have an 88-year-old grandma who still stays in the hood. She’s got 80-something grandkids. The majority of her kids got killed. Most of the males have been in jail. Eighty-something grandkids and great-grandkids, and I’m the only one that makes her happy every day. I’m the only one showing her something different. But she stays in the house. She hasn’t left that house in 50 years, unless we do events.

I asked her, “Why you don’t leave?” “It’s safe in here,” she said.

I have to let my grandma know that it’s safe now. Right? If we want to make it safe, then somebody else has to let their grandma know that we’re in it together now.
Having lived at the intersection of being a Black disabled woman for close to 11 years now, I regularly experience various injustices. Since I am part of both of these marginalized groups, sometimes I don’t know if the injustice is due to my Blackness or my disability.

I live in fear of being physically harmed or verbally abused. Once when I was in the parking lot of Whole Foods in Providence, Rhode Island, a white man verbally assaulted me for parking in between two spaces. When I told him there were no more accessible spots and I needed room for my wheelchair, he said that I shouldn’t be out if I have to park like that! This is a perfect example of “ableism.” Who knows if his issue really was just my parking job, or the fact that I was Black and disabled and a woman, but it made me both infuriated and sad. I had every right to be at that store to collect my groceries, just as he did.

Three years ago, I was at a restaurant in Chicago, Illinois, that would not seat our group of 10 Black people, claiming they didn’t accept “large groups” and that they were near closing time. It left me wondering if they did not seat us because we were Black or because we had two wheelchair users in our group. When I looked around the restaurant, I knew we were being discriminated against, as there was a large group already seated. It was quite appalling to experience and was maddening that we had to find somewhere else to eat when we wanted to eat there! Ironically, recently an article came out in one of the Chicago papers about stories of racism from patrons and employees of this restaurant. There was my proof that this restaurant turned us away due to our Blackness.

As I reflect on this country’s Constitution and how it only accounted for those who looked like our founding fathers, I realize that every other group of people that are not white males were not considered. Think about the number of acts and amendments that have thankfully been passed to include women, and Black people, and persons with disabilities. The Civil Rights Act of 1964 ended segregation in public places and banned employment discrimination on the basis of race, color, religion, sex or national origin, but didn’t cover disability.

It’s truly shocking to me that even 30 years after the passage of the Americans with Disabilities Act in 1990, I still experience inaccessible public spaces. How can a restaurant have an accessible parking spot and ramp into the restaurant but not have an accessible bathroom? How can a restaurant claim to be accessible but have one step outside, or its only no-step entrance be in the back alley amongst the trash?

Just as with the Black Lives Matter movement that is fighting for racial equality and justice, the fight for equal access and justice for all people with disabilities is also a tiring but necessary fight. Whether Black or disabled, we are all human beings and deserve the right to live in a world free of iniquities amongst our white brethren.
HINT: IT’S NOT THE FLU

My first experience with being Black with a SCI/D came with trying to be diagnosed. I was about 16 or 17 years old when I bruised my spinal cord at C5-6 and T7-8 in a sports accident and lost partial control of my legs. When I complained about a burning sensation across my torso and around my upper abdomen, I was ignored. Spinal taps showing elevated antibody count and EMGs showing weakened responses were disregarded.

I became sick with flu-like symptoms on my 18th birthday with Malice at the Palace as the last thing I could remember before passing out. The next morning, I could not move anything below my first row of abs, and it all became completely numb. I went to more neurologists with the expectation that they would treat the problem but wound up being considered crazy when their hypothesis didn’t pan out as to the cause of my issues.

I had to go see a psychiatrist for proof that I was not making up my symptoms and came out with a diagnosis of moderate depression. A new set of physicians had the willingness to review my medical history and actually research possible causes. It’s rather amazing that it took years to receive the official diagnosis of trauma-induced transverse myelitis.

BENCHED WHILE BLACK

I initially went to the University of Missouri where I studied civil engineering and played on the wheelchair basketball team. During my third year, the coach kept changing the offense every week. When I explained to him that the ever-changing plans were leading toward stagnation on the floor, he got upset, questioned my intelligence and benched me. When another teammate proceeded to do the same, he was rewarded with a co-captaincy. Yet when the team was in a deep deficit due to full court presses, I was immediately dragged off the bench to help salvage games and keep them somewhat competitive. At the end of that semester, I fell into a depressive episode, left the team and flunked out of school.

Eventually I rebounded and transferred to the University of Illinois to pursue a degree in agricultural and biological engineering due to its renewable energy systems specialization. While there I joined the wheelchair racing team, initially as a way to stay in shape, but I ended up turning into a Team USA athlete. But being on the U of I team allowed me to realize I was dealing with individuals who, despite their disabilities, displayed some of the greatest examples of white privilege. It is a sport where you need to have money coming in to be successful, and so many come from upper-middle class families whose parents helped pay for the equipment and other fees necessary to compete.

JOB HUNTING WHILE BLACK

The worst of what I’ve experienced in terms of being Black is employment. The thing about being an engineering student while Black is that in all of your classes you’re either the only one or one of very few, and that still does not prepare you for your outlook in terms of trying to get an internship or full-time position as a Black engineer. I stayed in athletics strictly because I had a hard time obtaining an internship before and after graduating with my bachelor’s degree.

It took me participating in the Rio Paralympic Games, at least two years after graduation, to receive an offer for an internship. In most cases, hiring managers and talent acquisition personnel hire not by what a candidate knows but whom they know, unless you bring something extraordinary to the table. This is usually reinforced by the makeup and experiences of those individuals. Most companies, including those that boasted “Black Lives Matter” after George Floyd, will hesitate to hire anyone that does not look like themselves. I’m thankful for the opportunities I have received, but if I have to rely on hiring managers who are actually looking for talent and potential and not just a cultural fit, my options are far slimmer than others'.
JASON HURST
Self-employed/Mortgage Broker
45, New Orleans
C5-6 Quadriplegia

I AM NOT A LAB RAT

Sometimes, I’ve felt like a lab rat, literally! The first thing that many in the medical field see is a Black man who has been shot. Immediately, they have formed an opinion that he must be a drug dealer or gang member. On more than a few occasions, I have had to qualify my situation. I was home from college, visiting friends. My being injured in a drive-by shooting was strictly an accident. I was in a house, minding my own business, when gunfire erupted nearby.

Several studies over recent years have confirmed the persistent bias among medical students, and in some cases their seniors, regarding the differences in Black physiology versus white, particularly in regards to pain tolerance. And I experienced this personally from one particular nurse during my last stint in the hospital. It is an idea that harkens back to people like Thomas Jefferson and his “Notes on the State of Virginia,” as well as Dr. Thomas Hamilton, who performed horrific experiments on Black slaves in an attempt to prove how much more tolerant they are of pain and that Blacks have thicker skin than their white counterparts.

While in the hospital, I suffered from open wounds and a bone infection. I was experiencing extremely rough bouts of autonomic dysreflexia and severe headaches as a result. I was in excruciating pain and was given morphine by my doctor. However, one particular nurse refused to give me the prescribed morphine, but instead gave me Motrin whenever I requested my pain medicine. She asked me why I needed it, even though morphine was the medication prescribed by my doctor. This same nurse would subsequently bombard me daily with her anti-Obama comments while he was running for office. And she would force me into racist litmus tests by asking how I felt about Louis Farrakhan.

LET EACH MOVEMENT BE ITS OWN

The disabled community is a sleeping giant for sure. Most people spend about seven years of their life disabled — whether due to old age or some other disability. But the Black experience in America is unique to Black people and unlike anybody else’s experience. I cringe even when I hear it compared to the Native American experience because as bad as their experience was, we were a part of that too. Many people don’t know that Native Americans kept us as slaves, also. Historically, when we have attached other struggles/movements to that of Black people, it served to delegitimize the Black experience. For that reason, I tackle the two separately.

KRS MCeluoy
Artist and Advocate
35, Eldersburg, Maryland
Multiple Disabilities

BLACK LIVES MATTER: MY EXPERIENCE

As the noise grows in the midst of historic national conversations about race, discrimination and police brutality, I am reminded of my own history and trauma around these conversations and my struggle to find space and inclusion within them:

• A history that showed me as a Black child I would be called “crippled n-word” and “retarded n-word.” Teachers continually kept me after or sent me out of class because my tics, tremors and coping mechanisms were seen as “disruptions” when I was being mocked and bullied and hurt because I didn’t know how to fight back.

• A history that showed me as a teen and young adult that I was seen as a “suspicious” person sitting on a curb. Some-
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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July 26th, 2020 marked 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.

STEFAN HENRY
Businessman and Inventor
31, New York, New York
C5-6 Quadriplegia

FIGHTING TO RISE ABOVE THE SYSTEM
To be honest, I’m lucky. I was one of the few people able to experience lifestyles outside of my own. I had friends like George Gallego, Manny De La Cruz and Alex Elegudin who swooped in and

one would call, and the police would come and question me about who I was, what I was doing and was I drinking or on drugs because of how my speech was slurred and stuttering.

- A history that showed the police interrogating me during the SAFE Exam following a rape. It felt more like I was the perpetrator as they asked me “how my disability impacted my ability to fight back” followed by having me “demonstrate by acting out what happened.”

Engaging in conversations about Black Lives Matter/All Black Lives Matter continuously shows me, as a Black man with disabilities, that basic barriers still exist. These barriers exclude my full participation in events, opportunities and conversations because accommodations cannot be provided, or the location is not wheelchair accessible. And if it is wheelchair accessible, I find myself navigating conversations and challenging stereotyped reactions by people calling me an inspiration, a hero and more before I even have a chance to introduce myself. I have to fight to have my voice heard.

These conversations are mixed in with memories of all those other times I got stuck manoeuvring between furniture while people watched but didn’t offer to help or when I fell and had to crawl to something I could use to pull myself up from the ground as crowds walked by me and no one asked if I was OK.

These experiences made me feel so small. And without the strategies and tools to navigate them, they had a grave impact on my mental health — mental health already impacted by previous trauma.

I know I need to share my experience. I need to protest. I need to continue to call and fight for change. I need to express my value, and I need to express that All Black Lives Matter, period. We need to work to create a society that shows this in action at every level.
chose to mentor me in the ways of living my life as someone with a disability and as a man who essentially can only be dependent on myself.

The truth of the matter is, most Black people don’t.

We don’t often have people coming into our neighborhoods and choosing to guide us through the ins and outs of life. Even when you search for a higher level of education, private school is normally too expensive to afford, and public schools only teach enough to get you through tests. They don’t teach you about personal finance or wealth creation. They teach you how to work a job.

Assuming you get through the school system, as a Black person you probably won’t get a job in your field because someone with a whiter name is a “better fit” for the company. You can try to build a business, but the banks will refuse to give you loans outside of predatory ones that make you pay twice as much as the loan costs with a higher interest rate because you are inexplicable a “high financial risk.” You go through this just to get home where cops are parked on your block waiting to give out tickets for petty offenses like being in the park after 10 p.m., jaywalking and “acts of aggression” such as asking questions. You are repeatedly getting ticketed to the point where you are too broke to pay your rent. However, you suck it up because the alternative to accepting the ticket is essentially death by the hands of the police, either in or outside of your house.

That’s what Black Lives Matter fights against. We fight against systemic racism. Right now, we fight to stop police brutality. Whether through abolishing the police (which I’m only for if another form of law enforcement is presented just as quickly as the police are gone) or defunding the police (which is a reallocation of funds to social services that can handle nonviolent issues in the community), we need to support Black Lives Matter. Everyone needs to remember that when we set a standard, then we can build off of it.

The Americans with Disabilities Act was able to be created because Title VII existed from the Civil Rights Act in 1964. Let’s all remember that helping each other helps everyone.
After the George Floyd killing, I was talking about the Black Lives Matter protests with three of my coworkers. One guy was asking, "Why aren't African American people with disabilities out in the march? We know that police brutality happens to people with disabilities, whether it's physical, mental health or whatever."

The four of us — a biracial coworker, two Caucasian coworkers and myself — we all got together, and within three days we were able to mobilize and organize a protest in Milwaukee. We mapped out the march where there were flat surfaces, so you wouldn’t have to worry about going up hills. We were able to get interpreters and medical people to come, and we had enough people that if anyone needed assistance, they could get it. There were volunteers set up to give marchers water, fruit and other foods.

We got together at the lake front, and our march was all together probably three to four hundred people. We notified the organizers of the original BLM marches about what we were doing, and that we weren’t doing this in separation of what they were doing, but to raise awareness for people with disabilities also in the community. They joined our march. You had all the people with disabilities up front, along with interpreters, and we dictated the pace that everyone went. The other organizers and marchers were all open to changing how they did things.

We were marching by a police station, and the police department decided to try to cut us off, detour people from marching and set barricades. By doing that, they literally made it inaccessible for people with disabilities to do what the Constitution and the ADA are set up for us to do.

With some of the recent protests, a lot of people were complaining about looting and rioting, but all of this is our government's fault. The only times there's protest is when there's injustice being done. So if our government was doing its job, none of this would be necessary, and none of this would be an issue.

**DRIVING WHILE BLACK**

I've seen it with the police. I'm a C6 quad and I use gloves, the same ones I wear to push my chair, while I'm driving. I've been pulled over three times, once in Chicago and twice...
MY FIRST PROTEST

BY EVITA RUSH

For many years, we as Black people have let so many injustices slide. I’ve lost count of how many times I’ve scrolled through my social media feed and read about some horrific killing of an innocent and/or unarmed Black person. I get angry, but I’ve always just kind of looked at my phone, shaking my head. I say “that’s a shame,” and then just go on about my business. I never would really say anything. As a Black person, particularly a Black woman, it’s kind of hard to voice your opinions on stuff like this because you don’t want to come off as the angry Black woman.

Me being a Black person living in the predominantly white city and state of Portland, Oregon, I just thought I should be there. This is my first protest. I’ve never really been to one because typically when I think of a protest, I automatically assume that it’s not feasible for me to take part in it because of a lack of accessibility in the logistics of it. Is the terrain going to be good for me in my manual wheelchair? What will parking be like? Will I have to push up hills and gravel?

I was fortunate to have a couple of friends and a support system lending a hand to make sure I could participate, but it wasn’t really easy for me. I pushed for probably close to five miles that day, and I didn’t ask for help until the very end when I was coming up on a hill and my shoulders were pretty much done. It was important for me to just push it all the way through as much as possible.

The route wasn’t too bad, but I did come on a situation crossing a bridge with metal grating on it. A lady almost tumbled over me because I had to turn around and go the opposite way to get up on a curb that was about 8 inches off of the ground, and I needed help to get up on it.

When I was marching, I remember thinking that to me as a Black person, being surrounded by people of all races, mostly white, holding Black Lives Matter signs, protesting for humanity, equality … just, that meant a lot to me. It would be good to be more involved in things like this, but I don’t think organizers are really thinking about people with disabilities. This protest is for equality, but I do wonder if they’re really thinking of everyone. I hope people who orchestrate these things think about everyone who wants to participate. Think about the route that they’re doing. Reach out to other people who may have a disability and get their input on how to make this inclusive for everyone — people with physical disabilities, blindness, sensory issues — to join in.

If you’re marching for equality, include everyone. I may not stand, but I wanted, and deserved, to be there for the cause like everyone else.

Harvey X. Ross, a manual wheelchair user and C7 quad, does outreach to underserved communities for Independence First, a CIL in Milwaukee, where he is employed as an independent living specialist.

Here because I had on gloves. In Chicago, my sister and I were all coming back from a Cubs game. We had just dropped off my mother and other sister, and the police stopped us. An officer came around with his gun drawn and asked why I had gloves on. That situation could’ve easily turned bad, so we had to explain about my disability.

Then here in Milwaukee, I was in my parking lot, getting ready to get out of my modified van. I dropped something to the floor and was bent over, picking it up. I had my gloves on and was using one hand to brace myself on the steering wheel. And the next thing, I look up, and there were flashlights and guns in my face, and they were like, “Wait a minute, are you stealing?”

I was like, “Stealing a car? No, this is my car. You see the wheelchair and the ramp?” The situation didn’t turn into anything because I didn’t get all belligerent, but you never know what could happen. This is just insanity. We were going through this stuff in the ’60s. We’re in 2020, and we’re going through the same thing.

I hope our accessible march helped join people with disabilities together with the other organizers and protesters and taught them something. We plan on doing more events — painting murals, hosting rallies, things like that. As things continue to go on and other situations come up, I hope that our voices will be included in those events without us having to bring attention to it ourselves. You would think that would be the same thing with race relations, but it’s clearly not. In the world, regardless of color of skin, people with disabilities are forgotten about. You have to make yourself prominent.
The brutal public murder of George Floyd was a touchstone for all of us, all around the world. With George Floyd’s tragic passing on Memorial Day, time stood still as our collective emotions reached a tipping point and people burning with the rage and pain of injustice had finally had enough. In recent years, a parade of appalling killings of unarmed Black men — Trayvon Martin, Tamir Rice, Michael Brown, Eric Garner, Philando Castille, Ahmaud Arbery, Botham Jean, Freddie Gray and many others — sparked numerous protests, social media debates and cries for justice that were largely unheeded by American society as a whole. But something about the casual hatred of Minneapolis police officer Derrick Chauvin as he choked the life out of George Floyd by kneeling on his neck for 8 minutes and 46 seconds provoked a visceral reaction that could not be stomached by most Americans.

NOTHING ABOUT WHO I AM MATTERED

One day nearly 17 years ago, my inner sense of myself and my life was tested unexpectedly, as I was driving through Five Points, the African American inner-city community in my hometown of Denver, Colorado. I wanted to visit a friend of mine, James Chapman, who lived near the heart of Five Points and also happens to be a paraplegic. I drove a two-door Dodge Avenger and had to go through a tedious process of taking my wheelchair apart, putting the wheels in the back of my car, taking the seat cushion out and folding the frame and pulling it across my body to place the chair in the back seat of my car every time I had to transfer in or out.

There was no parking on the street that day, so I pulled up along a side alley next to the lawn so I could wheel myself about 20 or 30 feet to my friend’s apartment. A motorcycle cop watched me and complained about where I parked after I came back to my car, even though I was not blocking traffic and he could obviously see that I used a wheelchair. As he spoke to me, I tried to explain to him that there was no parking on the street and in my condition, it was physically painful for me to try to park two or three blocks away and wheel over to my friend’s place. I was just trying to see if he was home — I could figure out the parking later. He looked at me with a mean sneer and said, “Are you talking back to me???” To be clear, he was threatening me. He was es-
sentially saying, “Shut up and get in your car, or I will put you in jail.”

I was shocked and stunned. I have a college degree from an Ivy League university. I am well-spoken, thoughtful, kind, considerate and helpful, and I am never loud or aggressive. I realized in that moment that nothing about who I am in my personality, education, character or demeanor meant anything to this cop, who was lording his authority over me in that situation. I don’t live in or near Five Points, but I immediately saw why there are problems with some police officers in that community. In retrospect, it is astounding that the officer didn’t simply offer to assist — where was the “to serve and protect” ethos?

If you are African American, you may be fine throughout eight or nine encounters with the majority of well-intentioned police officers who try to do their jobs with integrity. But that one bad-apple cop out of 10 can literally be deadly for a Black person. For all my efforts at personal peace — adaptive yoga, meditation, prayer, being a good Christian and attending church services — I was reminded of that potentially-dangerous reality on that disturbing day in Five Points.

If the threat of police violence can happen to me, an obvious paraplegic who uses a wheelchair, it can happen to anyone. These ongoing police killings and abuses captured on video — along with the attempted cover-ups — compel us as a society to make systemic changes in how police conduct their work and are held accountable for their actions.

WE’RE AT A TURNING POINT

As we celebrate 30 years of the Americans with Disabilities Act, we can see that we still have a long way to go in making our society more compassionate and understanding of people who are outside of the ordinary narratives of mainstream American society. In response to the protests surrounding George Floyd and Elijah McClain, the Colorado State Legislature recently passed Senate Bill 217, which has been signed into law by Governor Jared Polis. The new law mandates the use of body cameras, bans choke holds and limits qualified immunity for police officers, among other important policing reforms. Hopefully, similar laws will be passed in other states and municipalities, as national policing reform legislation recently passed the U.S. House of Representatives and is currently being debated in the U.S. Senate. As happened with the passage of the ADA in 1990, there is today perhaps a collective sigh of relief that a critical mass of political leaders has awakened to the importance of taking on a widespread systemic issue relating to social change.

I hope telling my story will enable people not of color to understand the problems that a Black person might face under the wrong circumstances with the wrong policeman. The murder of George Floyd is a turning point; our society is, and should have been all along, moving beyond a state of denial. Supporting systemic reforms in how policemen are hired, trained and held accountable will go a long way in changing the culture of policing and will also help create opportunities to build new bridges between police departments and Black communities.

As a man with a disability, and as an African American, I often find myself breaking through people’s stereotyped perceptions of me, to let them understand that I am a human being with love, dignity and an inner sense of value, deserving of recognition. People on different sides of racial or cultural divides should take risks and reach out to try to talk with each other. Get involved with community groups, churches or organizations that work on these issues. Simple day-to-day interactions can be life-affirming and at times can lead to authentic friendships.

Earlier this year, before the George Floyd incident, I developed a friendship with a former cop who had been in the Denver Police Department for 20 years. He told me that his main problem with being a police officer was that nobody ever invited him to sit down and have a cup of coffee. Instead, he was only called upon to talk to those who brought him problems that a Black person might face under the wrong circumstances with the wrong policeman; the more we get to know each other, the more we will break down barriers that create separation, emotional divisions, anxiety and confusion.

In the midst of this historic moment, it is my hope that people of all racial, cultural, nondisabled or disabled backgrounds can learn to approach each other with love and compassion and nuanced understanding. Just as with the monumental passage of the ADA 30 years ago, American society needs broad, systemic institutional change in policing, criminal justice reform and other racial issues. However, along with and beyond the changing of laws, flags and monuments, perhaps building bridges of communication and understanding between Black and white, young and old, nondisabled and those with all types of disabilities is something we can all partake in, collectively and interpersonally.

James Ainsworth is a journalist and copywriter in Denver, Colorado. He can be reached through his website, islandofspice.wordpress.com and his blog, islandofspice.wordpress.com.
Although an incomplete quad for 31 years, I only attended my first support group at Craig Hospital about three years ago. I've long recognized the importance of peer support during rehab and have been fortunate enough to learn from some true trailblazers throughout the years, but I didn't have access to a group of my own. This changed when a pair of Craig staff members — social worker Kathy Hulse and psychologist Lisa Payne — launched one. Having lost several chair pals to the Great Beyond, I knew I needed peers to help me separate reality from my tendency toward drama and hyperbole — and so I joined.

Our group ranges from people who are a few months post-rehab to a member who was injured more than 50 years ago. Some weeks we have well over 200 years of SCI/D experience in the room. We’re chemists, social workers, supervisors, engineers, students, teachers, volunteers, miners, counselors and ne’er-do-wells who come together weekly to seek and offer support. Some spouses and other family caregivers attend as well, and they offer a totally different and often instructive perspective. Once a month the men and women meet separately. Somehow everyone pretty much gets their needs met and grows in the process.

We normally have a dozen or more wheelers in each weekly session and we try to establish a topic for the hour to keep us focused and prevent a decline into a drama-laden bitch session. The magic comes as we see how our challenges and obstacles are similar to those experienced by other group members, and then experiment with a variety of successful solutions they have employed.

‘THE GROUP LETS ME SEE MYSELF IN A DIFFERENT LIGHT.’

Jon Forbes, 50, joined the group after our co-leader repeatedly suggested he attend. Forbes, a T6 paraplegic, was coming off a particularly rough losing streak. Following years of neuropathic pain, he underwent two successful dorsal root entry zone surgeries, only to have it return when the
Hardware that had been stabilizing his back broke down. The unrelenting agony returned and remains.

He was deputy treasurer of the state of Colorado when both his chronic pain and the pressure of the position got to him. “I lost it,” he says. “And told the entire board of the $40 billion public employee pension fund in Colorado to ‘go fuck themselves’ in a publicly-recorded meeting. I was totally prepared to be fired, but not for the public flogging I would take from the print and TV media.”

The combination of relentless neuropathic pain, terrible publicity, no job prospects, the death of his beloved cat and the loss of his dream home all crashed together to create an overwhelming crisis. Suicide was his plan. That’s when he joined the group.

After a while Forbes began to see aspects of his own situation while listening to other people’s problems. In time, as he began identifying with his fellow group members, he felt less isolated and more connected to them. “I started looking at myself in a different light, and I shined that light on some other more meaningful possibilities,” he says. “My general mood began to change, and I noticed I was a bit more optimistic. Something was working and that was good enough.”

He values the openness of his fellow group members and the comfort of being encouraged to talk through his problems with good, honest folk. “The group gives me information that is either relevant to myself or my mom, who’s dealing with severe Parkinson’s,” he says. “Someday, I will be able to measure what I bring to the group, but for now, I’m feeling a bit selfish.”

‘I FOUND OUT I WASN’T THE ONLY PERSON IN A WHEELCHAIR.’

Robbin Smith, 63, didn’t know what to expect after a bad steroid injection caused her T10 paraplegia and says she spent two years in tears.

“Initially I was quiet, afraid of how others might react. I was terribly ashamed and certain everyone was looking at me,” she says. Children staring didn’t bother her until their parents yanked them away as if she was contagious. And although she knew her family loved her, she didn’t like herself very much.

Then Ed, her husband of four decades, talked her into checking out the group. “Those first couple of years, she didn’t want to be alive,” says Ed, who also attends the weekly sessions.

After six or eight months, when Robbin felt safe enough to talk, her fellow group members listened and understood where she was coming from. “They opened my eyes to how good I have it,” she says. “I didn’t lose friends, but made friends. Ed didn’t leave me. Instead, he left a job he loved to take care of me. I’m not sure I could do what he does.”

Robbin says joining the group and being around other wheelchair users facing similar problems was the best thing she’s ever done. She discovered her peers are funny, loving and serious. She receives and welcomes support, and finds purpose in being able to offer something that might help someone else. As a bonus, she learns her own compassion deepens when she is able to realize other people’s pain.

She keeps coming back every week, despite a 45-minute drive each way.

‘SOME OF YOU HAVE SEEN IT ALL, BUT MY EYES ARE JUST OPENING UP.’

Kirsten Rosvall, a C6 quadriplegic due to a surgical mishap in late 2018, discovered the group when it appeared on her outpatient schedule during a routine PT/OT visit not long after discharge. Since Rosvall, 56, has a master’s in social work and has clocked about 15 years in childhood protective services, she’s had positive experiences with groups and decided to check this one out.

She describes herself as initially clueless to wheelchair culture and says she is taking it all in. “I think there’s this ‘outer culture’ of generally-shared wheelchair experiences and an ‘inner culture’ that comes with many years of experience. I’m in that outer culture, usually listening and learning,” she says. “Most of this is still pretty new to me and I don’t get everything people talk about. Some have seen it all, but my eyes are just opening up.”

Rosvall brings vocational insights along with her own shared wheelchair experiences. “What I like most is what I learn and how everyone shares information about anything and everything,” she says. “And I like the energy and knowledge that Kathy and Lisa bring. Mostly group is a great place to grow, and I’ve got a lot to learn.”
She appreciates the humor and support the group offers. "It's also nice to touch base with people each week and to have that connection in this time of isolation," she says.

‘PEOPLE ARE NOT ONLY ACCEPTED, BUT THEIR DIFFERENCES ARE HONORED.’

Dorie Gerhardt comes to group with all the lessons gained by 54 years of wheeling. She was a day shy of 15 when an automobile accident caused her C5-6 injury.

When Hulse suggested Gerhardt check out the group, she did and has returned most every week since. "I loved that first session. I saw immediately what Kathy described," she says. "People’s willingness to share and not judge makes this group special. I’ve made new friends, and I’m with people who understand what I — what we all — deal with, and there’s always something to take home.”

Gerhardt appreciates the atmosphere of camaraderie, non-judgment and total acceptance. "Actually, everyone is not only accepted, but their differences are honored. That makes for a very powerful support system. I’ve got my family and my church family,” she says. “And now I have my group family.”

‘I LEARN A GREAT DEAL THAT I KNOW I’LL BE ABLE TO USE EVERY SINGLE DAY.’

Sean Smith was recovering from Guillain-Barré syndrome at Craig when his social worker suggested he attend a session. “I knew immediately I was in the right place,” says Smith. “I call it class because I learn so much.”

At 51, Smith is the group’s Jeff Spicoli: He’s quick with a joke or laugh and, like Fast Times at Ridgemont High’s famous stoner, not shy about recommending the benefits of THC for stress relief. He can also be quite serious. “What I learn is often something I can use every single day, like how to pick stuff up off the floor without falling out of my chair.”

Smith appreciates the peace of mind he gets from the group. “There’s plenty to worry about, but I’ve learned to just take care of business,” he says. “There are people in group who do that, and I appreciate the no-nonsense aspect they bring. I’m so lucky to be part of it.”

Smith was the head of maintenance for an apartment complex before his illness and appreciates the group’s diversity of experience. “We’ve all been knocked down, and this group is helping me stand like a man again,” he says.

‘THE FEELING OF COMMUNITY AND CONNECTEDNESS KEEPS ME COMING BACK.’

Being a part of group has reaffirmed that I need to be with people who, regardless of background, age, gender, education or financial station, all share the profound, life-changing and potentially-transformative experience of paralysis. We come together weekly to seek or lend support to each other, and it’s a privilege to join with my peers in creating an atmosphere safe enough for us to cry, laugh, and offer and receive acceptance.

Our group is free of judgment, yet heavy with encouragement. I need their support to deal with my latest set of rapids. I gain some measure of succor by sitting silently for an hour with these folks; it’s even better for me when I talk.

It hardly matters whether you are five months or five decades post discharge, everyone runs into bumps in the road and can use some help, advice and support. And we should always welcome any opportunity to offer a shoulder to lean on.
Q. I’m having an issue with people not wearing masks. I’m a paraplegic, and I live in an urban community. I’d like to go out to my favorite local coffee shop and show my support while we’re all dealing with COVID-19, but some customers there don’t wear masks. I always wear one and, because of lung complications from when I was first injured, I’m mindful of whether others have face coverings. I went to buy coffee the other day and could see through the shop’s windows that the employees behind the coffee bar all had masks. The shop allows only a few customers at a time, to maintain appropriate distancing according to current rules, but some patrons weren’t wearing masks, and I didn’t see a sign requiring face coverings. I wanted to say something to the people without masks but worried they wouldn’t be receptive to my comments or could potentially respond with verbal aggression. Plus, I don’t like confrontation, so I went home without coffee. How can I go out to enjoy my favorite places without endangering my health? How do I help people understand that by not wearing masks, they put me at risk?

The decisions you make about what health precautions you should take regarding COVID-19 are very personal, and you should start by consulting your primary care doctor.

When it comes to going out, know the current COVID-19 rules in your area. It’s also a good idea to maintain a calendar of your activities outside of your home to make contact tracing easier if you are exposed to the virus on one of your outings. Requirements regarding masking at retail establishments differ by jurisdiction and are likely to change frequently because of the shifting nature of the COVID-19 situation. Before engaging in any conversations with other patrons and/or management, be aware of the regulations as well as related exceptions. For example, some jurisdictions have exceptions for individuals with disabilities who cannot put on or take off a mask independently. Also, research reporting mechanisms for noncompliance with COVID-19 rules within your jurisdiction; these may include email addresses, online forms, or telephone numbers for the local health department or other entities monitoring COVID-19.

After educating yourself, you have a few options that may be safer and more effective than confronting a non-masked patron directly. You might approach the management of the coffee shop to inquire about its COVID-19 policies in general. If local regulations do require customers to wear masks inside retail establishments like coffee shops, you might follow up with examples of noncompliance you witnessed and ask management how the policy is being enforced. Additionally, if the shop requires face coverings and you see noncompliant customers on your next visit, you might opt to report these patrons to management. You may need to explain the rules to the managers and educate them on why it is important to protect you and other high-risk individuals, but you don’t have to do this from inside the shop. Consider calling and asking to speak with a manager, either on the phone or in person outside, to avoid being indoors with unmasked customers. If you see widespread violations of current COVID-19 policies in your community, you may want to alert your local, county, state and/or federal representatives.

Another idea that eliminates risk but supports the shop is to call ahead to order your drink and have it brought out to you. When the drink is delivered, mention that you called ahead because other customers aren’t wearing masks and that endangers your health. Lastly, you can decide to avoid the issue entirely by either choosing to remain at home or staying away from establishments that are not complying with current rules and regulations related to COVID-19.

Many disability advocates feel strongly about speaking up in whatever format is most effective, including on social media, as the risk of developing severe symptoms from COVID-19 can be greater for individuals with disabilities than for those without. It is up to you to decide whether or not to speak up.

In sum, you have choices about your comfort levels and the risks you are willing to take based on your personal health and living situations. It also remains your prerogative to choose the advocacy route you want to pursue when dealing with COVID-19-policy violations you witness.

By Sheri Denkensohn-Trott

AUGUST 2020 39
VIDEO GAME REPRESENTATION

"Momma, you’ve gotta see this," my 5-year-old son River says from the living room where he is playing Lego City Undercover on the Xbox. "I unlocked a wheelchair. It’s so cool." As I roll into the room, I see his character, Chase McCain, quickly push down a street. "You’ve gotta try it," he says. I grab a controller and join the game. Once I choose my wheelchair accent color (teal of course), we race each other up a hill. At the top, we go over a cliff, soar through the air, and land on the street below. "Wow. Let’s do that again," says River.

Because disability is rarely seen in entertainment and is often portrayed in stereotypes, I’m always surprised how meaningful it is when I feel represented. "The feeling of seeing even a glimpse of who you are in a positive light is profound," says Cherry Thompson in "You Can Take an Arrow to the Knee and Still be an Adventurer," a talk Thompson gave to the Game Developers Conference in 2019. "It’s a nudge that you are not alone, and more importantly, that you are welcome."

In the 35-minute presentation, Thompson, an accessibility consultant who uses a wheelchair and is autistic, not only explores why disability representation is so powerful, but why the gaming industry keeps getting it wrong and how it can do better. "The lack of representation — or even worse, bad representation — can reinforce stigma," Thompson says.

Steven Spohn is the chief operations officer of AbleGamers, a nonprofit that provides custom setups to people with disabilities, and has been playing video games since he was a child growing up with spinal muscular atrophy. Because he couldn’t play ball or swim, gaming was a way for him to connect with other kids. "Almost always the good guys are big, beautiful, bold, muscular, and the bad guys are disabled, disfigured and have something wrong with them," says the 39-year-old. "They are always angry at the world, always mad about life, and therefore they are going to do this horrible thing, like blow up the world because they are disabled."

Spohn, who received the South by Southwest (SXSW) Game Industry Champion of Change Award earlier this year, is optimistic, though, about the future of disability representation in video games. AbleGamers has a certification program that teaches video game developers how to design with accessibility in mind and consults on the way disabled characters are portrayed.

One of the promising upcoming games, Marvel’s Avengers — a third person action-adventure developed by Crystal Dynamics set to release on September 4, 2020 — also consulted with Thompson, who did motion capture for a wheelchair-using nonplayable character, Cerise.

"Our goal is to normalize representation within our game world by reflecting the diversity of the real world," says Meagan Marie, the senior community and social media manager of Crystal Dynamics, in an interview with video game developer Square Enix. "There are
scenes in Marvel’s Avengers, like the celebratory day for Avengers, A-Day, where this diversity is reflected in a crowd of people who are all sharing their passion for superheroes."

Spohn’s favorite disabled video game character is Pharah from Overwatch, a popular shooter that features team-based combat matches set on a near future Earth. "Her background is vague, but her arms and legs have been replaced and she has a backpack for movement. She is essentially half-bionic. They don’t go into if she was in a trauma or born that way — they just say that her mind and body are agile and able, and that she needed some technology to enhance that. I am a fan of Iron Man and love that meching-yourself-up motif."

John Warren, the head of media of Fanbyte, one of the largest digital media networks in the world focused on the fandoms of gaming, entertainment and tech, appreciates the quirky and humorous furniture-moving video game Moving Out, where every character has the customizable option of being in a wheelchair. "The feeling of having to move out of your house is a universal one and having a character that is in a wheelchair and basically acts the exact same way ... I appreciate that," says Warren, who has minicore myopathy, which causes muscle weakness. Warren hopes to see more diversity in the way characters who use wheelchairs are portrayed in games. "Wheelchair users are not a one-size-fits-all category. You never really see them move their bodies in ways other than just arms push, neck turn, mouth move. There is such a wide spectrum ... like wheelchair users who are partially ambulatory. I’d also like to see these characters do things realistic to wheelchair users, like drive or use a grabber to get stuff off a shelf — things that have a tactile, interactive element to it."

"If I were going to advocate for a character," says Spohn, "I’d like to see a single-player, story-driven narrative where a profoundly physically disabled character — not just missing part of one ear — has an entire romantic story arc and saves the day."

My son and I recently started playing Animal Crossing: New Horizons on Nintendo Switch. In the game, there is a wheelchair. You can customize the seat color pattern, which is cool, but the wheelchair doesn’t move; it’s a piece of furniture. Hopefully Nintendo will address this in an update. As we know, a wheelchair isn’t something you are stuck in — it gives you freedom to explore the world.

To watch Thompson’s presentation, visit youtu.be/Vb39BFs1UK0

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"If a quarter of players are disabled, why are less than 1% of our characters?"
— Cherry Thompson, “You Can Take an Arrow to the Knee and still be an Adventurer”

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Meet New Member Anna Adams

Age 36, from Deltona, Florida Myelomeningocele Spina Bifida, Hydrocephalus and Arnold Chiari Malformation Founder, Mind, Body and Soul Solutions

Why I joined United Spinal: I joined United Spinal Association because I can relate to many of your members when it comes to living with a disability.

Can’t live without: The one thing I cannot live without is my lightweight Quickie sports chair.

If I could change one thing: I would create a clinic where disabled patients could have all their doctors come together in one place in order to come up with the best solutions to help patients live a full life with a disability.

Meet other members or join United Spinal at unitedspinal.org
I was at a neighbor’s house party this summer, doing the social distancing thing as people do now. A couple of the neighbors brought their young adult sons, and I remember discussing the college experience with them at some point, but I didn’t think anything of it.

Later that night, after the number of guests had thinned, I was sitting on a quiet part of their deck and overheard the voices of those same boys coming from below me. They couldn’t see me and didn’t know I was within listening distance. I wasn’t trying to eavesdrop, but when I heard them bring up “the MILF in the wheelchair,” I couldn’t unhear their conversation. That term pretty much narrowed it down to me, as the only woman in a wheelchair at the party.

On the one hand, it was flattering that they thought I was attractive, but MILF?! That made me feel really old. Forget the wheelchair part, I’m a single woman in my early 30s. I’m no Mrs. Robinson or even Stifler’s mom.

Not Your Mombshell
Our Mission
VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

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

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

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

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

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

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

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

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

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

VetsFirst is a program of United Spinal Association that assists veterans and their eligible family members in obtaining the benefits they are entitled to, deserve and need.
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