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NEW MOBILITY

Inside a College Crisis



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NEW MOBILITY

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BULLY PULPIT

By Ian Ruder

YOU TALK, WE LISTEN

Sorting through 650 lengthy surveys and responses to over 400 emails sounds like the kind of repetitive work that could drive someone insane. Yet having just finished doing this, I am happy to say that the process is a blast when all of that feedback comes from New Mobility readers.

The more time I spend digging into all of the responses we received to our reader survey earlier this year and ideas submitted during our annual call for stories, the more excited I grow about the magazine's future.

Sure, I love hearing from all the people who enjoy our content and encourage us to keep doing what we're doing, but I'm equally thrilled with the constructive criticism and suggestions many readers shared.

The simple fact is you all make my job a lot easier. As much time and effort as our team spends working to come up with relevant, interesting and useful content, there are only a few of us, and there's no way we can know everything going on in the community or read everyone's minds. The survey and call for stories are the closest we can get. I mine the pages of data that come out of them for every last nugget.

From possible people to profile to accessible destinations you recommend, there are always a number of ideas that are easy to put on the calendar immediately. What I find even more interesting — and potentially more helpful when planning what to cover — are the trends that emerge from looking at all the answers together.

Inevitably many of the stories most asked for, and the most repeated comments, are the same every year. As our longtime publisher Jean Dobbs says, "We'll never be able

to do enough bowel and bladder stories."

Additionally, practical guides and resources are always in demand, as are product reviews and ways to save money.

Still, this year the desire for stories focused on cutting costs and frugal solutions was especially powerful. Whether it was "lower-cost solutions," "foundations that offer assistance" or "how to pay for assistive tech," the message was loud and clear. We always have finances in mind when we process stories, but obviously, we can do better. And we will.

The other need that popped out of the data was to expand our coverage of people living outside urban centers. Readers from rural towns and less populated areas highlighted the different issues they deal with and their desire for suggestions and resources to address them.

We heard similar calls last year and planned a couple of stories we thought would be helpful, including one scheduled for this issue, but they didn't work out for various reasons. Thanks to so many of you volunteering to share your stories and experiences, I am confident those stories will turn out even better, and we will continue to brainstorm ways to improve and diversify our coverage.

So, for the Catholic reader who asked for more faith-related stories, the T5 para who worked for the National Park Service for 32 years, the seminary worker, the hobby farmer, the sports broadcaster and everyone else who took the time to share your thoughts and ideas, thank you. And to everyone else, it's never too late to give us your feedback, either through our new website or via email at iruder@unitedspinal.org.



BEHIND THE STORIES

With Ian Ruder

Editor emeritus **Tim Gilmer** wrapped up the inaugural edition of *NEW MOBILITY*'s college guide, "Wheels on Campus," almost a year ago. However, we are still reaping the rewards of the hundreds of hours he spent corresponding with colleges and crunching data. As he surveyed the landscape of specialized programs for people with mobility disabilities, he couldn't escape the feeling that things were getting worse. "Whatever our needs are, they just don't get the attention they used to," he says. His cover feature investigates why that is and how it is impacting disabled college students. For more college news, keep an eye out for a "Wheels on Campus" supplement later this fall.



This month's feature on cosmetics is **Esme Mazzeo's** first piece in *NEW MOBILITY*, and I'm hoping it's the beginning of a fruitful relationship. Mazzeo brings a lengthy resumé of writing about disability and representation for many sites, including *Elle*, *Marie Claire* and *Rooted in Rights*. As a wheelchair user who aspires to be better at doing her own makeup, Mazzeo pitched me the story and told me she hoped to see what adaptive cosmetics were out there. Four months later, the verdict is in: "It's honestly not that much," she says, "which is kind of sad." Still, she pulled together an impressive article chock-full of resources and ideas.

I was thrilled when **John Beer** reached out with the idea of writing about municipal programs that allow volunteers to help enforce disabled parking abuses. The topic always galvanizes our readers. Additionally, I have had a soft spot in my heart for Beer ever since his excellent 2019 review of the Obi mechanical arm, where he chronicled a "romantic" dinner he was able to enjoy without caregivers, thanks to the arm. He brings the same blend of humor, reporting and insight to this feature. "Writing this crystalized what it means to be disabled but fighting for what's ours," he says.



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

United Spinal's Resource Center provides information on any aspect of living with SCI/D. Contact: 800/962-9629; unitedspinal.org/ask-us; 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.



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spinalpedia.com



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JULY 2021

Accessible RV Life on the Road

Tell Us What You Love: I love this! We just took our travel trailer from Georgia to Utah. We camped at or visited 10 national parks.

@jamielogoodwin
Instagram

More Class Bs, Please: I hope Newmar, Winnebago and all other RV manufacturers consider a smaller accessible RV, like a Class B, for a variety of reasons: Class A is too big for only two people. Also, it's too expensive for most disabled people, who already have very high expenses. And once a large Class A is parked in an RV park, we would need to purchase an accessible van to tow to ride around locally.

My fiancé and I searched for an accessible Class B for two years with absolutely no luck. We, too, visited Camping World, but they couldn't provide any assistance.

@livingthislittleparalyzedlife
Instagram

Good Luck Getting it Repaired:

What people don't account for is the constant, expensive repairs. There are few repair centers nationwide and very few trained technicians. The technology in one of these coaches requires expertly trained service technicians. Often, qualified technicians or repairs are miles, or even several states, away. Getting parts for some repairs can take weeks or longer. The biggest problem is that the various systems are built by different suppliers, and they are supposed

"I love this! We just took our travel trailer to 10 national parks."

to work together but simply don't. They love to blame other manufacturers for problems, and problem-solving is very difficult. Nobody talks about the constant problems and service issues.

Marty Coopman
Facebook

Daily Dilemmas: The Imposter Canine Companion

Jane Could Go to Jail: You should tell your friend 'Jane' that what she is doing, slapping a vest on a pet dog to have it impersonate a service dog, hurts everybody who has put in the time or money to acquire or train a real service dog. And doing so — faking a service dog — is a crime in 23 states with penalties as stiff as a misdemeanor along with fines up to \$1,000 and up to six months in jail.



We can't promise you'll win a photo contest like Brianna Heim did, but if you'd like to see your image in *NEW MOBILITY*, please send it to executive editor Josie Byzek at jbyzek@unitedspinal.org. Who knows — we may just publish it.



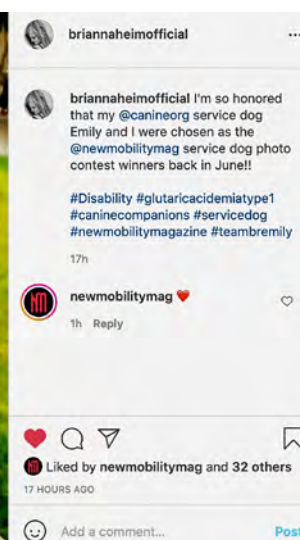
Furthermore, the Canine Companions for Independence organization name is copyrighted. They will likely take a serious (and probably not pleasant) interest in a person who puts a bootleg CCI vest on a pet dog.

Bob Vogel
Newmobility.com

NM Live with Andraea LaVant

Believe it: First-ever ramp [to the Academy Awards stage]?!? Hard to believe, but it's about time! Congrats on *Crip Camp*, a fantastic film.

Heavenly Wheels
Facebook





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More Manual Choices

Quickie expanded the configuration options on its lightest manual wheelchair, the Nitrum, adding a new Hybrid model and an Active Rigid option to give users more control over how they ride.

The new Nitrum Hybrid offers a dual-tube option for users who prefer this box-style aluminum frame's rigidity and increased weight capacity. Like the original, open-frame Nitrum, the Hybrid provides full

adjust-

ability. A unique caster system lets you adjust width and angle to finetune your setup for maneuverability and desired rear seat height.

Quickie says that "during development of the Nitrum series, we made it our goal to optimize weight savings of each component and to achieve maximum rigidity." The company offers an Active Rigid option that includes fixed backrest and axle stems on both the Nitrum and Nitrum Hybrid to decrease weight further, reduce moving parts and increase frame stiffness.

"With the release of this newest edition of the Quickie Nitrum, we are proving our commitment to listening to our end-users and continuously innovating in the segment of ultra-lightweight manual wheelchairs," says Larry Jackson, president of Sunrise Medical North America.

The Nitrum checks in with a 10.8 pounds transport weight, while the Nitrum Hybrid clocks 12.8 pounds. The starting retail price is \$2,695, and Medicare and most private insurances cover both chairs. For more information, visit: sunrisemedical.com/manual-wheelchairs/quickie/rigid-wheelchairs/nitrum



The Nitrum Active Rigid



Swinging Success

For everyone tired of not having accessible options at their local playgrounds, Landscape

Structures' new ADA-complaint We-Go-Swing offers some much-needed innovation and a whole lot of fun. Built with busy playground spaces in mind, the We-Go-Swing comes with a



Push All the Buttons

It's easier than ever to control all the smart devices around us by voice or app, but what do we do when confronted with a "dumb" power button or switch? The designers of the Fingerbot-plus offer a solution. This deceptively simple-looking tool helps you turn any tech into smart tech by allowing you to voice-control most but-

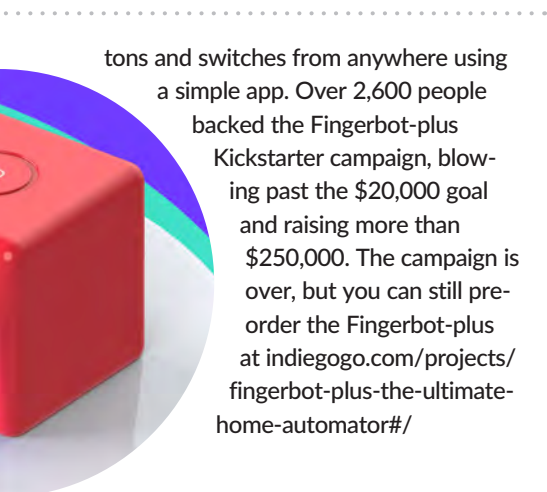




Photos courtesy of playlsi.com

ramp that provides easy access to one accessible bay and one bench seat or two accessible bays. "They don't look like they are designed for disability — they're just really cool designs," says Jill Moore, a Paralympian now working as an inclusive play specialist.

The We-Go-Swing is the latest addition to Landscape Structures' accessible playground catalog, including the We-Go-Round merry-go-round (above) and many other inclusive options. If you're interested in getting its equipment for your local playground, visit playlsi.com.



tons and switches from anywhere using a simple app. Over 2,600 people backed the Fingerbot-plus Kickstarter campaign, blowing past the \$20,000 goal and raising more than \$250,000. The campaign is over, but you can still pre-order the Fingerbot-plus at indiegogo.com/projects/fingerbot-plus-the-ultimate-home-automator#/

SUMMER FALL READING LIST

DEMYSTIFYING DISABILITY BY EMILY LADAU

Written to help make the disability experience more accessible, *Demystifying Disability: What to Know, What to Say, and How to be an Ally* is an enjoyable, easy-to-read guide to being a thoughtful, informed ally to disabled people. Ladau, who has been disabled since birth, explores topics like disability etiquette, history, culture, ableism, and media representation while weaving in stories from her own life. The book is available on amazon.com and other retailers. Be sure to catch Ladau on this month's episode of NM Live, and See more about that on our back page.

THE FABULOUS T-BABES BY MIKE ERVIN AND STEPHANIE LUPU

Longtime NEW MOBILITY columnist Mike Ervin, the one and only Smart Ass Cripple himself, lends his trademark wit to a graphic novel. Illustrated by Lupu, *The Fabulous T-Babes* follows the adventures of three "thalidomide babies" who must use their superpowers to escape danger. The first edition is out now. For purchasing info, email fabtbabes@gmail.com.

CONFINED TO ALIGN BY ASHLEY LYN OLSON

After years of writing about accessible travel for NEW MOBILITY and various other websites, including her own wheelchairtraveling.com, Olson shifts her focus to a less enjoyable but perhaps more critical topic: dealing with an unexpected medical catastrophe. In sharing her experience recovering from a devastating pressure sore, Olson provides a helpful template for others coping with hard times. Available soon on Amazon.

LIVE THE IMPOSSIBLE: HOW A WHEELCHAIR HAS TAKEN ME PLACES I NEVER DARED TO IMAGINE BY JENNY SMITH

Fresh off her July NM article on planning your dream trip, Smith (left) fulfilled one of her dreams with the release of her memoir. In *Live the Impossible*, she writes candidly about the ups and downs of 32 years of living as a C6-7 quadriplegic. Between her international travels, speaking career, blogging and YouTube videos, Smith has plenty of tales to tell and even more lived-experience to share. Available on Amazon.



GETTING YOUR BRAIN AND BODY BACK: EVERYTHING YOU NEED TO KNOW AFTER SPINAL CORD INJURY, STROKE, OR TRAUMATIC BRAIN INJURY BY BRADFORD BERK

Berk is the only one of these five authors who hasn't written for NM (yet). The highly-regarded medical researcher who sustained a high-level SCI at the peak of his career is also the only one who founded a neurorestoration institute. He brings his unique blend of personal and professional experience to this all-encompassing neurological recovery guide. Available on Amazon.

MEMBER BENEFITS

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

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

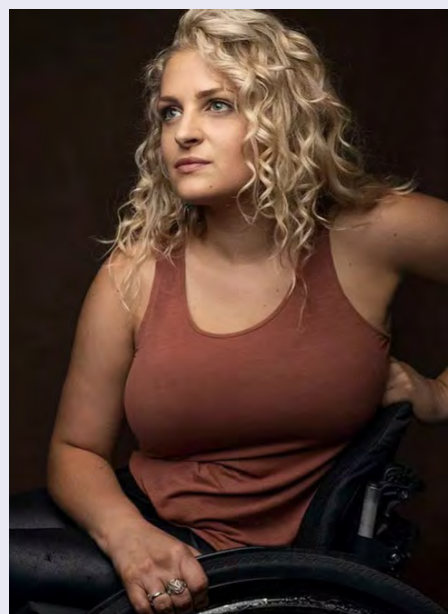
United Spinal has 75 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive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



NEWS FROM UNITED SPINAL



Carina Ho, musician and songwriter



Ali Stroker, Tony Award winner

UNITED SPINAL 75TH ANNIVERSARY GALA

How do you celebrate United Spinal Association's 75-year legacy of advocacy and empowerment, fundraise for current operations and generate enthusiasm for the future, all in one virtual event?

That was one of the many tasks facing United Spinal's new President and CEO Vincenzo Piscopo, when he joined the organization last November. The solution will be unveiled on Nov. 10, at United Spinal's star-studded virtual gala and community event, "Building an Inclusive World."

PBS NewsHour's Amna Nawaz will serve as emcee and introduce guests that include Lin-Manuel Miranda, who created and starred in the multiple-award-winning Broadway show, "Hamilton," Ali Stroker, who is the first wheelchair user to win a Tony, former U.S. Representative Steve Bartlett, and U.S. Senators Tammy Duckworth and Raphael Warnock. The evening will also feature a performance by Carina Ho.

"This is a great opportunity to let everyone know the impact that we're making. Also, it will let people with spinal cord injuries and disorders know that we are here for them and are committed to a brighter future," says Piscopo. "When we look back at what we have accomplished in the last 75 years, there is a lot to be proud about, and this is a good time to pause and celebrate the advancements. However, we cannot lose track of the fact that there is still a lot to do. I want to use this celebration as an opportunity to energize our community for the next 75 years because, from a perspective of inclusion, there is still more progress to be made."

The virtual gala is on Nov. 10 at 6 p.m. EST.

Registration is free at
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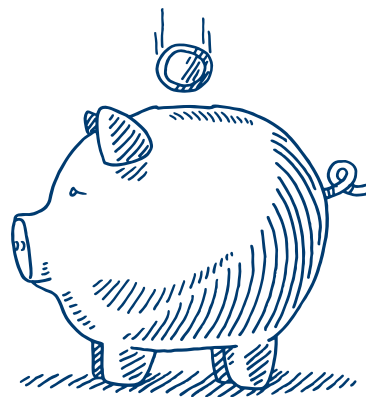


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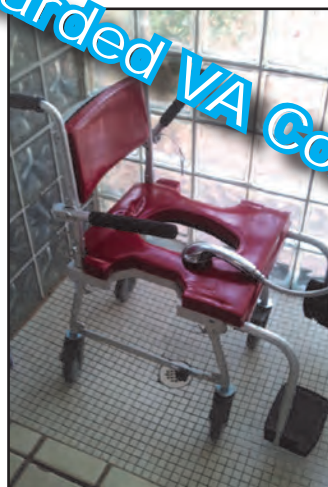
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GEAR HACKS

By Seth McBride

ACCESSIBLE FAMILY CAMPING HACKS

Back when my son, Ewan, was still flopping around in diapers, I remember a quad-dad friend of mine who likened parenting to playing a video game. “Just when you start to get better at it, the difficulty level keeps going up,” he joked, and he was right. Compared to the intricacies of managing an adamantly independent 4-year-old who’s suddenly turned functional enough to be dangerous, newborns are pretty simple.

Something my friend wouldn’t have known because he and his wife had twins and never delved into baby round two is that the second time you have a kid, it’s like going back to level one on that video game you already learned how to crush — everything’s just easier.

Enter Lou, our beautiful girl/bundle of gas, who is objectively a more difficult newborn than Ewan was while simultaneously being easier for Kelly and me to manage. Which is how, when Lou was 3 weeks old, we found ourselves straddling the line between ambition and stupidity and loading up the pickup truck for our first family-of-four camping expedition.

The realities of taking a newborn and a preschooler out into the woods made us rethink how we typically do things and helped us realize that simplifying the whole process can make camping a little easier for everybody.

The One Night Expedition

One thing we learned with Ewan was, don’t push it. Sure, spending a few nights out in the middle of nowhere is great, but know what’s even better? Making it home before everybody starts to hate each other. And from a disability perspective, one-night camping has its benefits. For starters, it simplifies bowel routines, which for a lot of wheelchair users, can be one of the biggest deterrents to camping. Simply poop before you go, take some Imodium if you’re really worried about it, and most likely, you won’t have to think about getting back on the pot until you get home.

If you pack up as much as possible the night before you leave and pick a camping spot close to home, you can get two days of camping in, with only one night of sleeping hassle. That’s just enough to make the packing effort worth it. Plus, if you go for a single night, you don’t really need to do any dishes, which is always annoying when you’re out in the middle of nowhere. Just dirty what you need to dirty and save the clean-up for when you get home. If you’re camping somewhere with critter worries, pack the dirty dishes in a sealable tub

Sleeping Matters

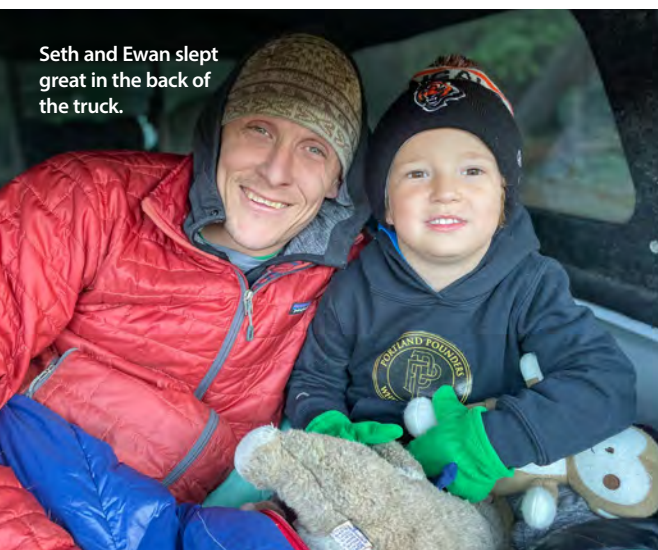
We have a tent, a big one. But somehow, with two adults, two kids, a wheelchair and a dog, that tent is no



Relax, Baby Lou.

longer big enough for our whole family. Since setting up a tent is generally a hassle if you use a wheelchair, and Kelly certainly didn’t need one more thing to do, we simply decided to go without a second one. Kelly and Lou, and Lou’s changing station, filled up the tent while Ewan, Kenai the dog and I took the truck bed. We blew up a generic queen-sized air mattress that fit perfectly with the back gate of the truck lowered. I had to transfer up from my wheelchair, but that was easier than transferring back up from a tent floor. If you don’t have a truck, the back of a station wagon has served me well in the past and generally makes for an easier transfer.

Similarly, a camping cot, available for around \$100 from various retailers, makes for a good sleeping surface up off the dirt. Often between 17-20 inches high, they allow a near-level transfer for many manual wheelchair users. Since many cots are only 36 inches wide, though, you’re probably better off cutting up a memory foam mattress cover to use as a sleeping pad than buying a fancy, ultralight blow-up sleeping pad, which



Seth and Ewan slept great in the back of the truck.

also tends to be ultra-slippery. Many companies sell wider versions if you need one. Coleman offers a camping cot that comes complete with a queen-sized air mattress and integrated battery-operated pump for about \$160.

If you are camping in the summer, when most people go anyway, you won't have to worry about getting too cold sleeping out in the open. Pack a warm sleeping bag, or if you don't have one, there's nothing wrong with sleeping in multiple layers, your jacket and an old blanket you don't mind getting dirty. Bugs can be a nuisance, depending on where you're camping, but whiskey helps, as does staying around the campfire smoke until a few hours after sunset when prime bug activity typically dies down. If you live in a region where Lyme disease or the West Nile virus is a concern, be sure to pack bug spray. You can get a cheap, string-up mosquito net, but you'll likely need a nondisabled helper to make any use of it. Rain? Pick a clear night and risk it. Worst case scenario is you'll have to scramble back into your car, and at least you'll have a good story to tell.

Cath Hacks

If you have a tent, waking up to pee in the middle of the night can be a pain — and same with the back of a car or a truck bed. Bottles work in a pinch, but spillage is an issue, and washing the pee smell out of tents, sleeping pads and bags is no joke. My preference is for a closed system. You can buy closed-system catheters for a few dollars each, or you can make your own reusable one. Simply connect an extension tube to your intermittent cath, then connect the extension tube to a disposable leg bag. Now you can pee inside the tent or car without worrying about it.

Success!

As for our expedition? Well, Ewan and I slept great in the back of the truck. The only poop or pee problems we had were with Lou, who decided to blow out her diaper four times between when she and Kelly went into the tent and when Kelly tried to go to sleep. We may have only spent a single night away from home, but we all got to spend two days out in a field on the side of a mountain, riding mountain bikes and playing camp bocce, or in Lou's case, passing out in a baby dome under the trees.

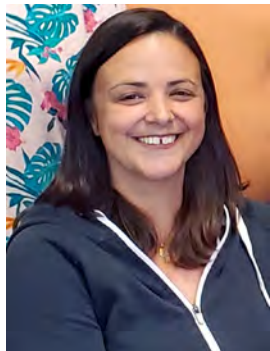


Bikes, bocce and Baby Lou — Seth is in his happy place.

HOW WE ROLL

LEGACY BUILDER

Tenesha Ulrich



As president of the Northwest Ohio Chapter of United Spinal Association and a member of the board of trustees for the Ability Center of Greater Toledo, Tenesha Ulrich strives to make the Toledo suburbs more accessible.

Embracing Community

Tenesha Ulrich managed her new life in a vacuum for the first few years after sustaining a T12 injury in a 2005 all-terrain vehicle accident. She was uncomfortable interacting with other wheelchair users and detached from the disability community. She tried to keep living her life but lacked the knowledge to adjust to her new reality. “I wasn’t cathing myself when I left rehab. I hadn’t been taught how,” says Ulrich. “There was a definite disconnect.”

Ulrich, now 41, ended up working crazy overtime hours in her job directing the news at a local TV station without going to the bathroom. Then she had a seizure caused by a urinary tract infection just before the 11 p.m. show went live.

“I don’t know if I’d fully come to terms with my injury because I thought, ‘Everything’s going to be fine!’” says Ulrich. “I remember a friend telling me, ‘If you don’t properly grieve this, you’re going to hit a wall.’ The seizure was my wall. I said, ‘I can’t



MOST CHALLENGING PART OF LIVING WITH YOUR INJURY: Finding a way to do things that need to get done. I’ve always got to come up with a new way to do it.

MOST ACCESSIBLE PLACE YOU’VE BEEN: Denver. The curb cuts wrap all the way around the street corners. It’s exemplary in many ways.

PROUDEST MOMENT WHEN DEALING WITH YOUR DISABILITY: I’m proud of the way I’ve made places more accessible, including downtown Perrysburg, Ohio.

Attending United Spinal’s Roll on Capitol Hill helped Ulrich find her voice as an advocate.



do this anymore.’ I wanted to prove myself at the station, so I overdid a lot and wasn’t taking care of myself.”

Following the seizure, Ulrich took a few years to get herself together. Things started to improve when she met Cathi Arcuri, former president of United Spinal’s Northwest Ohio Chapter, and started attending the chapter’s meetings. At first, being around other people with spinal cord injuries took some adjustment, but eventually, she embraced the community.

“I love resources. I love learning about where to find help for people. United Spinal had come up with solutions that helped its members, and a lot of those addressed the same problems I’ve had,” she says. “It got me further faster because somebody could give me tips on things like catheters, pressure sore prevention and avoiding autonomic dysreflexia.”

As the newly-elected president of the Northwest Ohio Chapter of United Spinal, Ulrich has many roles, including advocating for access and speaking to physical therapy



students about better ways to help people with SCIs. She also pursues increased access through her board position with The Ability Center of Greater Toledo, where she works to improve accessibility in her community.

“The suburbs of Toledo all have these older downtowns that are inaccessible, so we work with their city councils to make their entire downtown core accessible. That’s a project we’re still working on,” says Ulrich. “Our success depends on the community we’re working with. The town of Perrysburg has been gung-ho, but with another community, it has been like pulling teeth, and we’ve had to overcome a lot of backward thinking.”

Ulrich tries to influence them with grace and understanding.

“We’re not saying this has to be done right now,” she says. “We’re saying, we’re going to work with you, we understand it’s a big project, but this is the law, and it needs to be done — so let’s put a plan together to make it happen.”



WHAT KIND OF WHEELCHAIR DO YOU HAVE, AND WHY DO YOU LIKE IT? It’s a manual TiLite DualTube. I like it because of the way it’s weighted.

The Personal is Political

Tenesha Ulrich describes the moment at United Spinal Association’s Roll On Capitol Hill that she realized she could have a lasting impact on those running the country.

“ We went to see our senator, Rob Portman, for coffee. When Portman walked in, he headed straight over to us and gave us 15 to 20 minutes. I told him about things I learned through United Spinal, like the importance of independent living instead of institutionalization. But I wasn’t putting a personal spin on it, and nothing was clicking with him. So, I switched it up mid-conversation, making it personal. I told him when I see Ohio’s old county nursing facilities, I always think to myself, that’s where I would live if the ADA hadn’t passed because they made areas like that accessible rather than making the whole world accessible. His body language changed immediately, his facial expression changed, and he started to hear what I had to say. I could just tell. I took that experience home with me. From then on, I wanted to leave a legacy.”



WHY I JOINED UNITED SPINAL: I joined United Spinal to find community. I want to learn from my community’s life experiences and gain knowledge from them.



Disabled Women Share Their Cosmetic Hacks

BY ESME MAZZEO

Lucy Richardson is conflicted about some free makeup swag she was given recently. Richardson, the founder of Wheel New Yorkers, is also a makeup enthusiast who regularly visits places like Sephora and Ulta Beauty. Rolling into the unnamed business was not an extraordinary event for her, but as she explained to *NEW MOBILITY*, “The manager of the store was so taken aback by me coming in there with my fashionable outfit and makeup that they gave me a bag of free products.” She accepted the products and went on with her day but shared with the manager what actually went through her mind in the moment: “I’m glad I got this, but I’d also be pretty cool with you not having weird ideas about disabled people.”

Richardson’s experience exposes more than just one person’s obliviousness about disability. It’s indicative of

the ableism embedded in every aspect of the cosmetics industry, from ignorant and unwelcoming retail spaces to inaccessible product design to lack of representation in advertising. The journey toward true inclusion is long and slow, so disabled makeup lovers create hacks to adapt products and tools to their abilities.

“I TRY AND PINPOINT WHICH ASPECT OF APPLYING MAKEUP I FIND DIFFICULT AND THEN FIND A SOLUTION FOR IT.”

One hack is to put a rubber band around a Beautyblender so that gripping it is easier. Another is to use a magnifying mirror for improved visibility. Richardson, who has a rare degenerative motor neuron disease, goes further than these basic tips so she can apply intricate details to her friends’ makeup

without her hand getting tired.

“What I would do is try and pinpoint which aspect of applying makeup I found difficult and then find a solution for it,” she says. “So, for winged eyeliner, I would get a straight line, and then I’d shake and it would move.” She solved that problem by using winged eyeliner stamps. She also uses a drug-store brand of transparent tape on her face to achieve a straight line. Since there is less adhesive on it than a better brand like Scotch, it’s easier to rip off and it doesn’t hurt. Also, she converted a wrist rest meant for keyboards to an elbow rest for doing her own makeup and requires anyone she does makeup for to hold out their hands so she has a place to rest her arms if she needs it. She recently did makeup for all of the guests at her brother’s small wedding using these techniques.

Products exist for makeup artists



Brenda Gutierrez Baeza wishes there was better technology to help her apply makeup.

and beginners to assist with application, but it takes digging to find them and very few are specifically marketed toward the disability community. It's disappointing to Richardson, who has seen the cosmetics industry growing toward expanding its ideas about the "typical" customer to include many other groups of people recently.

"I look at the kind of products that are coming out and there are all these really exciting developments in the kind of ingredients that people are using and the types of application," she says. "And I'm seeing things about diversity and inclusion in terms of shade range that is available for foundation and concealer and that kind of thing. And I'm seeing men and nonbinary people being embraced and, you know, it's the same as happens in a lot of spaces where it's like, 'Yeah, that is fantastic, let's do more of that. But could we be part of it, too?'" She has found a few potentially useful products on GoFundMe pages, but that doesn't necessarily mean they are ready for purchase or universally available.

SIMPLE ADAPTATIONS

Some of the adaptations wheelchair users would like to see are simple. Brenda Gutierrez Baeza is a member of the County of Santa Cruz Commission on Disabilities in California. Her disability restricts the mobility in her arms, so she dictates her makeup looks

to her family and friends, who apply it for her step-by-step. She uses a Kinova Jaco Assistive Robotic Arm to help her do things like open doors but only has one device. "I was hoping that I'd be able to do my makeup with it," she says. "With most makeup products, you need two hands to unscrew a cap or twist the mascara bottle or whatever. So I wasn't able to do much of anything with my robotic arm. It would be nice for more products to come out for people with one arm so that it's easier for people to apply makeup without needing two hands."

Guide Beauty founder Terri Bryant made it her mission to create inclusion in the cosmetics industry after being diagnosed with Parkinson's disease. She is a makeup artist and educator who has created education-based programs for brands like Smashbox and Christian

Dior. When hand tremors threatened her ability to do her own makeup as well as makeup for clients, she refused to accept this reality without searching for a practical solution first, even if she had to create it herself.

Bryant developed prototypes for Guide Beauty tools at home and eventually developed a wand that looked like "a little finger puppet" to make it easier for her to apply mascara. She knew from her years of educating others on makeup application that what she created would help others, too. Her diagnosis gave her a completely new viewpoint to build a brand around.

"All of a sudden I landed in this unique perspective. I understand what it feels like to be a professional makeup artist and have that very natural, effortless movement with my arm. And now I could understand what it feels like



All that gorgeous glitter and pastel makeup made Lucy Richardson's Halloween mermaid costume elegantly fantastical.



Guide Beauty cofounder and creative director Terri Bryant designs makeup tools that are stable and easy to grip.

to have to disconnect,” she says, adding that makeup artists are usually the people invited into the room to develop application tools, which doesn’t help the average user, disabled or not.

TRUE INCLUSION

Though wheelchair users are not the exclusive target customer for Guide Beauty products, Bryant took the company’s quest for true inclusion seriously. When it came time to develop the products in the lab, she worked with a team that specialized in universal design. The goal was to “cast the widest net possible” with test users of all different abilities from a professional makeup artist to someone with rheumatoid arthritis or multiple sclerosis, for example. The team gave 200 testers traditional application tools and watched for what Bryant called “sticking points” in their process to figure out how to make tools to solve the biggest, most frequent problems for people with a variety of

experience applying makeup.

“The two greatest human factors we could really leverage in elevating the design were grip and stability,” Bryant says. “Now, when you look at a lot of traditional tools in makeup, you’re looking at these thin cylinders that encourage you to have a tighter grip that sort of locks up ... if you’re even able to grip. Some people can’t grip. But if you can grip that, what does that do to the whole arm, and is that comfortable?”

Stability is an issue if your hand is not rock steady. “If you watch people apply makeup, no matter skillset or ability, they’re always looking for ways to sort-of match the ground and steady their hand for application,” Bryant says. “So we thought if

we could build stability into the tools, if we could build those touch points that made it more comfortable, and if we could free up the hand and the grip, it would enhance the experience for everybody. Specifically, it would help people who couldn’t play in the world of makeup without doing that [holding a tool steady].” Guide Beauty produces a Lash wrap tool for applying mascara, a tool called Brow Moment for filling and shaping eyebrows, the Guide Line for eyeliner application, and unique eyeliner and mascara formulas.

Each tool has a “Guide ring” protruding from it that allows the user to loosely grip the wand with two fingers. This leaves the hand free to have a “lighter, softer” motion, explains Bryant. This also makes it easier to adjust your hand and steady yourself if needed. The Guide Line wand is also designed to allow the product to be applied vertically instead of horizontally so that your arm is closer to your face while applying it.

Bryant also paid attention to elements of her products that don’t seem to matter to accessibility on the surface — like product formulas and the thickness of the mascara wand. Guide Beauty’s wand is thin because Bryant said it’s a myth that fatter wands make for easier application. “Sometimes those bigger brushes [make it] harder to get to the base of your lashes. And so you’ll end up hitting the lashes too high and weighing them down. And then they don’t hold that nice, pretty curl that you want.”

She values “thoughtful moments” in formulas. So,

Guide Beauty’s mascara holds like it’s waterproof, but won’t damage your lashes like too much water-

Guide Beauty Full Collection



proof mascara does or smudge like a traditional mascara.

There are only a few Guide Beauty products in the complete line at the time of this writing and many of them focus on the eye. Bryant's dream is to create enough tools and formulas so that customers can have what she calls "the full Guide Beauty face" eventually.

Her development process might be slower than other cosmetics companies because she is committed to complete inclusion of people with all abilities at every stage. "If you feel like a product wasn't really designed for your needs, then why would you even bother to pick it up to begin with?" she asks.

She would like the cosmetics industry to dispel the notion that every makeup consumer should be able to pick up a product and automatically know how to use it. If companies take more responsibility for the usability of their product, physical accessibility could increase. For Bryant, another easy way to organically create true inclusion for people of all abilities in the beauty industry is to include people of all abilities in every aspect of product development from brainstorming the product to advertising it.

Makeup enthusiasts like Baeza and Richardson are also looking for tangible changes within their favorite cosmetics retailers like more space in the aisles, lower shelves, products that are easier to open, and mainstream attention for adaptive products. Baeza has a challenge for AI experts that dabble in the world of cosmetics. "If we want to picture a perfect world where anything is possible, then I would love to have a robot that does your makeup," she says. Why shouldn't she dream that big? There are robots that help people with mobility issues eat independently. We deserve ones that help us feel beautiful, too.

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Photo by Darlen Davis

A model applies makeup using Guide Beauty's Guide Ring.

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EVICTED: WHEN COLLEGES ABANDON STUDENTS WHO NEED LIVE-IN CAREGIVERS

BY TIM GILMER



Illustration by Mark Weber



What happens when an exemplary college for significantly-disabled wheelchair users encounters financial difficulties, cuts costs and ultimately abandons its historic mission to provide necessary everyday living supports for those who need them most? For dozens of Edinboro University students, the outcome was shockingly disruptive to their college progress and future plans. Furthermore, it deprived them of much-needed social interaction and a sense of community — both critical factors in overall quality of life, maintaining self-determination and continued progress in the battle for equality.

As disturbing and unjust as the Edinboro situation has been, it also serves as a warning of what may be in store for other university programs that serve disabled students who need personal assistance. The flip side of this ugly possibility — if it can be adequately envisioned and carried out on a national scale — could conceivably be a stable, self-sustaining model of how this nation finally makes good on the lofty ideals that underpin the Vocational Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. After all, higher education is the one best path to equality for this disadvantaged group. But how long will it take — and can it actually happen?

EDINBORO'S DEMISE

In September 2018, Edinboro's students who use personal assistance had made commitments for the academic year, including choosing one of the university's two fully accessible residence halls complete with the school's well-known 24/7 attendant care program. Then, when students were already situated on campus, they received shocking news from the administration — the program, which was over 30 years old, would cease to exist by the following May.

For 20-year-old Morgan Neumann, who uses a power chair and personal assistance due to spastic quadriplegic cerebral palsy, it meant her education — already well underway — had been upended. She had no idea how she would go on, where she would live or what to do. Like many of the 36 students in the program, she relied on round-the-clock personal care attendants for almost all of her everyday needs.

"The decision left most of us in the middle of our college career with a choice," says Neumann. "Either hire our own care and manage it" — something they had never done — "or transfer and lose credits and our happy life together."

"What made it worse was the terrible way the administration treated us. They fired the PCAs and support staff in the office of disabilities," says Neumann. "Students and parents were in tears when they announced it, and no one expected it. At the least, we hoped that they would grandfather in students who had already committed to the school."

Neumann, a communications student with a 3.9 GPA, found herself at a crossroads with no directional signs. "College was the most important thing to me, and my care needs are extensive, and my immune system is weak."

She and most of her Edinboro friends had come to Pennsylvania from other states. "We met at a summer camp out on Long Island, and we had always dreamed about going to college together," she says. "Edinboro was our best option." Their parents helped them move onto campus, and they began their college careers in an ideal setting. But only seven of



“Students and parents were in tears when they announced it, and no one expected it. At the least, we hoped that they would grandfather in students who had already committed to the school.”

the 36 students in the program could continue their studies at Edinboro since they were in-state residents with family members nearby.

MEAGER OPTIONS

Neumann's best friend, Courtney Allen, also a power chair user with spastic quadriplegic CP, was one of the lucky seven. She, too, came to Edinboro as a freshman. "I was in their attendant care program until it dissolved, but now I'm in the consumer-based option," she says. She moved into an apartment and arranged for care from a local private agency after Edinboro's program stopped. On campus, she had lived in Rose Hall next to Neumann. "We had the same set of aides, the same people. We took all our meals at the hall, and the aides were housed in the dorm in three different shifts."

But her private agency care option did not pan out. She had to move back home because staffing was so difficult. "The hours and pay for the aides are bad," she says. "For me, it's hit or miss, a lot of trouble. It's hard to find reliable aides. Since the uni-

versity is a state school, the workers there got a higher rate than they can get through a private agency."

Neumann, whose personal assistance needs are more extensive than Allen's, moved back home to Fountain Lakes, New Jersey, where her mother can care for her. She eventually enrolled in Ramapo College, a 19-minute drive away. "Before the pandemic, I got to live in a nearby assisted living apartment, but now I'm at home again. A PCA comes in, but only for two days a week. It is tough to find any good aides since the pandemic."

Part of the difficulty of maintaining adequate care comes from chronic poor pay. As of June 2021, Neumann says her aides made \$11.48/hour. By contrast, according to a 2018 Pittsburgh Post-Gazette article about the dissolving of the Edinboro program, the aides on campus at that time were paid anywhere from \$15 to \$28/hour. Many states have rates that hover near the federal minimum wage rate — \$7.25/hour.

The minimum wages of Alabama, Georgia, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Mississippi, New Hampshire, North Carolina, North Dakota, Oklahoma, Pennsylva-

nia, South Carolina, Tennessee, Texas, Utah, Wyoming and Wisconsin have been \$7.25/hour for at least the past 11 years. On the flip side, California and Oregon offer \$14/hour, the highest minimum wage, while New Jersey and New York's minimum wages are between \$12.00 and \$12.75 an hour.

Edinboro University's rates were exceptionally high, paid in collaboration with Pennsylvania's Office of Vocational Rehabilitation, which may have contributed to the university's decision to scuttle the whole program. From the students' viewpoint, the main problem was the administration's lack of transparency and warning, coupled with its decision to shut down the accessible dorm buildings and refusal to grandfather in existing students amid their college education. "Throwing the baby out with the bathwater" is an apt description of Edinboro's approach to solving its financial problem, and those students who were hurt the most were those who could least afford the sudden turmoil and financial strain.

As an early leader in establishing a wheelchair-friendly culture, Edinboro was considered for inclusion in NEW MOBILITY's *Wheels on Campus* guide. But our attempts to interview personnel from the university and current wheelchair-using students with the university's cooperation — the protocol used with all candidates for inclusion — were ignored. Higher-ups directed the assistant director of accessibility services to ask for our interview questions in advance, and NM complied by promptly sending them. When no response followed, NM followed up with emails and phone calls. After months of waiting and no reply, the decision was made to exclude Edinboro from *Wheels on Campus*.

THE NATIONAL PROBLEM

The disparity in PCA pay rates across the nation is more than substantial, and the difficulty of finding aides is not confined to Pennsylvania. Not only does each state have its own pay rate, but few states provide sufficient monetary motivation for job seekers to sign on for difficult hours and low wages. It is a nationwide problem, making moving from state to state especially difficult for students — and non-students — who need substantial personal assistance.

California, usually a leader in all things related to disability, has

been changing radically over the last several years. "We are going through a time of tremendous turmoil with PCA services in California," says Nancy Becker Kennedy, a longtime, dedicated disability advocate. "There is a big change between the states that unionized and the states that didn't. The ones that unionized got more money, California included, but I think we have lost much of our rights to freedom."

While aides in California get better pay due to unionization, a substantial downside affects wheelchair users who live in their own homes (such as students who reside near campus). Kennedy says the Service Employees International Union switched from a social model to a medical model, with much greater control and tighter rules, resulting in favoritism given to families whose wheelchair-using children live with them. It is a drastically different situation for those wheelchair users who live on their own. "They are treating us like we're under house arrest. They're putting EVV [electronic visit verification to track employees' hours] into our homes. We have lost our privacy and independence. They're limiting hours per day of pay, and it makes it much harder to get PCAs to come in for a few hours of work, twice a day."

Add to this the high cost of living in California, especially in urban areas. It becomes evident that the individual states with the higher pay rates usually have the highest living costs, reducing job seekers' motivation. Additionally, California micro-manages care from a centralized, unionized seat of power and follows a policy that limits caregivers' hours and works against the welfare of recipients and personal assistants.

California's EVV approach to verification of hours requires clocking in and out using a cellphone, making it virtually impossible to have a live-in aide since the new limitation on hours does not pay for time that is not strictly spent doing physical work of some kind. There is no incentive for aides to stay overnight in case they are needed — and that is sometimes when they are most needed.

This paternalistic approach is an overreaction to charges of billing fraud

“The hours and pay for the aides are bad. Since the university is a state school, the workers there got a higher rate than they can get through a private agency.”



Courtney Allen

and discriminates against those living on their own, including college students living on campus or in apartments. It is reminiscent of the federal government's earlier crackdown on Medicare billing fraud in durable medical equipment that resulted in "competitive bidding." Predictably, the bidding war was won by a handful of large national companies, resulting in long waits and fewer smaller equipment dealers, which DME advocates correctly warned would bring about dire service gaps, especially in rural areas.

Kennedy says this new crackdown on potential fraud in reporting wages includes a considerable windfall for Sandata, a national data tracking company green-lighted to install EVV devices in homes across the nation. Does this bring to mind echoes of *Big Brother is watching*? "It absolutely does," she says, "and it also scares off potential PCAs."

These changes result in an inequitable situation favoring large national corporations, families whose children live at home, and medical-model-minded managers who carry out the lopsided policies. In other words, as our top-down economy continues to favor large companies gobbling up smaller ones, we may be in for a prolonged time of "throwing out the baby with the bathwater" as a way of dealing with complex social problems. "We have come a long, long way — and not in a good way — from the days of Ed Roberts and the independent living movement," says Kennedy. Ed Roberts, the first wheelchair user to attend UC Berkeley, cofounded the independent living movement to help others with disabilities live where and how they choose.

MONEY: THE CAUSE AND THE SOLUTION

In the case of Edinboro and other colleges that have eliminated their on-campus PCA programs, the main culprit is financial distress, something that our national institutions of higher learning have been coping with for decades. A Feb. 22 article in *Forbes* chronicles the economic challenges facing colleges and universities:

"Colleges are not going to come out of this period [the

pandemic] and return to 'business as usual,' as too much has changed in the way we do business and the priorities of students." This prediction comes from economist Lucie Lapovsky, former president of Mercy College. Then she elaborates, forecasting that these changes could very well affect disability services and ADA accommodations across the nation: "Those schools, which have trimmed down and positioned themselves to be able to grow in new ways once the pandemic is over, will survive and thrive."

"Trimming down" often means doing away with those programs and services that are losing money. In that scenario, disability services are an easy go-to-choice for cutbacks, whether they are state-run programs or funded by universities. That is precisely what happened at Edinboro.

In his 2019 *Post-Gazette* article, Bill Shackner found that the small Pennsylvania university had been looking for ways to trim down since 2013. That's the year Edinboro began discussions with the state's Office of Vocational Rehabilitation to alter or end its decadeslong agreement to provide funding for the on-campus PCA program. The ultimate decision was to close down the PCA program. In this way, the school would save money by not repairing, upgrading or maintaining their two accessible dorms.

In other words, whether intentionally or not, Edinboro abandoned those students who most needed the specialized dorms as a way of solving its financial problems. Morgan Neu-

mann's mother, Julie, says the overall program change "gave them an excuse to get rid of the dorms."

Another part of the university's rationale for no longer providing PCA services came from a change in the OVR waiver program, which stated that reimbursable services must have an educational purpose. Therefore, in the minds of those who failed to see the critical need for attendant care in the first place, aides sleeping overnight in a dorm had no educational purpose.

EVEN EXEMPLARY UNIVERSITIES ARE AT RISK

In 2020, the leading university in providing a genuinely wheelchair-friendly culture, University of Illinois, Urbana-



Photo courtesy of UC Berkeley

Berkeley had an exemplary program for decades.

“ We have come a long, long way — and not in a good way — from the days of Ed Roberts and the independent living movement. — Nancy Becker Kennedy ”

HOW UC BERKELEY LOST ITS PCA PROGRAM. IS THERE A REMEDY?

Berkeley, California, has long been known for its progressive influence in the independent living movement. Due to the demands of Ed Roberts and the Rollin' Quads, the pioneering advocacy group that he cofounded in the 1970s, the University of California, Berkeley, created the Disabled Students Residence Program. The program provided personal assistance for up to about 10 students, all wheelchair users, to live in regular residence halls alongside nondisabled students and learn how to manage their care, according to Kevin Shields. He managed the program from 2008 until it closed in 2016.

When the Great Recession hit in 2008, the program began to be whittled down by, in Shields' words, "a thousand little cuts" in the form of regulatory changes by the state and federal government and UCB. Besides furloughing employees that year, the state Department of Rehabilitation changed to a "cooperative contract" with the DSRP, which according to Shields, "meant DOR continued funding at \$300,089 annually, but UCB would now have to match the price at 70%, with UCB staff doing special services related to the program."

At the same time, California's governor, Arnold Schwarzenegger, launched a \$50 million hunt for fraud in entitlement programs, which caused many cuts and changes that limited access to supports. Shields says less than \$1 million in fraud was discovered. Then in 2010, on the federal level, Republicans took over the House and Senate and passed an amendment to the Workforce Innovation Opportunity Act that limited the future of entitlement programs. The WIOA was "a great idea but resulted in no way to fund the web of complicated programs it created," says Shields.

California also passed a law in 2012 outlawing duplication in services, which prohibited DOR from funding DSRP's personal care program since the state already operated its own In-Home Support Services department. Also in 2012, the Service Employees International Union, which includes personal assistants, approved a step-increasing annual raise to its members, while DOR and Berkeley were unwilling to increase the DSRP budget. Consequently, the program laid off staff, dropping from 11 to two in just three years.

The last straw came in 2016, says Shields, "when Berkeley's Equity and Inclusion Division that oversaw the Disabled Students Program, which managed all accommodations for disabled students under the ADA, underwent a leadership change." The accumulated financial strain, internal strife and uncertainty took their toll, the result being UCB decided to close down the DSRP. The era of independent living at Berkeley as envisioned by Ed Roberts and the Rollin' Quads had come to an end.

"Despite a large public outcry, petitions and newly-formed groups, UCB would not back down on its decision, even though," says Shields, "the DOR was willing to continue funding."

Many similarities link the demise of the PCA residence programs at Berkeley and Edinboro, mainly relating to funding instability. While Berkeley's problems took time to gradually take down its storied program, Edinboro's collapse seemed sudden and shocking, perhaps due to a lack of transparency on the college's part. Other campuses nationwide who were pioneering leaders in disability services' residence programs have also had to pare down or limit what they can offer students.

When the problem is financial, the root cause seems clear. But given the confusing web of laws, regulations and bureaucracy, whose responsibility is it to provide funding?

Shields thinks that funding must happen on more than one front. For openers, the disability lobby, fractured as it is, has been largely ineffective in obtaining appropriate government funding. A stronger, more unified lobby is critical. Perhaps just as important is a public relations plan that can deliver a powerful and motivating message that influences the public, lawmakers and policymakers. But to make funding more consistent and reliable, Shields suggests colleges look to alumni to fund endowments specifically for residential care services.

Champaign, was faced with an unprecedented situation that brings to light another potential problem with delivering consistent, across-the-board support for students requiring PCA care and accessible facilities.

Unlike Edinboro, the University of Illinois has kept its vaunted dorm hall/PCA program operating for decades, right up to the present. But when the surge in COVID-19 cases hit home in 2020, the administration decided to temporarily shut down Nugent Hall, home to the university's Beckwith Residential Services, the contemporary caregiving model for excellence in higher education.

Rather than reacting to a situation brought on by financial distress, the university's response seemed to be driven by three different factors, all of which have become more important to colleges and universities and corporations throughout the nation — safety, liability and public relations.

Anyone who has a significant disability or works for a nonprofit that serves people with disabilities knows all too well the growing and dominant power of attorneys, whose job is to protect their clients from lawsuits and unfavorable publicity. When Illinois announced in July 2020 that it would have to shut down Nugent Hall for the fall, no one blinked an eye. On the surface, it seemed like the prudent, safe thing to do. That was the official reason given — safety — to protect not only those students who were seen as vulnerable, but also the university.

Barrett Patton, a student from Tennessee who came to Illinois due to the exemplary reputation of Beckwith Residential Services, was in his final semester of studies, living in Nugent Hall, where he received the daily care he needed as a power wheelchair user with CP. He was skeptical when he became aware of the university's plan to shut down Nugent due to safety concerns. "At first the reason they gave was they didn't have staff to support our needs. But other communications said it was deemed too risky to allow certain students to return." Right away, he began to read between the lines — "risky" can be a red flag for liability concerns, and "certain

students" strongly hints at the underlying assumption that wheelchair users, especially those who need daily help, are fragile and vulnerable.

While something as severe as the life-threatening novel coronavirus demanded extreme caution, Patton wondered why the university did not consult with the students and parents. Why did they have no voice in the matter? And why the mixed messages? Having been trained to be his own advocate for independent living by the university's disability resources program, he insisted that he have a say in the matter. With Patton as the point man, a group of eight students

who all needed care at Nugent Hall came up with their own potential plans, "the main one being to at least allow us to use the rooms," says Patton. "Even Beckwith administration would not express support. We even offered to supply all our own attendants."

Patton's main point has always been that policy decisions should include input from those whose lives will be most affected. So he started a petition that got over 5,000 signatures in just a few days. In a few weeks, he received a response from University Housing stating that his group would be allowed to use the rooms in Nugent Hall but had to provide their own staffing.

When classes resumed in the fall of 2020, Patton, as part of a group of five students with similar needs, was on campus, housed in Nugent Hall, but the five families had to pay PCA costs of approximately \$30,000 for staffing. The takeaway from Patton's experience points up the need for self-advocacy and mar-

shaling support in significant numbers to combat administrative policy changes that are certain to disrupt and potentially damage the futures of students who need caregivers.

"At the center of all this," insists Patton, "is self-determination."

WHAT WE CAN DO

On a potentially larger scale, Kennedy's experience with the state of California, which has a relatively large number of advocates and disability rights groups, shows what can happen even when strident and consistent protest and organizing is



evident. Too often, the authoritative sway of government and self-serving corporate entities and organizations results in ill-conceived policy changes that bring about harmful results; if not for all, then certainly for large numbers of people whose needs are disregarded. “In California, it’s like a ‘one-size-fits-all’ policy,” says Kennedy.

And scariest of all, more states are expected to adopt similar policies. Given the perfect storm of financial uncertainties building in our nation, how can we protect our community’s need for affordable and accessible higher education?

We need to anticipate unwanted consequences and build a national coalition that speaks with a unified voice to protect access to personal care and truly accessible campuses. We also need effective proactive advocacy from state to state, especially in this era of states looking for ways to make budget cutbacks. Every bit as important, we need to insist on being included in discussions about policies and laws that affect our ability to live meaningful and fulfilling lives.

Our strategy must include influential advocacy groups like United Spinal Association, ADAPT and other powerful organizations with our best interests in mind and speak with authority about legal and civil rights matters. Surely the Vo-

cational Rehabilitation Act of 1973 and the Americans with Disabilities Act provide authoritative and sound mandates for effective policies that guard the equal rights of those whose lives are at stake. The ADA’s promise of reasonable accommodation can be applied and enforced in higher education, but will the Justice Department be willing to act as the enforcer? More than likely, the DOJ’s Civil Rights Division will only act when influential disability organizations lead the way.

But we can go beyond advocating for our rights. We also need to win over legislators and policymakers by educating them about what our community has to offer when we transition from receiving services to paying taxes. And more: We need to tell our stories about successfully surmounting barriers and obstacles as a way of life.

We are the experts in this regard, and the mainstream public needs to see and hear it, time and time again. Hopefully, lawmakers and policymakers in sufficient numbers will begin to understand how spending money now on needed day-to-day personal care services in general, but especially in higher education, is an investment in our future. And by “our,” I mean our nation as a whole.

MM

- Detailed info on the Top 20 Wheelchair-Friendly Colleges, researched and written by wheelchair users

- Personal stories and photos of wheelchair-using students at every school, plus advice from successful grads

- Resources and scholarships for wheelchair users



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Meet the Parking Protectors — Avengers for Access!

BY JOHN BEER

If you polled people with disabilities on what superpower they'd choose, the ability to enforce disability parking would likely be near the top of the list. Eighty-five percent report having problems finding accessible parking, according to the International Parking & Mobility Institute. Sixty-two percent say they'd be more likely to go out if accessible parking were more available.

Telling this to NEW MOBILITY readers is preaching to the proverbial choir. But what if you could skip the hassle of calling the police and hoping they show up? What if you could

write the ticket yourself? Or snap

a few photos on your phone and file a ticket wirelessly? In some cities across the United States, you can.

Houston, Austin, Omaha, Portland, Oregon, and Onondaga County, New York, have volunteer parking enforcement programs that train people with disabilities and their allies to become avengers for access. The parking protectors are people with disabilities, family and friends, seniors, veterans, retired doctors and lawyers and anyone else who knows the importance of access. "They have a passion to want to make those parking slots available for disabled people," says Chuck Slaney, head of the Portland Police Bureau's Disabled Parking Enforcement Unit.

Jacob Wacker, a C5 quad from Portland, jumped at the opportunity to volunteer

and be a part of the solution. "There are very few situations where someone in a wheelchair can volunteer on the police force to make a difference in something that directly impacts them," he says.

Parking enforcement volunteers typically have no minimum hours or scheduling requirements. Each city has different rules for where enforcers can give tickets. "We don't do anything on the streets," Slaney says. "We have tons of private lots. We fill that gap."

Maria Irshad, assistant director of ParkHouston, that city's street parking agency, is thankful for the extra "eyes and boots on the ground." "There are hundreds of thousands of ADA parking spaces," she says. "I've got 35 [paid ParkHouston] officers. Police do enforce ... but they have other priorities that they need to be focused on."

Richard Armor, 73, is one of 57 fully trained volunteers in Austin's enforcement unit. Armor has a neuromuscular disorder and is on dialysis, but he checks ADA spots on his daily runs to supermarkets, Walmart or Home Depot. "I do not have a lot of time to do the job as often as I would like to because dialysis takes a lot of time, but I do love doing it," he says.

"All the people with disabilities that I know who are on the program do find it fulfilling," says Nancy Crowther, 63, who has participat-



ed in ADA parking enforcement since 1993. She checks around Travis County, where Austin is located. "They're enforcing what should be enforced in the first place, but it's awesome."

As a chair user with spinal muscular atrophy, her stake is personal. But she's a happy warrior, and along with her diligence comes a playfully pointed sense of humor. "I get in trouble, but I say, 'Look, vengeance is mine,'" she laughs. "Do you know how many times I've been cheated out of a parking space because some yahoo has their grandmother's parking permit placard on the mirror?"

"Having a disability myself and having earned the disabled placard, I certainly find it appalling that people would cheat that much," she says. "I'm really excited when I find some that have been altered to change the dates on the placards." It's fairly common, she says, to find the placard with expiration dates changed from threes to eights, besides all those that are expired, stolen or misused. "I want to help enforce the rules, but I also want to educate the community to let them know it's not right."

TICKET WRITING BOOT CAMP

In Austin and Houston, volunteers complete a state-required four-hour training. In Austin, two of those hours are spent in the field with a parking enforcement officer. Volunteers are given a ticket book, reflective safety vest and identification badge, all required when patrolling.

Portland's training under Slaney is broader, stretching over weeks. In addition to proper filing of citations and photos, there's a moot court to prepare for testifying. "We want to make sure that not only does the volunteer feel safe, but also the volunteer is under-

standing what the law is, and they're able to explain it to the citizens as well as be able to explain it to a judge."

Founded in 1991 by officers Clyde Harmon and his brother Stanley, who sustained a spinal cord injury in an on-duty shooting, Portland's Disabled Parking Enforcement Unit varies from 20-35 volunteers, many over 50 years of age, more than half of whom are veterans. Three use wheelchairs.

Volunteers submit monthly worksheets recording their time, mileage,

"DO YOU KNOW HOW MANY TIMES I'VE BEEN CHEATED OUT OF A PARKING SPACE BECAUSE SOME YAHOO HAS THEIR GRANDMOTHER'S PARKING PERMIT PLACARD ON THE MIRROR?"

spaces checked and citations written. Slaney uses the metrics to identify problem areas and times to tell volunteers about. In January 2020, pre-pandemic, they checked over 9,590 slots and issued 139 warnings. "Our basic job is to educate the public. It's not to write citations," Slaney says. "I mean, we will write citations, but we want to educate the public first what the spots are for, right?"

Wacker appreciates the emphasis on education. "There's a human element to where [the people we ticket] learn these accessible areas are there for a reason," he says. "A lot of people can't get out of their vehicles and may end up having to park blocks away. We all have been there, so it's nice to be able to educate someone face-to-face with a hopeful outcome that they don't park in a wheelchair accessible spot again."

Houston's Disabled Parking Volunteer Program, established in 1995, is one of the largest in the country, training more than 400 people who issue on average 8,000-9,000 tickets a year, each costing drivers \$500. Irshad puts active volunteers at 120, many with "a huge personal stake in it," having disabilities themselves or loved ones who do.

One is Tina Williams, 53, who uses a chair due to transverse myelitis. She's been volunteering since 2009, and soon she'll start keeping her ticket book in her bag again for her trips around town, including meetings of the Houston Commission on Disabilities, where she's a commissioner working on access issues like parking. "Some people just directly go out to write tickets," she says. "My schedule is too crazy for me to do that."

In over 10 years of volunteering, Williams says, "I've never had negative feedback," which echoes volunteers in all cities. "Ninety-nine percent positive," Crowther says. "People understand what we're doing and why we're doing it."

"They just come out of the woodwork all over and say thank you for being out here doing this. I bet you I get 10 a day, and I hear the same from the volunteers," Slaney says. Often people bring up



DAVIS

somebody in their lives affected by the issue. “We’ll get stuff on the phone calls saying, ‘You know, I really appreciate you guys being out there.’ They’re always surprised that we’re volunteers because I think they think we’re getting paid.”

CONFLICT

But in tens of thousands of contacts, rare confrontations have happened. In 2019, two Houston volunteers suffered minor injuries in separate incidents. A car pulling away from one scene made contact with a volunteer, and a Texas woman was indicted for allegedly slapping another.

“Probably less than 1% are just plain not happy they’re getting a citation and say, ‘I’ll see you in court,’” Slaney says. He says he’s never had anybody attacked.

Houston volunteer Williams doesn’t stress about it. “It’s actually done so fast that you’re gone by the time they come out of the store,” she laughs. “I write fast.”

Volunteers are trained to cite unattended vehicles and to walk away from uncomfortable situations. “If you’re gonna ticket someone, don’t talk,” Crowther says, “and if you’re gonna talk, don’t ticket.” But there is another strategy: app-based ticketing (see sidebar).

With America reopening, the parking protectors are getting out there again. “I went out today already. You know, it becomes an automatic thing,” Crowther says. “You just develop the awareness how you’re always kind of looking. ... Because I can’t not look.”

Asked why she’s going back to it, Williams hesitates to call the work fulfilling. “I think that the work is needed.” Her voice sets with determination. “I think that it’s important, because it’s not a victimless crime. For me, it’s necessary — it has to be done.” **MM**

An App for Giving Tickets

Parking Mobility is a free app available on all platforms that guides smartphone users to snap photos and fill out ADA violation reports that are reviewed daily by staff and forwarded to authorities. Mack Marsh, of Austin, Texas, developed the app because he knows that parking access can be a matter of life and death.

Blocked from entering his parked vehicle after his son’s ballgame, Marsh, 53, passed out from heat stroke. “It was early on after my spinal cord injury, and I didn’t realize that I didn’t sweat, that my body didn’t regulate its temperature,” he says. He and his son were whisked away by ambulance so quickly that “the violator never even knew it happened.” That is why his data-driven app focuses not only on ease-of-use but also education.

Travis County, Texas, and the city of San Marcos, Texas, accept Parking Mobility reports, and Marsh says the model could be expanded to more areas as users generate enough data of local violations. Currently it has over 100,000 users around the globe.

Users can find disability spaces by checking the locations of violation reports, all vetted for accuracy by staff. From a volunteer’s point of view, especially one with limited hand function, a phone-based system eliminates the need to handwrite paper tickets or to reach and place them on vehicles (usually under windshield wipers). “I use a power wheelchair,” he says, “and if I tried to put a ticket on somebody’s windshield I’d scratch their car.”

Parking Mobility is also part of an offender-education program that Marsh helped put in place, offering reduced penalties to offenders if they attend a class about access. It was an educational alternate for prosecutors who were seeing most cases dismissed because judges were reluctant to im-

pose heavy fines. “They didn’t want to punish people, they wanted to change their behavior,” says Marsh. He adds that of 15,000 who have gone through the class, only six have reoffended.

The other advantage is its covert nature, reducing the chance of a confrontation. Marsh says average recording time with photos is 43 seconds. The app’s undercover appeal is a favorite feature of fellow Austin enforcer Nancy Crowther. “People are kind of like, why are they taking a picture of my car?” she says. “Sometimes they ask, and I go, ‘It’s a nice car, yeah, I like it.’”

Parking Mobility is available via Google Play and Apple’s App Store.



Mack Marsh

LATE TO THE GAME:

THE GOOD & BAD OF SUSTAINING AN SCI WHEN YOU'RE OLDER



Once Terri Wickstrom extricated herself from the nursing facility she ended up in, she regained the freedom to live her life as she chose.

According to those who know these things, people who sustain spinal cord injuries today are nearly 14 years older than their counterparts from 40 years ago. In 1980 the average age of a person sustaining an SCI was the late-20s, but now it's 43. We're often quick to assume young people are more adaptable. Still, these four wheelers who became injured as established adults show that older sometimes really is wiser — and often has better insurance.

EXPERIENCE HAS ITS ADVANTAGES

Jeff Kletzmayer joined the SCI/D club in September 2018 by falling off a roof and sustaining a T12 injury. He was 52 years old. The fall also left him with two torn rotator cuffs, two shattered ankles, a broken pelvis, and sundry other scrapes and bruises. Technically speaking, he was all buggered up.

Due to all the physical complications, Kletzmayer's rehab was delayed, and when he did receive some rehab, it lasted a mere month. As a result, he was a bit behind from the beginning. "I broke my left femur within the first year and had gallbladder surgery the next," Kletzmayer recalled. "I believe I received poor medical care with the femur problem, setting

me back at least a year. I lost a lot of mobility in my left leg." He added that simply staying healthy enough to gain mobility sometimes felt like a full-time job.

Initially, Kletzmayer was extremely uncomfortable in crowds, often feeling like he was in everyone's way. "Getting through a crowded room is still very difficult," he says.

When asked about the emotional aspects of his accident, Kletzmayer says he deals with a bit of depression but that when he does, "I think of my family, and it brings me back." He is still adjusting, learning new tricks, remembering old ones and dealing with issues as they arrive. Fortunately, Kletzmayer's home was already set up quite well for him, which allowed him to quickly learn how to get through his days.

However, the emotional aspects of adjustment were somewhat different. "I thought I could figure all this out on my own. After maybe a year, I found and joined a support group, which has helped a ton," he says. "It also confirmed that my experiences are fairly universal."

Did being injured at a later age give him an edge? He believes so. "I had an established career, so I think dealing with this was easier being older. I was pretty much ready to retire," he says.

He also repeatedly expressed a great deal of gratitude for his financial standing, especially in contrast to many who must rely on Medicaid and SSI or SSDI. "After running a successful business for 23 years, along with having good health insurance through the company, I don't have the struggles many others have," he says. "I have a little extra cash to afford the items that make independence more achievable."

ON HER OWN TERMS

Terri Wickstrom, 58, has used a chair for about six years after sustaining a C6 injury in a bike accident. She says those years have been challenging. Before her injury, Wickstrom enjoyed being a cyclist, hiker and runner, so getting used to life as a wheelchair user was quite the jolt. "I enjoyed getting in the dirt," she says.

Following acute care, she did three months of so-so rehab at a general hospital. "The rehab I got there wasn't nearly the quality you get at an SCI center because the staff is much more familiar with stroke than SCI. Plus, I was the only person with an SCI receiving rehab, so I didn't have others to commiserate with," she said via email. She went to live with her brother for a short time, but that didn't work out. As a result, she went to a nursing home, where she could not practice much of what she had learned in rehab.

Her time in the nursing home was dark indeed. "I hated living there, and because of that, I came to hate the chair as well," she says. "They wouldn't allow me to transfer in and out of bed, most likely due to liability issues. The environment made me feel very dependent." Being surrounded by sickness caused her mood to suffer a great deal. She compared the facility to prison since she could not set her own schedule, eat what she pleased and go about her life unimpeded.

Yet another downside of living in the institution was her inability to access outpatient rehab at nearby Craig Hospital, as Craig's policy requires people to live in the community rather than in a facility.

Once Wickstrom extricated herself from the nursing home and found enough assistance with dressing, light chores and cooking, she finally regained a decent quality of life, free to do as she pleased and simply live on her own terms. As a bonus, she could access Craig for PT sessions.

She says she never went through a self-pity phase. "I don't dwell on being in the chair. This is just the way it is now," she says. "I try to accept what comes and live in the moment." As for age at the time of injury, Wickstrom regrets not being younger simply because she would have been more limber.

She now relies on religion and prayer for assistance. "Talking to God helps," she says. "I also look for things to be grateful for."

REFUSING TO BE DETOURED

Bill Fertig was 45 in 1999 when he got in a motorcycle accident that left him with 30 fractures, three of which were SCIs, and a traumatic brain injury. It took nearly a year for all his injuries to heal. He functions as a T7 complete para.

At the time of his injury, Fertig was in his 25th year working as a police officer. Having to give up the job he had dreamed of since he was a teen was tough to deal with, but Fertig refused to abandon his passion. His first post-injury employment was as a 911 emergency call-taker/dispatcher. He later secured a private investigator's license and began working cases for a local law firm.

Fertig says it only took him a day or two to wrap his head around his future as a wheeler before beginning to move forward and learn what he needed to live successfully with SCI. "There was no, 'Why me?' he says. "I was a big boy. I knew motorcycles were dangerous." The driving force behind that mental shift was his wife. "She quickly reassured me we would have a good life despite my SCI."

Anger, however, was another matter. "I was moving forward productively and hopefully, but I think the frustration of not being able to do this or that, or home/auto maintenance like in the past, caused a lot of frustration that came out as anger directed at those that were closest to me," he recalls. He profoundly regrets making it harder on his family that first year.

"Faith helped me with overall perspective as I fought back after sustaining my SCI," he says.

With the help of his wife, he battled to perfect their home modifications and find new ways of doing things. "We were a team, doing what was necessary to live successfully with SCI." Other than those fits of anger, he says his primary adjustment was to accept no longer being in law enforcement.

He recalls those early days with a smile. "We were so unorganized at first that it turned comical. But over time, we got faster, quickly learning more of what to do and how, until it



If Kletzmayer ever feels down about his injury, he thinks of his family and that gets him through.



As long as his wife, who he calls his soulmate, is by his side, Bill Fertig says he can deal with anything.

became second nature,” he says. “When I was injured, I’d been married to my wife, my soul mate, for 25 years, and together we tackled and overcame the common problems associated with life with SCI.”

Now 66, Fertig continues to work as the director of United Spinal Association’s Resource Center, offering help and information regarding home modifications, returning to work and low-tech, affordable personal transportation options.

SHE LETS FATE GUIDE HER

Shubha Ratnaparkhi’s introduction to life on wheels came at age 57 in the form of Guillain-Barré syndrome, which stole almost all of her physical abilities. “At my worst, I was unable to blink my eyes,” she says. She spent four weeks in ICU, followed by two months on a ventilator, then two more months in a longer-term active care institution, culminating with four months in a sub-acute care facility.

“Frankly, I had no time to think about anything,” she says. The whirlwind left her with the equivalent of C6-7 quadriplegia. Guillain-Barre involves the peripheral rather than the central nervous system, affecting the nerve endings that talk to muscles and impacting the ability to breathe but leaves sensation relatively intact.

“But here’s the thing,” she says. “I was old — I’d lived my life. I had few regrets because I always tried to live in a regret-free manner, so I was OK with it.”

She finds the dependency that comes with her condition to be her biggest challenge. “You have to put up with the pa-

tronization, even from strangers,” she says. “You have to get used to being invisible or treated as an imbecile. There are things you know how to do but can’t because of your limitations. You see the weeds but can’t pull them. You see something beautiful but are afraid to touch it for fear of breaking it.”

Ratnaparkhi describes Guillain-Barré as a condition “where you hit the bottom and then keep climbing up,” which led her to ask, “What now?” rather than “Why me?” And “what now” has led to near-total independence as well as some walking.

Religion is not central to her life, though she does believe in a benevolent God, which she says “makes it easier because it saves me from the anxiety that this is God’s punishment for me. I believe He has confidence that I am up to the challenge. So, in a way, religion does have an influence on my adjustment.”

Philosophy interests her more, and she points to this quote by Roman philosopher



Shubha Ratnaparkhi expressed gratitude she got Guillain-Barré later in life rather than earlier, noting that she has no regrets.

Seneca: “Fate leads the willing and drags along the reluctant.”

“Fate brought GBS in my life, but I still have a choice in how I deal with it,” she says. She has yet to adjust fully to her circumstances as she continues to improve. “I view this as a temporary state. If I ever plateau, I’ll try to adjust to my circumstances. Right now, it is still an adventure, with a goal to achieve and work to do.”

LIFE EXPERIENCE CAN SMOOTH THE WAY

Toby Houston, Craig Hospital’s director of psychology, would find many of the reactions and ways these older SCI survivors dealt with their injuries unsurprising.

“My experience has been that older individuals tend to demonstrate better coping and adjustment, at least during acute rehabilitation. Older people tend to have lived a life that includes some previous experiences with loss, managing uncertainty, grief,” he says.

Houston says older individuals can often use those life experiences to help manage their emotional reactions to injury. He adds that older people are more likely to be in

longer-term relationships that have some stability. Long-term shared commitment relieves older people with new injuries of the concerns about meeting someone new and being accepted.

However, there is one area that may be more difficult for established adults — navigating role changes. “Many are more likely to have established roles within their relationships — husband, wife, parent — and there can be unique challenges posed by threats to long-standing identities,” he says. “Someone who viewed themselves as the primary breadwinner, the financier or the steady emotional guidepost/problem solver for family members may need to explore what it will be like to shift roles. That can be more challenging when those roles have become comfortable over a lifetime.”



OWN IT

By Regan Linton

DATING AND ACCEPTING CARE

A lot of what I read under the heading of “dating and disability” doesn’t adequately address the complexities of the endeavor.

Articles with terrible titles like “What It’s Like to Date Someone in a Wheelchair” often elevate the non-disabled perspective. They focus on a basic approach for people who suddenly freak out when attracted to a wheelchair-using coworker and worry about encountering some Matrix-y otherworld if they go out for a drink. The illustrations are generally horrible stock photos of someone who clearly does not have a disability sitting in an antiquated wheelchair staring off into the distance at a beach.

There are also the opinion pieces that dissect the question of how you should present yourself on dating platforms when you have a disability: “Do you show your chair, or do you let your date be surprised?” Are we *really* still discussing this?

We’re getting screwed when it comes to addressing the more nuanced topics of dating.

Where’s the article on how to respond to the sad excuses for messages that only we disabled folk are lucky enough to get from potential dates? Here are a few of my all too real favorites, along with the responses I wish I had sent:

“So, I guess dating you comes with some pretty sweet parking!” *Good one, dweeboid.*

“Do you believe in healing? I’d like to introduce you to my friend. He’s, like, a spiritual guru. Maybe he could help

you.” *Sure. And too bad I don’t have a friend who is a plastic surgeon because clearly, you’re an assface.*

“What happened to you?” [I tell them.] “Oh, I’m so sorry for you.” *Not as sorry as I’d be after a date with you. Thanks for sparing me that.*

Where are the articles that address how disability can be an asset in dating? First, you automatically weed out any suitors who aren’t comfortable with human vulnerability and authenticity. Second, you have deep and meaningful life events to discuss right off the bat. And third, options for dates are immediately narrowed, so you don’t waste your time going through lists of inaccessible activities that neither of you was interested in anyway. For that, I say, “Thank you, wheelchair.”

But there is one topic I feel is woefully under-addressed: accepting care.

Now, I’m not talking about necessary post-injury routine care like bowels and bathing. That’s certainly important, and there are amazing partners who provide that sort of assistance to many in our community. But sometimes, it feels like that’s where the conversation on “care” stops, and we forget about the myriad of types of care that show up in our lives regardless of our bowel functionality.

From sitting with someone while they make a difficult phone call to giving a massage or washing a car, these are things that people want to do for each other, regardless of disability status.

You’d think I would be able to accept care, being that I have had no choice but to get it so much. After

“In the conversation on ‘care,’ we often forget about the types of care that show up in our lives regardless of bowel and bladder function.”

all, I’ve had 19 years of paraplegia-related surgeries, hospital visits, therapy appointments, alternative wellness visits, and caregivers spanning doctors, nurses, PTs, OTs, social workers and family members.

Yet, here’s what I recently realized: My care has predominantly been compulsory and transactional. When I’m sitting in the waiting room of the outpatient clinic at the rehab hospital, it is straightforward and easy for me to accept that I am a human being who requires care. But in the realm of dating, relationships and love? Not so much.

Over the past two decades, I’ve conditioned myself to feel like I only need or deserve care as far as I can pay for it. Or as far as it is expected to be given. Or as far as it relates to my disability. Beyond that, the idea that someone would actually want to care for me — that they would think, act and exist with my well-being as one of their priorities — often scares the shit out of me.

I blame hyper-individualist American values that have seeped into my psyche, along with the societal messages around disability — that we are

better, more acceptable or more desirable if we constantly push for greater independence, and that the less care we need, the stronger and more valuable we are. We can probably thank the for-profit health care system for that, too.

Because of that ethos, I have become care-receiving-challenged.

Recently I started dating a guy who, by his very nature, is a caregiver. Awesome, right?! He wants to do all these fantastic things for me, from cuddling and celebrating my accomplishments, to bumping me over curbs or cleaning my bathtub. What a winner. And he accepts my care, too, from head massages, to giving him input on cologne choices, to talking him through challenging friendship dynamics.

But I get stymied by the push-and-pull of care politics. I get frustrated when he helps "too much." I feel the need to assert my right to ask for help rather than accept it when he offers it or just does it, as though I need to maintain some measure of control through the act of the request.

In my opinion, figuring out the logistics of sex amid paralyzed parts or getting accessible tickets for a concert date are the easy part of dating. The most challenging part — regardless of disability — is determining the framework of care for another person: how and when to give it, request it, offer it, expect it, need it. It's hard to figure out the extent to which you can expect someone to want to care for you, or that you can accept it while not getting pegged as "needy" or "clingy," or having the relationship characterized as something other than a romantic partnership. It goes far beyond disability, but disability is one factor in it.

There is no straightforward answer or approach to the politics of care. It requires communication and honesty about what each human being can do, what they need, what makes them feel safe and respected and whole, and how much

they're comfortable giving of themselves.

We must remember that we people with disabilities are not the only ones who move through the world needing care. Some of our vulnerabilities might be slightly more obvious thanks to the wheeling pics on our dating profiles. But every person out there is porous and vulnerable, with injuries, insecurities, feelings and lots of baggage. Everyone has flesh, blood and spirit that need

to be tended. Frankly, on every dating app profile page, there should be a little flashing GIF that says, "Note: This human requires care."

As we put ourselves out there, we must do so with the belief that we deserve the care of another, regardless of disability. We must believe that people want to care for us in all the many ways humans do ... and we don't owe them a tip at the end of the meal.

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OUTDOOR TRACKS

By Kary Wright

GETTING RACE READY

There I was, sitting in a rented place during the long winter in the pandemic, feeling quite house-bound. I dreamed of getting another van since mine was consumed in the fire that destroyed our house and nearly all of our possessions. I hadn't driven anything for months and feared that my muscles were getting weak from no activity.

When I told my friend Landon as much while chatting online, he made a suggestion that changed everything: "You need to race online. It's fun and great exercise!"

Landon became a quadriplegic from a crash while racing motocross and is a racer extraordinaire. Since his injury, he has adapted many vehicles and sold me my adapted ATV buggy. Much of his driving ability and strength comes from a hand control driving simulator he built. It affords a realistic way to get used to hand controls, builds reaction times — which I need! — and is great exercise.

I texted him to send a picture of his setup, and he responded with a photo showing a racing steering wheel mounted on a desk with three big-screen TVs in front of it. The steering wheel had a tri-pin and hand controls, just like in an actual vehicle.

"The steering wheel is force-feedback, and you can turn the feedback up as you get stronger. I literally could only drive it for 10 minutes



With three HD screens, a headset, a joystick and a steering wheel, Kary Wright gets a fully immersive driving experience that helps him prepare for driving in the real world.

when I started and now can race for hours with the feedback turned up quite a bit," he said.

He told me the wheel was worth around \$300 but quickly found a spare — a Logitech G25 (newer models now available) — and offered it to me. It didn't have foot pedals, but that wasn't a problem for me. I suggested using my Thrustmaster T Flight HOTAS joystick for the throttle and brake, and he recommended using a simulator called Project Cars 2.

"You can configure input devices since there are lots of different tracks and cars, and a joystick

should work fine," he said. "The game costs about \$60 on Steam, but there are sales often."

On Black Monday, I arranged to pick up the wheel from Landon and ordered three 42-inch 4k TVs and HDMI cables. Landon texted that the software was on sale for \$20, so I downloaded it. Finally, I hit up Amazon for some headphones so Landon and I could chat while racing.

"Your wife's going to hate me because every time we chat, I give you more stuff to buy," he teased.

"This'll get me out of her hair," I replied. "All's well!"

Need for Speed

Since then, we've been hooking up and racing in the evening. The simulator is very realistic and so much fun. Some of Landon's friends join sometimes. We can see all the cars. They're labeled, so you know who they are. When you tap another car, the steering wheel gives a satisfying shake. The force-feedback on the wheel is very realistic — you can feel the road, and if you start to slide, that road-feel allows you to drift and get it back under control, although you'll still crash if you push it too hard or over-correct.

The setup allows me to practice driving inexpensively with hand controls anytime I want. My joystick is configured so that pulling back operates the throttle, and pushing forward applies the brakes, just like in an actual vehicle. The simulator helps me get used to how the road feels and recover from a loss of traction. Braking quickly and steering around sudden obstacles become automatic. It also helps with driving in traffic.

I recall driving my real-life van one night, and two large round bales appeared in the headlights. Without a thought, I dodged left and avoided the first one, then right to avoid the second one. It was all automatic, and I'm confident that was because I'd encountered similar situations on the computer. That was many moons ago, and the new simulators are light-years ahead of what I had in those days.

Since setting up the simulator, my morning "exercise" involves at least half an hour of intense racing, usually in an old muscle car like a 1966 Mustang (I love the engine sound). Often my arms are sore after this, and they're the right muscles to exercise for driving. Evenings bring another opportunity to race with Landon online.

After a few months of sim-time, we purchased an adapted van, and I got behind the wheel. My friend David and I putzed all around town with no trouble at all. Of course, there will be tinkering and tweaking to make driving more comfortable and reduce fatigue, but that is always the case for me when I drive anything new. David noticed right away that my steering was much better and stronger after a few months of racing.

And Landon?

"I want to drive everything!" he says. He drives an adapted van from his wheelchair, a sporty "Hot Wheels" Mustang, a pickup truck, a Rhino ATV, lawnmowers and who knows what else.

Using my adaptive setup with the

simulator has been an excellent, fun and exciting way to relearn to drive with hand controls. It hones my skill, drastically reduces reaction times and builds strength. It's a great addition to anybody's exercise program and would be a fantastic tool for rehab facilities to help teach driving skills.

When I was first released from the hospital, I was told that I wouldn't be able to drive, as I was too weak. Our family purchased a van with zero-effort steering, and I proceeded to try anyhow. At first, I could drive for about five minutes, but day after day, my brother and I practiced, and soon I was up to a half-hour. A year later, I could drive for hours. With a jump-start from a simulator, I'm sure it would have gone much faster.



Wright's friend Landon (above) has used a home driving simulator to build up the strength to drive his fleet of vehicles.

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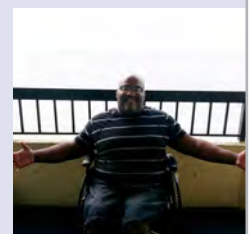
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PATHWAYS TO EMPLOYMENT

United Spinal Association's Pathways to Employment (PTE) program supports the pursuit of new job opportunities and a successful career for people with spinal cord injuries (SCI) by providing the tools and support necessary to successfully overcome barriers to gainful employment.

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

Meet New Member Dave Smith

Age 48, from Maysville, Georgia
Spina Bifida
Volunteer Social Media Technician
for Real Identity Ministries



Why I joined United Spinal: I joined United Spinal to learn about the experience of other people with disabilities. I also felt that it would give me a chance to meet others with similar experiences and health issues.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? I would change how people in wheelchairs are perceived by able-bodied people. People tend to think that since we are unable to walk, we cannot be smart and do some of the same things that nondisabled people can do.

Meet other members or join United Spinal at unitedspinal.org

LAST WORD



SPINOUTS

WHAT IF THE DISABLED GUY DOESN'T WANT TO CLIMB THE MOUNTAIN?

In 2011, our staff collected disability stereotypes and then skewered them for our first (and only) April Fool's Issue. One trope we wrecked was the Supercrip. He's the guy who swims oceans to raise money for the cure or whatever. Sure, that's laudable for anyone. But what if he just wanted to chillax at home watching Netflix instead?



NM LIVE VIDEO SERIES with Teal Sherer

SEPTEMBER GUEST: ROOTED IN RIGHTS EDITOR-IN-CHIEF EMILY LADAU

Demystifying Disability: What to Know, What to Say, and How to be an Ally, the debut book from celebrated disability rights activist and storyteller Emily Ladau comes out Sept. 7.

As the editor-in-chief of the *Rooted in Rights* blog and a contributor to outlets like *The New York Times*, *HuffPost* and *NEW MOBILITY*, Ladau is an experienced author. Still, she tells Teal that writing *Demystifying Disability* was especially meaningful for her. She also shares advice for fellow creators and lets viewers in on one of her favorite non-disability-related things.

WATCH THE NM LIVE VIDEO SERIES HERE:

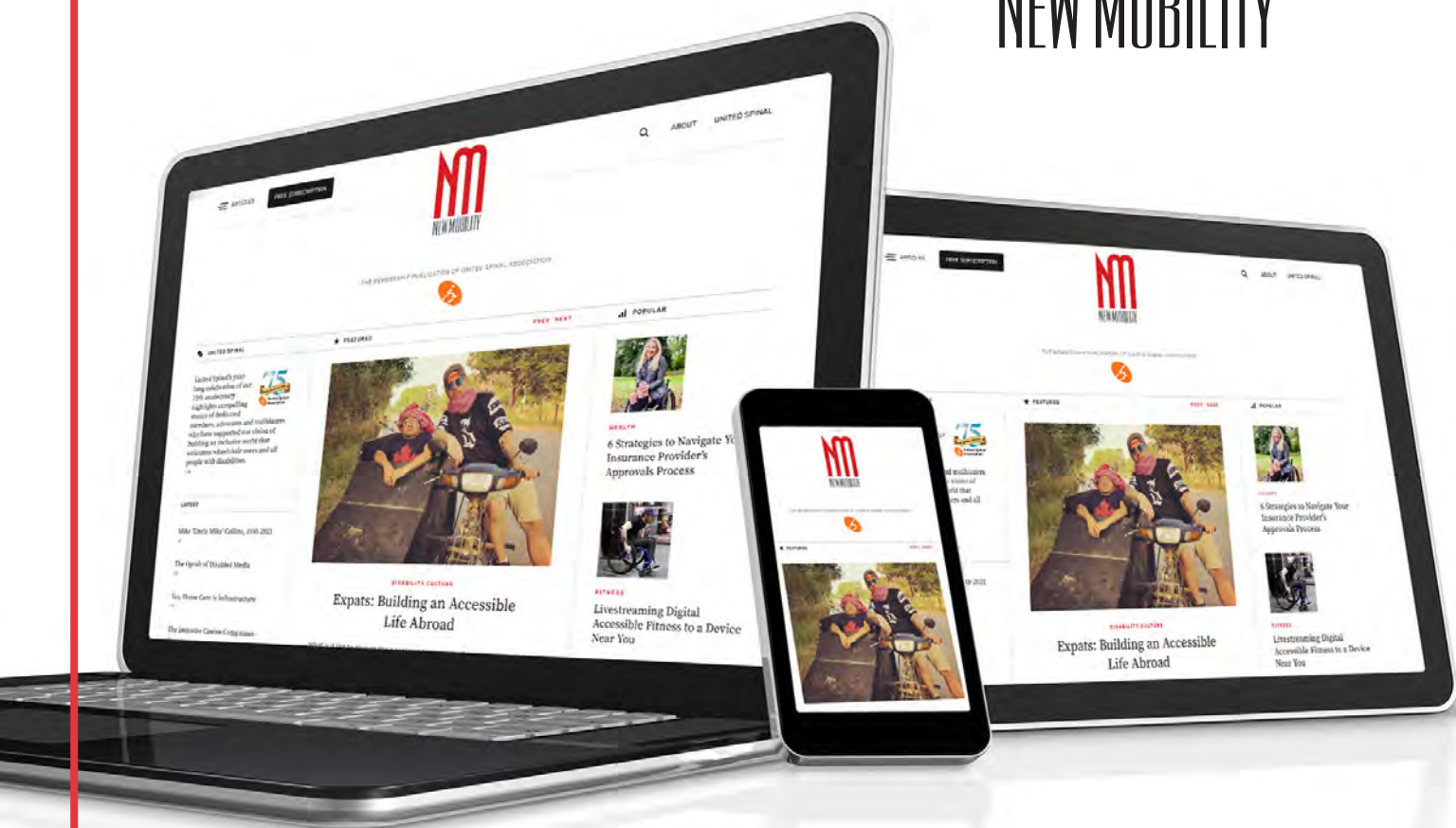
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