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IAN RUDER wore out the tires on his power chair to see how Grand Teton and Yellowstone National Parks rate when it comes to accessibility. He left wanting more of the beauty, more of the serenity and — bummer — better access. MATT KEENAN shares tips on how you can make the most of your next camping trip, whether you go to Wyoming or elsewhere.

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As I grow older, all the numbers in my life grow larger — age, weight, waistline, mistakes made, dollars spent, stories written, letters received. Everything goes up except my IQ. With all the numbers that weigh me down, there is one that will always remain my favorite — number of Bully Pulpits I have written. It is one of my favorite things to do. I've lost count, but I know I have written more than 200.

My first BP, which ran in the December 2000 issue, was an attempt to tell you, the faithful readers of NM, that I was just like many of you, someone who had been dealing with paralysis since the age of 20 (I was 55 then), someone whose life had been interrupted violently by an accident that seemed to come out of the blue. I wanted you to know where I grew up, something about my childhood, and I hoped that you would not be disappointed that my words would now fill the space that Barry Corbet's words had filled for the previous nine years.

Barry was beloved by so many readers — many who came to NM in its infancy — and rightly so, while I was not well-known at all. At that time, I had only written three or four stories for the magazine. Even though I was relatively new to the culture of NM, I was not new to disability and had many years of teaching writing and freelancing behind me, so I felt I could handle the job. Now here is the surprising part. I know now, after more than 17 years as editor of NM, that the job has handled me.

It has challenged me, supported me, molded me, made me grow, given me a passion for advocacy and fulfilled me. I realized this most recently when I cut back on work hours due to medical problems, and I began to miss the daily contact with my NM colleagues, readers and the ongoing issues that we all face. Lying in a hospital bed, the issues do not disappear, but they tend to become secondary to more basic concerns, like survival.

But that is what we all face every day of our lives — how to go on, struggling to maintain control when the challenges continue to mount. Despite the difficulties, and sometimes because of them, I have found these past 17 years that four things tend to make life worthwhile and enjoyable — close relationships, being part of a larger community, fighting the good fight and keeping a sense of humor.

“I have found these past 17 years that four things tend to make life worthwhile and enjoyable — close relationships, being part of a larger community, fighting the good fight and keeping a sense of humor.”

And one more very important thing: being able to imagine a future. It’s hard to envision what comes after retirement. Rest and travel, like money, only go so far. Many people who leave behind the work they love begin to feel a palpable void.

If this sounds like a farewell, it isn't. Not quite yet. I have one more BP to write for our June issue, and then comes retirement. In the meantime, I’ll be hard at work imagining a future that — God willing — flows naturally from the past.
CONTRIBUTORS
Our Staff and Freelancers

REVECA TORRES
Paralyzed in a car accident at the age of 13, Reveca Torres started a nonprofit for people with SCI/D called BACKBONES in 2009 to ensure others, especially those newly injured, had access to information and peer support like she had. She is the founding member of National Coalition for Latinxs with Disabilities and director of ReelAbilities Film Festival Chicago. She has also curated photography and art exhibitions that showcase the work of people with disabilities and bring awareness to disability rights. She uses her own illustration, photography and film to express herself and as a tool for advocacy and social justice.

ALLEN RUCKER
Allen Rucker has been a contributing editor and columnist with NM since 2008. He is the author or co-author of 13 books, including a memoir of life after paralysis, The Best Seat In The House: How I Woke Up One Tuesday and Was Paralyzed For Life. He also currently chairs the Writers Guild of America’s Writers with Disabilities Committee, co-chairs the annual Media Access Awards, and lectures widely on disability issues. He lives in Los Angeles with his wife, Ann-Marie.

MATT KEENAN
Matt Keenan is a 24-year-old student working toward a degree in therapeutic recreation at San Jose State University. He spent most of his adolescence tramping around the mountains of Northern California, “had an encounter with gravity” during a climbing accident, and sustained a C7-8 spinal cord injury as a result of the fall. These days he likes to spend his free time cooking, traveling and rolling around in nature. He hopes to bring confidence and happiness to people’s lives through writing about his experiences in nature.

Want to contribute to New Mobility? Please send queries and manuscripts to Ian Ruder: iruder@unitedspinal.org
An Emerging Star
Thank you for the article by Reveca Torres [Reframed: “Shadows and Light,” March 2018], a truly remarkable, original, moving piece of writing. I hope that Ms. Torres will continue to write, and in longer formats, such as an autobiography or a short story. She is an insightful, poetic communicator, an emerging voice of endearing grace and sweetness ... and, more rare, an optimistic kind of bitter-sweetness, yet in the end, positive. This reminds me of a hidden spirit breaking free, which I haven’t seen so effectively expressed since Kurt Vonnegut’s short story, “Who Am I This Time?” Brava!

Nathan Wise
Old Saybrook, Connecticut

Ethereal Floating
We were in Israel last June with my daughter, who is a vent dependent quad [“Rolling in the Holy Land,” March 2018]. Fantastic experience. They even got her into the Dead Sea.

Ellen Coe
NewMobility.com

Bureaucracy to Blame
No doubt we are dealing with one of the most inefficient and blindly stupid health systems around [“The Cost of Profit-Driven Health Care,” NewMobility.com, March 15 blog]. That said, it’s unrealistic to assume that all the shortcomings are attributable to profit-seeking. Some of the bureaucratic idiocy is the nature of administration, whether profit-based or not, and some highly-specialized, low-sales-volume medical equipment is just extremely expensive to research, design and manufacture. Folks with similar conditions in Europe may not face the same kinds of issues, but I imagine they can relay some stories of their own. Our system could be hugely improved, but only the current White House occupant thinks that doing so will be quick, simple and easy.

Kevin Lavrack
NewMobility.com

Through the Gauntlet
I’ve been through all the operations you’re going through – many times [“Hospital Production Line – On the Slab,” NewMobility.com, March 1 blog]. The stage IV pressure wound, the osteomyelitis, the IV antibiotics, the colonoscopy, the colostomy, the debridement, then multiple flap surgeries, all the doctors, the Clinitron beds, the nurses, aides or techs, months in bed, followed by extensive rehab — such has been my fate and experiences since 2004. I’m a T4-5 complete SCI para since 1978. I’ve survived and am doing pretty well now. They made me get a power chair capable of reclining “if I wanted to live.” I hate it, but I’ve adjusted to it. ... At this point, you can’t fight what has happened — go with the flow, but don’t take any shit either. I’ll be pulling for you and following your experiences.

Pete Smith
NewMobility.com

Bag Solution
I use The North Face Access Backpack. It opens easily with the flip of a button and has space for a laptop and other things, with easy access pull tabs to get everything out. It also has lots of space in the main compartment [Gear Hacks: “Backpacks and Under-Chair Bags,” March 2018].

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Despite years of progress, the media's coverage of people with disabilities and the issues pertinent to us all too often remains condescending. Instead of investigating and reporting on disability news, reporters get lost in warmhearted, patronizing platitudes. The coverage of two recent events — the death of physicist Stephen Hawking and the Pyeongchang Paralympics — provided contrasting examples of the good and the bad of mainstream coverage.

Stephen Hawking’s Death
When Stephen Hawking died March 14, the world’s media outlets were awash with obituaries and tributes to one of the most influential and famous physicists of our time. There were a number that got things right, treating his disability as one part of the much broader story of his life. But right there along with the respectable coverage was the ableist drivel that we’ve come to expect from media representations of disability.

In the lead sentence of its obit, CNN had this to say: “the brilliant British theoretical physicist who overcame a debilitating disease to publish wildly popular books probing the mysteries of the universe, has died.” The Washington Post wrote that Hawking "overcame a devastating neurological disease." A physicist who devoted his life to increasing humanity’s understanding of the universe, Hawking has said his disabilities “have helped me in a way by shielding me from lecturing and administrative work that I would otherwise have been involved in.” But as far as easy tropes to color an obituary go, “devastated” and “overcame” both fit nicely.

The misplaced focus on Hawking’s disability wasn’t limited to traditional media. An illustration that became a viral meme showed a nondisabled shadow with very nice posture strolling away from a power wheelchair toward a glorious cosmic sunset, with the hashtag #RIPStephenHawking. The Twitter thread that followed is filled with responses mentioning that Hawking was very publicly atheist and railing against the insipid metaphor of death freeing him from his wheelchair.

To be fair, the pushback wasn’t limited to pissed off disabled people on Twitter or niche disability publications. Teen Vogue — which has become a publication with surprisingly progressive, thoughtful coverage of political and cultural issues — published a piece by Keah Browne, herself a wheelchair user, that dissected the problems of the “free from his wheelchair” sentiment. Men’s Health published a similar piece, and USA Today corrected some ableist language that appeared in its own obit and followed with a story that discussed the kind of backlash that the use of such language to discuss Hawking has caused.

The positive note here is that in the not too distant past, all of this backlash from the disability community never would have made it beyond our own echo chamber.

Pyeongchang Paralympics
On the other end of the disability in media spectrum is The New York Times’ recent coverage of the Pyeongchang
Paralympics. They sent only one writer, Ben Shpigel, and a photographer, Chang Lee, but the two managed to produce some first-rate sports reporting that rivaled the best of the Olympic coverage. This is due in part to the talent and inquisitiveness of the duo, but also the editors at the Times. Shpigel describes their directive as such: “Feel free to explore a range of subjects and trends ... but don’t write traditional profiles of particular athletes, no matter how compelling their back stories may be.”

The result was wide-ranging reporting that was entirely absent of the typical “overcoming the adversity of their disability” profiles that usually dominate Paralympic coverage. Instead, readers were treated to an analysis of the financial reasons that military veterans are filling an increasingly greater percentage of the U.S. contingent, a piece on why many of the world’s sled hockey teams are getting older and older, and the transition of training for the Paralympics from a part-time DIY affair to a professionalized full-time job, among others.

In the article “Steve Cash Was Already the World’s Best Sled Hockey Goalie. Then He Got a Coach,” Shpigel focuses on the coach and the inner workings of USA Hockey, in addition to the brilliance of Cash’s goaltending. Cash’s disability is mentioned in the same manner as his 5-foot-7-inch height: only in relation to the sport. “Cash offsets the size disadvantage with agility, speed and an economy of movement and equipment. Unlike many other single-amputees — Cash lost his right leg to bone cancer at age 3 — he protects himself with discreet shin pads, not the bulky versions that allow a sprawled goalie to eliminate the lower part of the ice.”

After reading all of the coverage surrounding Hawking’s death, those two sentences were refreshing. They treat Cash the same way any good sports reporter would treat any athlete, rather than admiring him for something that has nothing to do with his sporting genius. It’s true that single, lower-limb amputation is a very different, and perhaps less-uncomfortable disability for society to wrap its collective head around than ALS. But the framework behind the way Shpigel talks about the disability in all his Paralympic reporting is more or less what the disability community has been demanding for decades — focus on the person not the disability, and mention disability only in the context to which it’s relevant.

Shpigel’s articles prove that you don’t need to dangle disability like a juicy piece of bait to catch the interest of mainstream audiences. This kind of thoughtful writing may be in the minority in a wasteland of clichés and stereotypes, but it is out there.

— Seth McBride
To protect the environment, fewer restaurants are offering plastic straws, and some cities are banning them. We asked for your thoughts on Facebook.

Stephen Feldman: Great question and one I would have never considered. The anti-straw campaign is hardly one I’ve followed closely but I can only imagine that the forces and funds organized behind it would easily (and sadly) quash a disability-community-initiated backlash.

Tim Vermande: I guess I’ll bring my own. Some stores have stainless steel straws.

Li Starita: It would be easier if restaurants recycled, offered a recycling bin for paper and plastic.

Judy Brewer Sutherland: Buy and take steel straws and re-use.

Jonna Lannon: We carry our own — I don’t think they have any idea of the effect some of these bans have on those of us who have different needs. We are trying to inform them.

Karla Berglund Hughes: We are part of the solution by bringing our own re-useable straw, in addition to using our own cloth napkins at restaurants that use flimsy paper napkins.

Susan Scofield: Amazon sells a bunch of different types of durable straws. I just ordered a package. It won’t be as convenient, but it will be more responsible. I liken this to buying my own grocery bags — once I get in the habit of using them, it’s not a problem. And we are saving the ocean, folks.

Beth Szychowski: Look at this company: Glass Dharma makes amazing and safe glass straws, glassdharma.com.

I think the “ban” idea is over-the-top. Straws should be available but only on request and when a notably thoughtful waiter or waitress realizes an individual might appreciate the option. In my opinion, paper straws are pretty much worthless and metal straws are a hassle outside of the house.

— Brook McCall
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How to read food labels is a question I often get asked. People with mobility impairments — like stroke survivors and people with MS — are at increased risk of strokes, so I cannot stress enough how important it is to know which fats to eat and/or avoid. Spinal cord injury survivors are at high risk for weight gain and developing type 2 diabetes, so it is essential to know the sugar content of the foods we are consuming. Individuals with cerebral palsy are more likely to have high blood pressure, making awareness of daily salt intake vital.

Here is a quick lesson on how to interpret health claims made on food packages, decipher nutrition fact labels and clarify ingredient lists.

First off, whole foods don’t need a label, and unprocessed foods such as whole grains, legumes, fruits and vegetables also need no explanation, so focus on eating these types of foods.

Also, beware of health claims made on packaging. If a label has to convince you that it’s good for you, it’s probably not. For example:

- “Contains omega-3” is often seen on bread, juice and even margarine containers. Yes, omega-3 fats are indeed very good for us, but here quantity counts. For instance, it’s recommended that we get 3-4 grams of omega-3 fats a day. However, when omega-3 fats come from sources added to foods such as margarine, you’re only receiving approximately 0.3 grams per teaspoon, which means you’d need to eat about a half cup of margarine to get your daily requirement. Enjoy a piece of fresh fish instead.

- “Made with Whole Grains” is often displayed on cereal boxes, which may contain a smattering of whole grains, but may also be made from processed white flour and a ton of refined sugar. Read the ingredient list. If it is indeed made from whole grains, it will be the first ingredient on the list — not white flour or sugar.

  - “Light” (one of my favorite misleading label examples) does not necessarily mean low in fat or calories. It can actually mean light in color or taste. Or in the case of olive oil, “lite” or “light” refers to the more processed versions, which are less healthy.

  - “Low in Fat” means no more than three grams of fat per serving. However, fat makes our food taste great and gives us a sense of satisfaction, so if it’s low in fat, then it may be high in sugar and/or salt to provide flavor — not a good thing.

  - “No Sugar Added” refers to refined sugar, not natural sugar. So, it might mean no refined sugar has been added to a heck of a lot of sugar already there.

  - “Low in Sodium” is allowed on food packages if the food contains less than 140 mg per serving. It is estimated that the average individual consumes two to three times the amount of recommended salt every day and that 75 percent of it comes from processed food. The best way to reduce sodium is to avoid processed/packaged foods.

Above is an example of a nutrition facts label, in this case for macaroni and cheese. When examining the calorie count, make sure you look at the serving size first. Are the calories listed for the whole package or just a portion of it? This can make a huge difference on calories consumed.

When reading the ingredient list portion of the nutrition facts, ingredients are listed from most to least used. If sugar is one of the top three ingredients, I recommend you don’t buy it. Also, beware of:

  - Unhealthy hidden fats listed as vegetable oils, hydrogenated or partially hydrogenated fat.

  - Hidden sugars listed as fructose, high fructose corn syrup, corn syrup, glucose, sucrose, lactose, maltose, invert sugar, corn sweetener, fruit juice concentrate, brown sugar.

  - Hidden salt listed as sodium chloride (table salt), sodium bicarbonate (baking soda), disodium phosphate, sodium caseinate, MSG (monosodium glutamate), sodium sulfite, sodium nitrite.

Don’t be fooled by labels. Learning how to read food labels properly can help you eat your way to better health.
They say you should go into a job interview with a firm, confident handshake. Paralysis has made my handshake floppy and weak, but it remains confident. I always reach for the handshake, even when the recipient is skeptical and awkward at touching my hands. I deserve the dignity of touch.

So, I drop stuff all the time and I look funny when I eat.

When I wave to children, it looks like I’m waving a fist and they wave back with a fist, too.

Everything that is childproof is impossible to open and therefore quad-proof.

Opening a bag of potato chips requires a combination of mouth/hands/chest tag-team skills.

In the morning, the palms of my hands have a stinky, sweaty smell from being closed all night.

I’ve learned to be accurate at knuckle texting.

The lady who does my manicure always messes up at least once because my fingers will spasm.

Most of the zippers on my jackets and bags have rings so I can loop in with my thumb and open them.

I love speaker phone.

I’m totally predictable when playing Rock, Paper, Scissors.

My hands have personified touch. They are utilitarian. They act sassy. They express tenderness. They exude confidence. They elicit sensuality.

Honestly, they don’t move gracefully nor will they ever be models. They may not be up for every task, but together their problem-solving is impressive. When they choose to participate in my conversations, I notice the person I’m talking to gaze from my eyes to my hands. For a moment I’m embarrassed, but I dismiss it because I am excited about what I am saying. I refuse to feel shame.

And sometimes, my hands just don’t cut it. They let me down. So someone else’s hands are my hands. And that’s OK, too.

“I’m totally predictable when playing Rock, Paper, Scissors.”
Sometimes I feel I’m asking a lot from my everyday manual chair. I want my wheelchair to slip between narrow store aisles and public bathroom stalls as well as push over grassy fields and dirt trails. I want it to be fast enough to take my dog for a run and not be marooned on the sidewalk — feeling the shame of the unprepared owner — when she decides to pop a squat.

There are occasions when having a dedicated off-road chair would be nice, but for everyday use I want to be able to roll off the pavement without having to think about it. Thankfully, with a few modifications, an everyday chair can be versatile enough for the city and the trail.

**Casters**

Front casters are an important component of rolling over soft ground. Small, narrow casters that come standard on many models of manual wheelchairs are prone to get caught up on small rocks, roots and other protuberances and send you sprawling to the dirt. Changing your front casters is an easy fix to make your everyday chair better equipped for off-road wheeling, but there are a few things you need to consider.

First is caster diameter. The bigger the front caster, the more easily it rolls over rough ground and avoids digging into soft surfaces. But putting bigger front casters on your wheelchair will raise your front end, giving the chair more dump. This isn’t necessarily a bad thing for off-road wheeling, as having more dump can give you a more stable base to push from. But anytime you change your seating position, be careful to watch out for skin issues, as sometimes just a small change can lead to big problems.

Also, if you have any camber in your wheels, changing the front-to-rear height ratio will affect your toe in/toe out. This can make your wheels scrub and roll less efficiently. Chairs with one or two degrees of camber won’t be affected noticeably by putting casters that are bigger by an inch on the front, but the more camber you have, the more effect you’ll feel. You can remedy this by either moving your rear seat height up to match bigger wheels and/or tires, or switching to a camber bar or inserts that have zero degrees of camber.

Those fixes beget their own considerations, so if you don’t feel like messing with all that, an easy upgrade is to simply get wider casters that are the same diameters as the ones you currently run. You can get a pair of forks and wide casters from TiLite, FrogLegs and Box Wheelchairs, among others, that start around $200, depending on caster diameter. Even if you don’t increase the diameter, you’ll be amazed at how much better a wide caster rolls over the rough stuff.

Another option is buying a Freewheel 12-inch front wheel attachment, which many wheelers swear by. At a cost of $600 and up depending on style, I think it’s a fine product and have one myself. But my everyday chair setup is functional enough in most off-road environments that I only use the Freewheel if I want to do some serious trekking, like pushing significant distances on surfaces such as gravel or soft dirt.

**Tires**

If you spend a lot of time rolling off-road, a set of rear wheels with knobby tires are a must. Fortunately, fatter, mountain-bike style tires will fit on a standard width wheelchair wheel, so you shouldn’t need to buy a dedicated set of rims. Most people who’ve been in a chair for any length of time have at least one set of old wheels sitting in a garage or closet. Knobby tires are readily available for standard-size wheelchair wheels of 24, 25 and 26 inches. In my experience, bike shops have better prices and variety than wheelchair specific stores — a basic MTB tire can run you anywhere from $20-40 and up per tire. But be careful with sizing, as 25-inch wheelchair rims take 26-inch mountain bike tires. To avoid confusion, give your shop bike-industry metric sizes — 540mm, 559mm and 590mm, respectively.

Another thing to consider is axle length. Because knobby tires are wider than typical wheelchair tires, they can rub on sideguards or clothing if you have tight
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Changing to longer axles with spacers (made with wheel bearings) adds more space for knobby tires, so they don’t rub on sideguards or clothing.

Seating Position
Center of gravity is a tricky beast — too much and it’s damn easy to flip over backwards, but too little and you’re putting more weight on your front end, making it harder to wheelie and easier for your casters to dig into rough ground. Over my 17 years of being in a wheelchair, I’ve found that I’m able to handle more tippiness than I, or my therapists, ever would have thought. Moving my center of gravity farther back puts me in position to use more wheel when I push, and it also makes my front casters float over small obstacles much more easily. Sidewalk cracks, roots, rocks and gravel — everything is a little easier to roll over when you have more weight on your rear wheels and not on your tiny front casters. A number of manual wheelchairs, like the TiLite TR I use, have an adjustable center of gravity. It can be worth playing with your CG to find the right balance point, something that is both safe and functional for your pushing purposes.

All of these hacks will make a difference on their own. When combined, they should give you the option to transition from pavement to dirt with little, if any, forethought. If you have any questions or comments, please email me at smcbride@unitedspinal.org and we can continue the conversation online.
Quick Study
Dallas Jordan Disbro

Two years ago, over Memorial Day weekend, Dallas Jordan Disbro was in the hospital recovering from SCI. Today he is living independently, working at his old job and riding the high of organizing a hugely successful fundraiser for his local chapter of United Spinal.

Using Financial Skills for Good

“It’s crazy,” says Disbro. “I’m just someone who keeps so busy that time flies. I’m very active and always doing different things. It’s kind of crazy how fast time goes.”

Time didn’t seem to be going so fast in the immediate wake of Disbro’s injury. After hundreds of successful dives as a collegiate diver, one freak dive off a dock damaged his C5 vertebra and stuck him in a hospital watching his friends enjoy the start of summer. “The toughest weekend for me, knowing where everyone was at and where I would have been, was the Fourth of July,” he says.

Disbro resolved to look forward and stay positive from that point on and saw an immediate uptick in his rehab. Despite both sides of his body functioning totally differently, his left side lagging way behind his right, Disbro relearned to stand and walk a little with crutches. More importantly, he gained the skills to move directly from rehab into a situation where he was living independently.

“That’s literally all I wanted,” says Disbro. “My parents wanted me to move back to North Carolina for a little bit or they wanted to stay with me, and that was not part of my plan. I moved into an awesome apartment complex in Washington, D.C.”

Thanks to supportive managers who helped push for the accommodations he needed, Disbro was back at work as a financial advisor for Merrill Lynch in April, less than a year after his injury. “I was anxious to get back to work after rehab and it turned out to be easy,” he says. “All I needed was voice recognition software and an updated schedule.” He recently celebrated his first year back by posting what may be his best quarter yet. “I’ve really been pushing,” he says.

That pushing hasn’t been limited to self-improvement. Feeling a strong need to give back and help others in the SCI/D community, Disbro signed on to be the treasurer for the Washington, D.C., chapter of United Spinal. The opportunity to apply his business skills and personal experience was a perfect fit. “There’s just so much room for growth, so much room for improvement,” he says. “Between Harsh [Thakkar, the chapter president] and I, we’re really making moves,” he says. “We are working on getting more member engagement with our...
chapter through events, fundraisers and mentoring groups. It’s exciting getting more people involved and active in the local SCI community.”

On February 25, the Metro DC Chapter held Wheel 2 Win, a 3-on-3 wheelchair basketball tournament and the chapter’s first big fundraiser since Disbro came on as treasurer. The all-day Sunday event, held at Yates Field House at Georgetown University, drew 20 teams of three to five players and was a huge success. “I couldn’t believe how well it went,” says Disbro. “We want this to become an annual event for years to come and keep getting bigger. It was a lot of stress, a lot of work, but it was so worth it.”

The money raised will support the local wheelchair basketball team, the organization and scholarships for people in the community with SCI/D who need them.

Disbro is proud of how far he has come in the last two years but isn’t content. “I want to be as successful as I can within my career and also when it comes to impacting or inspiring lives,” he says.

I used to be a big dancer, and not being able to dance on my feet is definitely the number one thing I miss. For a while I worried that I couldn’t be in a relationship with someone who didn’t know me before my injury because it was so important to me that they knew how I danced. I still have a great time doing 360s and wheelies and those types of things, but I was so light on my feet and I liked to swing dance and flip girls around.

This past July, I got together with a bunch of friends in Ibiza. I used to live in Spain and I studied there. This was my first time back since my injury. We had a big party and it was tough not being able to run on the beach and dance with all my friends. But my friends are great and have been an amazing support system. They said, ‘No, you are coming with us!’ They’d just pick me up, or I’d piggy back on them, and they made sure I did almost everything with them.

For a while it was so important to me that people knew who I was before and how actively I lived my life, but then I came to realize that people see me as the same Dallas whether I’m in a chair or not.

"Why I Joined United Spinal": A lot of people raised money for me after my injury, and I wanted to start a nonprofit for people who didn’t have financial support or health insurance to get what they needed. I found out there was already a United Spinal chapter near me, got in touch and signed on to head its fundraising committee.

PRO TIP: I’m not really good at clenching my legs to hold a drink or whatnot, so I actually have dual KneeRover cup holders on both sides of my chair ($14.99 on Amazon).
Since its inception in 2012, Roll on Capitol Hill has served as an annual rally to educate lawmakers about the needs of the SCI/D community and to train the next generation of advocates. This year’s event, held June 24-27, couldn’t come at a more important time with numerous threats looming over our community. Thankfully, United Spinal’s voice will be stronger than ever, thanks in part to the rapid growth of advocacy efforts at the state and chapter levels.

For people with disabilities, it hasn’t been the best couple of years to follow the national news. With attempts to weaken and dismantle the Affordable Care Act, threats of huge cuts to Medicare and Medicaid, and the House of Representatives passing H.R. 620, it can often feel like the tide is against us.

Yet when you take a closer look at the issues most relevant to our community, there have been just as many recent wins as losses. Yes, Congress tried to repeal the ACA, but disability activists and protesters helped save it. The Centers for Medicare and Medicaid Services put into place a permanent policy that exempts complex power wheelchair components, such as cushions and headrests, from Medicare’s competitive bidding program. The tax overhaul ultimately retained many essential disability programs that had been on the chopping block. Veterans also scored a win during last year’s Roll, when the Accountability and Whistleblower Protection Act, which United Spinal advocated for, was passed and signed into law. This law helps U.S. Department of Veterans Affairs leadership maintain a healthy workforce by removing bad employees more efficiently, which, in turn, helps the agency fulfill its mission effectively.

Many of these successes are direct results of hard work and activism from the disability community. United Spinal’s policy team, headed by Vice President of Government Relations Alexandra Bennewith, has been leading the fight on behalf of the organization. Central to its work has been an effort to grow United Spinal’s community and grassroots advocacy network. Each of the six regions across the country now has an advocacy coordinator, and those coordinators are quickly working toward identifying an advocacy coordinator at each of the 50 chapters across the country.

Brook McCall is the grassroots advocacy manager for United Spinal, focused on growing and setting up the communications channels for this nationwide advocacy network. “There are lot of people in neighboring states or across the country who are doing parallel advocacy work, but people don’t know about it,” she says. “We’re getting that communication line set up so that everyone will know if they’re working on parallel issues, they can connect and learn from one another.”

McCall hopes the network can get more chapters involved in advocacy efforts. “It’s not as daunting as a lot of people think it is. Legislators really want to hear from us,” she says. “I’m just trying to be a spokesperson for getting people involved and taking it,” she says. “We’re getting that communication line set up so that everyone will know if they’re working on parallel issues, they can connect and learn from one another.”

Accessible Arizona hosted a Roll on Arizona’s Capitol in January that focused on legislation to increase the number of accessible showers in new multi-unit housing projects. The Greater Atlanta chapter hosted a Rare Disease Day to speak with state legislators about the needs of that community. The Richmond chapter recently got legislation passed that requires Virginia to keep data and a registry of all spinal cord injuries in the state. Members
from both Richmond and Atlanta joined up with a group called Warrior Momz to rush the U.S. Capitol in March to demand better access to and insurance coverage for activity-based therapies.

“We kind of just learned how to be a citizen and talk to the policy makers and voice our needs and concerns,” says Sharon Drennan, chapter leader of the Richmond, Virginia, chapter.

The state-level events may all have been advocating for different policies — measures that make sense for individual chapter's states and communities — but they all share one thing in common: They came about from what organizers have learned attending ROCH. “Last year was my first year that I went, and I had such a great time,” says Gina Schuh, who serves as chapter leader for Accessible Arizona. “I really saw the amount of impact that it can make, and it inspired me to do it on a state level.”

Drennan echoed similar sentiments. “It’s always been inspiring and motivating for me,” Drennan says. “It’s how I learned to be an advocate. If I didn’t have that experience with ROCH, I wouldn’t have the confidence or the know-how to do what I’m doing locally.”

“Because we have United Spinal, we have so many people we can reach out to for help first. There’s no way I would have continued on with what I’ve done if it weren’t for ROCH,” adds Kim Harrison, of the Greater Atlanta chapter of United Spinal. “By the time we were done [at ROCH] we just all had goose bumps from our last meeting because it was so productive. … You just felt like you had moved the whole world in one day by one person taking interest and actually caring about what you’re saying.”

Bennewith and McCall say getting attendees excited about advocacy is one of the biggest goals of ROCH. Thanks to the new advocacy network there is more support than ever to help state leaders advocate on the local level. By being active throughout the year, individuals and chapters can start to build relationships with their local policymakers, to the point where policymakers feel that they can reach out to United Spinal folks for information when they need it.

It’s only by being visible, building relationships and advocating for the things that are essential to our lives that we start to see substantive change. But as anyone who has attended ROCH can validate, advocacy is a lot more accessible and fun than it might seem. As Harrison puts it, “I don’t care what anyone says, one person can make a difference, and you will. You’re gonna love it.”

POLICY PRIORITIES

The policy priorities for the 2018 Roll on Capitol Hill are centered on three of the most pressing issues for people with disabilities — travel, healthcare and the ADA.

Air Travel Rights

Sen. Tammy Baldwin (D-WI) and Rep. Jim Langevin (D-RI) are championing air travel rights for people with disabilities with the Air Carrier Access Amendments Act, S. 1318 and H.R. 5004. The bills would:

- Increase penalties for damaged wheelchairs, and allow air travelers to sue in court to recover damages.
- Ensure higher standards for accessibility, safety, and airport and airline employee training.
- Help create a Passengers with Disabilities Bill of Rights along with a federal advisory committee on the air travel needs of passengers with disabilities.

Healthcare — There are a number of healthcare priorities, including:

- Fight against ACA repeal-and-replace efforts, and preserve the prohibition on insurance companies discriminating against people with pre-existing conditions, while advocating to reduce copayments and deductibles for eligible ACA enrollees.
- Advocate for the correct rehabilitative therapy for the SCI/D community.
- Oppose cuts to Medicaid and ensure people with disabilities have the rehabilitative benefits and pharmaceutical and medical equipment coverage they need such as:
  - Ensure individuals who use manual wheelchairs have access to needed complex rehab technology — seat cushions, backrests and other essential components — by supporting H.R. 3730, which would make Medicare exempt these items from its competitive bidding program.

ADA — Stop a Senate companion bill to H.R. 620:

- Earlier this year, the U.S. House of Representatives passed H.R. 620, the ADA Education and Reform Act, a measure that would require a person with a disability to give a business a notification letter and wait no less than 120 days before filing a lawsuit when encountering a physical barrier. For it to become law, the Senate would have to pass a companion bill. ROCH attendees will be making sure senators understand how this “notification and cure” provision violates the civil rights of people with disabilities and actually leads to more barriers to public accommodations, not fewer.

VetsFirst

- Support the Caring for our Veterans Act, S. 2193, which permits veterans with physical disabilities to continue to have the opportunity to secure care close to home without having to fight VA bureaucracy to receive medical benefits, as they currently do under the VA Choice Program. S. 2193 also outlines improvements to patient safety regarding prescription medications, and continuity between VA and non-VA providers regarding service-connected injuries or illnesses.
- Support HR 4146, the Disabled Veterans Life Insurance Act of 2017, which increases insurance amounts for service-disabled veterans, since no updates have been made since the 1940s.
What if we could be transported out of our disability-unfriendly environments, and what if race and gender didn’t matter? These are some of the questions choreographer and dancer Alice Sheppard explores in DESCENT, which premiered March 22 at New York Live Arts. Along with dance partner Laurel Lawson and lighting and video artist Michael Maag, Sheppard creates a new world in which wheelchair users are free to play and love and just be.

As DESCENT opens, a starry moonless night lightens to reveal a stage-wide ramp that curves and rises to a platform on the top left corner. On the right-hand side is another smaller, lower platform, where we see a silhouette of a boulder. The sun rises and the boulder becomes a gray rocky outcrop with a woman, Sheppard, hunched on it. She’s modeling a pose from a Rodin sculpture featuring Greek mythological figure Andromeda and Roman goddess of love Venus.

Sheppard, as Andromeda, frees herself from the rock on which mythology has her chained, the original princess in need of rescue from a dragon. She slowly stretches and slides on the ramp’s sharp curve, as water splashes and the night sky flickers into ocean then back to bright stars on black. The lighting resolves the ramp as being between the water and the sky, and Laurel Lawson, as Venus, appears, evoked from the ocean by Andromeda, and the dance starts in earnest.

So what is the story about?
“Partly, I wanted to ask, what happens if you pull Andromeda out of her mythological system with all that history,” says Sheppard. “Who is she when she is not chained to the rock? And same with Venus. So many of her stories have to do with jealousy, competitions between males. When she is not in that system, who is Venus?”
“Rather than retell-
Because the ramp is designed to center wheeled movement, Sheppard and Lawson can do much more on it than if it were a static, flat stage.

Choreographer Alice Sheppard took her first dance class on a dare — and loved it so much she gave up her academic career as a professor of medieval studies to pursue dancing. She has performed with AXIS Dance Company, Ballet Cymru, GDance, Full Radius Dance and more.

“After all, Venus and Andromeda never meet in any known story, they don’t even come from the same pantheon. So within this world of the ramp, think of what is not there — there are no men, these women are defined by and in relationship with only themselves and each other. There is no heterosexual baseline. There is no nondisabled normate. This allowed us to explore and discover this intersectional story in a way that hasn’t previously been done.”

There is no racial whitewashing, either. Andromeda, an Ethiopian princess, is often portrayed as being ivory-skinned, which makes no sense. It’s more accurate for Sheppard to play her than, say, Taylor Swift.

And in addition to all of that, there’s the beauti-
ful ramp stretching across the stage, centering the wheeled movement of the two leads.

That Glorious Ramp

“Can I tell you about this ramp?” asks Sheppard. “We’re on the top of the platform and when you push off you can imagine flying downhill. But it’s just a little steeper than you quite feel comfortable with, and you’re going so fast, and you turn a corner, and it’s banked and it takes you and it takes you and it takes you and it turns you and you’re a little out of control. The chair’s front casters vibrate. It’s a little terrifying and you’re reveling in it because that’s the way the chair responds.”

It is dangerous by design, which forces the dancers to respond in ways they couldn’t on a typical, static stage. “DESCENT relies on that steepness and danger to tell our story,” says Lawson. “Everyone who has ever been on our ramp has fallen — feet, wheels, it doesn’t matter. However, it centers our particular physicalities and we have trained ourselves to accommodate it and create choreography as the ramp dictates.”

A member of Atlanta’s Full Radius Dance company, as well as cofounder of CyCore Systems, a software architecture and design consultancy, Lawson, 38, has given talks on universal design, which she says has pros and cons. “Ramps in general are actually one of the better examples of universal design in that everyone can use them,” she says. “Like anything, however, ramps can also be used to exclude when they’re clearly begrudged, tacked on the side thoughtlessly, or hidden around the back.”

It’s as if DESCENT gives voice to the universal ramp. Without ramps, wheelchair users especially are cut off from society, unable to participate freely and fully — not unlike Andromeda chained to a rock. Yet often in our real-life society, as Lawson notes, access is around back and maybe a sign will point the way, or maybe
Although only two people appear on stage, DESCENT has three performers: Alice Sheppard, Laura Lawson and lighting director Michael Maag, who is also the resident lighting designer for the Oregon Shakespeare Festival.

As Lawson and Sheppard dance with each other, Maag’s lighting is intertwined with the choreography and the geography of the ramp. “Lighting sculpts the body, the chairs, the ramp, the space,” says Maag, 53, a wheelchair user from Ashland, Oregon. “Each tilt of the hand or crazy bird lift or pose imitating a Rodin sculpture has meaning, significance and forwards the narrative. The choreographer and lighting designer must work closely together from the beginning of the creation.”

And did the ramp affect him as powerfully as it did the dancers? “If you are asking if I fell out of my wheelchair the first time I rolled on it, then the answer is YES!” he says. “If you are asking if it moves me as a piece of art in its own right, YES!” He was inspired by it as a projection surface. “It provides such amazing opportunities to create shapes, move light, help the story. It is a canvas to me.”

Sheppard and Lawson talk about the ramp as a teacher, and Maag agrees. “The ramp taught me not to try to roll up peaks without proper training,” he deadpans.

For more information on DESCENT, including bookings, go to www.kineticlight.org.
Grand Teton & Yellowstone National Parks

Two of our most stunning national parks offer more access to nature than ever before, but still leave much beyond the reach of people with mobility limitations.

BY IAN RUDER

I can’t say I’ve ever had my breath actually taken away by a vista, or been left speechless by a stunning landscape, but the closest I’ve ever come was at the end of the week I spent exploring Yellowstone and Grand Teton National Parks last summer.

After five days spent trying to check out all the accessible attractions and lodging spots, I was enjoying my last sunset in Yellowstone on a boardwalk alongside the LeHardy Rapids. On a day where I’d watched a herd of bison ford a river and rolled among some of the most unique hot springs and geysers in the world, it would have been easy to be underwhelmed by the view; there were no animals and no identifiable landmarks in sight, just the steam rising off...
the crystal-clear water and the fresh smell of wet earth and pine left behind by the thunderstorm that had just passed through.

For the first time all day, I couldn’t see any other tourists and the sounds of the nearest road were drowned out by the crashing rapids. Sitting alone in my power chair, breathing in the fresh air and listening to nature’s cacophony around me, I struggled to find the words to express my surroundings. My attendant and I had a running understanding that if I slipped into saying, “It’s so pretty,” one more time, he was free to hit me, but sitting there, all I could do was laugh and say, “Damn, it is so pretty.”

I have no doubt that Yellowstone and Grand Teton have been causing that same nature-induced aphasia in visitors since long before they received those names, and long before they became national parks, in 1872 and 1929 respectively.

Today, thanks to the efforts of the National Park Service, both parks are more accessible than ever to visitors with disabilities. If you want to watch Old Faithful erupt or roll through the superheated Mammoth Hot Springs, you are in luck. Lengthy boardwalks give wheelers the same access as everybody else to these and many other famous spots. A growing number of accessible overnight options lets you choose how you want to experience the parks, whether it’s camping under the stars or living it up in one of the parks’ high-end lodges, like the famed Lake Yellowstone Hotel. But access has its limitations.

Obviously, there is no way to provide access to every inch of the often-extreme terrain while preserving the inherent natural beauty, but watching walking visitors explore the hundreds of diverse trails throughout each park, with surprisingly few wheelchair accessible trails, it can be hard not to feel left out. The immersive satisfaction in nature I enjoyed at LeHardy Rapids is available for wheelers, it’s just not as easy to find.

With almost 2.5 million acres between the two parks, it makes sense to have a robust plan before embarking, even if your only desire is to lose yourself in nature. Each park has a unique vibe and distinct character, but the beauty of visiting is that, since they are right next to each other, it’s easy to go back and forth as much as you want until you figure out what fits you best (especially if you have an Access Pass, see sidebar).
**Getting Set Up at Majestic Grand Teton**

Grand Teton Park is the younger, less famous sibling of the two national parks, but you’d be foolish to judge it based on those two qualities. Situated just north of Jackson, Wyoming, and just south of Yellowstone, Grand Teton is bordered on the west by the majestic Teton Range and on the east by the Bridger-Teton National Forest. In between those boundaries, a series of pristine lakes reflect the snow-capped peaks as the Snake River makes its way south. If it sounds idyllic, that’s because it is; once you descend into the park there is not a bad view in sight.

There are seven lodging options inside Grand Teton, each offering some combination of campgrounds, RV hookups and cabins, and each with some accessible offerings. Unlike Yellowstone, where all the lodging options are run by a private company, the concessions in Grand Teton are split between different concessionaires, leading to more diversity in experience. Randy Duchesneau, a quad from Maryland, stayed in a cabin at Colter Bay Village. The village is one of four lodging options in the park run by the Grand Teton Lodge Company and offers two “fully accessible” cabins.

All of the accessible options tend to get reserved months in advance, and everyone I spoke with suggested calling up to 17 months in advance. Duchesneau wasn’t able to snag a fully accessible cabin, but made do. “I had one step to get in, which was OK with the manual wheelchair,” he says. “The cabins were pretty old and rustic, so it wasn’t the most accessible, but you could make it work if you had to.”

As a C5 quad, I wanted a comfortable room that could accommodate my caregiver and I, and had a roll-in shower. The roll-in shower ended up being the decisive factor and I booked one of the two accessible cabins at Signal Mountain Lodge, the only property in the park run by Forever Resorts. Located on the southeast bank of Jackson Lake, the largest lake in the park, Signal Mountain Lodge gets its name from the adjacent mountain, which offers 360-degree views of the valley floor and the scope of the park. With a cozy bar, the best affordable restaurant in either park, a gas station and a well-outfitted store, Signal Mountain is perhaps the best situated base from which to explore both

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**Access Pass — Your Free Ticket to the Park System**

Whether you are planning on visiting Grand Teton and Yellowstone or not, don’t wait to get an America the Beautiful Access Pass from the National Park System. The Access Pass gets you in free to every national park and is available at no cost to all U.S. citizens and permanent residents with a permanent disability. At $30 per car for a seven-day pass to get into Grand Teton or Yellowstone, or $50 for a joint pass, the savings add up quickly. The Access Pass is good for life and available at most federal recreation sites, or via mail with a $10 fee.
parks. Bill Peace, a manual wheelchair user from Denver, has visited Grand Teton around 30 times and has always stayed at the Lodge. “It’s just the only normal place,” he says. “You see families, you see locals. You’ve got the camp ground. You’ve got good food.”

On top of all that, the two accessible cabins are on par with the nicest accommodations I have seen in any high-end hotel. Completely remodeled in 2014, the interiors are lovely and very spacious, but what put it over the top for me was the roll-in shower. Beautifully tiled and large enough for my power chair to completely turn around while my shower chair was in the shower stall, I honestly can’t say I’ve seen a nicer setup.

**Tackling the Trails**

When I asked a ranger to tell me what differentiates Grand Teton from Yellowstone, he said that Grand Teton was the better park for hiking and wildlife viewing. The website and free trail maps available in the lodge listed too many trails to count, but disappointingly only seven trails were listed on the Accessibility guide, with only two receiving the “fully accessible” endorsement and only one measuring more than half-a-mile.
That one longer trail is 20-miles of paved heaven that runs from nearby Jackson, Wyoming, all the way to Jenny Lake. Duchesneau regrets not having his handcycle in tow and missing the chance to cycle through the park. “It’s nice and flat and paved and it would be perfect for handcycling,” he says.

While there is nowhere in the park to rent handcycles, visitors can rent adaptive gear through Teton Adaptive Sports in nearby Jackson. The 12-year-old nonprofit offers classes and events for locals but is also a great adaptive resource for visitors looking for help planning adaptive excursions. Christy Fox, executive director of TAS, says TAS is happy to help in any way it can.

“We recommend visitors look at everything that’s available and see what the rest of your travel group and your family wants to do and then call us before you book anything so we can direct you a little bit,” says Fox. “Sometimes when you call outfitters trying to get the help or equipment you need, you get the wrong person and they’ll turn you away. We don’t do that.”

Years of experience and working with local outfitters give TAS the knowledge to make informed recommendations tailored to visitors’ needs. Rafting, boat trips, climbing assistance, hay rides — you name it, they know who can help and are happy to connect you.

Of the other trails listed as accessible, the intermittent paved paths and boardwalk around Jenny Lake are the cream of an underwhelming crop. My power chair had no trouble navigating alongside the shores of the glacial lake, and the boardwalks are lovely, but there was no more than 30 minutes of trail to explore. An accessible boat can take you across the lake to more trails, but it wasn’t working the day I was there and the ranger said he didn’t think the trails would be manageable in my chair. Still, Jenny Lake is ideal for canoeing and kayaking, and worth visiting if for nothing more than to see the reflections of the Teton Range in the crystal-clear water.

Another can’t miss is the relatively new Laurance S. Rockefeller Preserve. Located a few miles south of Signal Mountain, the 1,106 acres preserve was privately owned for almost 100 years before the Rockefellers donated it in 2007. The Preserve encompasses a striking, modern interpretation center, 8 miles of trails and some of the better wildlife viewing in Grand Teton. I was content exploring the center and taking in the views, while Duchesneau ventured on the trails and found them to be mostly accessible and worth tackling.

The Colter Bay Marina and Menors Ferry also offer short accessible paths, with Menors Ferry perhaps the more interesting of the two, while Colter Bay has more accessible trails. Built around the first ferry to port passengers across the Snake River, the Menors Ferry Historic District consists of a few remaining buildings, including a general store, a cabin and a barn. All are stocked with historical artifacts and pictures and info, making for a fun and informative, if brief, stop. Colter Bay Marina is another good place to put in for any sort of accessible water sports. A gravel-paved path rings the smaller part of the bay and serves as the starting point for a number of the more manageable unpaved trails. As lacking as the park is in fully accessible trails, there are a number of trailheads that looked wheelable under the right conditions. I started down a few, only to turn back because of a root or log that my power chair couldn’t handle.

If you are looking for more adventure and demand access to more difficult trails, Peace has a solution. Years ago, he bought a satellite phone, got a four-wheel drive car and approached the Park Service about a permit that would allow him to drive on their roads and trails. “I told them exactly what I wanted to do. I explained that my car had a GPS, that I could navigate, you know, I gave them a route, told them when I was going, how long I would be gone,” he says. The approach worked, and Peace and his son were
able to access a number of trails most wheelers would only dream of. “If you’re mister hard-core back-packer you can get off the beaten trail real easily, especially for somebody who’s in a manual wheelchair,” says Peace. His favorite of the extreme trails: Teton Crest Trail. “It’s very difficult,” he says, “I just exploited my son. He was young and strapping. We couldn’t make it all the way around, but together there was maybe 30 percent of it we could navigate. It’s just awe inspiring.”

I asked the Park Service if there was an official policy allowing visitors with disabilities to petition for extended access permits, but their answer was rather vague: “Wheelchair users, whether using a manual or power wheelchair, may access any of the hiking trails or boardwalks in the park, unless there is a closure for wildlife or other safety issue. Bicycle trails may be an option, too.”

Yellowstone Lodging: a Mixed Bag

If you spend any amount of time in Grand Teton, transitioning into Yellowstone is like cresting the peak of a rollercoaster. Leaving behind the tranquil shadow of the Teton Range, the increased traffic as you head north is the first sign things are changing. The topography follows suit. Whereas nearly every view in Teton is framed by the Teton Range, every corner in Yellowstone holds the promise of completely different terrain. Over the course of a short afternoon drive, you can go from the moon-like flats of Mammoth Hot Springs to the grizzly-filled forests near the park’s northern border to the placid calm of Lake Yellowstone — and that’s only covering a few of the park’s diverse regions.

Unlike driving through the mostly flat confines of Teton, a trip through Yellowstone turns your car into a four-wheeled mountain climber, with elevations varying from 6,000 to 11,000 feet. With nearly eight times the acreage of Grand Teton, Yellowstone is truly massive, making

An accessible bathroom can make or break a trip. The beautiful and spacious setup at Signal Mountain Lodge (right) is on par with the nicest hotels, while the Lynchian red light in the Lake Lodge cabin could have been straight out of a horror film.
where you stay all the more important. The park’s attractions are laid out around Grand Loop Road, a 142-mile loop with a connecting road in the middle that creates two shorter loops — the north and the south loop. Five park entrances feed into the loop — the south entrance from Grand Teton, the west entrance from West Yellowstone, the north entrance from Montana and the lesser used north-east and east entrances. One hundred and forty-two miles may not seem that long, but the terrain and traffic often make for slow going and you should figure at least four to seven hours to drive the entire loop. And that’s without stopping to take in the sights.

The south loop has more of the park’s tourist attractions, including Old Faithful, Lake Yellowstone and the Grand Canyon of the Yellowstone. It also has seven of the nine lodging options that have accessible accommodations. The north loop is home to the famed Mammoth Hot Springs, Tower Fall and some of the park’s highest elevations.

Peace recommends basing your adventures toward the south. “The challenges just get bigger and bigger the further north you go,” he says. “The southern loop is the way to go. It really is. You will see more animal life along the northern loop, but it’s really, really remote.”

All of the lodging and concessions in the park are run by the same company, Xanterra Parks & Resorts, and there are a number of accessible options — none cheap — ranging from the extravagant Lake Yellow-
Planning Your Trip

Each spring and summer, over 7 million visitors flock to Wyoming’s northwest corner to experience the raw beauty Yellowstone and Grand Teton offer. The result is packed campgrounds, bumper-to-bumper traffic and crowds that wouldn’t seem out of place at Disneyland.

Assuming you are not just passing through, there are three main accessible options for overnighting: staying outside the park in one of the nearby towns, camping at one of the parks’ campgrounds or staying in one of the parks’ lodges or cabins.

Camping is the cheapest and most plentiful bet if you can handle it. Between Yellowstone and Grand Teton there are 18 campgrounds, 14 of which claim to have fully accessible sites, with prices ranging from $15 to nearly $50/night. Some allow reservations, some are first-come, first-served.

Staying outside the park is the next cheapest route, and the two best options are to the south, in Jackson, Wyoming, and to the west in West Yellowstone, Montana. Jackson, just below Grand Teton, has lodging options at every price range to go with an overwhelming number of fancy boutiques and restaurants. As Peace says, “The joke out there is, ‘the good news is all the millionaires moved out, but the bad news is the billionaires moved in.” West Yellowstone offers a toned-down experience directly out the west entrance to Yellowstone.

The in-park lodges and cabins are all on the pricey side and vary in quality and amenities. The few accessible rooms go fast, especially in July and August. Check the official sites for prices and call early to reserve. Thanks to first-class accommodations and a good location, I would recommend Signal Mountain Lodge in Grand Teton, and one of the lodging options at Old Faithful or the Mammoth Hotel in Yellowstone. While those are two of the busiest areas of the park, there are a number of shorter accessible trails and things to do at both spots.

As far as getting to northwest Wyoming, if money is no object you can fly directly into Grand Teton via Jackson Hole Airport on United, Delta and American. Don’t expect jetways and do expect limited rental options. If you don’t mind a little road trip, you could follow Duchesneau’s lead and fly into Salt Lake City and then make the drive. “It was a very beautiful drive,” he says. “It went by really quickly, too, because there was no traffic or anything.”

Whichever you choose, remember that getting around both parks requires a lot of driving, and the potential for lots of transfers, as most of the attractions require getting out of your vehicle and walking or rolling a short distance. It’s worth having a vehicle that makes life easy for you, whether you take your own or rent one nearby.

A Bounty of Attractions

Once you’re set up with lodging, you can turn your attention to the park’s bounty of attractions. This is one of the rare cases where the normally-handy maps the rangers give you when you enter a national park may actually hinder your decision making. There are just too many options. To help people with disabilities, the Park Service has a free 40-page accessibility guide that breaks down all the lodging, concessions and attractions. I picked up a copy at Grant Village, home of the southernmost visitor center, and in doing so saw that Old Faithful was scheduled to
erupt in less than an hour. At the time, I didn’t realize that it erupts every hour, but in my ignorance, my attendant and I hopped in the car and made a beeline for the famous geyser.

The first thing you notice upon pulling into the never-ending parking lots at Old Faithful are the hordes. Every hour, as the predicted eruption time nears, waves of humanity descend on the viewing areas around Old Faithful. The actual eruption was cool, if slightly underwhelming, but the area around the geyser offers way more to see. From where we watched Old Faithful blow, we could see and hear two other eruptions, and were less than a mile from a number of hot springs so rich in color that they have to be seen to be believed.

Thanks to its unique geologic background, Yellowstone is home to almost 60 percent of the world’s geysers and in the square-mile around Old Faithful there are at least 150 hydrothermal events. In part for accessiblity and in part because of the fragility of the terrain, the park service has built a lengthy network of boardwalks for visitors. All of the boardwalks were doable in my power chair, but there were steep sections that would try even the hardiest of manual chair users. There is also a wide, paved path running alongside the main boardwalk from the lodge. The path was one of the better (and few) spots I saw for handcycling in the entire park.

Another can’t miss path is the lengthy boardwalk to and encircling Grand Prismatic Spring. A few miles down the road from Old Faithful, Grand Prismatic is the largest and arguably the most stunning of all the springs — offering a tableau of colors unseen elsewhere in nature. Again, the boardwalk was easily do-

Winter Wonderland

If you’re looking for a hearty adventure and don’t mind getting cold, a winter visit to Yellowstone promises a unique spectacle. While the main roads in Grand Teton remain open, all of its lodging options close for the winter. In Yellowstone many of the roads close, but two of the nine lodging options remain open — Mammoth Hot Springs Hotel and Old Faithful Snow Lodge. Mammoth has two accessible rooms and Snow Lodge has five. Just know that other than the northeast entrance road to Mammoth, the only way to move through Yellowstone is via snowcoach. Xanterra, the manager of all Yellowstone lodging, operates three accessible snowcoaches, each with one wheelchair slot.

Peace isn’t sure whether the adventure is worth the effort. “I’ve got to say I’ve been there once in the winter and I did not have fun,” he says. “It just made me nervous. If a blizzard moved in, you’re not going anywhere until the blizzard is over.” Should you decide to go, Fox says Teton Adaptive Sports would have your back. The organization has sit skis available and Fox says she’d be happy to connect visitors with outfitters who organize other trips, including sleigh rides.

If you’d like a taste of winter without the hassle, Peace recommends booking a room at Signal Mountain Lodge near its Mother’s Day opening. “If you’ve ever heard a mountain lake as it’s melting, it’s one of the weirdest sounds, like women crying, or like the most unusual groans you’ve ever heard. I mean, I can’t even describe what it sounds like.”
able in my power chair but had steeper sections that might be tough for a lone manual chair user.

The entire southwest quadrant of the park is dotted with geysers and springs, and if the crowds at the big-name destinations are too much there are plenty of quieter options. “You could not find a more touristy spot than Old Faithful,” says Duchesneau, “but if you go one mile away, say to Lone Star Geyser or even just to the end of the boardwalks, there is no one there.”

There are sure to be plenty of people at Mammoth Hot Springs, but the 50-mile drive north is a must. Divided into upper and lower terraces, Mammoth Hot Springs is the only major thermal area in the park outside the caldera and offers otherworldly landscapes and views that look like the work of a mad scientist with an eye for art. It’s easy to see most of the highlights on two short roundabout drives, but it’s worth getting out at all of the boardwalks to explore the full panorama.

Beyond the geyser basins and hot springs, there are plenty of roadside attractions worthy of stopping at: waterfalls like Tower Fall and Gibbon Falls, short scenic detours like Firehole Canyon Drive, and self-guided tours like Forces of the Northern Range. Almost every one offers some degree of accessibility and stunning views, but don’t expect more than a short roll. It was frustrating watching people enjoy access at prime locations like the lush swimming hole and waterfall at Firehole Canyon and knowing there was no way to get there in my chair.

Access, With Limits

If you spend any amount of time in Grand Teton or Yellowstone, you are sure to come away with a number of unforgettable memories. Yet even with all the boardwalks and accessible areas that have been built, after a few days spent mostly driving around, I couldn’t shake the feeling that I wasn’t really experiencing the parks. Much of the time, despite my best efforts to get out and explore, it felt like I was on a safari.

Looking back on my trip, I find that the moments

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Duchesneau directs his attendant on how to capture the best shot of one of the park’s many picturesque waterfalls.
that have stuck with me most are the ones where I went off the paths and found my own slices of nature. Like when I dropped my ramp over a curb in a small pullout on the Virginia Cascade Scenic Drive in Yellowstone. I rolled a few hundred feet over some packed dirt to the side of a small creek and just sat there, enjoying the faint sounds of a trickling creek and the eerie smoke-tinged sunset. It was one of the only moments of anything near solitude I had in the park. In those minutes, I felt transported back in time, before the cars and tourists flooded the park.

Duchesneau and Peace singled out similar moments as the highlights from their time in the parks. For Duchesneau, simply watching the light hit the Teton Range was unforgettable.

“I had never seen mountains like that and it was just mesmerizing,” says Duchesneau. “Every time I'd look at the mountains they looked different, because the light would change or my position would change. If you see a monument or something like that, it kind of looks the same all the time. But those mountains change all the time with the light and the time of day. It was really beautiful and really cool.”

Watching the sun set into the Teton Range left Peace with the same struggle to communicate I had at LeHardy’s Rapids. “I’ll never forget, my dad was still alive, and I remember he called me near sunset. And I remember telling my father, ‘It’s too beautiful outside. I really just can’t talk to you right now.’ You know, how many places are there in the world where you’re not gonna talk to your father because you want to watch the sunset?”

Not many. But Grand Teton and Yellowstone are just those kinds of places. Neither park succeeds in providing wheelchair users and people with limited mobility the same experience as the general population, but they have done enough to make visiting enjoyable and definitely worthwhile. The Park Service is conducting a Self-Evaluation and Transition Plan to identify and address areas where accessibility can be improved, and ongoing construction throughout the park can only continue to help everyone enjoy the majesty of some of the world’s most spectacular land. I’ll be back, and until then I will have the images and sounds from my trip replaying in my head.

**Resources**

**Access Pass**, nps.gov/planyourvisit/passes.htm

**Grand Teton**

Grand Teton National Park Service, nps.gov/grte/index.htm

Accessibility brochure for Grand Teton, nps.gov/grte/planyourvisit/accessibility.htm

Teton Adaptive Sports, 307/203-2223; tetonadaptivesports.com

Signal Mountain Lodge, 307/543-2831; signalmountainlodge.com

**Yellowstone**

Yellowstone National Park Service, nps.gov/yell/index.htm

Accessibility Guide to Yellowstone, nps.gov/yell/planyourvisit/accessibility.htm

Wilderness Inquiry, 612/676-9400; tetonadaptivesports.com

Xanterra, Yellowstone National Park Lodges, 307/344-7901; signalmountainlodge.com

**Bison, Bears & More**

The one area where both parks fully delivered was wildlife viewing. With millions of acres of designated wilderness abutting the parks, pretty much everywhere is a good place to see wildlife. The area is home to bears, moose, elk, bison, wolves, deer and countless other animals not commonly seen elsewhere.

In fact, there are so many large animals it can be slightly surreal. The night my attendant and I got to Signal Mountain Lodge, in our haste to be done driving after a long day on the road, we pulled out to pass two cars that were blocking the road with their lights on. As we quietly cursed them under our breath and passed them, we could see their headlights illuminating the enormous shape of a moose that had stopped for a twilight snack on the side of the road. The moose paid us no attention while the stopped passengers shook their heads and looked at us like idiots.

Over the rest of our trip the same scenario occurred too many times to count with every type of wildlife you can imagine: bison, deer, moose, and what I’m pretty sure was a bear, though I never saw it. You quickly learn to equate the brake lights of cars slightly pulled off the road to an impending wildlife sighting. The longer the line of brake lights, the bigger the animal, with the bison herds sometimes stopping traffic for as far you can see. There are pullouts scattered along all the main roads and rangers will help direct traffic and parking around some of the more major events, like bison herds or bears.

I stopped to watch bison herds and passing moose several times and came to appreciate the automatic wheelchair lockdown in my van more than I ever have. If you want to stop and watch the animals, be prepared for a lot of transfers and don’t expect accessible parking spaces alongside the busy roads. I learned to leave my ramp down to prevent over-eager sightseers from crowding into open spaces by my van.

Duchesneau didn’t have the luxury of an automatic lockdown in the van he rented, but he learned to adapt. “At a lot of these pit stops, we’d just position the van in a place where I could just look out the window at everything, and get the best view,” he says. “But if there’s something really nice, then I’ll get out for it.”

Despite the hassle, seeing the animals exist as they have there for thousands of years is worth it. Watching an aging male bison slowly swing his testicles over a large boulder as if to itch them is an image that will not soon leave my mind.
Camping as a wheelchair user can present many unique challenges, but few that a little planning and common sense can’t overcome. Over many camping trips I have fine-tuned a low-on-luxury approach that allows me, a C7-8 quad, to enjoy the wilderness and find that mental refreshment that only nature can provide. Here are seven tried-and-true techniques and equipment solutions.

1. Tarps, Not Tents
Instead of spending hundreds of dollars on one of the few tents designed for accessibility, a simple tarp can keep you out of the elements, provide ample coverage and be set up in a variety of ways to optimize views or privacy. Correctly set up, tarps make it easy to roll in and out and remove concerns about damaging the lip of a tent. There is a learning curve to setup, and it’s critical to know the ground and tree conditions where you are camping and whether a tarp-based setup will work there.

2. Cots Change Everything
A sizeable cot will be an excellent upgrade to your sleeping setup, making transfers easier and more stable and helping protect your skin. A foam pad will further boost your sleeping comfort and warmth. I also use my extra travel ROHO cushion under my hips to ensure a good night’s rest. If space is no obstacle, a queen-sized cot will bring more comfort and mobility. Lastly, cots are more reliable and quicker to set up than an oversized air mattress.

3. Well Ac-Quilted
I can recall no more terrifying a moment in the woods than waking up stuck in a sleeping bag. Tiny zippers and thin nylon just don’t mix well, especially for those with limited dexterity.

A backcountry quilt is made of the same materials as a traditional sleeping bag, but it doesn’t have a zipper and does have a pocket for your feet. I have used a backcountry quilt for well over a thousand miles of backpacking and now use it in the front country as bedding. If I am hot, it is easy to vent. If I’m cold, I tuck the quilt around me. You can get a very high quality custom quilt for less than or the same amount as a high end sleeping bag, due to less material and labor.

4. Bucket Brigade
With a padded commode, a bucket and a privacy tent you can guarantee you will have a nice accessible bathroom to poop in style. A separate bucket for keeping yourself clean is another necessity; sponge baths are key to backcountry living.

5. Fun Food = Faster Fun
Planning meals ahead with easy-to-prep ingredients can really help maximize your independence around camp. My camp meals consist of boiling some water and mixing in dry ingredients. Choosing one or two ingredients from each category on this list can result in a fun, tasty choose-your-own-adventure meal.

**Carbohydrates:** Couscous, oatmeal, macaroni, instant rice.

**Fats:** olive oil, nuts, butter.

**Protein:** cheese, nuts, beans, dry meat.

**Flavor:** dried fruit, spices, powdered cheese, sugar.

Premixing all the dry ingredients and combining them with water in one pot will minimize prep and clean up time.

6. A Boiling Affair
Cooking during camping can entail large open flames. One safer alternative is the Jetboil all-in-one cannister stove. I have found it works well with my limited hand dexterity. The stove has a large wire control and an igniter, there is no need to prime or use a lighter. The included pot has a neoprene sleeve with a handle snap-on lid that makes handling a hot pot much easier. Additionally it has a heat indicator that changes colors to let the user to know when a boil has been reached without looking into it. The whole system locks together, providing excellent stability and moderate wind resistance. Building up the controls with heat resistant materials could increase safety of operation.

7. Other Must Haves
**Caregiver:** Including an enthusiastic caregiver to accompany you will open up the wilderness.

**Freewheel:** Makes getting around uneven terrain that much easier.

**Extra Medical Supplies:** An extra day of catheters and whatever else you need (in a waterproof container) keeps the doctor away.
Sailing in gorgeous conditions, I’m at the helm during my first watch on a 60-foot catamaran, 130 miles offshore in the north Atlantic. The crystal-clear night is alive with stars, the Milky Way and constellations are planetarium-bright, accented by a sliver of a crescent moon rising in the distance. After a while, the stars seem to move in slow motion.

Around 3 a.m., a tiny light on the horizon matches a blip on the radar screen. The tracking system identifies it as a three-mast square rig tall ship, and we are gaining on her. I expect to see her sails by morning. I feel like a pirate ship hunting its prey. Yarr! The experience is so perfect and ethereal, I don’t want to risk pinching myself lest this is a dream, but it’s real. I’m on my first off-shore voyage, a 900-mile passage from Boston to Canada on board an ocean-going catamaran built with universal design, aptly named the Impossible Dream.

I had a boat that I sailed on the San Francisco Bay, and I had long dreamed Mitty-esque adventures of making an extended off shore voyage. However, as decades passed, this seemed less likely, especially on a conventional sailboat where wheelchairs don’t fit, and getting around the vessel requires lots of dragging yourself by your arms. The Impossible Dream became the key to achieving my goal.

**BUILDING THE DREAM**

The Impossible Dream was custom designed and built in 2002 for Mike Browne, a British paraplegic who wanted a boat on which he could sail the oceans independently. At 60 feet in length and 27 feet wide, with an 80-foot-high mast, she is spacious, stable and swift. Every detail of the catamaran is based on universal design and is equally accessible whether you are walking or wheeling. There are three hydraulic lifts, one to get from the dock onto the boat, and one on each side of the main cabin going down to the hulls where the boat’s two bathrooms and four cabins are located. The futuristic-looking vessel has features like push button hydraulics for sail management and trim, and a helm that looks like it could double as the bridge of the Starship Enterprise.

In 2012, Impossible Dream was purchased by Deborah Mellen, a business woman with paraplegia who had discovered the exhilaration and freedom of sailing through Shake-A-Leg Miami, a nonprofit adaptive sailing and aquatics program located in Biscayne Bay, Florida. Mellen formed a nonprofit, also called Impossible Dream, which has a multifaceted mission that includes introducing sailing to groups of
people with disabilities and their families and friends, raising awareness of the equalizing power of universal design and working in synergy with Shake-A-Leg.

Impossible Dream’s home mooring is at Shake-A-Leg, where she spends her winter months taking groups, many of whom are still in SCI rehab, for day trips that often inspire return visits to learn to sail. Each summer, the boat sails up the east coast stopping at many ports, usually offering three multi-hour sails a day. Last summer she stopped at 25 ports and took over 1,000 people, mostly wheelchair users, sailing — all for free, as the boat’s operations are funded by donations from individuals and corporations. “Something that has become very important to me is when we take out newly injured people and their families, the boat somehow lifts some of the physical and emotional pain they are going through,” says Mellen.

Beyond the daily sails, the nonprofit accomplishes its mission in unique ways, including competing in races crewed by a combination of disabled and nondisabled sailors, and hosting charters, like a 2016 sail from Key West, Florida, to Cuba for a week-long cultural exchange that I wrote about in “Wheeling in Cuba” [August 2016 New Mobility].

In my research for the Cuba story, I mentioned my interest in joining a passage on the Impossible Dream. In April 2017, Mellen emailed me an offer that I couldn’t refuse: “In June, the Impossible Dream will be providing a week of day sails in Boston harbor during Sail Boston Tall Ships Rendez-Vous 2017 — a regatta of 40 tall ships from around the world — and will join the tall ships on their 900-mile, seven-day offshore sail from Boston to Canada. Would you like to go?” Even better, my longtime friend Allen Fiske, a T11 paraplegic, who I had sailed with for years, phoned me and said he would be on the passage. This was an opportunity to realize our dream together! I booked my flight.
of June 22, we released the dock lines and headed for Canada. It was both exciting and a big leap of faith. I’d never sailed out of sight of land for more than an hour or so, and there was a little voice that said “what if it turns out I don’t like it?” And I’m not immune to sea sickness.

THE OPEN SEAS

Any trepidation about being offshore vanished during my first watch, from 1-4 a.m. The sailing conditions were epic. I basked under the stars before being greeted by a radiant sunrise at 3:30 a.m. Although the weather remained perfect throughout the day, the weather charts showed the tail end of a tropical storm was bearing down on us. It arrived the following day with 10 foot swells, winds gusting to 35 knots and a cold rain that reduced visibility to zero. We were navigating by compass and electronic chart plotter. Fiske and I were encouraged to practice steering by hand because the seas became big enough to overpower the auto helm. Fiske went first and quickly dialed in. “It was some of the roughest water I’ve been out in, but the universal design combined with the stability of a catamaran helped a lot,” says Fiske. “I had to have one hand for the chair and one for the boat, and even though it was uncomfortable, it was way easier than it would have been in a mono-hull.”

I took the helm to practice hand steering next, and soon caught on. It was so fun that, later, on one of the smoother days, I did a double watch, hand steering much of the time, grateful to have the opportunity to be at the helm of this amazing boat.

The trip had been so exciting I hadn’t had much sleep for about two days. When the first mate took over, I took the lift down to my cabin for a quick afternoon nap. As I lay there, the sound of water rushing by the hulls seemed inches from my head. I could feel the rise and fall as we surfed wave after wave, the motion quickly lulling me to a deep sleep, my dreams a continuation of the previous two days — sailing a catamaran in the north Atlantic, a boat so accessible my wheelchair was irrelevant. In what seemed like a moment, my alarm went off, time for my midnight watch.

The storm raged for a day and a half as we sailed up the

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Bob Vogel and Allen Fiske enjoyed the accessibility of the universally designed catamaran.
coast of Nova Scotia, and then abated as quickly as it arrived. A calm, clear morning welcomed us to Canadian customs, and we passed into the Gulf of Saint Lawrence. I found that at sea, the problems and stresses of land tend to vanish, or at least are temporarily left behind, replaced by the rhythms of weather, wind, waves and tides. Fiske and I were getting used to, possibly spoiled by, living in the universally design environment on board the catamaran. My back even felt better, pain free for the first time in a long time, likely due to constant gentle stretching from the rocking of the boat.

Since we were three days ahead of schedule, we made time to explore. Highlights included dodging lobster pots on our way to anchoring in scenic Malpeque Bay on Prince Edward Island, learning to shuck and feasting on world-famous Malpeque oysters, fresh off a local boat.

Much of our spare time at sea was passed talking and sharing stories. One of my favorites was about Fiske’s five-year renewal of his captain’s license. “Earning my license included taking a physical, which clearly states ‘T11 paraplegic,’ he says. “When I went to renew it, they said ‘You can’t be a captain, you’re a paraplegic.’” Fiske replied, “I know, I’ve been paralyzed for 25 years, and I’ve had my license and been doing charters for the last five years.” Fiske didn’t back down, and the Coast Guard agreed to go out with him on a sea trial, where they threw a life size dummy overboard and said “man overboard, save him.”

“I did exactly the right maneuver. I pulled up next to the dummy and threw a life sling, and my buddy fished him out. They renewed my license,” says Fiske.

The next day, we set sail on the final 100 miles to Caraquet, sailing on light winds, glassy seas, with a line of picturesque thunderstorms off our port side. Arriving in Caraquet the next day was the completion of a successful trip and the realization of a dream. (Continued on page 46)

Cynthia Payne-Meyer was surprised to learn she can sail with a chin control.
As you’ve no doubt heard, the TV business in America is going craaa ... zzy. There are now more scripted TV shows airing in one season — 500 and counting — than at any time in the history of mankind. That’s double the amount just six years ago and 10 times the amount when Archie Bunker and the Fonz ruled the earth. You can’t watch all the great new shows, let alone just the good ones, even if you are an insanely dedicated binge-aholic.

Have we reached the pinnacle of this great TV programming glut? Hardly. The first Netflix streaming series, House of Cards, aired Feb. 1, 2013. Five years later, Netflix will spend six billion dollars on new content, adding to the 126 or so original series it ran in 2017. The streaming revolution, already at full-bore with Netflix, Amazon and Hulu, is about to accelerate to infinity and beyond with new, deep-pocketed entries like Facebook, Apple, YouTube and probably your brother, Larry. Cable pioneer HBO is spending $3 billion a year on new shows, joined by AMC, FX, Freeform, Showtime, British imports, Swedish imports ... the glut will only get gluttier.

Why should you care about this media muddle? Because — I boldly predict — this is a major game changer for the up-to-now pathetic representation of people with disabilities on TV. Shows that are categorically unique or off-beat now stand as good a chance to be seen on your TV, computer or iPhone as original gangster cop shows or white family sitcoms. Unique, in the world of standard TV tropes, includes stories about disability.

Here are a few examples of this coming groundswell. Start with just adding disabled characters. On Jan. 31, YouTube Red, an original programming channel you’ve likely never heard of, uploaded a new series called Step Up: High Water. It’s about a performing arts school in Atlanta — not the newest idea on the planet. What is new is that one of the main characters, a dancing phenom, is a double amputee, played by double amputee, Eric Graise. This isn’t Artie from Glee. This is a dancer.

Another example: the hit Netflix reboot of the ’70s sitcom, One Day At A Time, not only shifted the cast from white to Latino, but also added a recurring wheelchair-using character played by actor Santina Muha, who has an SCI. Muha, also the recent host/performer of the United Spinal fundraiser, "Don’t Just Stand There," has personally felt the impact of TV’s increased appetite for casting performers with disabilities.

“This is finally an exciting time for actors with disabilities!” she says. “I’ve been pursuing this field for most of my life, and it’s been a frustrating ride. But in the past few years, I’ve been called in for more roles specifically written for a character who uses a wheelchair. And I’ve also been given more opportunities to audition for roles where it doesn’t matter either way.”

“Please submit actors of all abilities’ has become one of my favorite sentences, second only to ‘You’ve got the part!’”

Gloria Caldron Kellett, the executive producer of One Day At A Time, echoes Muha’s optimism. “Absolutely, I think there will be more [hiring of disabled actors]. People are starved for real representation. I am committed to continuing to tell sto-
ries about people with disabilities."

An even bigger shift is toward whole shows focused on disability. A few weeks back, Sundance Now, another streaming service that just came online, premiered This Close, the first series in history to have been written, produced, and created by deaf people, Shosannah Stern and Josh Feldman, who also star as deaf best friends in a hearing world. The great Marlee Matlin is in it, too. Even much of the crew is deaf.

Other, on-the-cusp examples come from Nic Novicki, a little person actor/advocate who, in 2014, created the annual Easterseals Disability Film Challenge to encourage and showcase short films made by and/or about people with disabilities. The format of this competition is unique: Entrants are given a long weekend to write, film and edit a movie between three and five minutes long. Anyone from working pros to first-timers can enter. Winning films tend to get enormous exposure.

In 2015, the Best Filmmaker award went to deaf actor/director Dickie Hearts. Building off that success, Hearts went on to win a top prize awarded by the Project Greenlight Digital Studio for his sitcom idea about a deaf barista who gains superhero powers from a radioactive cup of coffee. Another Disability Film Challenge winner, David Harrell, an amputee, took a second top prize with the same project at the Australian Focus On Ability Film Festival. The resulting web series, Lefty and Loosey, is now in production.

Disability film events like this are popping up all over — scriptwriting competitions, filmmaking workshops, and full-fledged, Sundance-like festivals. The ReelAbilities Film Festival: New York, now in its 10th year, is one of the trailblazers. For a week, in 30 venues around New York City, the public can see features, documentaries and live performances, all about disabilities. There are 13 other ReelAbilities festivals around North America, with a Los Angeles version currently on the drawing board.

These forums are incubators — a nascent farm system — for a new generation of disabled film and video makers who have some distinct advantages. As Novicki points out, "Anyone can now do it. Go down to Best Buy, pick up an inexpensive digital DSLR camera, shoot something, edit it on your computer, and enter a festival or put it on YouTube. You can live in Illinois or Alabama, and it doesn't matter. YouTube doesn't care where you live."

And it doesn't care if you have a disability. Two other factors make this a propitious time for breaking in. The first is fragmented viewing patterns among young people, especially online, which means you can start small — very small — and grow. Another Film Challenge winner, Whitney's Weekend, starring Jamie Brewer of American Horror Story fame and made by double-amp actor/director John Lawson, has been seen by more than 100,000 people online. Maybe one of those people is from YouTube Red or Amazon, and that will lead to a meeting.

The second factor is acceptance. People under 40, especially those looking for edgy entertainment, are much more open to seeing people with disabilities as part of any story. In the post-ADA era, it’s no big deal. They have seen Larry David get into shouting matches with chair users over disabled bathroom stalls and have viewed and loved multiple videos by web stars like Zach Anner, a comedian with CP first spotted by Oprah Winfrey and now a writer on the network series, Speechless.

Television is a tough, tough business. You don’t get a trophy for just showing up. But for the first 50 years of its existence, TV was akin to a monastic order, rigidly controlled by network and studio clerics. Now it’s much more like the very earliest days of Hollywood — if you have a good idea, a little talent, a cool camera, endless perseverance and a boatload of chutzpah, you can take a shot. And if you have a disability, I just named a half-dozen venues where you can get your wheels wet.

Or, along with the rest of America, you can just sit back and watch a whole new world of disability TV materialize on your video device of choice. Like TV itself, it’ll soon be too much to keep up with.

Resources
• Easterseals Disability Film Challenge, disabilityfilmchallenge.com
• ReelAbilities Film Festivals, reelabilities.org
• Focus on Ability Film Festival, www.focusonability.com.au
Complex rehab power chairs are fantastic when it comes to performance and comfort, from suspension to power seating. However, among their biggest limitations is transportability. Traveling with a power chair can be challenging. However, all is not lost. There is a new generation of very affordable portable power chairs that can serve as secondary travel mobility options for even those who typically use complex rehab power chairs.

Redefining the WHILL
WHILL burst into the mobility market several years ago with the Model A, followed by the more funding-compliant Model M. What made the WHILL line unique was its avant-garde look and its use of omni wheels on the front, giving it remarkable maneuverability for a rear-wheel drive, full-size power chair. What held it back was its lack of features found on complex rehab power chairs, and a staggeringly high base price. Fortunately, the WHILL team recognized its successes and shortcomings and dramatically changed its approach. The result is the Model Ci, which hits a market sweet spot.

The Model Ci’s patented front omni wheels give the distinct advantage of eliminating swiveling casters. This allows the use of a larger wheel without interfering with the user’s foot placement. It also allows for extraordinary maneuverability. The Model Ci is about the length of a compact scooter, but due to the omni wheels, it turns in half of the space needed by a travel scooter. This maneuverability is among the biggest benefits of the unit.

From there, WHILL departed from its prior platform and made a slimline design that is sleek and portable. A simple but supportive seat with joystick and controls integrated into the armrests provides meaningful positioning for most users — at least for part time use. As for portability, the frame quickly disassembles into three separate pieces, easily fitting into a taxi’s trunk. Speeds up to 5 mph and a range of 10 miles are powered by a 10Ah lithium-ion battery.

Among the most groundbreaking features of the Model Ci is its Bluetooth connectivity with an iPhone. The app not only displays all of the chair’s data, but also allows driving it via your phone remotely, so you can fetch it from across the room or wherever it may be, within reason.

The Model Ci has a MSRP of a mere $3,999, available through SpinLife.com and other online mobility retailers. That’s a lot of product for the money. So, how do they do it so cost-effectively? The answer is, although it’s marketed to wheelchair users, they make it clear that it’s a “personal electric vehicle” that hasn’t been submitted or tested as an FDA-regulated medical device. With WHILL’s exceptional reputation, this shouldn’t be a deterrent to the buyer, but it certainly has reduced the design and manufacturing costs dramatically. In all, it’s a fantastic portable power chair at a reasonable price.

Your Power Chair Passport
A ton of inexpensive folding power chairs have been sold on the internet in recent years, mostly imported from China. All look ultralight and remarkably easy to fold, but quality and support have been questionable. Now Pride Mobility Products has entered the market with its Jazzy Passport.

The complete Jazzy Passport weighs in at a scant 53 pounds, offering true portability. The key to this is how it folds. While the Jazzy Passport looks somewhat traditional as a rear-wheel-drive power chair, the folding mechanism is a showstopper. With the release of a single latch, you simply push forward on the backrest with one hand and the whole chair folds to the ground flat, like a lawn chair. To unfold it, you simply pull up on the backrest and it unfolds. Unlike other products in its class, nothing must be removed from the chair, and it stays in one piece. It literally can be folded and
stored in a trunk in under a minute. The seating is a traditional sling, and with its armrests and high backrest, along with slight seat dump, it’s quite supportive. A rehab cushion is easily fitted as well. The Jazzy Passport carries an airline-approved 18 Ah lithium-ion battery, delivering a 9.6-mile range, with a top speed of 3.6 mph. A PG controller combined with high-torque motors delivers impressive performance and handling. The Jazzy Passport’s best attributes may be that it’s among the few in its class that meets ANSI/RESNA power chair standards. This means although its performance may be less than a full complex rehab power chair, its durability and safety meet the same standards. With an MSRP of $2,899 but sold online on discount sites for $1,999, the Jazzy Passport is an affordable way to get into a true travel power chair, and be comfortable with knowing it has the quality and service it should.

KD Smart Chair

WHILL and Jazzy have elevated the portable power chair market with these new offerings, but they didn’t invent the field. In our April 2016 issue, Mark Smith reported on the KD Smart Chair:

The key to the 50-pound KD Smart Chair is its integration of state-of-the-art technology to create a balance of portability without sacrificing performance. The power chair begins with an ultralight aluminum frame that folds like a lawn chair. From there, an impressively supportive integrated seat — which accepts a rehab cushion — and a supportive footplate provide meaningful positioning for a range of needs. Instead of heavy, conventional batteries, it uses 10 amp-hour lithium ion battery technology, offering compact, ultralight power up to 15 miles. To complement the lithium ion technology, small but powerful brushless motors are used on the drive wheels, allowing impressive torque and a top speed of 5 mph.

There are two models available, the Standard and the HD. The standard is 50 pounds with the battery and is 13 by 23.2 by 29.5 inches and a 16.75 by 15.25 inch seat. The HD is 59.6 pounds with the battery and is 33 by 25.75 by 16.75 inches when folded, with a 17 by 17 inch seat. Pre-owned Smart Chairs start at $1,600 through the company’s website, kdsmartchair.com; new models start at $1,995.

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Marketplace
DREAMING BIGGER

When asked what Impossible Dream means to him, first mate Evan Duffy says it makes sailing about ability, not which body parts you can move. It enables nondisabled people and people with disabilities to work together, with everybody doing their fair share.

Rey and Mellen want more people to share in this experience and realize their dreams. “We have found that this is so powerful that even doing three trips a day we need more space to take out more people,” says Rey. Mellen says the organization is raising money for a larger, 80-foot catamaran that can take more people and offer even more access. On the current boat, the lift down to the cabins and bathrooms cannot support power wheelchairs, forcing users to transfer to a manual chair to go down. A larger boat would ideally rectify this problem and add advanced technology to enable higher-level quadriplegics to drive the boat. Mellen estimates a new vessel would cost around $10 million, no small change, but as Rey is apt to say after a busy day of taking people sailing, “We need a bigger boat!”

For information about sailing on Impossible Dream, including the 2018 summer schedule, check out the website below.

RESOURCES

- Impossible Dream, impossibledream.us
- Shake-A-Leg Miami, 305/858-5550; www.shakealegmiami.org
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Instagram is the second-most engaged social media platform after its parent company, Facebook, as it turns out we really do want to see photos of what your dog just did. In addition to keeping up with family and friends, we can also follow accounts of interesting people, including the three briefly profiled here.

3 INSTAGRAM WHEELERS TO FOLLOW

**Fashion Goddess Jillian Mercado**
She’s stunning. She conveys wit with a glance over the top of her oh-so-stylish sunglasses. And, on her road to becoming a pop celebrity, she gets into the best parties! Which makes her Instastories must-sees, before they melt away in 24 hours. Join Jillian Mercado’s 80,000 followers at Jilly_Peppa.

**Olympian Amy Van Dyken**
It’s not easy becoming paralyzed while in the public eye, yet six-time Olympic gold medalist Amy Van Dyken has done it openly with grace. Her heart and humor shine through on Instagram, whether it’s for mentoring or for #dogshaming. Follow her and 25,500 of her closest friends at vandyken.

**Rollette Chelsie Hill**
The youngest Pushgirl, Chelsie Hill, has been experimenting with concept videos, and you get a glimpse of the emerging artist with her "Freaky Friday" offering. Always the optimist, she’s learned to tackle obstacles head-on. Follow her, along with over 40,000 others, at Chelsiehill.

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