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COVER STORY

CHANGING THE MEDICAL SYSTEM FROM WITHIN

Wheelchair users are making it through medical school and rolling into emergency rooms, operating rooms and private practices with greater frequency. TIM GILMER reports on how their presence is beginning to move their field in directions that promise to benefit everyone who seeks medical treatment.

Cover Photo by Keith Barradlough

FEATURES

18 THE JOYS OF ADAPTIVE ROWING
TEAL SHERER found adaptive rowing to be the perfect physical outlet when she moved across the country. She reports that the growing sport may be just what you've been looking for.

30 PUSHING THE EDGE OF FUNCTION
Patience. Stubbornness. Creative thinking. These might not be the traits most associated with independence, but SETH MCBRIDE discovers they may be even more important than physicality when it comes to maximizing your function.

34 RAPPER, ADVOCATE ... MAYOR?
Kalyn Heffernan made a name for herself as the rapping frontwoman for the band Wheelchair Sports Camp, but now she's got even bigger things on her plate, including a run for Denver's mayorship. REGAN LINTON goes behind the music with the colorful rising star.

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By Ian Ruder

“May you live in interesting times.”

That was the ambiguous fortune I pulled out of a cookie after a recent Chinese dinner. I didn’t think much of it at the time, but it clearly stuck with me on some subconscious level, because days later, it popped into my head as I was scrolling through one of the many SCI/D forums on Facebook.

After spending a good chunk of time reading incredibly compassionate responses to a newly-injured woman who was having suicidal thoughts, I clicked on a post a friend shared from another SCI forum. It started, “Tonight while in the shower I was brushing my teeth and decided to use the electric toothbrush on the head of my ...”

Interesting times, indeed.

Of course, I am cherry picking — but if you’ve spent any time at all scouring the vast wilds of disability social media, you no doubt know that these “interesting” juxtapositions are more common than they are uncommon.

A lively discussion on the merits of suprapubic tubes is just as likely to be followed up by a vitriolic rant about a parking violation as it is by a thoughtful list of posters’ preferred UTI remedies.

A link to a thorough guide on how to maintain your benefits while transitioning back to work may have no comments or likes, while a silly meme repurposed for wheelchair users will get shared more often than your friend’s HBO password.

Someday, when scientists are confident they have created true artificial intelligence, their creation’s final test will be to discern the logic underlying which posts resonate and which fall flat. Good luck, robot overlords.

It may be tempting to sign off from this oft-confusing e-landscape. The noise can be overwhelming, frustrating, depressing — you name it — but I would argue that doing so would be a huge mistake.

Because in between the noise, in between the memes and the probably-better-not-shared pics of pressure sores, we are witnessing the creation of the world’s largest catalog of our community’s authentic stories. Every day, tens of thousands of people from across the disability spectrum pour out their hearts and minds, writing candidly and often emotionally about everything from advice, to ideas, to general support and much more — pretty much any topic you can think of.

The closest analogue I can think of for the SCI/D community is Rutgers CareCure Community forum. Thanks in part to its massive size, the social media community is imminently more accessible and easier to find than anything that existed before. Also adding to the appeal is the lack of commitment required. If you’d like to be involved, great, you can share as much as you want and connect as deeply as you desire. If you just want to ask a single question and bail, that’s fine too.

I remember not wanting anything to do with other wheelchair users in the wake of my injury. But I also had a lot of questions, and I’m pretty sure I would have been all over the opportunity to tap into such a vast wealth of knowledge that asks for such little personal commitment. At the least, it would have made 20 years of showers a little more ... “interesting.”
There was no doubt in my mind that **Regan Linton** was the right person to profile Kalyn Heffernan, a rapper turned political candidate. Two fierce and outspoken female artists who happened to both live in Denver — it was meant to be. The two had already crossed paths, but Linton came away even more impressed and ready to vote for Candidate Heffernan. “The idea of Kalyn disrupting the exclusive political environment is awesome to me.”

When **Teal Sherer** pitched a story on adaptive rowing last year, she wrote that joining her local team “has been one of the best experiences of my life.” Months later, to the surprise of no one, she still loves it. Even in the winter Sherer is training regularly and looking forward to getting back on the water. She has competed in two more regattas but says the competition is secondary for her. “It’s really about the community and having a place that I can go to and work out and feel challenged.”

---

*Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org*
Great Choice
You’re so lucky to be able to live your dreams and see so many places! (“2018 Person of the Year: Cory Lee Woodard,” January 2019)
Mary Beth Middlebrooks
Newmobility.com

Breaking Barriers
Cory, you’re breaking barriers and showing the world that people who have disabilities can and should be able to travel the world! You deserve this honor. Enjoy your success! (“2018 Person of the Year: Cory Lee Woodard,” January 2019)
Amy Aquino
Facebook

Real Leaders
Awesome leaders with a purpose and not a “problem” is what you all are (“How They Won: Three Wheelchair Users Share Stories About Their Election to Office,” January 2019). The best is yet to come for all of you wonderful human beings.
Daria Dillard Stone
Newmobility.com

Leadership Training
AAPD has had programs to teach people with disabilities how to run for public office (“How They Won: Three Wheelchair Users Share Stories About Their Election to Office”). EMERGE trains Democratic women to run for public office, and some Emergenistas have disabilities. The Association of University Centers on Disability network presents year-long trainings on [how to participate in public policy-making],

Cost-effective Fun
I like the three-wheeler version (“Cheap Power-Assist From Scooters,” Gear Hacks, January 2019). It would get me farther down the road than my combination Smart Drive/FreeWheel that I only get about five miles out of. The older model Smart Drive I had with the bigger battery use to get me 10 to 15 miles and that is what I mostly used it for. That scooter looks like a great cost-effective way to put some miles on the roads near Newfound Lake, New Hampshire, where I live.
Alan Duboyce
Newmobility.com

Inspiring Finalists
Thanks to all the finalists for your great ideas and to Toyota, for investing in technological advancements that will be life changing for those of us who need them! (“Toyota’s Mobility Unlimited Challenge Finalists Named,” Jan. 7, Newmobility.com)
Linda Richards
Newmobility.com

A Life Saver
Thank you for your wonderful magazine! It’s my only source of inspiration out here in the boonies!
Thomas Jimino
Newmobility.com

Welcome Support
Have you been reading my diary? Glad we have the love and support around us when we get into these unexpected insane hurdles (“Un/Conditional Compromises,” Jan. 18, Newmobility.com).
Nancy Crowther
Newmobility.com

A Great Community
I’m so glad for you and others out there in the community who help wheelchair users like me “feel OK and better” about being in a wheelchair and that there is life outside of being paralyzed (“Joining the Club,” Reframed, January 2019).
Brittany Able
Newmobility.com

“You deserve this honor. Enjoy your success!”
OUR QUEST TO PLANT TREES

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MTA Fall Leads To Calls For Change

Disability leaders in New York City are citing the tragic death of a mother forced to use the stairs at an elevator-free subway station as evidence of the pressing need to make the famed system more accessible. On Jan. 28, Malaysia Goodson, a 22-year-old mother, fell trying to take her 1-year-old daughter’s stroller down the stairs at the Seventh Avenue B/D/E station. Goodson’s daughter was not injured.

Susan Dooha, the executive director of the Center for Independence of the Disabled, New York, dismissed the MTA’s pledges to prioritize accessibility at a rally held outside the station Jan. 30. “If the MTA wants to assure the public that this matter will be addressed finally and forever, they would come and put that down on paper with precise details and a timetable and one that is enforceable by the courts,” she said. “They would not leave the air filled with promises that may never be realized.”

According to a recent report from the city comptroller’s office, only 118 stations, or about a quarter of the MTA’s subway system, are accessible via an elevator. There are about 200,000 mobility-impaired residents in the city as well as another 340,000 seniors and 200,000 children younger than 5.

Sip-and-Puff Skiing

Billed as “the world’s first independent alpine sit-ski for any physical disability,” the TetraSki combines a joystick and custom-designed sip-and-puff system to offer heretofore unprecedented levels of control for people with all types of function. The TetraSki is the result of five years of engineering and development at the University of Utah Rehabilitation Center and Tetradapt, a nonprofit. Thanks to a grant, they were able to build five TetraSkis, which were then spread around the country this winter for users to try and provide feedback. “I didn’t think I would ever go skiing after my injury,” says Lina Nguyen, a C4-5 quad. “I’d never skied before but it was a really cool experience.” Nguyen, who lives in West Valley City, Utah, tried using the joystick on her first few runs, but found she had more control with the sip-and-puff. “Once I got the hang of it, it was much easier.” She’s used the TetraSki twice now and says knowing a facility had one would definitely make her more likely to go there.

Ross Imburgia, a research engineer on the TetraSki, says Tetradapt is looking at launching a fundraising campaign to build more skis. Follow their progress at tetradapt.us.

DON'T MISS THE LATEST UNITED ON WHEELS PODCAST ON HEALTHY LIVING AND SCI. NEW MOBILITY COLUMNIST JOANNE SMITH HELPS YOU MAKE THE MOST OF WHAT YOU EAT, AND HOLISTIC LIFE COACH KRISTINA RHoades EXPLAINS MINDFULNESS AND HOW IT MIGHT CHANGE YOUR LIFE. LISTEN AT UNITEDONWHEELS.BLU BrRY.NET
The Ingenious Lapstacker

An invention that helps wheelchair users carry items hands-free reached its $10,000 funding goal on Kickstarter in less than 26 hours. The LapStacker features two retractable straps that snap together like a seat belt over whatever the manual wheelchair user is carrying in their lap.

The campaign runs until March 8, and backers can have their own LapStacker with manual buckles for about $134, or with magnetic buckles for about $154. The two models are expected to retail for $259 and $289, respectively. See Adaptdefy.com for more information.

#ThingsDisabledPeopleKnow

The world got a crash course in #ThingsDisabledPeopleKnow on Jan. 17 when people with disabilities posted nearly 20,000 tweets with the hashtag. Covering everything from common misconceptions, to personal stories and social advice, the hashtag trended globally and received coverage on many major media outlets.

Imani Barbarin, a blogger and content creator who focuses on disability, race and feminism among other topics, started the hashtag. "When hashtags like this take off," she says, "I'm surprised at how many nondisabled people seem shocked with the realities of disabled life. At times, some become belligerent at the idea that what they're conditioned to know doesn't reflect the community."

Watch

WITH AN HONEST LOOK AT 17 PEOPLE WITH DISABILITIES IN THEIR PURSUIT OF LOVE AND HAPINESS, "TAKE A LOOK AT THIS HEART" HAS WON RAVE REVIEWS IN SMALL SCREENINGS AROUND THE COUNTRY. NOW YOU CAN WATCH FROM THE COMFORT OF YOUR OWN LIVING ROOM BY DOWNLOADING IT FROM THE ITUNES STORE. $12.99.

Third Time's a Charm

Supporters of the Disability Integration Act held parties all over the country on Jan. 15 to celebrate the bill’s reintroduction for the 2019-2020 session. Written by ADAPT and first introduced in the Senate in 2015, the DIA would ensure that people with disabilities who are eligible for institutional care have the right to access those same services in their own homes. Learn more at newmobility.com/2019/02/disability-integration-act-reintroduced

There was barely enough room for the overflow crowd at the grand opening celebration.

PAINTING HOUSTON ORANGE

A packed house turned out Feb. 2 for the grand opening celebration for Opening ARTS & Minds, United Spinal Association of Houston’s new art education program. Designed as an inclusive art experience for people of all abilities, the program offers a dedicated studio and weekly classes for anyone interested in creating art.

United Spinal Association of Houston secured a grant from the Craig H. Neilsen Foundation to fund the program and enlisted chapter member Wes Holloway to lead it. Holloway is an artist with nine years of experience working in the non-profit art world. He sees his new role as completing a circle that began when his OT in rehab encouraged him to pursue his artistic dreams. That OT was Rafferty Laredo, the founder of United Spinal Association of Houston.

Holloway is passionate about inspiring fellow artists and novices alike. "An artist will never know their voice until they find it," he said at the opening. "Even if you don’t create work that’s what you imagined it to be, your story will come out in that work itself. ... Someone will get something out of it as a viewer. That’s just the power of art. It saved my life and put meaning into my life and I hope to do that for any other people."

Find out more at unitedspinalhouston.org/education-series2018.

MARCH 2019 9
MEMBER BENEFITS
unitedspinal.org

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

BENEFITS INCLUDE:
- Personalized Advice and Guidance
- Peer Support
- Advocacy and Public Policy
- Veterans Benefits Counseling
- Accessibility Advocacy
- Local Chapters
- New Mobility Magazine
- Informative and Educational Publications
- Ongoing Educational Webinars

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

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

Suggestions for Navigating Divorce

Jill Asks:
I’m in the process of getting a divorce and I need a new insurer, a new lawyer, a new place to live so I can be closer to my family, new personal assistants, a new emotional support system and so on. Are there any groups for those of us with SCI undergoing divorce? And do you know of any resources to help me with my immediate needs and lifestyle changes?

Spinal Cord Injury Resource Center Director Bill Fertig responds:
If divorce or separation becomes a hard reality that you must face in order to move on, we recommend that you face it as you did your SCI when you first sustained it. Go about the process one puzzle piece at a time. “Fix” one part, then move on to the next. Life after SCI has shown you to be resilient. You can move into this next phase and put it behind you, just as you have learned to adjust to your disability.

There are agencies and support groups that can help you through the process of rebuilding your support system, including finding and retaining personal care assistance. Your local Center for Independent Living can connect you to PCA programs in your new location and provide an overall local benefits review. CILs are private, nonprofit corporations that provide services to maximize the independence of individuals with disabilities and the accessibility of the communities they live in. They’re typically an excellent place to learn about transportation options and other resources available to people with disabilities.

You may wish to connect with our United Spinal chapter affiliates and support groups in your new community to find others with SCI who have gone through divorce. Additionally, reaching out on social media to connect with others who have faced this same set of challenges may provide you with emotional support.

Lastly, the National SCI Statistical Center ‘Facts-at-a-Glance’ overview includes first year and subsequent year costs of care by level of SCI — this can be an important part of settlement negotiations managed by your legal team.

Resources
- ALLSUP TrueHelp healthcare transitions guidance, truehelp.com/healthcare-assistance/
- CareCure SCI Forum, sci.rutgers.edu/forum/showthread.php?133972-divorce&highlight=divorce
- Center for Independent Living directory, ilru.org/projects/cil-net/cil-center-and-association-directory
- Special needs/divorce lawyer network, specialneedsalliance.org/when-people-with-disabilities-divorce/
- State by state resource pages for United Spinal chapters and support groups, askus.unitedspinal.org/index.php?pg=kb.book&id=40

Got Questions?
If you have a question for United Spinal staff, please submit it at unitedspinal.org/ask-us or call 800/962-9629 (choose option 1). For nonemergency medical questions, try the Craig Hospital Nurse Advice line, 800/247-0257.
For more information on how you can support United Spinal and become a corporate member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
CUT THE CLEANSE

Clients, friends and family often tell me about the latest “cleanse” they are doing. In the past, these cleanses were usually mentioned in association with a New Year’s resolution or as part of a springtime detox, but the trend now is to do them several times a year. This concerns me. While they can sound like quick, healthy ways to purify the body, increase energy and/or lose weight, many of these intense, short-term concoctions are actually detrimental to liver function and can make you feel worse.

Your liver is an amazing organ with over 500 functions. For example, it regulates glucose, produces and secretes bile, stores vitamins, converts thyroid hormones, purifies and clears harmful substances such as bacteria, as well as breaks down and detoxifies unwanted and potentially harmful toxins. This last function is particularly important for anyone living with a disability or chronic health condition who regularly consumes prescription or over-the-counter medications such as ibuprofen, acetaminophen, antibiotics and steroids. When medications are metabolized, toxins are created.

Consuming these medications on a long-term basis, while necessary to control infection, pain and inflammation, places extra burden on the liver. Long-term toxic build-up from substances such as medications can potentially cause damage to your liver and affect its ability to function optimally. It is essential that you consume the proper nutrients the liver needs to help ensure these medications are being properly detoxified and cleared from your system and to help reduce burden on your liver.

To help give you a better understanding of the important role specific foods play in detoxifying medications, I want to briefly explain the roles of your liver’s two detoxification phases. As Dr. Michael Murray and Joseph Pizzorno explain in The Encyclopedia of Natural Medicine, Phase One modifies the chemicals to make them an easier target for one or more of the seven Phase Two enzyme systems. Often referred to as pathways, each is responsible for detoxifying specific substances. A healthy diet can optimize your liver’s two detoxification phases.

Each phase is responsible for detoxifying specific toxins, and each requires particular nutrients. Phase One detoxifies common disability-related medications such as codeine, warfarin, amitriptyline, steroids, ibuprofen and acetaminophen. Vegetables from the cruciferous family, such as broccoli, cauliflower, bok choy, cauliflower and cabbage, contain a compound called indole-3-carbinol that stimulates this phase.

In Phase Two, two pathways have special implications for many people with disabilities who experience chronic infection or pain. The acetylation pathway detoxifies and eliminates sulfa drugs like the antibiotics that are often used to treat urinary tract infections. Some of the nutrients required to support this pathway include vitamins B1, B5 and C — found in foods such as legumes, mushrooms and citrus fruits, respectively. The glucuronidation pathway detoxifies and eliminates pain medications such as acetaminophen and morphine, as well as the antispasmodics. Some of the nutrients required to support this pathway include gluconic acid and calcium-D-glucarate, which are found in foods such as Jerusalem artichokes, oranges, broccoli and Brussels sprouts.

The trick to supporting both liver detoxification phases is to do it throughout the entire year with the foods you eat every single day — not by drinking the three-to-14-day liquid gimmicks a couple times a year that I keep hearing about. These kinds of so-called “cleanses” are often too harsh for your liver, creating free radicals, which, in excess, can damage cells — including liver cells — and leave you feeling tired, irritable and headachy.

I highly recommend that you skip the packaged quick-and-easy cleanses. Instead, try to consume at least one of the liver-friendly foods listed below every day. I’ve also included two liver loving recipes to boost your health and help out your liver.

LIVER-LOVING FOODS AND DRINKS

Broccoli, cabbage, cauliflower, Brussels sprouts, asparagus, mushrooms, legumes/lentils, Jerusalem artichokes, citrus fruits/fresh lemon water, protein

EAT WELL

By Joanne Smith
SOLE MATES

I've always loved shoes. Before my injury, my companions were a pair of knock-off combat boots that I wore with cutoff jean shorts, black minis and dresses. My mom hated them! I was wearing them when I got injured, but between the rollover, ambulance and someone cutting off the shirt I was wearing, the boots were lost forever. I still think of them often.

As a new wheelchair user, I experimented with soft and oversized shoes. They were easy to put on and reduced the possibility of pressure wounds, but every time I was in a trendy shoe store I felt robbed of the opportunity to wear cool and sexy footwear. I began to spice it up. A camel-colored wedge made me feel beautiful, even though I had to MacGyver straps underneath my skirt to keep my knees in place.

The metallic silver boots with chunky heels, the sexy red pumps my friend insisted I wear on New Year's Eve before proceeding to break my footrest putting them on. …

When a fancy event calls for fancy footwear, I buy a fierce pair of shoes for a one-night adventure and save the receipt. They make me feel like the most exquisite woman. The next day we part ways. No hurt feelings, just the memory of a great night.

Some shoes have been with me for years. I treat them like royalty — riding in my chariot, never touching the ground, privileged to experience my life’s adventures, forever young. Others have moved on to a new partner who happily accepts them. I know we aren’t right for each other, but part of me wants to hold on.

My relationship with shoes is complicated. Together, we have gone through trauma, healing, exploration and adventure. Although they’re no longer meant for walking, shoes help me still feel like me — in sickness and in health — and that is love.
THE JOGGER CHAIR

If you’ve sat in a racing chair, then you’ve probably noticed what a pain in the ass (and neck) they are. Transfers are tough, then you have to wiggle your hips down into an impossibly narrow seat bucket and fumble with straps to keep your butt from popping out as soon as you start pushing. When you’re in, you have to crane your neck just to be able to see the road in front of you. During a relay, I once put my head down to take a few hard pushes on a slight downhill and ran right into a stop sign — no more racing chair.

There were things I liked about the racer — the efficiency of my push stroke, how smooth it was at speed and how well the front wheel coped with bumps and cracks in the road. After bending my first racer beyond repair, I sure wasn’t going to spend thousands on a replacement, but I missed having the equivalent of a well-fitting pair of running shoes. I was looking for something in between an everyday chair and a racer, something comfortable and easy to take out for some laps around the neighborhood ... I wanted a jogger.

Use What You Have

My first idea was to copy the seating geometry from my rugby chair, since it provides the best mix of comfort, pushing efficiency and maneuverability that I’ve found so far. I sit with my butt low and my knees high. Sitting far below the wheels gives me a lot of wheel to push and I can lean over my lap when I’m really wanting to sprint. The high knees give great stability and make it easy to get back into an upright seating position for quick turns — essential for dodging potholes, traffic and pedestrians out in the real world.

I considered having my dad weld a simple frame using that geometry, something we’d already done to fabricate a cross country ski frame. But while connecting a frame to a pair of skis is a fairly simple process, mounting a cambered axle and casters is another story. He’d have to build a jig — basically a brace that holds all pieces at the proper angles while you weld them — to make sure the geometry stayed true, and putting a jig together is a serious undertaking.

Then I had another idea: What about using an old rugby chair? It would need to be modified, as the frame is heavy, and the front casters will rattle you to death on anything but the smoothest pavement. Making some modifications to deal with those issues seemed like it was going to be a lot easier than fabricating a new chair from scratch. Plus, I had an old frame languishing in storage. We decided to give it a shot.

The Hack

This job started with some actual hacking, as the front bumpers on my rugby chair would serve no purpose now that I wouldn’t be using it to bash into people. My dad used a grinder to cut off the bumpers and support bars, saving me a few pounds of weight.

Next step was to replace the small,
rollar-blade style front casters with something better able to cope with variable road conditions. But because rugby chairs have a ton of camber, raising up the front end causes the back of the wheels to be closer to each other than the front of the wheels, and this “toeing” reduces rolling efficiency. That makes it difficult to use larger casters.

I’d seen social media posts of people attaching a Freewheel onto their rugby chairs for long-distance pushing and decided to try that. I created a mounting bracket for it by bolting a thick piece of aluminum plating to the front end of the rugby chair. Since the Freewheel can be adjusted with Allen wrenches, attaching it at the right angle only took a few minutes. Because I’d always be using this chair out on the road, I decided to remove the front casters all together, which let me adjust the Freewheel to a position that kept the front-end height the same, minimizing toeing. This also removed the potential for the casters to jam on bigger cracks.

The last step was to remove the anti-tips so I could wheelie over curbs and other large bumps without getting stuck on them. I was concerned that without the anti-tips, I’d easily flip over backwards, and initially, it was too tippy. The housings for the rear anti-tips kept me from flipping over, but it was difficult to push because the front end kept bouncing in the air with every stroke. I moved my feet as far forward as they would go and tightened up the back upholstery to move my center of gravity forward, both of which helped.

Once dialed in, the jogger performed as well as I could’ve hoped. It was perfect for a quick push without worrying about the smoothness of the pavement on my route. Plus, after adding an attachment for a child’s front bike seat, I could strap my son on the front and use him for a little extra resistance. Before I made it, I hadn’t thought about using it off-road, but with the big front wheel and long wheel base, it does great on soft and bumpy terrain. This summer, I plan to mount some knobby tires and test it as a trail chair. I’ll let you know if I wind up in the bushes.

**Cost Considerations**

The Freewheel wheelchair attachment is available from Epical Solutions (epicalsolutions.com) for $599. That’s not cheap, but its far below most other adaptive mobility options. Given its durable construction and utility for off-road wheeling, it’s got as much value for price as anything out there.

If you don’t have an old sports chair cluttering your garage, it’s worth skulking around your local adaptive sports teams and organizations. You’d be surprised how many people have an old chair that they never got around to getting rid of.
Born and raised in Los Angeles, Candis Welch has seen all sides of life in Tinsel Town — from interning at red carpet events, to hustling as the personal assistant to an HBO star, to working with the city’s homeless residents. Whatever the job, Welch succeeds thanks to a strong work ethic and the confidence that she has the skills to succeed.

Welch was an undergrad at Cal State University Northridge, studying journalism but unsure whether the news business was right for her, when an advisor recommended she give public relations a try. “My first internship was with BET, and I got to work one of their very first award shows in Los Angeles,” she says. “I liked working the red carpet and being able to work with the press.” But as a wheelchair user — Welch has spinal muscular atrophy — getting started in Hollywood wasn’t easy. “The entertainment industry is a very vain industry. If you don’t walk and talk and look the same way, they pretty much don’t know how to accept you,” she says. “I knew very early on I was going to have to be the one who stayed late, overworked and did the things that nobody else wanted to do because I was going to have to prove to them that just because I was in a wheelchair didn’t mean I was incapable of doing the job.”

Welch’s work ethic helped her land plenty of internships while she was in school, but she graduated in the middle of the recession and struggled to find a job. She was eventually hired by the dating website eHarmony, but was laid off. In a stroke of good luck, a friend called as she was leaving the office building for the last time and told her about a friend who needed a personal assistant.

That friend was Issa Rae, an actor who was just starting to make a name for herself with the YouTube series “Misadventures of an Awkward Black Girl.” Welch didn’t (and still doesn’t) have a car, so she took the Metro to interview with Rae. “I gave it my all, and basically told her, ‘I can make your life simplified if you’ll give me the opportunity.’ For her part, Rae gave Welch something she’d yet to experience in an interview: a fair shot. “She never mentioned my wheelchair, she never asked if I was going to be capable of doing it, it was just based on my skill set and how I performed.”

Welch got the job and she spent six years as Rae’s personal assistant. Welch was with her — scheduling interviews, arranging travel, responding to emails and just about anything else.

**DREAM ADAPTIVE EQUIPMENT:**
A track system on my ceiling so I could be lifted from couch to kitchen to bathtub. That would be so dope.

**TRAVEL HACK:** I bring a Hoyer lift sling and put it under me as an easier way for people to help me transfer, whether getting onto the plane, onto a beach chair or anything else.
Issa was a pivotal person who showed me if I want to see a change, I need to be the one that starts the creation of it. I just can’t keep sitting back and saying, ‘Oh, that’s not accessible, or there’s not any representation of disabled people in the media, oh well.’ Issa didn’t see what she wanted on the TV screen for people of color, so what’d she do? She created a platform for them to grow and network. I want to do the same thing for people with disabilities.

If I’m going to complain about something, I better come up with a solution. That’s what started me creating my blog and calling out businesses and corporations that aren’t accessible — because we aren’t going anywhere, and our money spends the same as anybody else’s.

I’m also obsessed with travel. I’m going to Spain soon — to Madrid and Barcelona and I’m going to be doing a whole series on those travels, from what I pack, to what suitcase I bring and why. I’m going down to the nitty gritty, from how you get help when you travel, to how you pay for your nurses. I’m really excited to show how you can travel on a budget in a wheelchair.

WHY I JOINED UNITED SPINAL: I’m a long time New Mobility reader, but I didn’t know about United Spinal until a friend connected me with some NM staff. When I found out about the organization, joining was a no brainer.
As I sat in the middle of Seattle’s Lake Washington last spring, the sun touched my face and a breeze rocked my boat. It was my first time in a double scull. I struggled with the oars, but that was OK. Outdoors, on the water, almost in another world, away from the hustle-bustle, it was just me and my rowing partner. As we became more comfortable with the boat and each other, we started to row in unison, gliding, almost flying, through the water.

A New Challenge
I’ve always been active and athletic but knew nothing about rowing — much less adaptive rowing — until November 2017. While participating in an adaptive CrossFit workshop in Seattle, a classmate mentioned there was a local adaptive rowing team named Seize the Oar. “It’s a great endurance sport and I love being on the water,” he said. “It feels like a small family with all of the athletes and volunteers.” He mentioned winter training was starting soon and I should check it out.

When I rolled into the gym for the first time, it felt a little like the first day of school. During the cold, rainy months, Seize the Oar moves indoors for weekly strength and rowing machine workouts. As we circled up to introduce ourselves, my eyes kept shifting toward two exceptionally fit female paras, both lean with beautiful Sarah Connor arms. Having never been on a rowing machine, or erg, as they are known, I kept my gaze on them as they set up.

First, they placed their adaptive seats on the erg and locked them into position with clamps. Then they put their wheelchair cushions on top and transferred over. After strapping their feet on the footplates, they began to secure the rest of the straps. Straps are an important part of adaptive or para-rowing and athletes use them differently depending on...
Now it was my turn. I transferred onto the seat and, with guidance, got strapped in and started to row. It wasn’t as easy as the two women made it look. Like anything, it was going to take practice and hard work. But I liked it — my heart rate was up and my arm and back muscles were firing.

**Filling a Void**

Adaptive rowing is a fairly new sport. Para-rowing didn’t become a part of the Paralympics until 2008 in Beijing — 48 years after the first games. “There are nondisabled athletic communities who are used to seeing and interacting with adaptive athletes, and rowing is not one of them,” shared Seize the Oar founder Tara Morgan. “It’s been a learning curve for the rowing community as a whole to learn about our adaptive rowing and know what our needs are and how we can fit in with the nondisabled Masters races,” she says. According to USRowing, the national governing body for the sport of rowing in the United States, more than 60 USRowing member organizations now offer adaptive programs.

Seize the Oar began in 2013 when Morgan, a competitive rower who taught a beginner rowing class, was forwarded an email from a local man with a spinal cord injury who wanted to learn to row. “There were no programs in the Pacific Northwest for adaptive rowers,” Morgan said. Even though she had never taught anyone with a disability, Morgan didn’t hesitate. “I told him to come on down. And lucky for me, when I asked him what he did for work, he revealed that he was not only a doctor, but he specialized in physical medicine and rehabilitation and worked with people with SCI.” From there, with the help of donors, friends and rowing colleagues, Seize the Oar grew quickly. Now it has around eight adaptive athletes on the team at any time.

The team rows out of Renton Rowing Center, which is tucked between a Boeing plant and The Renton Municipal Airport. During practice, the team glides past 737s being built and looks up to seaplanes flying overhead. Seize the Oar travels to regattas across the country and up into Canada. Because the para-rowing competition pool is small, the team often competes against itself or in nondisabled races where adaptive athletes get a head start.

‘Tiny Mighty’

Over the winter workouts, I got to know the two women who had initially caught my eye, Amy Brodsky and Erin Martin — or as they were more commonly known, “Tiny Mighty.” They earned the nickname because they were strong and fast, despite lacking the traditional rower body mass.

Brodsky, a T5 para, and Martin, a T4, joined Seize the Oar about a year apart, fairly soon after their spinal cord injuries. Both had rowed before and were drawn to the sport for similar reasons — it would get them active outdoors again. Martin, who was injured in a climbing accident, had also been a runner, biker, hiker and camper. “When I tried rowing, I didn’t have anything to compare it to. It felt new, exciting and challenging. Also, as I rowed, I could see changes in my body and performance.”

Brodsky, who was hit by a car while riding her bike and then later got my-
The Health Benefits of Rowing

One of my favorite things about rowing is it’s a counter motion to all of the forward movement we do as wheelchair users. Corley McBeth, a physical therapist with Movement Systems PT, agrees. “While rowing is a great exercise for just about everyone, it has particular benefit for wheelchair users given the strengthening of the opposing muscle groups to those required for chair propulsion,” she says. “This may minimize the risk of repetitive overuse injuries that can arise from dominance of the pushing muscles when they are left unchecked.” Plus it’s good for our hearts, and builds strength and endurance, “which is beneficial for overall health in any population,” she says.

Movement Systems Physical Therapy is an official sponsor of Seize the Oar and attends practices and works with the team to enhance performance and efficiency, reduce the risk of injury, and promote gains in strength and mobility. “We have a strong relationship with the coaching staff,” said McBeth, “and that allows us to act as a resource for them with regard to best serving their athletes with adaptations.”

As for the future of adaptive rowing, Martin and Brodsky would like to see the sport continue to grow and become more inclusive for athletes with higher spinal cord injuries. “Right now, the sport favors people with lower injuries,” says Brodsky. “FISA, the international rowing federation, changed the strapping rule — you have to have a chest strap. It can be as loose and low as you want, and that shuts Erin and I out from higher level competition. In adaptive skiing there are so many classifications; hopefully one day it can be like that.”

Morgan envisions the sport and its leaders continuing to push innovation in all areas — especially equipment design, racing opportunities, and injury prevention and recovery methods. Seize the Oar is also working on implementing inclusive strategies across the sport in the Pacific Northwest with coaching mentorship, training programs and evaluations of area boathouses to assess who they can best serve inclusively.

“Rowing is the ultimate sport for all abilities,” says Morgan. “It challenges and transforms mind and body and no day on the water is the same. I love the...”
team aspect — how interconnected you have to be with your boatmates, with Mother Nature. Finally, rowing challenges the idea of perfection — there are so many variables you can’t control. Rowers are in an ongoing journey, luckily experiencing little perfections here and there.”

My First Time On the Water

After training on the erg all winter, being on the water in springtime is an adjustment. Now I have two oars to maneuver, and I have to steer and watch out for water traffic. The boats are sensitive, so a pontoon is attached to each side to help stabilize them. And then there is Mother Nature. Depending on her mood, the water may be serene and smooth, or rough and choppy.

In June, my rowing partner and I pulled into the start line at our first regatta, the Northwest Masters Regional Championship in Vancouver, Washington. Our first race was 1,000 meters to the finish line. I had a death grip on my oars as we waited. “Attention,” announced the starter, raising a red flag. After a moment, he snapped it down — “Go!” Five quick strokes propelled us into the race, and then we settled into a rhythm. Making our way down the lane, we encouraged each other: “Pull harder!” “Don’t forget to breathe!” We were the last boat to finish, but that didn’t matter. Our cheeks were red, we were out of breath and we were smiling.

Resources

- USRowing, usrowing.org/adaptive-rowing
- Concept2, concept2.com/indoor-rowers/adaptive-rowing/adapting-indoor-rower

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Brodsky straps into her shell.
It’s 1992 and the Americans with Disabilities Act is the new kid on the block. Jim Post, a 23-year-old C4-5 quad who recently graduated summa cum laude from King’s College in Wilkes Barre, Pennsylvania, is on NBC’s The Faith Daniels Show. He sits straight in his power wheelchair, well-groomed, handsome and composed, as the live TV audience listens to Daniels describe his dilemma. “He graduated top of his class and is the only one of his class kept out of medical school,” she says. Post has been rejected by all seven med schools in Pennsylvania. “Jim, did you ever think this would happen?”

“No, I never thought all of them would reject me,” he says. The audience feels for him, but they can see why his application would be denied — his fingers are permanently curled. Wouldn’t that in itself keep him from being a doctor?

What they don’t see is the larger institutional problem — the prevailing assumption among most medical schools that a quadriplegic candidate will not be able to satisfy certain “technical standards” — non-academic tasks or protocols that all med students must meet to become doctors regardless of their chosen specialty.

Daniels asks a member of the audience, Dr. Stanley Wineapple, a doctor with a visual impairment, why he thinks Post was rejected. He says that technical standards [see sidebar, page 25] don’t account for all the options that may allow people with disabilities to function. “What is not being considered are advances in technology and the use of personal assistants. … If microsurgeons were not allowed to use their telescopes and their special lenses, they wouldn’t be able to do microsurgery, and addition-
ally, physician assistants are ideal to help a person with a disability meet the technical standards.”

Daniels then turns to another guest in the front row, Dr. Herbert Schaumburg, professor and chair of neurology at Albert Einstein College of Medicine in New York. He says a paraplegic female just graduated from AECM, and another student, a male, became quadriplegic after he enrolled. “The big thing that they have to do is they have to provide some help for themselves, in physician assistants. … He [Post] wants to be a radiologist, it is well within his grasp.”

Daniels then throws out the challenge: “Can Jim come to Albert Einstein?” Schaumberg, surprised, stumbles at first: “It’s, it’s … well, he has to apply first.” The audience cheers and applauds, and Daniels abruptly wraps up the show — right on time for the commercial break.

THE PERVASIVE UNDERLYING BIAS

Of course, the problems of the everyday world are rarely resolved in neat TV show increments. Case in point: compliance with the 1990 Americans with Disabilities Act.

The medical establishment in particular has been slow to comply with the ADA. Dr. Lisa Iezzoni knows why. Not only has she researched the topic, she has lived it. At the end of her first semester in medical school in 1980, she was diagnosed with multiple sclerosis, which complicated her future — but not nearly as much as the prejudicial attitudes that had already shaped the profession she hoped to enter. In short, she successfully completed her studies and graduated from Harvard Medical School but was prevented from applying for an internship or residency by HMS higher-ups, whose biased,
uninformed views on her disability led them to withhold support for credentialing.

Since then, Iezzoni, now a professor of medicine at Harvard Medical School, has distinguished herself as an expert in healthcare inequities, especially for the disabled community. In a 2016 American Medical Association Journal of Ethics article, she writes that physicians “have little understanding about living with disability or the consequences for daily life or health-related behaviors.” She cites a seminal study of the attitudes of 233 doctors, nurses and emergency medical technicians toward treating persons with spinal cord injury. She then compares their responses to people who actually live with SCI. One statistic stands out starkly: Only 18 percent of the medical personnel said they could imagine being glad to be alive following SCI, compared to 92 percent of those living with SCI.

Iezzoni attributes the negative view that healthcare professionals have of SCI survivors to their limited interactions with them in mostly clinical settings. Doctors have little or no direct contact with patients in their everyday settings, so they remain ignorant of the adaptations and accommodations that disabled people routinely rely on to live independent, productive lives. Along with other factors, this lack of knowledge explains why people with disabilities who want to enter the medical profession often face attitudinal barriers that limit or deny their choices. As a result, the disability population is disproportionately underrepresented in the medical profession. A 2016 study found that a mere 2.5 percent of medical students have mobility impairments. Prior to 1992, becoming a doctor as a wheelchair user was almost unheard of — only .19 percent of medical students with physical disabilities (a much broader category than wheelchair users) graduated.

Iezzoni hypothesizes that “increasing the number of physicians who actively identify as having a disability and who require accommodations to practice their profession could improve health care experiences and outcomes for patients with a disability” [emphasis added].

WHEN DOCS ‘GET’ DISABILITY

Brad Frazee, 42, an ER doc for 18 years, has a unique front row seat from which to test Iezzoni’s hypothesis. In 2006, he was struck and run over by a Range Rover while riding on a bike trail near his home in Mill Valley, California. When he regained consciousness three weeks later, he was a patient with a T10 spinal cord injury and a badly damaged shoulder.

He was transferred to the University of California, San Francisco, where he had graduated from med school. From there he hoped to go to rehab at Santa Clara Valley Med Center, a Model Systems SCI Center, but as a patient no longer calling the shots, he was told he wasn’t ready. “They sent me instead to Kentfield, mostly old folks,” he says. “I got despondent, thinking I probably couldn’t return to my work. So I lifted weights like crazy to get out of there. By the time I got out and went to Santa Clara on my own, they wouldn’t take me because they said I was too far advanced!”

Eight months later, he showed up at Highland Hospital in Oakland in his wheelchair, ready to resume his job. Whenever a person with a new spinal cord injury came in for emergency treatment, the encounter was strange. “There’s usually no real opportunity to make a direct connection then,” says Frazee. “The person may be in shock. It’s unclear how permanent it is. It’s actually a bit PTSD-generating. Everyone in the room looks at me like they are thinking about me, not knowing what to say. It is so awkward.”

Later, when the patient is stable, Frazee visits. “They are in a whole different section of the hospital, and I can make a connection when I go see them,” he says. “I give them the kind of info no one else knows, encourage them, tell them they are going to be OK.”

His experience has given him a new point of view about not only spinal cord injuries, but life-altering medical events in general. “In the hospital you’re at the mercy of all these people who don’t know you. There is a profound sense of powerlessness, a lack of control, and being a patient in this situation is what most doctors do not appreciate.” But with patients, when he rolls in, “they instantly know I have been through what they are going through. It could be any of a host of things with life-changing consequences, cancer, trauma. I know they are in for hell, and I tell them ‘listen, you need to kick back and let the docs work — it will be tough … but you will get through it.’”

Frazee can say this with confidence. More than 12 years post-injury, he is an avid handcycler, in good health, comfortable working eight-to-10-hour shifts, splitting his time between overseeing ER cases, teaching and doing research. Since his injury, he has published 24 original research papers. He is board certified in internal medicine as well as emergency medicine and has a passion for researching infectious diseases.
Daniel Grossman is another ER doc who confronted getting back to work after being paralyzed. Injured in a mountain biking accident in Minnesota in 2017, he woke up in a hospital as a T7-8 para. Just five months later, he was back at his part-time job at Mayo Clinic’s Rochester ER department. He credits his quick turnaround to the quality of care he received, his own aggressive attitude and a mentoring relationship he had with Dr. Robert Brown, a Mayo neurologist and wheelchair user of more than 40 years.

Grossman immediately decided to get back to work instead of filing for Medicare. “I didn’t consider any other set of options. My mind was fixed on returning to work.” At the time of his accident, besides working part-time as an ER doc, he was in the early stages of starting up a private insurance business. Now he goes to his office at Bright Health Insurance regularly and drives to Mayo in Rochester once a month to work four nine-hour ER shifts over a four-day period.

Like Frazee, Grossman’s personal experience with SCI has changed his outlook as a doctor. “I’m more compassionate now,” he says. “Being in a hospital is an incredibly scary experience. How someone speaks to you can invoke fear or calm — the way they do it can create either response. The more you can place yourself in the viewpoint of a patient, the more you can empathize and create a helpful way of communicating. So having been a patient, I’m better now as a doctor, knowing how I would want someone to explain something to me. Real experience is more thorough than textbook learning.”

As paras, Frazee and Grossman encountered relatively little resistance when they returned to work in wheelchairs. But when Sam Simms became an incomplete C6-7 quad in 2003 and wanted to return to his ER position at St. Mary’s Hospital in Jefferson City, Missouri, he was told that limited hand movement and dexterity would prevent him from sewing and doing other hands-on tasks, which meant he could no longer be credentialed as an ER physician. He pushed the boundaries and convinced his superiors that a helicopter flight nurse, skilled in emergency protocol, could do the sewing and other tasks, and he would supervise and employ the nurse. They balked, citing liability concerns, but Simms convinced them that they could be credentialed as a team. They finally gave in and Simms has remained on the job to this day, 18 years as a quad doctor, without a single lawsuit.

“More importantly,” Simms says, “having a personal nurse has freed me up to spend more time with each patient, which is a luxury to doctors these days. I would never go back to the way it used to be. This is a better model, and I can afford to pay for a nurse.” Simms makes $260-$300/hour and the nurse charges $35/hour. Considering that the average on-the-job

### Double-Edged Sword: Technical Standards in Medical Schools

Within the context of educational admissions, the term “technical standards” was first articulated in Section 504 of the 1973 Rehabilitation Act, but guidelines for medical schools were not issued until 1979 by the Association of American Medical Colleges. Those outdated technical standards guidelines remain the primary reference to this day, despite subsequent attempts at clarification.

A November 2018 publication in the AAMC’s journal, *Academic Medicine*, entitled “Leading Practices and Future Directions for Technical Standards in Medical Education,” states: “Many TS may not be compliant with Americans with Disabilities Act standards as they are vaguely articulated, rely on outdated language and concepts, and/or are not clearly presented in the schools’ admissions materials or websites.”

Among other technical standards, students are required to perform a complete physical exam, draw blood, perform CPR and other physical tasks without assistance. “Reasonable accommodations” are often not being supported by current technical standards. The main problem is schools too often delineate how technical standards must be satisfied rather than what must be done. The authors of “Leading Practices and Future Directions …” [Laura B. Kezar, et al.] recommend that the principles of universal design be used to create a more inclusive approach.

They say that “functional” standards, which allow students to “provide or direct” care, are needed to comply with federal law as well as offer equal opportunity. “Organic” standards, on the other hand, are based on the candidate’s physical skills. Functional standards allow the use of technical innovations and intermediaries, or helpers — without which, most quads can be screened out of medical school.

The practice of medicine has changed substantially since 1979. Depending on the way they are defined and implemented, technical standards can either provide opportunities or serve as barriers. “We anticipate that the emerging focus on universal design and competency-based medical education will eventually render TS obsolete,” contend the authors. “In the meantime, the prevailing approach to technical standards must be revised.”

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Dr. Sam Simms kept his credentials as an ER physician by teaming up with a nurse.
“lifespan” for ER docs is around 10 years and Simms is approaching the 30-year mark, it’s hard to argue with his claim.

Simms, Frazee, and Grossman are among an unknown number of physicians in the United States who practice from wheelchairs — most of whom acquired their disabilities while they were doctors. In preparation for writing this article, I assumed that I might find only five or six wheelchair-using docs, but after two months of researching and interviewing, I had compiled a list of more than 25. Who knows how many more are currently practicing or in the med school pipeline?

FINDING THE RIGHT MED SCHOOL

Even though the Rehabilitation Act of 1973 and the ADA provide for reasonable accommodations in education, finding a medical school that complies with the spirit of these laws has always been difficult. Jim Post was fortunate to find Schumberg as his mentor at AECM in 1992.

Chris McCulloh was also fortunate to find his mentor. He was 28 when he became paralyzed in 2008 from a fall and sustained a C6-7 incomplete injury. At the time he had applied to med schools, but his future was now in doubt. Then fortune, so recently his nemesis, smiled on him. Within weeks he started regaining sensory and motor function. A year and a half later, now functioning more like a T8 para, McCulloh resumed his career path.

He had heard the stories of prospective med students in wheelchairs being screened out due to enforcement of outdated technical standards but had a good feeling about Case Western Reserve School of Medicine in Cleveland. “Most important is finding a place that wants to work with you,” he says. “I had doubts about several places where I interviewed. Some I knew pretty soon were not a good fit — they were not asking the right questions. They have to take an interest in your disability and how they can help.”

At Case Western he discovered his passion — pediatrics. Dr. Edward Barksdale, head of pediatric surgery at Case Western, became his mentor and McCulloh followed him through different rotations for a month. “I loved the school. They were incredibly willing and helpful. I realized in an instant that’s what I wanted, and the kids drew me in.”

Prior to entering Case Western, McCulloh had found a doctor in Hawaii, Dr. Peter Galpin, who would do for him what a team of engineers at Mayo had done for Brown 30 years earlier [see sidebar, next page]. “I shot an email to Dr. Galpin, and he told me all about standing wheelchairs, where to get one, funding and everything.”

Now, more than 10 years post-injury, McCulloh uses a LEVO C3 standing wheelchair in his fourth year of general surgery residency at Morristown Medical Center in New Jersey. He has applied for a fellowship in pediatrics. “My focus will be all things pediatric, except for the brain. Pediatrics is the one true surgical field where everything goes — all kinds of surgery are possible.”

THE NEW PARADIGM

Technical standards that discriminate against people with disabilities, especially those with sensory or mobility impairments, are still in need of upgrading, but antiquated paternalistic attitudes that devalue the lives of people with disabilities are gradually beginning to fade away. One med school in particular, the University of Michigan, is leading the way. Dr. Oluwaferanmi O. Okanlami, director of the University of Michigan’s Medical Student Programs, is at the forefront of the new paradigm that may one day replace the outdated medical model.

“Dr. O” is another incomplete quad-turned-para who ex-
experienced remarkable motor and sensory return. He graduated from Stanford Medical School before coming to the University of Michigan. In addition to his involvement with medical students, he is clinical assistant professor, department of family medicine, department of physical medicine and rehabilitation; and director of adaptive sports. Okanlami states unequivocally that physical disability should not be seen as a legitimate reason in and of itself for screening out med students. This view is supported by the Association of American Medical Colleges, but only a small percentage of med schools have instituted guidelines, programs and protocols that make it a reality.

"Universal design is what it is all about," says Okanlami. "I believe that technology will allow a quad to be a surgeon. Robotic surgery is like playing a computer game, sitting behind a screen and looking at a video game. Tech is increasing so rapidly that there will be other ways for a quad to do this kind of work. The field is evolving. I am not willing to put up barriers.

No doubt Dr. Karen Muraszko, 62, had something to do with Okanlami’s progressive mindset. Born with spina bifida, Muraszko did not begin using a wheelchair until after she had graduated from medical school, practiced pediatric neurosurgery at the University of Michigan, and was named chair of the university’s neurosurgery department in 2005 — the first woman to hold such a position in the United States. She still teaches and performs operations from her power chair, proving that a wheelchair is not an obstacle to practicing even the most demanding of medical procedures — brain surgery.

"Disability or not," says Okanlami, “in a life or death situation, you need the knowledge and organizational skills above all else, so disability should not exclude someone from the profession because of others’ limited perceptions. We currently have two quads enrolled in University of Michigan's Medical School — Chris Connolly, a C6-7 incomplete quad in his second year, and Maureen Fausone, a C5-6 incomplete quad, who has one year to go to graduate.”

Dr. Cheri Blauwet is also outspoken about the importance of inclusion. She is an attending physiatrist at Brigham and Women's Hospital and Spaulding Rehabilitation Hospital in Boston, where she is director of disability access and aware-

Pre-ADA Model for Accommodating Para-Docs

A more difficult path is taken by those who must gain entrance to medical school as wheelchair users, especially those who graduated from college prior to passage of the ADA. Dr. Robert Brown, injured in 1975 and a graduate of Mayo Medical School in 1987, is a notable exception.

"I chose neurology," says Brown. "It’s a cognitive process I can do easily from a wheelchair. As a specialist in the field of stroke and other issues affecting the blood vessels in the brain, I often see people who have had strokes, aneurysms, and other vascular malformations, as well as Parkinson’s, Alzheimer’s, seizures, migraines and other neurological conditions. I freely interact with the person and their family members, learning all I can about their specific symptoms and past medical history rather than focusing narrowly on some technical procedure.”

Brown had sustained a T10 spinal stroke when he was 14. An excellent student, he flourished in college, applied to Mayo Medical School and was invited for an interview. “The reason I'm still here is because the day I came to interview, the dean and associate dean and other faculty visited with me during the interview, and they could not have been more welcoming. They were not worried about my disability and said, ‘absolutely, we can make it happen, let’s see if it is a good fit for you.’"

Later, he spent a day with the head of the gross anatomy lab and other basic science courses, and clinical directors, talking about the logistics of doing gross anatomy lab work and course work from a wheelchair. "After discussing how I might have access to all the lab activities, the head of the lab invited engineers over, and they got to work designing and building a one-off mobile power chair that raised up and down and allowed me to swivel, and I used it in anatomy lab and surgery. I kept it there, it was mine, designed just for that purpose.”

Brown’s pre-ADA med school experience was both exceptional and prophetic. Thirty years later, med school students have used commercially manufactured standing wheelchairs to level the playing field, even in the operating room.
Physiatry: A Welcome Path for Wheeler-Docs

A number of doctors who use wheelchairs have successfully specialized in physical medicine and rehabilitation. Of the more than 25 wheeler docs I have found, eight have become physiatrists, half of whom are women. In addition to Cheri Blauwet, Suzy Kim, Meghan Wilson and Allison Kessler, are now practicing in the PM&R field. Wilson graduated from the University of Pittsburgh Medical School and now has her private practice in Youngstown, Ohio. Kim, well-known in the disability community through her affiliation with Rancho Los Amigos National Rehabilitation Center in Downey, California, also practices at St. Jude Medical Center in Brea, California. She received her medical degree from Keck School of Medicine (University of Southern California).

Kessler, in her first year as a physiatrist at Shirley Ryan Abilities Lab, a state-of-the-art facility in Chicago that combines research with ongoing rehab in an innovative teamwork setting, became a T12 para from a ski-jump accident at age 15. At the time she was an all-around athlete at a well-known private boarding school in Connecticut.

“I went back to Choate because I valued the community, but reintegration was not easy. I mostly had to make all new friends.” Administrators offered to waive Choate’s athletics requirement for her, but she said no. A friend she respected told her she had the right qualities for the crew team. “She told me I should be a coxswain. She knew I was a leader, excelled in a team environment, and was very competitive.”

Kessler participated in crew through high school, during college at Harvard, and while getting her master’s from London School of Economics and Political Science, where she concentrated on public health and Sociology. “It was absolutely important to my identity after losing my friends following my accident.”

From London she moved to Chicago, where she got her medical degree at Northwestern’s Feinberg School of Medicine. “I used a standing chair to do my surgical rotation. Everything took planning and logistical foresight, and I learned it was OK to ask for help. I don’t need to walk to do what I do.” At Feinberg she also met her husband-to-be. During her fellowship at the SRA lab, she became pregnant. Her daughter, Brooke, will soon be 2 years old.

Working in a state-of-the-art rehab center is the perfect placement for Kessler. Like Blauwet, Kim and Wilson, her background in sports prepared her for the rehab environment, where hard work and commitment are critical to the recovery process. And SRA, with its emphasis on teamwork between doctors, patients and researchers, is not that different from crewing, where everyone works in sync to move the boat forward, one stroke at a time.

JIM POST: THE REST OF THE STORY

And what about Jim Post, the C4-5 quad? Did The Faith Daniels Show help him make the all-important connection with Dr. Schaumberg and the Albert Einstein College of Medicine?

It turns out that Daniels had asked Post if he would like to invite someone to be on the show. Post had heard of Schaumberg but they never met until the day of the show. Post applied to AECM and successfully earned his medical degree. His wife attended classes with him and acted as his assistant in gross anatomy lab and did other tasks as well.

Schaumberg and Post became good friends and helped others with disabilities get started in their medical careers. “He had experienced the same thing with his polio,” says Post. “He was such a great help. He gave it his all. He just retired this last Christmas after 58 years in medicine at Einstein.”

Post did not become a radiologist. “I considered physiatry, radiology, psychiatry, whatever I thought would not involve
my hands, but what I really wanted to be in was internal medicine, a tough road for people with disabilities,” he says. “Other doctors told me I should stick with what I love, and I love internal medicine, so I went for it.”

After graduating from AECM, Post did his residency at Lennox Hill Hospital in New York. “They had a physician’s assistant program, so I knew I would have a pool of potential assistants I could rely on at any time. Now I’m board certified in internal medicine and nephrology.” He was hired to work in the nephrology department at the James J. Peters VA Medical Center in the Bronx in December 2003, distinguished himself in the hemodialysis unit and in 2015 was promoted to chief of internal medicine.

“When I first started out, back when I was on The Faith Daniels Show, I never ever thought I would become this. I remember when I was interviewed at a different hospital, one doctor told me, ‘If you can’t palpate my liver, I would never come to you.’” During another interview a different doctor offered Post this analogy for why he was not admitted to his medical school: “Go downtown to the performing arts school and apply to be admitted to the piano program.”

“What a shot that was!” says Post. “But instead of discouraging me, it motivated me all the more.”

“Other doctors told me I should stick with what I love, and I love internal medicine, so I went for it.” — Dr. Jim Post
I still remember the first time I saw Eddie Crouch transfer into his car. I had packed up my rugby gear after a national team tryout at the Lakeshore Foundation in Birmingham, Alabama, and was rolling to the dorms to get some food before my flight. Crouch lived a three-hour drive up I-65 and was heading home. He was a C5-6 quad and the lowest classification level in rugby, .5. The .5s I knew either drove converted vans with lifts, or they didn’t drive at all. Crouch drove a Chevy HHR wagon, stock except for a set of hand controls. He angled his chair next to the driver’s seat, leaned forward so that his head was between his knees, locked his arms out and somehow got his butt up and over into the driver’s seat. I slowed down and watched as he broke down his chair and put it in the passenger seat. I shook my head — that was impressive.

In the SCI world, function is often thought of in terms of musculature — what remains and what doesn’t. In that mindset, there are two ways to maximize your function — either to increase strength or to wake up dormant musculature through rehab and therapy. But with minimal physical function, Crouch had figured out ways to do just about everything he needed to do in his life, independently — bed and car transfers, his bowel routine, showering, getting dressed, you name it.

I recently called Crouch to get the story on how he’s able to do everything that he does. As we chatted, I kept hearing echoes of my own experience maximizing my functional independence: while some of it came down to strength and physicality, a much larger part was mental. On the road to everyday functionality, physical strength might be helpful but it’s not going to get you anywhere without stubbornness, critical thinking and a great deal of patience.

**Stubbornness**

I started packing my own lunches when I was in first grade. Sure, I occasionally packed a Ziploc bag full of olive juice (I have no reasonable explanation for this), but at least my mom wasn’t doing it for me. I was paralyzed at 17 and having to get help with the simplest tasks grated on me to no end. Anything I possibly could do on my own, I wanted to figure out. My parents got it rather quickly, because I told them explicitly, “If I want help, I’ll ask.” But the general public was another story.

Two of my classes senior year were in a part of the school that was up a half-flight of stairs. I could only access them by using a janky wheelchair lift, and abhorred starting the process only to have some well-meaning student come and help because I was struggling with it. So, I’d wait to head onto the lift until after classes had started and the hallways were empty. Then I’d be guaranteed a few minutes on my own. The days I made it on and off without being thwarted by a good Samaritan were major victories. Early in my post-SCI life, I learned that if I wanted to make it through a task without offers of help, I couldn’t look like I was struggling.

So I practiced. I worked on simple, everyday tasks, like opening doors — figuring out how to angle my wheelchair so I could open and get through doors in what looked like a smooth motion. If society was predisposed to view me as always needing assistance, my only workaround was to do them quickly enough that I’d be done before people had a chance to intervene.

Crouch was 26 when he was injured. He says that he was lucky to not have many complications, which let him get into the business of moving forward fairly quickly, before he lost a lot of his preinjury strength. He set functionality, rather than recovery as his primary goal. “I was never one of those, ‘I’m going to walk again’ kind of people,” he says. “I always felt like I would take whatever I had and do the best with it.” He made a habit of asking his therapists if there was anyone else with a similar level of function who could do a task independently — whether transferring into bed, driving a regular car or showering. “I figured if there was somebody else who could do it, there’s no reason I couldn’t.”

Crouch had just bought a house when he was injured. He says deciding to stay in that house after rehab and not go back to live with his parents was one
He angled his chair next to the driver’s seat, leaned forward so that his head was between his knees, locked his arms out and somehow got his butt up and over into the driver’s seat. I slowed down and watched as he broke down his chair and put it in the passenger seat. I shook my head — that was impressive.
of the best things that happened for his independence. Going back to work right away — he had a job with his family’s business in the commercial plumbing industry — and getting involved with adaptive sports were also key. He had a lot to do in his life, and the more you want to do, the more you have to figure out how to do on your own. When Crouch started going to rugby practice, the team had no nondisabled support staff, so the most assistance he was going to get was that of another quad. “I was sort of thrown to the wolves,” he says.

For both of us, rugby helped enormously on the road to independence. It requires travel, and it forces you to hang around others with similar function. It’s like a support group for Type As who hate support groups. Because rugby tends to attract independence-minded personalities, you can learn a ton just watching people get ready. “After 30 years, I’ll still pick up on things occasionally that might work for me,” he says.

There are plenty of people for whom taking help isn’t something to be avoided at all costs, as it can make getting through the day a whole lot more efficient. That’s not a bad thing, it’s just a different approach. But it would be very difficult to learn how to push the edge of your function without stubborn independence as a base. It can be such a pain in the ass that you need a powerful motivating force.

Critical Thinking

Pushing your boundaries also requires thinking through a problem in a few different ways. One is the ability to figure out the worst-case scenario. When I was learning how to do difficult transfers — whether out of a bathtub, onto a handcycle or into vehicles — the worst-case scenario was usually that I’d wind up on the ground. Once I’d fallen a few times, I realized that my body wasn’t as fragile as doctors and therapists had led me to believe. It took me a few years before I had the strength and learned a functional technique to do a floor-to-chair transfer. That opened up the world, because now winding up on the ground just meant I’d have to pop back up into my chair. For most everything else, the worst-case scenario was that I would somehow fail and then have to ask someone to help me. If I didn’t make an attempt, I’d have to ask for help anyway, so it seemed silly not to at least give it a go.

Crouch employed a similar mindset — it’s not really a lack of fear, more like a willingness to try. Case in point: his transfers, which look unlike anything I’ve ever seen. Face between his knees, his head will go so low its almost at his ankles when he’s pushing over from one surface to another. With no triceps, it really is the only way that he can off-weight his butt enough to be able to lift it, and even then, he has to externally rotate his shoulders so he can push off his arms without them collapsing at the elbow. Crouch credits a therapist in rehab with introducing him to the head-on-
the-floor technique. “I’ve tried to get other people to do it, but they’re always scared they’re going to fall on their face or something,” he says.

I ask if he’s ever fallen on his face while doing a transfer. “Probably,” he chuckles. “Sure, over the years. But the thing is, if you do fall, your head is almost to the ground already, so it’s just a little roll onto the floor.”

Working through a task as a low-functioning wheelchair user also involves reframing the problem you’re trying to solve — thinking about the intended goal of a given task instead of how to adapt the task itself. Showering is a good example — the goal is not the process of showering, but to clean yourself. Crouch takes a traditional shower at home, where he has a setup that works for him. But when traveling, hotel room bathrooms are usually tight and designed in a way that makes showering unsafe to do independently. His solution is to bring a plastic basin, about 12 by 8 by 3 inches. He pours cups of water over his head, using the basin to catch the runoff, and shampoos his hair that way. For the rest of his body, Crouch uses a soapy wash cloth and sometimes, baby wipes. “Doing things the normal way doesn’t work,” he says. “You really have to slow down and use your mind to think things through.”

**Patience**

There’s nothing that will get me cussing quicker than working on my wheelchair. My hands suck. And there’s nothing that drives this point home quicker than trying to hold an Allen key in one hand and a socket wrench in the other. I’ll drop each somewhere between three and a dozen times before I even get started. I have thrown wrenches and casters across the room. Still, with long waits from DME repair companies, crap hands and all, I’m often my least-worst option.

Slowly, as I’ve gotten more experience in pulling the hair from my casters, adjusting my backrest or changing out my bearings, I’ve learned to take a deep breath as I start. “In through the nose, out through the mouth,” as my dad used to say when I got fired up as a kid. The closer the task is to the edge of your functional abilities, the more patience you’re going to need to find your way through it. That’s because you’re going to fail, repeatedly, before you start to figure out a method that works for you.

Perhaps the best illustration of the depth of Crouch’s patience is how he learned to tie his shoes with zero hand function. “It took me about two hours and a lot of finger licking to get one shoe tied the first time I tried it,” he says. He slowly found a method that didn’t take all morning. Breaking his chair down was a similar process. “The first time I did that it took me about two hours to get the wheels off, and by the time I did that I was too tired to finish. I had to go back in and go to bed,” he says. “The next day I did it, it took me 30 minutes, then 15 minutes. Once you do it the first time, it’s a quick progression from there, but you have to be willing to fight it for a while.”

Talking with Crouch, all of his daily tasks took a great deal of patience to master. Just putting his pants on, let alone socks, shoes and everything else, would take 30 minutes when he first got out of rehab. Figuring out how to transfer onto the toilet took him 10 years — a decade of having to do a bowel routine on his side in bed when he traveled. He was finally able to master that transfer when he got D’s Locks on his everyday chair and he didn’t have to worry about hitting a brake lever with his leg or a wheel moving slightly while he transferred. As much as anything else, what makes Crouch unique is his ability to work through problems over and over again, stacking marginal gains atop each other, without getting so frustrated that he says, screw it, not worth the effort.

Even so, in any life, there are tradeoffs. The one thing I asked Crouch about that he doesn’t do is cooking. It’s the microwave or nothing for him. It’s not that he couldn’t figure out how to cook on his own, many people with similar function do. But Crouch feels that even with practice, it would take way too long to cook a decent meal. It’s just not a priority for him. And when you don’t have much function, sometimes there aren’t enough hours in the day to do everything on your own.

Stubbornness, critical thinking and patience aren’t a guarantee for success, even for the things that are worth the struggle. But they’re the best option we have. Even when I spent significant time trying to master something that turned out to not be worth it, I rarely felt like the effort was wasted. Problem solving skills are like any other — they get better with practice.
On a cold Saturday morning at the end of December, Kalyn Heffernan is huddled just inside the door of Swift's Breakfast House in the Santa Fe Arts District in Denver. It’s a somewhat cramped storefront — a “grab a seat by the door because you can’t wheel in much further than that” joint. It’s clearly a local favorite, with a diverse blue-collar clientele cycling through. And it’s just the kind of place you’d expect to find Heffernan.

Thirty-one years old and a Denver native, Heffernan is a female rapper and the front person of Wheelchair Sports Camp, a band she co-founded, which has made its mark by showcasing both live and electronic instruments in a noisy, jazzy, experimental — but otherwise traditional — hip-hop group. Born with osteogenesis imperfecta, Heffernan’s slight stature only amplifies her impactful presence as someone who clearly has a lot to say and isn’t afraid to deliver it straight.

Those same qualities that helped make her a thought-provoking, witty and insightful rapper are now assets as she pursues a new goal: becoming Denver’s mayor. Having authored songs like “Hard Out Here for a Gimp” and “Dolphins are Whores,” she doesn’t fit the traditional politico persona and could be dismissed by some as a joke. But watching her converse with staff and customers over her usual late morning breakfast order, "Kalyn for
Mayor” doesn’t seem far-fetched. Denverites clearly know and love her. She has an easy way with people and a measured thoughtfulness. Her cool demeanor, musician’s intellect, and activist passion all converge to make her a formidable candidate. And like all great candidates, she has a compelling backstory.

FROM CAMPER TO RAPPER

Heffernan doesn’t fit into any mold and doesn’t try to. She’s lived outside the box from an early age, growing up as the only child of two “nutty” parents. “I didn’t have too much time to worry about my disability because there was so much other shit going on in my life. My parents were like, ‘It is what it is.’” She points out that being small made it easy for people to involve her. “As someone with brittle bones, you kind of have to let go.”

Heffernan embraced rap music with the same abandon as she approached life. “I have a vivid memory of finding it when I was 5, and being like, ‘Dad, this is awesome! Turn this on!’ And him being like, ‘Turn that shit off!’” Despite the complete absence of rap artists who looked or sounded like her, the art form reached her immediately. “I feel like rap was my first identity, before I identified with anything. And it was like, yes, this is mine.”

She surmises that being young and having a disability gave her just enough distance from rap content that she could listen without anyone giving her grief. “I could listen to gangster rap, and you know, I’m probably not going to join a gang. I was 5 listening to sex rap, but I wasn’t at all sexually active. I didn’t know half the stuff they were talking about.”

Aspiring to be like the artists in her favorite band, TLC, Heffernan wrote her first rap for a sixth-grade talent show, then honed her craft through high school, working at a local amusement park to save up for a beat machine. She didn’t plan on going to college but ended up with a scholarship to University of Colorado-Denver, where she learned the engineering aspects of recording.

It was also in college that she reconnected with an old friend from middle and high school, the future co-founder of Wheelchair Sports Camp. They chose the band name as a semi-sarcastic shout-out to an actual summer camp Heffernan had attended as a youngster. “I felt like a lot of the kids lived for it, that was their favorite week of the year,” she says. “I was more of a kid that was too cool for everything. I didn’t want to follow my group to the different activities, yet I still had a blast. But a lot of that was me bringing my friends and finding the rebels and saying, ‘Fuck this, let’s get out of here and smoke pot.’ Just being bad. We got in a lot of trouble.”

Heffernan feels the band name allows them to acknowledge her disability and move on to more important topics. But she admits it can also be complex. “If some people don’t know I have a disability, they may think it’s offensive. Which
I kind of like. I’m pretty offensive sometimes. But, it runs the risk of being a gimmick, which I hope it never is too much.

“We still play with the imagery of Wheelchair Sports Camp and identifying with my disability. But the music has always been first.”

**FINDING HER VOICE**

While the two friends appreciated political and conscious rap, they initially strove for humor and silliness. “It was very sarcastic, anti-establishment, just rage against everything — rage against Denver, rage against ourselves, really,” says Heffernan.

The band gained followers and started including live musicians. A busy touring schedule combined with a minimal budget and sometimes questionable venues made life on the road unpredictable. “We kind of joke that a tour is like Wheelchair Death Camp. Sometimes the venues are accessible, but the stage usually isn’t.”

Alongside the power that comes with performing, Heffernan battles with the psychological complexity of being onstage. “It’s hard to get out of my head,” she remarks. “Putting yourself out there, and then using a wheelchair, and then you’re saying some vulnerable piece of music or talking about real shit.”

She is highly aware of how she is perceived by her audience. “As a rapper with a disability, it’s always gonna fall on me, like, ‘Oh a disabled rapper.’ I’m not going to ever really outlive that, even though I gotta rap because I love rap, not because I’m disabled.”

She constantly works at balancing her aspirations to be better with not debilitating herself through self-criticism. “I
usually have that ‘fuck it’ mentality,” she says. “Which is how I’ve been able to do as much as I have, just by letting go. And remembering it’s not all about me.”

Becoming aware of global politics had a profound impact on Heffernan and her music. “I got pretty messed up about world affairs and our country, and history, relearning the actual history, and starting to care. I felt so let down, like I’d been lied to,” she says. “After going into two wars, there was nothing you could tell me to make this OK in my heart or my head.”

Her “mostly kitschy, sarcastic” takes on disability gave way to more political and personal lyrics:

I might drown if I settle down in this town till the end of my days
What I’ve learned is that getting burned is the only way to change your ways
Life feels dire, down to the wire, can’t inspire, got nothing else left to give
Why worry, what’s your hurry, life is blurry, this is where we all live

— Where We All Live, 2012

She grew more conscientious of her lyrical content and not going against the system just for the sake of it. This included her awareness as a queer and disabled person about how sexuality functions in her identity. As Heffernan has developed her awareness of her own social identities, she’s discovered the power and privileges that come along with them. “I have an opportunity to say a lot more than most people can because of my disability, because of my gender, because of my stature. I’m physically not a threat, and because I’m white, and a woman, and small, I have the privilege of getting through doors where other marginalized people can’t, and then I can say whatever I want.”

they’re like Kalyn you talk too much
shut up you walk too much
“is the sex still the same” I’m like “nah boo hush” gave me a little confidence now I got too much

inspirational porn star
ahh “my cute wheelchair?” cost as much your sports car
look we got enough problems
no need for you to call a cop who can’t solve one

— Hard Out Here for a Gimp, 2015

Now in the process of writing a new album that focuses more on relationships, love and heartbreak, Heffernan feels like her rapping is digging into personal topics and vulnerability like never before. “The more personal I get, I hope the better it’s gonna get,” she says. “I can easily tell other people’s stories. … Rapping about myself is twice the vulnerability.”
INTO THE FIRE
Beyond the music, Heffernan had her own unexpected personal awakening around her disability identity. She became more active in all types of social protests and movements, attending marches and rallies like Denver’s MLK Marade (a mash-up of “march” and “parade”), Occupy Denver and the 2016 Standing Rock protest against the oil pipeline on a Sioux reservation in South Dakota. She started to notice that at many of the activist events, she was the only person with a visible disability. “The last few years, ‘intersectionality’ is such a hot topic and buzz word, and yet, disabled people are left out or last on the list. And they represent such a huge population, and they intersect with all these other marginalized groups.”

Feeling left out of the conversation, and aware of her inclination to blame everyone else, she instead started examining her own culpability in the problem. “I thought, what’s your connection to the disability community outside of starting shit at wheelchair sports camp? I started having to unpack my own ableism and realize that I haven’t really done my work for the disability community.”

Getting involved with longtime disability activists at Denver’s ADAPT and boning up on disability history made Heffernan more aware of the depth of the issues facing people with disabilities. “I’ve been really checking myself on how much I’ve stood up for disability,” she says. “It’s not just getting me backstage at a concert.”

Heffernan is committed to holding others in the disability community accountable and advocating for a more representative movement.

“Inclusion is something everybody loves to throw around these days ... but I mean the Women’s March is SO not inclusive,” she says. “There are people of color movements that really left out a lot of people with disabilities, and there’s the disability movement that’s still leaving out people of color.

“It’s just selfish. It always ends up going back to that person who can’t take a check, they can’t take hearing about their own privilege. We all have privilege.”

Yet, Heffernan doesn’t consider it an obligation for people with disabilities to be disability rights activists. “It’s not easy to advocate for yourself when you’re marginalized every day, and pitied and patronized and discriminated against, and you add all these other marginalized identities — queer, people of color, indigenous folks — it’s nonstop,” she says. “There’s so much more to deal with — just the survival of it.

“It’s not anybody’s responsibility or obligation to do anything except for themselves. But if you do survive and you are doing shit for yourself, then eventually the movement will get stronger.”

DENVER STATE OF MIND
Heffernan is embracing her responsibility by running for, or, as she describes it, “sitting for mayor” of Denver in the May ele-
tion. Her platform revolves around access, in more than just a physical sense.

“It’s about access in the shelters, access to education, access to safety, access to wealth and power,” she says. “All these stories are being told about Denver and how attractive it is, and how cool and hip, and those aren’t the stories of this community. ... Denver has a really cool, resistng, movement-based community. We’ve always pushed hard and fought hard for our rights, and for access.”

“It’s ironic that I jumped into this on the 40th anniversary of the Gang of 19,” says Heffernan, referring to the 1978 disability rights protesters who achieved landmark accessibility overhauls with Denver’s public transportation. “Denver was kind of this epicenter for disability rights, and to me it should be the most accessible city in the country, and it’s not. And the way that we treat our homeless people is a clear indication of how inaccessible it is.”

Accordingly, Heffernan’s first goal as mayor would be to end the urban camping ban. “We’ve lost more homeless people last year than ever before, and as we all know, most homeless people have some type of disability and have been marginalized and experience a lot of trauma, so the more that we criminalize our homeless people, the more that we’re oppressing marginalized folks.”

While excited to be a candidate, her candidacy has revealed what she thinks is an unfortunate truth about mainstream society. “They don’t want us [marginalized people] to do this, they’re not expecting people like us to show up.” She consequently harbors another ironic concern: “I’m afraid of being mayor because I don’t want to lose my Medicaid.”

Heffernan has seen enough to know that change is hard. People in positions of power get comfortable. “I stayed in a resort for one night, and I was like oh no wonder rich people don’t give a fuck. It’s so external to people in positions of wealth and power. It’s easy to lose touch with reality. And this disparity keeps growing and growing.”

As someone who embodies everything BUT the monotony of normalcy, Heffernan thinks there is hope by way of the “normal” people. “If we elected actual people, and not just people who are doing this for their career move, just real-ass people . . .”

As she sits in the small diner, a female rapper mayoral candidate who is unlike any other in the history of ... probably just about any city, she runs into a friend who has recently been part of the successful effort to have slavery language removed from the state constitution. Sounding more and more like a candidate for mayor, she congratulates him, and remarks that they should get together for lunch soon.

Heffernan is a woman of the people. She means every word — she’s as real as they come.

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My friend David and I are navigating a dirt trail alongside the Adams River in British Columbia on the lookout for salmon. "Just around the corner there are a bunch on a different path. I think we can get your wheelchair there," says David. "Should be no problem."

"No problem" is a possible overstatement.

David and I have been known to be a tad overly-optimistic when it comes to what is considered wheelchair-accessible — the snickers and comments from the peanut gallery are duly noted and filed away for future reference.

"Sounds like a challenge to me," I say, assessing the narrow path. It looks passable, and we’ve forced this poor chair through worse.

David leads the way and I follow. Our wives are along as backup to make sure Murphy — of Murphy’s Law — doesn’t blindside us. I’m a quadriplegic strapped to a 400-pound wheelchair ... what could possibly go wrong? Barely-audible chattering and giggling can be heard. I head down the path, choosing which wheels are to follow the ruts, as of course, it’s too narrow for all four. David climbs a steep hill, surveys around and comes down to help.

"OK, we’ll help you up the hill, then you STOP at the top."

Noting the emphasis on stop, I head up. "So, what’s on the other side?" I ask, half-knowing.

"An undercut-bank and drop-off into deep water."

As expected.

With some pushing and pulling I am up on the bank overlooking the river. I immediately turn my chair off to lock the brakes. A quick accidental tap of the joystick and I’d be in the river!

Below us is a pool of crystal-clear water with several large sockeye and chinook salmon. The sockeye are obvious, easily spotted by their bright-red color. Some are chasing each other, others are resting in the calm water by the banks for their next burst up the river.

"Watch that one," says Dave, pointing at a salmon scooting upstream. The fish looks like it is zooming almost on the shore, water spraying as it flies up the rapids. The scarlet beast has most of its humped body out of the inch-deep water, seemingly able to swim on rocks.

Why We Are Here

Every four years, millions of salmon make a fall pilgrimage hundreds of miles up the British Columbia river system to reach the Adams River spawning grounds. To celebrate North America’s largest sockeye salmon run, the Adams River Salmon Society holds a three-week-long celebration — the Salute to the Sockeye Festival.

The salmon return to the same spawning grounds they were born in, laying eggs in the fall that hatch over the winter. The fry swim to the freshwater Shuswap Lake and stay there, growing and gaining strength for a year. Then they venture to the ocean to feed on krill for three years. The krill are plentiful, and the carotene in them turns the salmon’s flesh that familiar red color. Sockeye are the reddest of all salmon. When they get the urge to spawn at age 4, their bodies are full of fats and proteins to fuel their long journey upstream to the spawning grounds.

Once at the grounds, they compete for the best sites. The eggs need gravel and fresh water running over them to supply oxygen. They make a “redd” or a
dished-out area to lay their eggs, then a male fish will fertilize them. A female will lay between 2,000 and 4,000 eggs. On average, only two will hatch and survive the arduous journey to the ocean and back. After spawning, the salmon stay and protect their nest until they die, about 10 days later. Their bodies decompose and add nutrients to the stream, which feed insects, bears, birds and their fry when they hatch.

We carry on down the trail toward the lake. It is not paved but is easily travelled in my power chair. The trail opens to where the river enters the lake with a series of rapids. Out in the fast-moving water, there are hundreds of large salmon jumping. We see several fly-fishermen casting their lines. One of them approaches us with his fishing rod.

“Are you allowed to fish here?” I ask.

“Yes, you can fish. You can’t keep any salmon though,” he replies.

“Do they bite your hook?”

“The salmon won’t feed after entering the fresh water, but the trout will,” he says. “The trout like to eat the salmon eggs so we use a fly that looks like them, and you can keep trout if you want.”

We continue down the trail to the parking area. There are tents set up with items for sale inside. There is salmon jerky, souvenirs, clothing, hats, native foods such as bannock and interpretive shows. What an amazing natural wonder to see, and it’s all wheelchair-accessible.
WINTERTIME SCI SKIN PROTECTION

Q. I’m in my second year as a T9 complete paraplegic and I do my best to keep my skin healthy, including routine weight shifts and nightly mirror checks for potential trouble spots. Although I’m careful, I’m currently tending quarter-sized burns on each knee, which I now realize happened when I was warming myself near a wood stove after a day of cross-country skiing.

When I shared this cautionary tale at my local SCI support group, others chimed in with their winter-related skin injuries. I thought I had a handle on skin protection, but this is a whole new area that I don’t recall from rehab. Are there any online resources that list potential winter skin dangers?

— Todd

T. odd, your question brings up the importance of developing year-round awareness of potential weather-related skin dangers like heat, cold and sun exposure for areas that no longer have sensation. I was unable to find a website that details winter-time SCI skin protection, so I turned to several SCI experts, starting with Diana Elledge, a registered nurse who works on the Craig Hospital Nurse Advice Line.

She explains the primary winter threats to your skin are cold, heat and dryness that can lead to cracking. In cold weather, frostbite is arguably the most obvious skin danger, more so when sensation and blood flow in extremities are compromised by SCI. “The best way to stay warm and avoid frostbite is to put on lots of layers while your extremities are still warm,” says Elledge. “Also, don’t forget a warm hat and scarf, as we can lose a great deal of heat from our head and neck.”

To protect your hands, mittens are warmer than gloves, and silk liners inside mittens are even warmer. For your feet, in addition to wearing insulated boots, thermal socks designed to trap heat work well. In very cold weather, be sure to take frequent indoor breaks to inspect areas with no sensation for skin that looks different than usual, or has a pallor, as this can be an early sign of frostbite.

Burns are another, perhaps less obvious, cold weather danger to skin. Kathleen Dunn, a retired clinical nurse specialist and rehab case manager, laid out some of the main things to watch for to prevent burns:

**Car heating** — Heated car seats have been known to malfunction and cause severe burns in people with reduced sensation. Either do not use them or be extremely careful. Also, do not let your feet rest against the floor heater, and be sure heater vents on the floor of the car’s front seat do not blow directly on your feet.

**Hot water** — Always use an area of skin that has sensation to check the temperature of shower or bath water. Although plumbing codes state maximum water temperature from a sink, shower or bathtub fixture should be 120 degrees Fahrenheit, this can cause burns. For perspective, the human pain threshold is around 106-108 F, and 120 F water can cause a burn in 19 seconds. Use insulated mugs to avoid the danger of hot beverages spilling into the lap.

**Heating devices** — Do not use any type of heating pad, electric blanket, electric socks or foot warmers; hand warmers designed to be shaken and put into gloves or pockets; heated rice bags or blue ice pad on areas with no sensation. They all have the potential to cause burns. “Also, be careful using these on areas where you do have sensation. I’ve had clients that were burned when they fell asleep and had a heating pad shift to an area where they had no sensation,” says Dunn.

**Proximity to heat** — Stay a safe distance from fire places, space heaters, wall heaters, radiators, wood stoves and camp fires. Keep in mind that when you are in your wheelchair, your feet, shins and legs are at least two feet closer to the heat source than your face and arms, so you may not know you are too close. In addition, be aware that wheelchair parts can absorb enough extra radiant heat to cause a burn.

**Vents** — Don’t park your wheelchair over floor heating vents to warm up; it can cause burns on the backs of calves.

**Sunburn** — Be sure to put on sunscreen and wear sunglasses if you plan to be out and about on a sunny, snowy
day. Snow reflects 80 percent of the sun’s rays back at us.

Since many of the potential burn dangers involve trying to get warm, it raises the question — how do you warm up safely? I find that when my legs become cold to the touch, the best way to warm them is in a warm shower or bath. Dunn suggests using a towel warmer to warm a towel or blanket for your legs, or to pre-warm your bed. Other “warm hacks” for sleeping include using flannel sheets and a down comforter, and wearing pajamas or long underwear and socks.

Keeping your skin hydrated is another challenge in cold weather. As air temperature drops, so does the moisture content. When cold air is heated, it becomes even drier, pulling moisture from the skin. “The most important thing you can do to combat dry skin is drink water, water and more water,” says Elledge. Skin is 64 percent water — dry skin is an early sign of dehydration and can lead to cracking and skin breakdown.

Craig’s module on Hydration with SCI suggests drinking 12 eight-ounce glasses of water a day — that’s almost 3 liters, or three-fourths of a gallon. If you can’t do that, at least drink enough water to keep your urine in the clear to straw-colored range. As always, be sure to empty your bladder frequently enough to keep volumes below 450 cc (about two cups).

Elledge also reminds that while showering or bathing in hot water can help warm you up, it also zaps moisture from the skin. Keeping your bathing water temp lukewarm will help keep your skin soft.

Even with proper hydration, arid air can still cause dry, flaky skin. Dunn recommends a good moisturizing cream that is high in urea to help treat this. Avoid products that contain alcohol or perfumes because they can irritate the skin. Dunn has seen good success with moisturizers such as Bag Balm, as well as U-Lactin cream or lotion.

Last but not least are the dreaded, painful cracks around fingernails and fingers from pushing a manual chair in slush and snow. Dunn says the best way to prevent them is to wear waterproof gloves anytime you venture out in winter weather.

When fingers do crack, try soaking them in tepid water for five minutes and then apply a thick cream like Cetaphil hand cream. For fast healing of cracked fingers, fill the fingers of disposable vinyl or nitrile gloves with Cetaphil, and wear them overnight. This usually heals cracks within one or two applications.

Resources
• Craig Nurse Advice Line, 800/247-0257
• "Hotel Hot Water and Rental Car Burn Dangers," newmobility.com/2012/03/hotel-hot-water-and-rental-car-burn-dangers
• "Hydration with A Spinal Cord Injury," craighospital.org/resources/h2o-to-go-hydration

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

The basketball arena my college played in was about a mile from my dorm. When you love basketball like I did, pushing my chair to games didn’t seem too bad. I happened to know a girl who liked basketball too. So, I took a shot and asked her to walk with me to the game. In the second half of our date, I began to notice a lingering, offensive smell. When we got to the dorm’s lane, the odor was pressing. My game plan was to make a play for a kiss when we got to her door. I posted up and took my shot. My play for a kiss was blocked. She passed and I couldn’t rebound. The smell blanketed me as I headed home. Once in my dorm, I discovered that I had rolled through dog poo and managed to get it all over my body and chair. Game over, no rematch.

Doos and Don’ts

NOCTURNAL ADMISSIONS

I have a tendency to carry on conversations in my sleep. Recently, I have taken to engaging Siri and voice texting people mid-dream. Not only is this embarrassing, but sleeping-me tends to only talk about three subjects: sex, food, and for some reason, a variety of games I’m trying to get the person to play with me. Friends and caregivers delight in sharing recordings and screenshots of the awkward and nonsensical things I’ve said to them late at night. After the fact, it’s hilarious, but I’m so concerned about who I may chat up or what I might say that I now sleep with an alternative phone with emergency contacts only. Some guy I went on a couple of dates with last year does not need a 3 a.m. text that says, “I need to heat up my pizza,” and my old boss is never going to understand why am asking her to “protect the goal!” in the middle of the night.

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