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Did you know that the Department of Veterans Affairs has updated its national policy to expand access to ReWalk exoskeletons through a VA SCI Hub and Spoke or the VA Choice Program?

What is ReWalk?
ReWalk is a robotic exoskeleton that enables individuals with Spinal Cord Injuries to stand and walk, and is cleared by the FDA for home and community use.

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“Using ReWalk, I have more energy and less pain.”
Ret. Army Specialist Gene L.
In the second installment of our look at how wheelchair users are changing the medical field from the inside, TIM GILMER shifts his focus from doctors to nurses. Despite facing many of the same barriers, stereotypes and blatant discrimination that wheelchair-using doctors encounter, a growing army of nurses on wheels is fighting the system and advocating for changes that will benefit everyone, with and without disabilities.

Cover Photo by Mark Woolcott
Contents Photo by Christian Guerthault/Abilities360

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THE MOST ACCESSIBLE PLACE ON EARTH

Google tells me that the Los Angeles Convention Center is approximately 30 miles from Disneyland. In Southern California terms, that’s anywhere from one to three hours away by car, but when I attended L.A.’s recent Abilities Expo, you could have convinced me that I was rolling through Anaheim’s famed theme park.

Over the event’s three days, a record crowd overtook an empty hangar and transformed it into a raucous and bustling bazaar of all things disability, rivaling the world’s busiest markets — a diverse feast for the senses unlike anything found elsewhere.

I’d imagine the three-day whirlwind is overwhelming for even the most seasoned attendees, but as a first-timer I found it particularly hard to know where to focus.

By the time the hordes of attendees had filled the floor, banners hanging high above the rows of vendors served as the only indicator that any sort of order had ever existed. I was stationed at a booth somewhere near the center of the madness.

Groups of wheelchair users and scooter riders blocked the majority of the intersections between rows, while herds of occupational therapy students roamed from booth to booth, and intrepid solo attendees weaved their way through the occasional openings.

At the booth to my left, a gentleman and his wife demonstrated a device to help wheelchair users ascend and descend stairs. With a handsome suit and well-coiffed hair, he could have easily passed for an emcee or magician, and watching him effortlessly lift the dolly-like device he was peddling up and down the stairs, over and over again, I did begin to wonder if he was hypnotizing me.

Turning the other way, I was equally drawn in by the specter of a salesman showing off his indoor lift by raising himself up from a chair, over a few feet and down to the floor, only to then reverse the process and repeat. When a customer inquired, he’d engage, but for the majority of the three days he silently went about his business — up, over, down, repeat.

These were but two of the hundreds of exhibitors, all proudly displaying their wares and trying to convince you that your life would be better with their products in it. Every sort of bed, lift, wheelchair and accessible vehicle you can imagine was somewhere on the floor, waiting for you to test it. There were even leaf-guard gutters and a futuristic vacuum-like device for washing your hair.

That’s not even getting into the regularly scheduled events: all types of adaptive sports (para badminton, anyone?), a climbing wall with every adaptive aid you could dream up, and dance and music performances highlighting an endless array of abilities. At one point, over the din of the crowd, they even announced that a support wolf was prowling the premises (take that, Mickey Mouse!).

In one quadrant, an endless line waited for free wheelchair repairs next to a queue giddily anticipating the arrival of TV and internet star Zach Anner. Circles of friends commandeered some of the few open spaces to catch up, while newbies looked to the banners for guidance. Smiles and engaged faces abounded.

Other than one overtaxed elevator with a perpetual line, everything was incredibly accessible, and we were surrounded by people who just get it. Even if we weren’t officially at Disneyland, together we provided a pretty good template, should the park planners want to replace its Small World with something a little more accessible and, shall we say, less annoying? How about, Ability Land?
Looking back over my emails from Tim Gilmer since he started working on his two-part series on how wheelchair users are impacting the medical system from the inside, a common theme quickly emerges: “Can I get another page?” “Is there any way we can add more space to this story?” “I just interviewed a new doctor, is there any more room?” The requests became so frequent I began to associate seeing his name in my inbox with the need to reconfigure our plans. What started off as a single story evolved into two cover-length features and too many redesigns to count. We are all the beneficiaries of his tenacious reporting, as he has provided the most current and in-depth look at the topic that you will find.

Based in Colorado with deep connections to Craig Hospital, Richard Holicky has managed to keep his finger on the pulse of the SCI/D community since he was injured 30 years ago. His contacts, combined with his own personal insight, made him the perfect person to tackle the question he looks at this month: Does the sting of SCI ever go away? “It’s an important subject and it’s one we don’t discuss that often,” he says. The responses he received were illuminating. “There was something about this topic that just opened people up,” he says.

If you’ve been reading New Mobility for the last few years, you have probably seen or read about Brook McCall — she graced our August 2017 cover and has been quoted in many stories. In her debut as a feature writer, she delves into the role body language plays for wheelchair users. “I think a lot about body language and the limitations I personally have and how that reflects on my relationship building,” says McCall, a C4 quad. “Hopefully the conversations were as helpful for others as they were for me, and maybe they will consider it more in the future.”
The Many Sides of ‘The Upside’

With over $100 million in domestic revenue, The Upside is one of the box office surprises of 2019. It has been equally successful in provoking passionate responses about the decision to have Brian Cranston play a quadriplegic. Responses to Allen Rucker’s two articles about the film, and its French predecessor, The Intouchables, highlighted the discussion:

Be Glad You Got Anything

As a person with a disability myself, I am really tired of this conversation. What a lot of people are neglecting to remember is that first society needs to be conditioned to us. I’m 33 years old and still treated like a germ. It makes people feel better to go see a movie about a disabled person when they know that person is actually OK. It depresses them to think that’s how their [a disabled actor’s] life actually is and they will NEVER see that movie. Beggars cannot be choosers. You can be mad about it or glad you get anything at all.

Natalie Zayas-Bazan
Newmobility.com

How About a Body Double?

As a person with SCI, I agree that it would be great to have an actor with a disability in the leading role. It would be great to have a body double to "stand in" for the actor in the wheelchair if they are filming flashback scenes before the injury, which I didn’t see in The Upside.

Alex Jackson
Newmobility.com

That’s What Acting is About

It does not bother me to see non-disabled actors portray people with disabilities. After all, that’s what acting is all about — portraying a character unlike the actor. I was OK with Breaking Bad casting Bryan Cranston as a meth manufacturer (which, presumably, he is not) rather than casting an actual meth dealer. But it would be good to see more actors with disabilities portraying characters that are not ability-specific. Then when one of those actors becomes a star in their own right, they would be more likely to be cast in a leading role written with the same disability.

David Ward
Newmobility.com

Turny-rific

I have a Turny seat that just rotates in a three-door Audi A3 with a roof-mount ed wheelchair carrier (“The Fight for Independence,” February 2019). This allows this 62-year-old C5-6 quad of 42 years with aging shoulders to still drive independently. It’s really important to me, too. My seat is on the driver’s side, so I only need to transfer horizontally once. I don’t know anyone else who has done this, but it has worked for me the last eight years. I like driving a sporty car, and I’m not keen on moving to a van.

Colin Johanson
Newmobility.com

How Do You Do It?

When you get in on the passenger side how do you get to the driver seat? (“The Fight for Independence,” February 2019)

Alan Duboyce
Newmobility.com

Author Tim Gilmer’s response: I get in on the passenger’s side for two reasons: I find it easier to pull my chair in with no steering wheel to deal with, and if I got in on the driver’s side, I would have to remove the seat behind the driver’s seat to roll my chair in, and that seat is reserved for my grandson, Cooper. As for how I get to the driver’s seat from the passenger’s side, Chrysler and
OUR QUEST TO PLANT TREES

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Dodge minivans (at least the ones I have owned) have no console or an easily removable console, so it’s an easy transfer over from the passenger’s side.

**Fight for Independence**

I can really relate to your problems (“The Fight for independence,” February 2019). I’ve been a T4-5 para for 65 years. I have had pretty bad scoliosis for much of my life. Somehow, I have been able to work until retirement with no formal schooling. I hated to go to a van when I couldn’t transfer any longer but really lucked out when my mechanic told me about one that was seven years old with 10,000 miles, and I got it for $20,000. The fellow’s father passed away and he didn’t know what to do with it. It had an automatic ramp, kneeled 5-6 inches. I put in a six-way seat and hand controls.

*Dennis Manning*

Wappinger Falls, New York

**Compromised Caregiving**

Thanks for sharing (“Un/Conditional Compromises,” January 18, Newmobility.com). This is powerful and very authentic. It gave me goosebumps.

*Jennifer Sunshine Byers*

Newmobility.com

**Helpful Tips**

Due to problems with stones, my right kidney is nearly non-functional (“Taking Care of Our Kidneys,” February 2019). I love salty things and yours is the first article I’ve read that explains part of the “why” we should limit salt. I have also struggled with ways to get adequate protein that do not include meat, because of digestive problems with meat. I will check the book you recommend.

*Patricia Woodruff*

Newmobility.com

**Envisioning a Better World**

It’s about time this happened (“Netflix Casting for Wheelchair User to Co-Star in New Series,” February 4, Newmobility.com). If we want truth and honesty in entertainment we need to make an opening for people with disabilities to give a realistic portrayal of what life is really like. There should be openings for people with disabilities in all areas of entertainment, fashion, business, community, education, etc. There should be no area in life that is off limits to a person with a disability and no boxes that you have to fit. Yes, adaptations and adjustments are sometimes necessary, but in the case of TV and films they could be written so that the necessary things I needed to be done didn’t have to be obvious. We should be a world that includes everybody.

*Cheryl Hillson*

Newmobility.com

**Loss of a Legend**

Best tribute, NM! (“Carrie Ann Lucas, 1971-2019,” February 26, Newmobility.com) Bravo to Aaron Broverman and Josie Byzek. Loved that you said the piece about her always answering calls, questions, requests for info. It always surprised me how rapidly she responded and the quality of her heart, mind and information. Although I did appreciate that the Forbes tribute actually mentioned the insurance company that [many believe] caused her death.

*Janine Bertram*

Newmobility.com

**A True Champion of Disability**

Thank you for this beautiful tribute. (“Carrie Ann Lucas, 1971-2019,” February 26, Newmobility.com) She was a true champion of disabled people everywhere. And I am lucky enough that she was my friend. I will miss her forever.

*Trish Humphrey Day*

Newmobility.com

**Thanks for the Insight**

Tim, your advice is great — right on! (“Everyday Ethics,” February 2019) So glad to read whatever you write.

*Marge Heatley*

Newmobility.com
THE WAHLS PROTOCOL FOR TREATING MS WITH DIET

In 2000, Dr. Terry Wahls was diagnosed with relapsing-remitting multiple sclerosis and by 2003 she was taking chemo for secondary-progressive MS and using a power wheelchair. "I continued to decline and thought, this is terrible, and the best clinic in the country is not stopping this," says Wahls, a professor of medicine with the University of Iowa, where she conducts clinical trials. "So I went back to the basic science and experimented on myself. That was in 2007, when she applied her knowledge of neuroprotection to her own case by creating nutritional supplements. "It helped, but I still declined. A couple of months later I realized, what if instead of taking supplements I ate food to get those nutrients? And I redesigned my diet to get in enough of those nutrients." She upped her vegetable and lean protein intake in a very specific way. "Three months later I was using a cane, six months later no cane, nine months later I was bike riding. It changed how I thought about disease and how I practice medicine."

Her recovery was greeted with skepticism. "So many people say, 'Did I have progressive MS, or did I have MS at all? Did the physicians make a mistake?' And OK, let's say everybody was incompetent. So I held a clinical trial with 20 others with progressive MS and published multiple papers showing dramatic improvement from quality of life to improved motor function." That was the breakthrough, and two years ago the National MS Society funded a $1 million ongoing study directed by Wahls to look at the role of diet in MS.

"We have outside statisticians," says Wahls about the NMSS study. "I don't handle the data, and there are other safeguards, and now other scientists are studying whether diet matters. It's had a huge impact."

Wahls' book and other resources, including a free Wahls Paleo Diet Food Pyramid, can be found at Terrywahls.com/diet.

FIERCE, CENTERED SELF-CARE

Millie Gonzalez says it took her a while to choose "#LiveFiercely: Take Control of Your Life Through Self-Care." as her winning Ms. Wheelchair New Jersey 2019 platform. Then, while dealing with being laid up in bed with health concerns, she realized, "We can't do anything we love if we're dead."

Here are some of her self-care suggestions:

- Take a break from life, work or volunteering when necessary.
- Focus on improving your health in ways that are under your control — from eating well and drinking more water to sticking to bowel and bladder schedules.
- Develop boundaries in your relationships.
- Face your addictions.
- Prepare for emergencies.
- Remember to write, play sports, dance, take pictures, listen to music — to do that which brings you joy.

Follow her reign at facebook.com/MWNJ2019

DEBUNKING THE SHOULDER BLOW-OUT MYTH

When asked if it’s inevitable that a manual wheelchair user with an active lifestyle will blow out their shoulders, ADAPT Training Vice President Jerod Warf says absolutely not.

"For starters don’t fear being active," says Warf, whose organization’s clients span from everyday people who want a gym, to those in need of physical therapy, to NFL players and wheelchair rugby Paralympians. "The human body was designed to be active and move."

Think of the shoulder as a ball and socket joint. "It should move in many directions, horizontally and vertically, or you’re not giving the shoulders what they need," he says. "Ask yourself: ‘When I’m out pushing my chair, what am I doing to relengthen those pushing muscles?’ You can be highly active, you just need to do supplemental shoulder routines, they’re just like your daily vitamins that fill in the gaps of what you can’t get enough of on a daily basis."

To help supply these shoulder-saving supplemental routines, Warf has shared two exercise cards that can be accessed on newmobility.com. Additional resources are available at adapttraining.com/adapt-advanced.
Back in January 2016, insurgent presidential candidate Bernie Sanders announced a plan to expand Medicare to all Americans, regardless of age or disability. On the right, it was widely derided as a government takeover of health care (which it is). Among the Democratic Party establishment, it was dismissed as so radical that it wasn’t even worth considering.

Yet, come posturing time for the 2020 elections, the progressives have grown in influence, and recent polls find that a majority of Americans support the general idea of “Medicare for all.” This evolution has made support for universal healthcare a litmus test for 2020 Democratic presidential candidates. Though getting any serious health care reform through Congress would require almost everything falling the Democrats’ way, it’s worth taking a look at where the disability community sits in the current health care debate.

The Problem
Few people across the political spectrum think that America’s health care system is sustainable, and it’s easy to see why many think it is broken. A 2014 Commonwealth Fund report put the U.S. last in overall healthcare ranking of the 11 most industrialized nations. International health care rankings from a variety of sources, including the World Health Organization and the Bill and Melinda Gates Foundation, tell a common story: U.S. health care is more expensive, inefficient and inequitable than in most industrialized countries.

There are conservative policy proposals — universal catastrophic coverage, removing the tax deductibility of employer-sponsored insurance and encouraging price transparency, among others — that seek to address the crisis, but Republican repeal and replace efforts failed to introduce or explain any of these policy alternatives. That leaves progressive Democrats dominating the health care debate with talk of universal health coverage. And while “Medicare for all” has a nice ring to it, the disability community knows all too well that Medicare coverage has significant gaps.

It does cover hospital, medical and DME, as well as prescription drugs, if you qualify. But Medicare has no out-of-pocket maximum cost, meaning that anyone facing significant medical costs needs a secondary insurance — like Medicaid, a Medicare Advantage plan or private insurance — to not get bankrupted by a lengthy hospital stay or the 20 percent coinsurance on most doctor visits and procedures. Furthermore, there are a number of important services that Medicare doesn’t cover — vision, dental, personal care attendants and other long-term support services, to name a few.

To access any of those, you need either private insurance or Medicaid. One of the problems with Medicaid is that it’s not a single, national program but a collection 56 state and territory-run programs, each with varying benefits and eligibility requirements. You need only watch “The Disability Trap” — a short documentary by Jason DaSilva about trying to move from New York to Texas to coparent his young son — to understand the horrific choices state Medicaid variations can force people with disabilities to make. Medicaid is also income-restrictive, meaning that in some states it can be impossible to maintain coverage while earning a living wage. “Part of the problem with programs like Medicaid is that they force people with disabilities and aging Americans to remain in poverty in order to receive the long-term support services that keep them alive and in their community,” says Nicole Jorwic, who works on health care policy for the Consortium of Citizens with Disabilities and the ARC.

One of the reasons fighting to save the Affordable Care Act was so important for people with disabilities was its protection for those with pre-existing conditions.
conditions helped provide an option for some disabled Americans to transition off Medicare and Medicaid when they started to earn a decent income. But private insurance often doesn’t provide coverage for long-term care, so even with the ACA, those who need personal care weren’t able to share in its benefits. By packaging their repeal efforts with broad Medicaid cuts, Republicans all but ensured that the disability community would protest, which it did — in spectacular fashion. “While we fought so hard to defend Medicaid, we know it’s far from a perfect program,” says Jorvic, “but it’s also the only game in town when it comes to long-term support services.”

The Solution(s)?
What exactly is “Medicare for all”? That depends on who you ask. There were eight different Democratic health care bills in the last congress, and there are already a few that have been introduced in the current session. The major universal healthcare proposals (as of March 2019) include: The “Medicare for all” Senate bill by Bernie Sanders (D-Vt.), which has yet to be reintroduced in the new congress; the “Medicare for all” House bill by Pramila Jayapal (D-Wash.); the “Medicare for America” House bill by Reps. Rosa DeLauro (D-Conn.) and Jan Schakowsky (D-Ill.); and “Medicare Extra for All” by the Center for American Progress. Here’s what those plans propose on some key issues:

Long-Term Support Services: The Jayapal, DeLauro and Schakowsky, and CAP plans all include LTSS coverage that prioritizes home and community-based services. While the original version of Sanders’ plan didn’t include LTSS coverage, he has recently announced the new version will expand to include these services.

Single Payer or Multiple Programs: The Sanders and Jayapal plans create a single-payer government-run health plan. The CAP and DeLauro/Schakowsky plans retain some forms of employer-sponsored health insurance while creating a new government-run plan that covers everyone else. There are many within the disability community that favor retaining private insurance in addition to a public option, because they don’t want people who already have good coverage to be negatively affected by inherent problems of starting a new, enormous and complex system from scratch.

Other Services: All four of these plans include medical, prescription drug, dental and vision coverage.

Complex Rehab Technology: None of the plans directly address reforming Medicare’s restrictive complex rehab technology policies. Disability organizations are actively working to move CRT reform through congress, regardless of broader reform.

All of these plans include many of the policy specifics that the disability community is asking for — no income or asset limits, comprehensive coverage that includes LTSS, methods for reducing prescription drug prices, priority for community-based services and a cap on the out-of-pocket maximum. They might have Medicare in their titles, but they go far beyond what Medicare currently offers.

For the disability community, there are some inherent benefits to having a comprehensive, government-run program that’s available to all Americans. The patchwork of Medicaid programs would be gone, replaced by a national program providing equal access to healthcare regardless of which state you live in or how much you make; those who need long-term care would no longer be required to live in poverty in order to abide by Medicaid’s income and asset limits. While this wouldn’t fix access issues and ableism in the workplace, it would lower a major hurdle that keeps many from even attempting to find employment.

It would also normalize and stabilize government-run health insurance by turning it from chronically under-funded, at-risk enclaves of the disabled, the old and the poor into a system that everyone has an interest in maintaining.

You Need Both
For the disability community, there are encouraging signs as “Medicare for all” moves from a slogan to policy proposals. The original “Medicare for all” bill by Bernie Sanders didn’t include LTSS, but long-term care services were added after intense lobbying from the disability community. The Jayapal and DeLauro bills were both written with input from the disability community. Of the Jayapal bill, Ady Barkan, a disability-rights activist with ALS who worked with the Consortium of Citizens with Disabilities on the bill, told The Intercept: “She wrote it with our community holding the pen. Over months, disability rights activists went back and forth on the language. We are included. Not just as a sidebar or footnote.”

Organizations like the CCD, of which United Spinal Association is a contributing member, have been doing the detail work of disability activism in Washington for decades. The CCD outlined the health care needs of the disability community, and its members have been hounding policy-makers to ensure that these priorities are included in any reforms. This is a different method of self-determination than the protests over the ACA repeal efforts — less headline ready and a whole lot more granular — but it’s just as important. “You need both,” says Rebeca Cokley, a longtime disability-rights advocate who now works at the Center for American Progress. “Movements don’t survive on advocacy or protest alone, they need both in order to thrive.”

Political momentum for a system-wide transformation is an opportunity that doesn’t come around very often. If it is done right, universal health coverage has the potential to transform disability in America in a way we haven’t seen since the ADA was signed. Making sure whatever comes next addresses the needs of the disability community won’t be easy, but what else is new?

Resources
• CCD Disability Principles for Inclusion of Long-Term Services and Supports in Universal Health Care, c-c-d.org/fichiers/CCD-Principles-LTSS-in-UHC_Sign-On_8-20-18_FINAL.pdf

April 2019 11
Injured at 24, Kevin Mullin dedicated himself to studying SCI rehab and recovery to improve his own functionality and get back to all the activities his South Florida home has to offer. He used that knowledge to help launch a now thriving training center that takes a comprehensive approach to improving strength after neurological injury.

Mullin, a C5 quad from a swimming accident, is one of the founders of the Center for Neuro Recovery (centerforneurorecovery.com) — the seeds of which were first planted while he was still in rehab following his injury. He quickly tired of his medical team's rather gloomy prognosis for his post-SCI independence and activity level. "They actually instructed my family to put me in a nursing home," Mullin says. With support from his family, Mullin started to research the latest in functional rehabilitation for SCI — a four-and-a-half-year process that took him all over the world. What he learned would help form the basis for CNR. "We opened up a gym based on comprehensive, research-backed neurological training," he says. "At first, it was going to serve locals in the area, but we filled our capacity within the first six months of it opening and now have national and international recognition."

Mullin describes what CNR does as, "following the latest research, having the best equipment and really giving someone the best chance to improve their strength and functionality outside of the traditional therapeutic model." Of course, operating outside of the traditional medical system means CNR is unable to bill insurance. To help broaden access to CNR, Mullin partners with philanthropists to keep the program costs low. "It's three hours a day, five days a week, but it breaks down to $59 an hour," he says. "That's cheaper than any physical therapist, occupational therapist or even a trainer you can get at Gold's Gym."

For clients of Center for Neuro Recovery, a typical day starts with a full body stretching routine. While you're getting loosened up, a therapist will touch base to see how your body is, inquiring about your sleep, whether you are sore or irritated, and how your energy levels are. Once stretched, you'll move to some light mat work consisting of balance and core exercises to get the blood flowing and muscles engaging. Then you'll move onto the meat of the day, which can vary based on your present goals and previous day's work — anything from robotic gait training, to FES cycling, to core or upper body strengthening.

Mullin recognizes the bad rap associated with some training...
I've been on Royal Caribbean's disability advisory board now for four and a half years as United Spinal's liaison. We've helped with different ship modifications and accessibility tools, working on the accessibility of ship cabins, quarters and bathrooms. I truly love the cruising experience because it's such a universal and inclusive environment. I don't always have that to share with my family and friends, but a cruise ship provides a great gathering area for everybody.

I was able to go on one of Royal Caribbean's newest ships, Symphony of the Seas. It was unbelievable. Its staff was so accommodating — they wanted to make sure that my trip and my experience were top-notch, just like everybody else's. I was able to get to every part of the ship, and every pool had a lift. The access was amazing.

I'm also one of the founding members of Unlimited Abilities Foundation (unlimitedabilities.org), which assists many people with different disabilities with beach and ocean access. One of our current programs is working with city and state officials on accessible beach mats, so that everybody, tourist or local, can get out and enjoy the beach experience. We also do adaptive scuba diving, which I am most passionate about. Being able to give others the opportunity to explore our beautiful oceans is one of the most rewarding things I've been fortunate enough to be a part of.

WHEN I JOINED UNITED SPINAL: I was trying to learn tips and tricks for living life in a chair, and every subject I would research, United Spinal's resources kept popping up. I learned more about them and knew I had to make contact.
Don’t look now, but your body is talking about you. As we readjust to life after illness or injury, it’s easy to lose sight of the conscious and unconscious signals we are all sending out from our chairs. How our bodies communicate and what they are revealing about us can seem like an afterthought, but there are important benefits to paying closer attention.

After my fall at age 22, the severity of my injury seemed to leave me no other option but to face the reality that, as a C4 complete quad, the silent partnership I had with my limbs was severed along with my spinal cord. Instead, a requirement to clearly verbalize my requests became the lifeline that insured my needs were met. To my surprise, once I was out of my hospital bed, I started to recognize the new nonverbal cues I could rely on to express my emotions and engage with those around me.

As a high quad without arm function, my altered body language introduced an additional pickle to my paralysis. Despite this, boundless curiosity and a slightly dusty social science degree have helped me recognize how my heavily-limited physical mobility alters my personal and professional interactions. In an effort to relate with others more effectively and lessen the likelihood that I am misunderstood, I have found ways to be mindful of my own unspoken behavior. Over time, my nonverbal communications have become a crucial element in making the kind of lasting impressions that lead to fruitful relationships.

FEELING THINGS OUT
Emotions can be overwhelming after an injury, and finding ways to communicate what you are feeling when you don’t want to, or can’t, explain becomes a necessity. When I needed to be left alone, I let my facial expressions speak for me. I shook my head, shrugged my shoulders, avoided eye contact or simply shut my eyes when I wanted to detach. Conversely, when I paid attention and showed signs that I was listening and ready, I noticed that clinicians and therapists reacted positively and adjusted their treatment to match my level of enthusiasm. Relatedly, it was through knowing glances and empathetic smiles across the therapy gym and hospital hallways that I began to feel connection beyond the bubble of isolation I felt surrounding my wheelchair early on.

The initial weeks of being paralyzed leave most of us figuring out how to modify our gestures as we learn to modify the way we live. In rehab, Patty Schroeder, a C5-6 quad, had to find visible ways to express that she found something funny through facial expressions associated with amusement and slight nods in her neck brace. “It was difficult,” she said, “The loud laugh everyone knew me for had gone poof and was now totally non-existent. It made me feel like I was reacting in a bizarre way.” Daniel Minx, a C4-5 incomplete quad noted changes in simple tasks, like pointing for something. “The fact that now I use a fist instead of the standard finger extension makes things less clear.”

As we get back out into the world, environmental factors — like crowded and noisy rooms — leave us even more dependent on adapted nonverbal cues. “When it’s loud, I have to poke people’s backs or butts to get their attention and get through,” says Schroeder. “Half the time they don’t hear or overtreact by jumping out of the way or apologizing unnecessarily.”

As a disability trainer and community advisor for a large hospital, Ian Jaquiss often finds himself pushing through crowded events in a professional capacity. Jaquiss, a T10 incomplete para, goes “full gentleman” — making the choice to always stop and formally gesture for someone to pass. “I don’t love having to do it,” he admits, “but it curbs irking comments about running over toes and helps me appear and feel in control.”

“As a high quad without arm function, my altered body language introduced an additional pickle to my paralysis. But I have found ways to be mindful of my unspoken behavior.”
To avoid frustration, I choose to stay put when I can. I find a spot with good potential for inclusive foot traffic and put on a friendly face, making welcoming eye contact to encourage others to approach me. Schroeder still likes to mingle but plans her path with consideration of her power chair’s wider berth. “In my chair, I have a radius of space that makes it harder to slip into conversations,” she says. “The abruptness of moving around limits spontaneous connection, so I have to plan more. Before, I could maybe bump into someone to start a conversation. If I bump into someone now, it will just hurt.”

EMBRACING YOUR GOALS

There are a number of ways that body language can help you find success. It is wise to be respectful of the formality of a situation and display mannerisms that match the culture of a workplace or event. Experts tout posture as exponentially important in creating power dynamics and establishing dominance. You can roll into a room with your head held high, letting your body and presence lead your chair, or slumped down and self-conscious, letting your chair lead you. As a T7 para, it took a few years for Joe Pomeroy to recognize that when he shows up and “rolls-the-roll,” people notice. “I felt a bit more passive and more likely to move out of others’ way at first,” he says. “When I got stronger and in better shape, it helped me get out and get things done with purpose. People often step out of my path now because they see that I am more focused on the task at hand than I am on them.”

Whether you are networking professionally or just meeting someone new in a social situation, handshakes will happen. Jaquiss has tried lots of approaches. “Back in high school, I purposefully strengthened my hands for a crushing shake,” says Jaquiss, who was 2 years old when he acquired his SCI. “Over the years, I’ve gotten over that. I go for a fist bump now.” For those of us with limited upper limb mobility, handshakes can seem like a hurdle. Schroeder, who has
Recently, I have been hearing a lot of talk about the importance of wheelchair users being able to “look people in the eye.” Whether it’s a standing wheelchair, a power wheelchair that elevates or an exoskeleton, the underlying message is basically the same: Your social interactions and status will improve if you are on the same eye level as a standing person.

Really? Just raise me up and people will respect me more? By no longer literally looking down on me, people will stop figuratively looking down on me? Is it that simple, or is there more to it? What we are actually talking about here refers to body language, social status and social conventions. And there is a lot more to these concepts than how high your eyes are relative to someone else’s.

When someone looks you in the eye, what does he or she see? Do they see someone who is confident regardless of his or her physical positioning? Or do they see someone desperately trying to be accepted as “normal.” Who are these people that you want to look in the eye?

My guess is that your family and friends aren’t affected by your eye level. For better or worse, how they feel about you and interact with you is unlikely to be swayed by whether you are up high or down low. They have a lot more data points to consider.

But encounters with strangers are different — first impressions matter. You want to make a “good” impression on a stranger, and you feel the need to be upright or elevated to do so. But let’s not forget, when it comes to first impressions, people take into consideration the entire package of what they see. Your eye height is only one consideration.

Not all eye contact is created equal. Twice a week or so, I use my long leg braces at the gym. I “walk” in a loop around the gym. OK, so it’s not walking. It’s an awkward two-legged swinging gait, but I am upright. I have been using my braces for many years at the same location. Therefore, I can compare my standing interactions with my seated interactions since all other factors remain the same.

Here is what I notice: People make even less eye contact with me standing in my braces than they do when I am using my wheelchair. When they do look at me, I can tell many of them are thinking “Dude, you are really messed up.” I am not experiencing the “fun and engaging” eye-to-eye social interactions that are supposed to happen. When I talk to people I already know while standing, I don’t notice any improvement in the conversation. Don’t get me wrong — I think any kind of standing/ambulation/walking that you can do is great for multiple health reasons. For many people, it’s also psychologically beneficial to be upright for periods of time. But the whole thing about needing to be on eye level with other people to engage with them on equal terms is an artificial construct.

If you want to be upright, great. Go for it! But if your desire to be upright is based on feeling socially excluded or-disrespected for being seated, being at eye level will not solve this root problem. Your level of confidence, your ability to exude competence and warmth, your appearance and your skill at leading the conversation will have the greatest effect on how you are perceived. You can project all of these qualities from a seated position.

In my personal experience, there are two best moments in being upright. The first is the instant that I stand up to my full height. The second is the wave of relief I feel when I sit back down in my wheelchair.
a doctorate in psychology and works as a private therapist, discloses her quadriplegia before meeting clients. At their initial appointment, she takes the lead by sticking out her hand first in order to get in front of any unnecessary discomfort or interruption in the rapport she needs to build with each client.

Offering a hand isn’t always an option for a higher quad. “If I can’t shake their hand, then already there’s a lot of judgment going on in their head,” says Minx. “That awkwardness can mess up the potential for some relationships to blossom because of confusion or embarrassment.”

To avoid this scenario, I try to meet my prospective shaker’s gaze right away and give them a friendly but firm nod in greeting. I avoid looking down toward their hand or my own to wordlessly suggest a nonphysical greeting is adequate. For those who stick their hand out anyway, I find it helpful to smile, lean in and use words to lessen the chance of an unintentional faux pas.

NO ONE DESERVES TO BE HERE MORE THAN YOU

Our nonverbal cues won’t always provide perfect solutions or look as suave as we might like, but they can be powerful tools when used thoughtfully. The connections I’ve made since I started being purposeful about my unspoken communications have proven to be more meaningful. It has been a nice reminder that my success isn’t determined by level of functioning or muscle mass, but instead has a lot to do with things I can control, like how I carry myself and the effort I put into relating to others. The icing on the cake is that the more I make the effort to reach out to others, both mentally and physically, the more they return the recognition and understanding I seek.

After paralysis, we are all just navigating our interactions to the best of our abilities, and there is no simple right answer. When I feel nervous about a social situation, I often remind myself that, as the title of a book by Miranda July says, “No one deserves to be here more than you.” This little self-compassionate reality check helps me reframe my perspective and shrug off unproductive insecurities about my physical circumstances. With reassurance that I most definitely do belong in the situation, I find my body can more comfortably play the role it has all along, as an aide to my experience and inextricable part of my ongoing dialogue with the world.

“The loud laugh everyone knew me for had gone poof and was now totally nonexistent.”

— Patty Schroeder
Figuring out how to express your feelings and intentions through your body language after SCI can be key to finding love. Everyone I spoke with emphasized the importance of using nonverbal communication to show others you are comfortable with yourself. This not only puts others at ease, but also helps to draw attention away from unnecessary concern about your wheelchair or disability. First impressions are important, so going that extra mile to look self-assured and put your best “wheel” forward is critical.

Beyond the basics of choosing relaxed locations and activities for dates, Patty Schroeder makes conscious choices with food and beverages based on her physical ability. “I will purposefully stay away from foods that involve being cut with a knife or are hard for me to hold, like tacos or pasta, to not make a mess of first dates,” she says. Schroeder doesn’t want functional distractions or personal frustration to get in the way of a burgeoning connection. She adds, “I try to be easy-breezy and make things seem as simple as possible, to subconsciously highlight me and the conversation, not my struggling with food.”

Researchers have shown that we are subconsciously drawn to partners that exhibit physical behaviors associated with availability. Visible clues, like sitting up, opening your posture, uncrossing your arms, or positioning your chair angle in a way that comfortably faces the person you find interesting, casually suggest an openness to attention. Minx recommends something all of us can do, “Smile more, and flirt with your eyes.” Demonstrate you have interest in someone by making it clear they are your focus. Engage and genuinely react in conversations, laugh when appropriate and maintain a comfortable level of eye contact — don’t look down, around the room or at your phone.

Once you know the attraction is mutual, it’s natural for new partners to express romantic feelings and connect physically. I know that for me, physical limitations and the introduction of my wheelchair can vastly change the landscape of what it looks like for someone to make a first move, give or receive a kiss or initiate a sexual encounter. Luckily, there are universally recognized ways to visibly drop hints that signal we are receptive to being touched without having to shout it from the rooftop.

When you want to get close, actively situate your chair beside that person. If you are feeling captivated by another, don’t be afraid of lingering eye contact and playful smiles to communicate you are on the same page. Given that rejection packs a punch, it’s smart to be mindful that body language is a two-way street. Be observant of the signals you receive to help assure your romantic overtures are welcome. Minx has his own tactic for doing this. “I look at a woman’s lips when I feel like kissing them,” he says. “How she visibly reacts says a lot. I want to know beforehand that she is going to meet me halfway if I lean in to kiss her.”

While our chairs are helpful in so many aspects of our lives, when it comes to romance, sometimes they are just in the way. I’ll let you in on a secret: Almost all of the first kisses I’ve had postinjury have happened outside of my chair. For me, eliminating the physical barrier of my wheelchair expedites intimacy by allowing another to get close, and then closer. On a couch or loveseat, if someone wants to playfully nudge my arm, I can lean my head in and rock my torso over to nudge them back. When my hand is not on an armrest, it’s easier for someone to interlock their fingers between mine or comfortably put their arm over my shoulder to snuggle.

Moving things to the bedroom opens up more options for physical expression. Schroeder found new freedom when she felt comfortable enough to invite a partner into her bed to get closer. “It was a huge step for me because one of the biggest things I miss is being able to full-on hug someone,” she says. “I’ve hated not being able to just wrap my arms around the people I care about and pull them in tight.” Getting on the same level was an important step in her relationship and a new way to bond through touch and a novel flexibility to adjust their positioning. “It was a big deal for both of us that he could sit behind me and put his arms around me without the chair being in the way,” she says.

After paralysis, when you are ready to explore things sexually, there is no need to be coy. When it comes to consent, safety needs and personal desires, it’s best to just clearly say things aloud. Everyone is unique, so only in time do we learn how to send and receive nonverbal cues about what is and isn’t working with a new partner in the bedroom.
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Traveling to the Galápagos Islands has been a dream of mine ever since I learned about Charles Darwin and the unique wildlife he studied nearly 200 years ago. Now that our three children are aged 9 to 13, my wife and I decided it was the perfect time to visit this exotic ecosystem.

The Galápagos are an archipelago of volcanic islands located 600 miles west of mainland Ecuador. They became part of the Republic of Ecuador in 1832, just three years before Darwin’s famous visit, and since the islands are a national park and World Heritage Site, all tours to protected areas must be led by a park-certified guide.

I wanted to find a tour with activities that could engage the kids as well as the adults, and also provide accommodations for my C5 quadriplegia. We wanted to swim, hike, snorkel and sea kayak to fully immerse ourselves in the assortment of natural habitats that the Galápagos offers. I found the exact experience I was searching for with Adventure Unbound, an ecotour group that specializes in customized active travel. After weeks of correspondence in which I described my access needs and activity interests, they organized a nine-day Galápagos tour that included lodging, transportation and most meals, leaving me only the responsibility of getting us to and from Quito, the capital of Ecuador.

Adventure Unbound employs GalaKiwi, the premier land-based tour operator in the Galápagos Islands. The warmth, friendliness and can-do attitude of the guides and staff from GalaKiwi elevated our trip from being simply memorable to the experience of a lifetime.

SAN CRISTOBAL ISLAND
If you’re planning to visit the Galápagos, be prepared for a series of flights. All tours to the islands begin with a flight from Quito, which is located in the Andes at an elevation of 9,350 feet above sea level. There are direct flights to Quito from Atlanta, New York City and Miami. From Quito, all flights to the islands make a quick stop in the coastal city of Guayaquil before embarking on the less-than-two-hour flight to the islands. There are two major airports in the archipelago, one located on San Cristobal and the other on Baltra.

To give us a well-rounded understanding of the islands, our ecotour consisted of spending three days each on three different islands. We began in San Cristobal, the easternmost and geologically oldest of the Galápagos archipelago. When we first arrived, our guides presented me with a modified off-road wheelchair that had two removable poles coming off the front, rickshaw style. Because this beast of a chair didn’t have push rims attached to the wheels, it was difficult to navigate independently. It was easy enough to stay in my everyday chair for many of the activities but I found the off-road chair was essential for exploring some of the harder-to-reach spots.

After checking into the picturesque Casa Playa Mann hotel, we began our first afternoon at the San Cristobal Interpretation Center. This was a great way for us to get our bearings and learn about the unique wind and ocean currents of the area.

There are three powerful currents that are responsible for the amazing diversity of life found in the Galápagos. The Humboldt current brings cold water from the south that joins with warmer waters brought by the Panama Current that comes from the north and heads west along the equator form the mainland. A third equatorial counter current, called the Cromwell, heads east to the Galápagos, bringing with it marine life from the deep waters of the Pacific seafloor.

After learning more history of the islands, we followed an accessible hard-surface trail constructed of sliced lava rock to the bay where Charles Darwin first visited, unofficially called Darwin Bay. Directly next to the water is the basal cliff of Cerro Tijeretas, or Frigatebird Hill, where
WE ENJOYED OUR FIRST ENCOUNTERS WITH MARINE IGUANAS, AND WE WATCHED SOME OF THE BIGGEST WAVE BREAKS ON THE ISLANDS. IT WAS OUR DAUGHTER’S BIRTHDAY, AND SHE CELEBRATED IT WITH AN UNFORGETTABLE SWIM WITH SEA LIONS.

”
not only did we see many of these fork-tailed pirate birds, but a full rainbow appeared for our viewing pleasure. We then continued to Carola Beach, where we enjoyed our first encounters with sea lions and marine iguanas and watched some of the biggest waves breaks on the islands. It was our daughter’s birthday, and she celebrated it with an unforgettable swim with sea lions.

We started our second day early by getting fitted for wetsuits and hopping on a charter boat. Our guides helped us find the best fit, plus they actually assisted me in and out of the snug neoprene gear. On the two-hour boat ride to Kicker Rock, we saw mating sea turtles and a 2-day-old dolphin swimming close to its mother. Kicker Rock, also known as León Dormido, is the remains of a volcanic cone that stands 500 feet above the water. Because the National Park regulates visits to Kicker Rock, our group was able to enjoy snorkeling near the channel between two rocks without other crowds of boats and snorkelers. It was my first chance to be in the water and see the colorful fish, graceful sea turtles and even a Galápagos shark swimming below.

Our guides, both nicknamed Peluche, meaning Teddy Bear, were conscientious and helpful, getting me safely in and out of the water despite the steady wind and noticeable current. One of the guides carried an orange flotation ring for me to hold onto, solving stability issues for me in the open water and giving everyone else a chance to catch their breath and fix their mask and snorkel. After nearly an hour in the water at Kicker Rock, we headed over to a beautiful isolated beach to anchor, have some lunch, and enjoy the wildlife before returning back to Casa Playa Mann.

On day three on San Cristobal, we headed toward the highlands to visit La Galapaguera de Cerro Colorado, a reserve to protect the island’s vulnerable tortoise population. The giant tortoises of the Galápagos are the largest and longest-living vertebrates in the world, with lifespans averaging over 100 years. Only 10 of the original 15 species of Galápagos giant tortoises remain, each endemic to their unique volcano. The reserve runs a breeding program that releases them back to the wild after they’ve reached sexual maturity. Since it was a feeding day, our first encounter with the tortoises included two adults fighting over a large elephant’s ear plant, one of their major food sources. The tortoises were certainly not fast movers, and by the end of our visit, each one was given a nickname by the kids for their unique styles and personalities.

After visiting the reserve, we took an excursion to the lovely beach at Puerto Chino where we enjoyed more wildlife and the kids did some bodyboarding. We had lunch at the beautiful Otoy Restaurant, which offered a view of the water and some of the nicest gardens we encountered on any of the islands. After lunch, we headed to El Ceibo Treehouse, a unique site that our guide’s parents had built. A swinging bridge led to a treehouse that was big enough for a couple of beds, a toilet, and a fireman’s pole quick exit. There was even a room below ground inside this massive kapok tree. The treehouse is not wheelchair accessible, but with some assistance I was able to check out the gardens, sculptures and restaurant. After enjoying some local coffee and avocado ice cream, everyone joined in a fun and muddy game of soccer. We all had a laugh when one of our teens lay face-down on the ground while ducks ate grain off of his back, a supposed therapy to help relieve stress. It appeared to work for the entire group because everyone couldn’t keep the smiles off their faces for the rest of the day.

ISABELA ISLAND

Because of mechanical issues delaying an early flight to our next island, our “superplan” for day four was quickly adjusted to include a morning snorkel activity. We headed to La Loberia, a protected pool that offers calm waters during low tide. The snorkeling at La Loberia did not disappoint, and was highlighted by friendly sea turtles and a shy blowfish.

Later that day, we took a short propeller flight on an eight-seater plane to Isabela, the largest and geologically youngest island. Shaped like a seahorse, Isabela Island comprises five active shield volcanoes, including Sierra Negra, the most active Galápagos volcano that erupted as recently as the summer of 2018. Of the three islands we visited in the Galápagos, Isabela has the smallest human population, currently approximately 3,000.

After checking into our beach-front accommodations at Hotel Albemarle, we headed to Isabel’s giant tortoise breeding center nearby. We were amazed to learn that 18 giant tortoises were individually evacuated by helicopter from the Cero Azul volcano area during its 1998 eruption. This rescue from their certain demise and subsequent placement in this breeding center illustrates the gallant efforts to prevent the extinction of these amazing creatures. From the original 18, there are now already hundreds of young adult tortoises returning to their original wild habitats near Cero Azul.
We returned from the breeding center along a flat path through lagoons, where we enjoyed views of pink flamingos and other migratory birds.

Day five began with a leisurely sea kayaking trip around the bay adjacent to town. Though I wasn’t able to paddle due to balance issues, I enjoyed views of sea lions, marine iguanas, blue-footed boobies, Sally Lightfoot crabs, rays and frigate birds. After kayaking, we strolled down a wooden planked path through mangrove trees to a beautiful snorkeling spot called Concha de Perla. Though it was complicated getting me down and back up the stairs, the crew made it seem routine. The swimming was wonderfully easy and I rarely needed the orange floatation ring in the calm, protected waters. Swimming through an exposed lava tunnel was a new experience for the whole family. This was our last snorkeling excursion and not one we’ll soon forget.

Day six was considered a “free day” but was still filled with remarkable experiences. After a relaxing morning of beach volleyball and soccer, the guide told me there was a collection of blue-footed boobies sitting at the end of a lava flow and asked if I was interested in seeing them. I was a bit hesitant as the terrain appeared treacherous but our guide was adamant that the view would be well worth the effort. It took three people to get me there, and at times I felt like a king being carried on a throne, but it was incredible to be next to hundreds of these unique creatures.

We went on a stroll through a path filled with mangroves, majestic candelabra cacti, and another lava tube while the rest of the family took a bike ride up to the Wall of Tears. This historic site was constructed by inmates of a penal colony between the years of 1945 and 1959 and served no purpose but to punish the prisoners, many of whom died while building the structure that rose 65 feet high in places.

We had superb days in Isabela but we were moving to our last island the following day.

**SANTA CRUZ**

We woke up early on day seven to take the two-hour ferry boat from Isabela to Santa Cruz, the most populated island of the Galápagos. After arriving in Santa Cruz, we headed up to the highlands to see the giant tortoises living in their natural environment at El Chato Reserve. It was pouring down rain as we headed out to visit these magnificent creatures, giving us the chance to see them in a more active state. After a delicious lunch at the reserve, we headed to El Trapiche to experience some of the cultural aspects of the island. The kids were put to work learning how to operate a mule-driven sugar cane press and techniques to traditionally roast coffee. After demonstrating the distilling process, the adults got to sample some moonshine. We then returned to town for some rest.

Our eighth day began with a visit to the beautiful El Garapatero beach. The well-constructed path to the water led us through giant prickly pear cacti with trunks as wide as huge mature trees. The waves were calm and I was able to swim independently in the glorious warm water with the kids and sea lions for a couple of hours. After an exceptional lunch at Andrea & Valerio, we enjoyed the walkable waterfront access and souvenir shops before our farewell dinner at the elegant restaurant, Almar.

Our last day consisted of an epic return trip home utilizing multiple modes of transportation including a taxi, ferry boat, bus and multiple airplanes. We were extremely weary after the long hours of travel but grateful for the wonderful adventure we were able to experience.

With Adventure Unbound organizing the logistics of the nine-day tour, I really didn’t have to worry about wheelchair access while on the Galápagos Islands. All of the rooms I stayed in had roll-in showers with handheld shower heads. The guides were there to help if there were any steps at the sites or restaurants. They assisted with every transfer in and out of the taxis, planes, buses and boats, and they made sure I felt safe and comfortable.

What was most remarkable was the ease and confidence every guide demonstrated when faced with accessibility questions. The attitude of inclusion on the islands prevented me from ever feeling that I’d be left behind while the rest of the family went exploring. This attitude freed me from the guilt and resentment I can often feel when traveling with my family and also lifted weight off of my wife, who often feels stranded having to do extra tasks for me when we travel. The entire tour felt effortless and gave us the space to enjoy this unique place in a way we’ve never felt possible before.
The premiere issue of American Nurse Today in 2006 described the changing landscape of nursing by emphasizing the need for mobility and portability due to “growth in freestanding clinics, ambulatory care centers, and other nonhospital settings,” adding that nurses being educated in a hospital-based model “doesn’t mesh with today’s trends.” More recently, a 2013 Huffington Post article described nurses’ expanding roles this way: “Nurses are giving TED talks, publishing scientific research, developing mobile medical applications, and actively addressing health care policy. … The field is growing, and so are opportunities for nurse practitioners, DNP and Ph.D. nurses, nurse educators, nurse-anesthetists, and nurse researchers.”

In 2019, a greater percentage of the U.S. population than ever before is covered by health insurance, thanks mainly to the Affordable Care Act. The popularity of the concept of Medicare for All, currently favored by two-thirds of Americans, is likely to grow as the 2020 election nears. Set against this backdrop, opportunities for nurses who use wheelchairs are also likely to grow — except for one major obstacle.

Despite the expanding need for nurses in dozens of different settings, an antiquated, stereotypical view of nursing still persists: the hospital bedside nurse, hustling from room to room with little or no time for breaks, all the while carrying armfuls of supplies while answering call lights and pagers in the midst of caring for and lifting patients. This stereotype, while based in fact, ignores the growing necessity of teamwork in nursing, and it also excludes most nurses who use wheelchairs and wheelchair users who want to become nurses.

Thankfully, a modest but formidable number of dedicated nurses on wheels is committed to breaking down this barrier of bias that too often leads to outright discrimination.

The Pioneering Nurse
In the late 1980s, Karen McCulloh was working in neurosurgery intensive care nursing when she began experiencing symptoms of multiple sclerosis. With its attending vision and mobility losses, as well as an unexpected significant loss of hearing, eventually she had to confront an unimaginable question: Can I still be a nurse if I’m blind, deaf and use a wheelchair?

Even though multiple disabilities significantly reduced her...
physical function, McCulloh still had years of training, valuable job experiences and a passion for nursing. She wanted to continue doing what she loved. “At this time, I was blind in one eye with low vision in the other, deaf in one ear, a hearing aid in the other, and used a cane or wheelchair in some situations. So I went to a rehab counselor, and he says, ‘So, you were a nurse.’ I said, ‘No, I AM a nurse.’ I walked out of his office and never returned.” Another rehab counselor told McCulloh they were evaluating her for a sheltered workshop. “I told her, ‘I am a licensed RN with extensive work history!’ I cannot tell you how this impacted me. All of a sudden your life experience and employment history counts for nothing.”

McCulloh decided to return to college but was denied entrance to several Bachelor of Science in nursing programs. She was finally admitted to Loyola University of Chicago, but not to its BSN program. With two kids in college, she graduated from Loyola with a Bachelor of Science, but couldn’t find a job in health care. The year was 1994.

Andrea Dalzell knocked down every obstacle that her professors put in her way to become a nurse.
“I decided I had to write my own script,” she says. “Non-disabled nurses rejected me because I was disabled, but I knew I needed to confront bias and not give up, so I moved more into education and set up my own business, focusing on community health disability education. I created that field — you won’t find it in any workbook — maintained my license and moved into executive leadership.”

In 2003, she co-founded the National Organization of Nurses with Disabilities. She was also the founding executive director of disabilityworks from 2005 until 2010. She was appointed by the Secretary of Labor as the only person with disabilities to sit on the National Job Corps Advisory Committee from 2006 until 2008, while serving as chairperson of the Subcommittee on Disability. McCulloh also served as the chairwoman of the board of directors for Access Living of Metropolitan Chicago, and in 2008 was a member of the Obama-Biden transition team. In 2011, President Obama appointed her to the AbilityOne Program, where she served until 2016.

Summing up her struggle to re-enter nursing, she says, “The irony for me is, I was not considered qualified to enter school for a BSN, but the president of the United States saw me as qualified to work for him.”

Today, she has her own consulting business where she focuses on diversity and inclusion working with businesses and nonprofits. “I’m interested in the workplace development side. We will lose 500,000 nurses to retirement by 2022. Bureau of Labor statistics predict we’ll need 1.5 million nurses in the coming years. We are seeing an increase in nursing students with disabilities, but the challenge is still at the workplace, especially for nurses who use wheelchairs.”

Nevertheless, she has reason to be optimistic. The nursing field is changing with more and more non-hospital nursing opportunities. But one thing, thankfully, never changes — the most important factor of all: “What drives us,” says McCulloh. “Our passion.”

‘The Hardest Thing I’ve Ever Done’

Passion is a prerequisite for becoming a successful nurse, especially if you must convince others that a physical limitation — such as quadriplegia — will not affect your overall proficiency.

In the summer of 2008, Michelle Kephart, a University of Iowa nursing student, broke her neck in a fall. Now paralyzed, after six weeks in intensive care she was transferred to Craig Hospital in Denver. She was halfway through her nursing program, and a friend’s suggestion that she would be out of rehab in time for next semester caught her off guard. “It was the first time I ever thought of going back,” she says. “I was so busy dealing with everything. But thinking about returning to the path I had chosen made me happy.”
Gillian Aitken, 31, graduated from Grand Canyon University with a Bachelor of Science in nursing in 2014. Born with spastic diplegia and a wheelchair user since the age of 12, she hoped to be an emergency room trauma nurse, but she found nothing but rejection.

“I’ve applied for thousands of jobs all over, talked with every major hospital in Phoenix,” she says. When she applies on Skype, she gets offers, 20 so far, but when she shows up for an in-person interview, the offers are withdrawn.

ER nurses in wheelchairs may be nonexistent, but trauma nursing is Aitken’s passion. “I even volunteered and went to the Woolsey Fire in California,” she says, referring to the fire that devastated Southern California in 2018. After four years with no paid work, she sought a different path. “I applied to Duke University’s nurse practitioner program and was accepted. It’s both online and in-person. I’m in my first year of a two-and-a-half-year program, and I continue to volunteer as a Red Cross disaster relief nurse.”

Nurse practitioners are more like doctors than nurses. “They can prescribe and do almost anything else a doctor can do, except no narcotics,” says Aitken. “It is less physical, less hands-on than nursing. The NP tells the nurse what to do.”

No doubt her career chances will improve as a nurse practitioner, but she will still have to hustle to find a job. If she can’t, she can always open her own office.

Rosemary Ciotti was a nurse practitioner in 1992 when she got waylaid by an autoimmune disease and ended up a wheelchair user. She moved to Arlington, Virginia, in 1994 because her husband was hired in the Washington, D.C., area.

“I landed in the land of the ADA,” says Ciotti. “I was the new wheelchair user in the hood with a baby on my lap. Disability activists in the area saw I would get stuck in doors, had problems with Metro trans, and the rest was history. They did a kind of ‘intervention.’ All these politically engaged advocates saw I was an NP and realized they needed me. So a whole new career was born. I started advocating for their medical care, taking on docs who discriminated, organized peoples’ care, made house calls, went to hospitals. I was a patient advocate, would see them at bedside and could make things happen so they could get immediate care.”

All this happened quickly after Ciotti moved to Arlington. “I was 40. They reached out to me with my baby and helped me build my life back. We traded what we knew.” Later, at a Harvard conference she met Karen McCulloh of NOND, who invited her to be on her board of directors. “I’m NOND’s person at the capital, lobbying right here, active in Capitol Hill actions.”

At 61, Ciotti is now a seasoned advocate: “You are either at the table or on the menu,” she says.
Her friends and staff at Craig were supportive, and her boyfriend, Devon, was especially helpful. “Even though we had no idea what nursing would look like, we decided there was no reason not to go on,” she says.

She soon found that returning to nursing school as a C5 quad was going to be tough. “I had to fight hard to get them to continue the program for me. We finally agreed I would take only two courses, one day per week, to see if I could do all I needed.” Determined, she did well in both classes but was told she would have to redo a patient assessment even though she had completed one before her injury. “The first time I did it with another classmate and one professor evaluating. This time I had to do a full head-to-toe videotaped assessment that would be evaluated by three different professors, pass or no pass.”

Kephart fought the altered assessment with help from the local Independent Living Center, met with faculty and sent a complaint to the Equal Employment Opportunity Commission. She was allowed to have an LPN student assist by holding a stethoscope, but the assessment was done entirely by Kephart. She passed, got her RN degree and the EEOC

“National Organization of Nurses with Disabilities”

Karen McCulloh co-founded NOND in 2003 and served as the first president of the nonprofit. Currently she serves as director. Besides McCulloh, three nurses in this article serve on NOND’s board of directors with specific roles: Rosemary Ciotti, Dawn Dubsky and Michelle Kephart. A fourth, Gordon Ninde, a co-founder, is no longer active in NOND but has made a successful career in nursing in Colorado (see other sidebar).

Calling itself “the voice of disability in nursing,” the nonprofit “promotes equity for people with disabilities and chronic health conditions in nursing through education and advocacy.” Their website is proof of this statement, with extensive listings of articles, helpful resources, a job board and one of the most comprehensive, information-packed FAQ sections available anywhere. Go to nond.org.
ruled, essentially, “no harm, no foul,” even though the nursing school had clearly violated the ADA. “I would not be hired in any position that I couldn’t do something physically, so it [the altered assessment] was unnecessary,” she says. “Their job is to teach, not screen out.”

In 2010, not yet ready to live on her own, she moved to Houston, lived briefly with her dad, then moved to Georgia. There she lived with her mom and volunteered at a community hospital in Savannah. Kephart took a part-time position as a disease management coordinator and diabetes educator. “I had an office, and a lot of what I did was counseling and guidance and making adjustments.” The program grew to include cardio, women’s health and nutrition over the next three years, and she was promoted to full time. “It worked out well, but there was never any certainty to it,” she says.

In 2015, Devon, who had joined the Peace Corp and, later, the Air Force, returned from serving overseas and was stationed in Colorado. They married, and Michelle got a job teaching in an online nursing school program at Western Governors University in Salt Lake City. Twice a year she travels to attend academic meetings at WGU, but the rest of the year she telecommutes from her home office in Aurora, Colorado. Her main daytime helper is Rumba, a golden lab who picks up dropped items for her, opens the fridge and gets her lunch.

Ten years after her injury, she is now three years into her teaching job. “Other than adjusting to paralysis, returning to nursing school and finding a career path is the hardest thing I have ever done,” she says. As far as I know, I’m the first quad to graduate from nursing school and begin a nursing career. You have to be willing to get out of your comfort zone.”

And she is grateful that she did. “I am so happy with my job now. It is ideal, it is perfect. I love it.”

The Path of Education
When accident or disease forces a nurse to become a wheelchair user, they must be courageous, creative and willing to make career moves to continue working. Dawn Dubsky was a pediatric nurse when she contracted malaria in Ghana, in 2008, and had to have all four limbs partially amputated. As a power chair user, she thought her days as a bedside nurse were over, so she decided to become a nurse case manager and further her education. In 2010, after rehab, surgeries and complications, she went back to work as a case manager and enrolled in a doctoral program. She also created America-AgainstMalaria.org, a nonprofit, to help educate children in Ghana about malaria. In 2017, she graduated from the University of Illinois at Chicago with a Ph.D.

In 2018, she moved to Seattle and is now working at Seattle Children’s Hospital as an inpatient pediatric case manager. She helps manage length of stay, transition to home, and advocates for services and equipment. “Now I get the big picture better,” she says, “how all this affects patient care. From childhood to adult, there is a gap in health care for people with disabilities. Pediatrics has much more support and resources, but that changes when you go from youth to adult.”

She says the inequities are more related to policy than money. “In Western medicine we engage in a lot of highly technical services for maintaining life, but we don’t think about outcome later when people need additional services.” She should know. The hospital she works for provides employee transportation, but not for her. “Every day I have to sit and wait for a public bus, and the employee vans drive past me, none of them accessible,” she says. “The hospital is out of compliance with the ADA. I have to sit out in the rain in my wheelchair and watch buses go by. I am an employee but I can’t utilize the same services as others use, so it makes me feel unimportant.”

As a case manager with a Ph.D., she is overqualified for her job. “You have to fight one battle at a time and advocate for yourself,” she says. But her dissertation, which will be published soon, speaks for all nurses with disabilities. “I interviewed 21 nurses with disabilities, four of them wheelchair users, about accommodations in the workplace.”

She found that the same lack of accessibility that creates healthcare inequities for wheelchair-using patients also discriminates against nurses with disabilities: too little room to maneuver, inaccessible bathrooms, exam tables that are
Can a Wheelchair User be a Floor Nurse in a Hospital?

In 1992, Gordon Ninde, a climbing and mountaineering enthusiast from Durango, Colorado, fell 40 feet while rock climbing and sustained a T9 complete spinal cord injury. Instead of being taken to Craig Hospital, one of the best SCI centers in the nation, he was flown to St. Anthony’s in Denver — where he stayed for a month. “I had just graduated from college and didn’t have any health insurance. I had to stay at St. Anthony’s until I could qualify for Medicaid before they would move me to Craig,” he says.

At the time of his injury, nursing was not on his radar. He had a bachelor’s degree in environmental biology from Fort Lewis College in Durango. “I had wanted to do field biology so I could do climbing and outdoor things I love,” he says.

Following his discharge from Craig, he moved in with his parents for a year and a half, then rented a subsidized housing accessible apartment. “The rehab people got me a forest service job doing computer mapping of watersheds, but I didn’t enjoy sitting in a cubicle,” he says. “I wasn’t sure what I wanted to do, but I had an interest in medicine, so I went back to college and took more biology courses, genetics and physiology to round out my degree.”

He picked up his licensed practical nurse certification from a local vocational school, then applied for nursing school at Pueblo Community College. The ADA was in its infancy. “The instructors wanted to make it work but were very uncertain since they hadn’t dealt with anyone in a wheelchair. I just wanted to do the best I could,” he says. “At the time I didn’t know much about ‘reasonable accommodations,’ so we just worked it out.”

When it came time to demonstrate his ability to do CPR, he climbed down out of his chair, did the compressions on the practice dummy, and activated the proper code to get help.

While in his second year of nursing school he got a part-time job as a unit secretary at Durango’s Mercy Regional Medical Center. Since he had already made connections at the hospital by the time he graduated, he applied for a part-time nursing position and was accepted.

And so began a career in nursing that many thought would never be possible. Now 50 and a registered nurse for more than 20 years, Ninde currently works as a nurse case manager at Mercy Regional Medical Center, having started on the medical surgical floor, eventually becoming charge nurse of that unit, managing the night shift as well as performing other duties. “I worked a total of seven years at night before transitioning to days. Nights were easier for me as a chair user, since days involve a lot more moving patients around.”

He is unique in more ways than one. As far as anyone knows, he is the only wheelchair user to be accepted into and graduate from a nursing school in Colorado, and as a full-time floor nurse who uses a wheelchair, he is a rarity. More importantly, his dedication and competence have been recognized by his peers. In 2013 he was honored for his “innovation and adaptation” by the Colorado Nurses Foundation, one of 38 nurse “luminaries” in the entire state who were recognized for “excellence in nursing” that year at the annual Nightingale Awards ceremony.

Near the beginning of his career, Ninde met and married Claire, who is communications director of the San Juan Basin Public Health Department. They still live in Durango and have a 13-year-old daughter. Besides nursing, Ninde remains active in adaptive skiing and other outdoor activities — such as rafting, adaptive dog sledding, and traveling — but that is another story.
too high, steep ramps, too-narrow doorways, hard-to-reach items, unclear process for asking for accommodations, and on and on. “In hospitals, we need to make accessibility improvements for not only clients but employees. It’s just not disability-friendly. Of all places, hospital design is not aimed toward wheelchair use. Universal design should include pediatrics, wheelchair users, strollers and more.”

Now, despite her everyday challenges as a pediatric case manager, as Dr. Dawn Dubsky she is equipped for the next step in her life. “If I want to go into research or managerial or administrative roles, I have a lot of opportunities that I didn’t have in the past.”

Still, she keeps coming back to what happens to her pediatric patients when they become adults. “We need more facilities and providers that can help people in their homes. In the community. What if you don’t live in a major city? It’s difficult to get to work. What if you need public transport but you are in a rural area and there isn’t any?”

The Need for Community Nursing in Rural America

Lindsey Freysinger, 32, lives with her husband on the flanks of Mount Hood in the small town of Parkdale, Oregon, population 311 — about as rural as it gets.

Six years ago she was in McAllen, Texas, doing her residency to become a certified registered nurse anesthetist, a program offered by Midwestern University in Glendale, Arizona. On a trip with a friend, an auto accident changed everything. After spending 11 days in the ICU with a C5-6 incomplete burst fracture, she was medevaced to Providence Portland Medical Center in Oregon.

She began regaining sensation and function during her three-month stay in the PPMC rehab unit. She started walking with braces and crutches but lacked stability and had to use a wheelchair at times. “From hour one, I knew I wanted to return and finish my anesthesia residency because it was my passion,” she says. Her school agreed to let her resume her residency after an 18-month leave of absence.

Having returned from her leave of absence, after a week of working in a lab, she had to complete a test that involved working with five practice dummies doing five different procedures. She wanted to use her wheelchair but was told the chair wasn’t allowed because it presented an “infection control issue.” She got up on her crutches, completed multiple procedures, ran into a few issues but recovered. Then she had to look through a camera while standing, lost her balance, and was told her inability to maintain equilibrium was a violation of technical standards.

“Because I lacked proprioception and sensation, when walking I had to depend on my sight rather than my sense of feeling,” she says. “Standing without support, with one eye closed, I lost balance. They closed the door in my face at that point.”

Rather than fight an unfair process, Freysinger decided to
take time off. "I realized I had gone back to school too soon. I needed to learn all the practical and adaptive ways of getting along."

In 2016, she married and made plans to return to school and obtain her master's in nursing administration and leadership. She enrolled in a web-blended University of Michigan program, her parents moved to Alaska, and she and her husband stayed in the Parkdale home. "I would fly to Ann Arbor once a month, take classes and return to Oregon. With financial help from scholarships, I got my master's in December 2017, did a streamlined application for the doctoral program and transitioned immediately with help from another scholarship."

Now she is in the second semester of her Ph.D. program and should finish by mid-2020. "I can't say enough about the University of Michigan. I have been astounded by their willingness to accommodate. They are excited about it! They continually try to get my input on things. And their services for students with disabilities are absolutely top notch."

Freyssinger foresees a role for herself in community nursing in her rural county in Oregon. "More people are going back to their homes earlier, spending less time in hospitals," she says. "They are expected to navigate their own health care, but they need help."

People with disabilities in rural communities are isolated. "Getting nurses back out in the community to address the social determinants of health — your ability to socialize, exercise, get good food, all of that — that is where I think we nurses with disabilities can make an impact, because we get it," says Freysinger. "I'm not talking about home health nursing, which is still task oriented. I'm talking about a team of nurses focusing on people with disabilities in rural communities. It is important to get them resources and connections that can change their quality of life. Number one for a nurse is to be a patient advocate."

The Needle in the Haystack
Wheelchair users who must gain admittance to nursing programs, complete their training and then land a job face even more formidable bias and discrimination. Andrea Dalzell, 31, was born and raised in Brooklyn. At the age of 5 she was diagnosed with transverse myelitis and started using a wheelchair at 12. Complications with hip dysplasia diminished her functional ability but did not dampen her ambition. "In high school, nursing wasn't in the picture. I wanted to be a lawyer so I could come back and sue," she jokes.

Lindsey Freysinger earned her master's degree in 2017.

Andrea Dalzell finished her bachelor's with high marks.
Later, at City University of New York’s College of Staten Island, she wanted to be a doctor, but changed her mind. “I had sat through a med class, and it wasn’t what I wanted to do — wasn’t the way I wanted to care for patients. Doctors are taught how to treat disease and the process, and nurses are taught to treat the person and how they are handling it. Nurses pick up the phone and tell doctors what’s going on.”

Dalzell applied to the CUNY College of Staten Island nursing program in 2016. During orientation, one of the professors, assuming she could not do bedside care from her wheelchair, told her she was dismissed for the day. “I just looked at her and said, ‘I’m not going anywhere,’” says Dalzell. “She had no clue as to my ability level. After orientation I went straight to the access and accommodations office and the diversity office and told them I was being denied entrance due to my disability and would go to the highest court that I could.”

During the meetings that followed, she made it clear that the only accommodation she needed was that she would tell them what she needed when she needed it. “It came down to letting them know that I am vocal about my needs, and communication is all important, and that nurses embody this.”

When it came time to demonstrate her ability to perform CPR — one of the most difficult technical standards for a wheelchair user — rather than ask for an accommodation, Dalzell took up boxing to build up stamina to be able to do chest compressions. “Nurse managers sometimes thought it was more of a hindrance to have someone in a wheelchair on the floor,” she says. “I had to tell them, it’s not just bedside care, it’s teamwork. Don’t judge me before you know what I can do.”

Dalzell passed the CPR test and became an RN in February 2018 and finished her bachelor of science in December with high marks. Now she is working as a case manager for a long-term managed care company.

“I’m not there yet,” she says. “I’d love to be a pediatric rehab nurse in a facility like Kessler, or where disabled children are being treated. It’s important for kids to see people who have disabilities doing the things you are interested in, extremely important to break the barrier — especially at a young age, especially when doctors don’t give much hope.”

Now, at the beginning of her career, she knows that entering and completing nursing school as a wheelchair user is a rarity. “New York State’s nursing board told me I was the first in the state to graduate with a credential,” she says. “I guess that means I’m one of the few needles in the haystack.”
Disability etiquette videos typically instruct normies on how to best engage with those of us who have disabilities, who are different. This approach, however, makes it feel like we — the people with disabilities — are the problem. It suggests we’re the thing to DEAL with, the thing to navigate, the problem that has to be solved. It’s as though we are so weird and alien that we fall beyond the realm of standard rules of human decency, respect and consideration, and therefore must create special lessons for everyone on how to approach us.

I object!

You’re telling me that a human of average intelligence and character can’t figure out that they shouldn’t illegally use accessible parking as a loading zone? Or they shouldn’t ask a perfect stranger in the elevator about overt physical scars that are clearly remnants of catastrophic trauma? Do we really think normies can’t figure out that comparing their two weeks spent using a wheelchair to our lifetimes of modified ambulation and identity overhaul is a no-no?

We — the people with the chairs, the walkers, the prosthetics and beyond — are expected to do so much: To navigate a world that often treats us like shit. To be forgiving and understanding when normies lean on us, pat us on the head, treat us like babies, and say rude and ignorant things. To brush it off, be “understanding” and constantly act from a place of love and empathy when people pity us, infantilize us, desexualize us, turn us into passive objects of their own inspirational journey, or diminish the complexity and wholeness of our lives. We are expected to do the work to make them feel comfortable and OK, while they can just sit back, watch a video and claim that it’s too much for them to put in the time, learn and care about how all these different people want to be treated.

The true hurdle of disability etiquette is the normie — the person who doesn’t think before they speak. The one who acts rashly or impulsively rather than taking a moment to observe the situation and consider, “Hmm, what is the respectful and human thing to do here?”

I was tired of spending my energy on educating normies on how they should behave … and therefore decided to put my energy instead into creating some
You don’t need to have a wickedly dark sense of humor to enjoy The Disability Etiquette Video with Regan Linton, but it helps. Linton, a Shakespearian actor, skews the genre’s do’s and don’ts by turning it on its head. This is not a video for nondisabled people who have to be told that yes, we really are people just like them. No! As Linton says in the intro, “This video will give YOU — other people with disabilities — some simple etiquette tools for dealing with the ignorant people that we have no choice but to encounter in our everyday lives.”

How to deal with the “I’ll just be a minute” parkers who steal accessible spots? Deflate their tires, that oldie-but-goodie.

Bar dudes who make drunken lap dance jokes? Good thing your elbows are crotch-height.

Weak people who insist upon hugging you because they think you’re so strong? Be friendly. “After all, everyone needs love,” Linton says, “and it presents the perfect opportunity for a cosmetology arts project.” Cue the scissors.

Folks who ask what happened to you? Repeat the question: “What happened to you?” “What happened to YOU?” “I mean your chair.” “I mean your FACE.”

The video can be seen at youtube.com/watch?v=DOncEUExdzI and we heard a rumor that soon there may be a whole series. Watch our online news column for updates.

— Josie Byzek

THE DISABILITY ETIQUETTE VIDEO TO END ALL DISABILITY ETIQUETTE VIDEOS*

*unless Regan does more of them … which she may …

ETIQUETTE DILEMMA: “I’ll just be a minute” parkers who steal accessible spots.
APPROPRIATE RESPONSE: “So will I.”

ETIQUETTE DILEMMA: Folks who ask, “What happened to you?”
APPROPRIATE RESPONSE: “What happened to YOU?”

valuable tips for my friends in the disability community on how to deal with the inappropriate comments, the ignorance, the apathy or the people who are unapologetically bold about the fact that they will speak or act disrespectfully, and they don’t care.

HOW TO DEAL WITH:

TSA AGENTS: The TSA spiel about what I call the “airport massage” is tedious when you’ve heard it for the 52nd time. “I will use the back of my hand on sensitive areas, do you have any external devices, do you want a private screening, blah blah blah …” It’s even more tedious when they are training and cautiously engage their novice TSA spidey senses to explore every crinkle of clothing while they disguise their own insecurity in safe drivel talk: “Oh,
you're off to San Diego? Sunny! Heh heh.” I’ve often thought of asking them to do my breast exam while they’re at it, or to check the skin on my butt while they’re back there.

You must simply keep in mind — as you watch the minutes tick on and the other passengers stream by — that while YOU don’t have heroin stuffed into your cushion, the elder lady in the wheelchair behind you just might. These blue-shirted warriors deserve to have at least 10 minutes of their lives feel significant, so just smile, avert your eyes as they cautiously caress your inner thigh for signs of a crossbow, and engage your calming breaths as they remove your shoes to test them … the ones that are in pristine shape because you haven’t walked anywhere in the last 16 years, much less through a warehouse filled with gunpowder. Maybe they should check the tires instead?

**ONLINE DATING INQUIRERS:** How do you possibly respond to the New Agey guy who says you look “interesting,” asks why you use a handcycle rather than a foot pedal bike (despite your FIVE wheelchair pictures and reference of paralysis in your profile), and then implores in his third message that you meet his personal guru who miraculously taught himself to walk again through sheer mind training? What do you say to the guy who starts ranting about his other disabled friend who preys on his generosity and selflessness while ignorantly dismissing his own obvious narcissistic behaviors? And what about the guy who sends you a dick pic and wants to see your picture, but won’t deign to entertain any sort of real meeting because you are apparently not his type? The answer is, simply treat them as a research project in which you are the scientist and they are messed up weirdos about whom you can draw curious conclusions and make funny jokes. And when appropriate, respond to uncouth messages by typing “Barbaloots in their Barbaloot suits.” It throws them off enough to allow a clean getaway.

**INACCESSIBLE PLACES OF WORSHIP:** For those religious establishments that don’t feel the need to invest in ramps for their sacred houses, keep in mind that what they offer inside can be accessed in numerous other places. A quiet focused environment? Sit under a tree. Wine and bread? Italian restaurant. Live music? The local bar. Community? Again, the local bar. A sense of charity and righteousness? Be kind to the homeless person on the corner. Everlasting life? The library. Frankly, sometimes being excluded is the blessing … it reminds

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you of all the other places in life where you can get inspiration.

**PEOPLE WHO DECRY INACCESSIBILITY BUT DON’T DO ANYTHING ABOUT IT:** You know the type. They watch you in a restaurant as you struggle to squeeze through tightly situated chairs or move kitchen supplies so you can get to the bathroom, or strain to see over the high top because there are no low tables. They might even say something to you: “Ugh, that’s really challenging for you, huh sweetie?” “Jeez, they really should make that easier for you!” But that’s all. They couldn’t possibly take the initiative to actually say something to the business owner to rectify the issue. They leave it at the comment and feel better about themselves for having noticed it.

As frustrating as it may be for us to continually deal with those who are all talk and no action, in their silence, we get stronger! It’s as if they are sitting eating cupcakes and watching crappy network TV while we climb rock faces and practice swordsmanship.

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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.
Does the sting of injury or disability — that twinge of anger, regret or self-pity over what’s been lost — ever go away? A conversation with a friend left me pondering that very question. I realized only a fool would declare himself sting-free, though for me, after 30 years it’s rarely more than a twinge. But I wondered how others felt and whether there are things we can do to help the sting out the door. Most of us weather the initial storms following injury, but do we ever truly get over all we’ve lost? Is that even possible? And if it is, how long can we expect to wait for that healing to happen? What helps ease the sting and/or speed the process along? I spoke with other wheelchair users to see what they think and to learn from their experiences.

Face it Head On

“I don’t think the pain ever really goes away. It may not take up as much real estate, and it may decrease, but go away? Not really,” says Minna Hong, 55. Twenty years ago she was injured at T12-L1 in an automobile accident that also took the life of her husband, the father of her two young children.

The sting still revisits her in small ways almost every morning and can return big-time with something major, like a broken hip. She suggests people manage the sting, so as not to be managed by it. Hong credits taking a full-time job 18 months after her accident as being very beneficial.

“Work gave me structure, purpose, meaning, a more positive identity,” she says. The nature of her job as the SCI peer support coordinator at Shepherd Center — daily interaction with inpatients and wheelchair users in the community — was especially helpful, as it provided a constant reminder of how far she had come. “I couldn’t just dwell on the injury or compare myself to what others were doing. That can make your world very small. You must participate.”

Therapy was also beneficial, says Hong, noting, “If my arm was bleeding badly, I’d go to a hospital; if my heart’s hurting, I’ll see a therapist.” Hong says it required work getting used to this new life, this new skin. It took work to rebuild self-esteem, to be her true self and recognize that everyone has value and worth as they are. Now retired, she left “the nest of Shepherd center with all the lessons I have learned and applied them elsewhere.”

Hong says facing the sting head on is key. “Rather than denying it, I’ve learned that it’s important to acknowledge that this sucks. I’m gentler with myself regarding my ‘predicaments’ and have developed the grace to be gentle with myself asking for help or taking short cuts rather than dwelling on it or comparing myself to what my friends are doing.”
Words of Wisdom: “How you live is important. Be your true self. Participate and be in the community.”

It Never Goes Away

“Maybe the sting of being disabled goes away for some people, but not for me,” says Hank Stampler. “It’s just always there. For me, the sting of becoming disabled is different than the sting of being disabled.” Stampler, 44, who became a wheelchair user following a spinal infection 14 years ago, sees himself as a work in progress. “Bad days can bring the sting back to me, but I’m learning that’s when I need to reengage, get out and do something.”

Prior to the infection, Stampler was a chemist working in a lab. Mixing chemicals with quad hands wasn’t practical, so he became a stay-at-home parent to his two young children. He muses moving past the sting “probably means getting back into life, staying busy with activities not related to disability, finding some way of insulating disability so it’s not interfering with what I want to do.

“I think to drown out the sting you have to get so occupied with life that you’re too busy to think about it,” he says. He’s quick to add that he’s not there yet and still struggles at times.

After a few years of learning to be more independent, he found he had too much time on his hands. “Disability creates so much time to fill. I was parenting two young children, but kids grow up and leave. I didn’t plan for that.”

Getting involved with adaptive sports, working out and volunteering with his local rehab center’s peer mentor program helped him feel more positive. Connecting with other wheelchair users who saw disability as a new life, he began to see what he needed to do to get where he wanted to be.

“I let too much time pass raising my kids before volunteering, and not enough time thinking about what I wanted to do afterwards,” he says. “I’m definitely more engaged in life since I began working out. I’ve also found volunteering is a good way to fill time and build up some self-esteem. If people asked me for advice, I’d tell them to get back to work as quickly as possible or find some meaningful activity. Work is an issue for me because the skills I have [in the lab] are not transferable.”

Stampler also emphasizes the importance of a strong support group. “Being surrounded by positive people also helps. Solid relationships are so important, and they and need to be nourished.”

Words of Wisdom: “It’s important to say yes to opportunities. When we say no to them, fewer come our way.”

The Value of Letting Go

“Our trauma is with us every day, and the sting is part of that trauma,” says Regan Linton. A New Mobility contributor and the artistic director of Phamaly Theatre Company in Denver, Colorado, Linton joined the SCI club in 2002, the result of an accident that made her a T4 paraplegic. “The injury will always color our reality. Disability’s a cyclical experience, popping up in different situations ... it’s like losing a loved one, but in some ways it’s even worse. With the injury, we’re facing ourselves and our vulnerability every day, and every challenge we deal with reminds us of all that’s lost and changed.”

Linton was injured while in college and needed time to figure out her way forward. “My biggest mistake was trying to hold on to what I’d lost, trying to be what I was. The greatest gift I gave myself — what allowed me to move forward — was letting go. I needed to feel the pain, to just say ‘fuck it!’ and start baby stepping, doing a complete overhaul of who I was.”

At the same time, she found strength in her own character traits. “My sense of humor, cussing and fearlessness helped me the most,” she says.

Linton surrounded herself with peo-
ple who could relate to not fitting the “normal” mold and who would openly and honestly share feelings. “It took at least three years before I began making new memories,” she says. “I learned that the sting definitely decreases and it doesn’t have to define my life. It’s just one aspect of who I am.”

Instead of fighting the sting, Linton worked to make meaning and find purpose from it. “A life of joy, love, humor, awesome experiences and extraordinary things is still totally possible,” she says. “I’m never going to thank the universe for this, but I love my life, despite the occasional shitty day. It reminds me not to take the good days for granted.”

Words of Wisdom: “Do what they teach you in rehab! That will prevent a lot of the doldrums from coming back. … Mostly, just keep laughing and moving!”

Strength in Others
“The sting lessens with time, but never really disappears,” says Roanne Kuenzler. Now 64, Kuenzler has lived with a T12 injury for 41 years. Following a long career spanning many jobs in the legal and sports worlds, she retired in 2005 and splits her time between Denver and Arizona.

What has she learned? “When I was injured, I knew I had a choice of either accepting and adapting to this, or fighting reality. I thought it was easier to just adapt and move on. My goal was to get back as close as possible to the life I had before injury.”

Kuenzler relied on the people around her. “Family and work helped immensely, as did attitude,” she says. “I learned that I was much stronger than I thought, to focus on possibilities rather than losses, and to find something to care about and look forward to.”

She also found satisfaction in adaptive sports. She was on the U.S. Disabled Ski Team in 1984 and 1986, took part in numerous marathons, including Boston, and played wheelchair tennis. But she tore her rotator cuff in 2004 and retired on disability in 2005.

As important as it is to nurture your passions, life has shown Kuenzler that sometimes enough is enough. “I try to cut myself some slack and do what has to be done but leave until tomorrow what can wait and rest when I need it,” she says. “I find this is more important the older I get.”

Words of Wisdom: “Establish and maintain relationships, especially with little kids or animals. They’re like mirrors, they reflect back to you what they see from you.”

Keep It In Perspective
“Even though I went through the normal grief cycle, I doubt the sting ever really goes away, because the disability is just always there,” says Jason Regier, a C5-6 quad. Between serving as the head coach of Denver’s wheelchair rugby team and his work as a professional speaker and consultant, the 44-year-old, three-time Paralympian medal winner has come a long way since he was injured 22 years ago.

“My first year was monumental. I didn’t know what I didn’t know,” he says. “The next few years gave me some glimmers of good — mastering a task, a good talk with a friend. By five years, the disability was my new normal. I think we’re always trying to figure out who we are.”

His early struggles coping with the sting included a bit of denial and
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Positive Growth
Researchers and doctors have a more official name for keeping the sting at bay — they call it post-traumatic growth. Theories hold that 30-70 percent of people experiencing trauma find ways to create positive experiences after trauma. How? By paying attention to five key areas: relating to others, embracing new possibilities, personal strength, spiritual change and appreciation for life.

What’s apparent from the people we spoke with is that the only way past disability is through it. Their stories reveal the way to beat the sting of disability is to feel the pain, get past the denial, accept, adapt to and embrace this new life with the same or greater gusto than before. Everyone in this group is adapting, finding new things to focus on and saying yes to opportunities. It hasn’t been easy for any of them. It’s clear the sting is hard, if not impossible, to shake. But by taking chances, having adventures and above all getting involved with people and with life, it can be tamed.

To paraphrase the words of wisdom shared by this impressive group: Be in the world. Be part of the community, be with people, understand and appreciate what you have, be brave, take chances and live life as a verb — by doing!

Words of Wisdom: “Things aren’t good or bad. They might be opportunities. Early on, explain to family and friends how you feel, don’t make them guess.”

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Rugby expanded Jason Regier’s world.

acting. “I might have talked a good game, telling friends, family and myself that things were good and I was making progress, but I realized I was depressed and my situation sucked.” His saving grace was curiosity: “Despite my situation, it was still an amazing world to live in, and I knew I’d be foolish not to be part of it.

“I was fortunate to have so many positives in my life. My family was very supportive and I lived in Denver, where I did my rehab. I had lots of friends here. I had things to hold onto.”

Following injury, rugby became his focus. “Rugby really expanded my world. I got to travel internationally and gain a broader perspective. I recognized how privileged I was as a white male in this country. I realized my situation wasn’t terrible and that work was possible. Without that something,” he says, “the injury can eat at you.”

Seeing the world while traveling for rugby also had a profound impact. “Travel opened my eyes to racism and places where people with disabilities aren’t even fourth-class citizens. Disability is always humbling, but I realized I was better off in a chair than most nondisabled people in the world. It all helped me focus on the positives.”

He knows his persistence has helped him come a long way, but the sting still creeps in. “Back in rehab even small steps like brushing my teeth could provide some forward traction. Now bad days seem to happen when I’m alone, dealing with the same stuff over and over. That’s when I have to get something positive going to not get too far down.”

Words of Wisdom: “Things aren’t good or bad. They might be opportunities. Early on, explain to family and friends how you feel, don’t make them guess.”
Disruption. It's a word you hear all the time if you listen to business gurus or political consultants. A product is disruptive when it innovates in such a way that it upsets a market — think of Uber and the effect it had on transportation or Airbnb and how it has changed both the hotel and the housing rental industries.

In more general terms, a disruption is some kind of disturbance — it's something that interrupts an ongoing process. That's why I got excited when Lyn Jakeman announced last fall that she was part of a team organizing a conference called SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research. Jakeman is the neuroscientist/administrator who directs The National Institute of Neurological Disorders and Stroke, the program at the National Institutes of Health aimed at spinal cord injury research.

The conference took place February 12-13 in Bethesda, Maryland, sponsored and hosted by NIH. (See Resources for video link.)

As Jakeman explained it back in October, the idea was to invite representatives of all the groups that play a part in what might be called the "cure/care industry." Those who design devices, investigate different kinds of cells, engineer implants, capture data, provide physical therapy, perform surgery or work as caregivers would join together to find ways to improve function and quality of life for people living with paralysis.

If ever there was an industry that could use some disruption, SCI research is it. Why? Because in spite of more than $100 million going into this project annually just in the United States, we don't have anything. There is not a single medication or device or cellular therapy approved by the FDA specifically for use by people with SCI. Zero.

Early on in the first day, United Spinal member and cure advocate Rob Wudlick rolled his power chair up to the microphone. His presence there was more than the usual tokenism scenario, in which a person living with the injury describes how they got hurt and what their days are like now. Those talks — always well-intentioned and powerful — are meant to create, however briefly, a sense of empathy and urgency for the listening researchers.

Wudlick's talk certainly did that. And for me, it also did much more. There was a moment in it that kept tugging at the back of my mind as I watched the rest of the presentations. Wudlick described his injury day. He and a group of friends stopped for lunch 19 days into a 25-day rafting trip down the Colorado River in the Grand Canyon. He went to fetch something off his boat when a friend called out that a piece of trash had fallen into the river. It was 90 degrees, the water was deep, and he dove. We know how that story ends: C4-5. ASIA B.

What caught my attention was what happened next. Wudlick, a trained emergency medical tech, was face down and immobile in the water. After a moment of wondering if he was messing with them, his friends came to his aid. Once he was flipped over and breathing, he proceeded to tell them how to get him safely to the beach. How to keep his head stabilized while they pulled an aluminum table off the boat to form a backboard. How to move him. How to check his vitals. What to say when they called for the helicopter.

It was a scene I still hadn't shaken off, days later.

Lots to Discuss

Spinal cord injury research is a vigorous beast — one with many disconnected tentacles and no brain. There's a lot of moving around, but it's disorganized

"People living with SCI are a readily-available resource, with thousands of years of knowledge about this injury to contribute. What if we could get inside those silos, not once a year or for one panel, but every day?"
movement that slouches toward no particular destination. That’s why the idea of a conference to bring various segments of this monster into the same room seemed — to be blunt — way overdue. On the first morning, Jakeman explained the goals her group had defined:

- Review the current state of the science.
- Break down barriers between different groups and get them talking to one another.
- Name priorities for research and development going forward.

To that end, the organizers had set up five panels of scientists, plus one from our community. The scientists were an impressive, highly educated and highly productive bunch, with dozens of doctorates and hundreds of published papers among them. These people represented, in every sense, the SCI research system at its very best.

The members of these panels held long phone calls prior to the conference, during which they worked out plans for their joint presentations. The groups focused on Acute Post-Injury, Repair, Plasticity and Regeneration, Sub-Acute and Chronic, Neuromodulation, Health and Secondary Health Effects, and Prosthetics and Robotics.

It’s a familiar list for those of us who have been trying to follow the direction of research being undertaken on our behalf. It’s also reflective of how much has changed in the last five years or so — and how much has not. Scientists work on acute damage for two reasons: It’s cheapest in terms of animal models, and there is still much to be learned about what is happening inside a recently damaged cord.

The second item on that list, repair of the chronically-injured cord, is the most difficult and complicated task, by far, and the one that will change lives the most dramatically if it can be done. The third panel focused on epidural and transcutaneous stimulation, currently being tested on dozens of men and women with spinal injuries in labs all over the United States and in Switzerland. The fourth panel addressed the need to understand how a damaged cord impacts health overall, and the final one gave us a window into the work of engineers who are busy designing ways to help that don’t involve the damaged cord at all.

Each scientific panel had a chairperson, three speakers and two people to facilitate question and answer sessions once the presentation was done. These took place, over and over — an hour and 15 minutes at a pop — for two long days. If this sounds exhausting, it was. A whole lot of very complex and inter-related issues present themselves when you move to the 40,000-foot level and try to take in the whole landscape at once.

The Greatest Resource

When Jakeman described the event’s goals on the first day, she used a slide to illustrate the problem as she saw it. It was a picture of a group of five silos, each self-contained and unconnected to the others. The silos were labeled clinicians, pre-clinical researchers, healthcare providers, engineers and industry. To her mind, this was the problem — these people weren’t talking to one another. Off to one side of the image, floating in the empty blue sky, were the words, "People with SCI." People with SCI aren’t in any of the silos. People with SCI are outside the system of silos. People with SCI are floating, useless and impotent, somewhere out of range.

Rob Wudlick, in the moment of his extremity, wasn’t floating uselessly. He was directing the action. He was using his knowledge and authority to save his own life, with the help of his friends. That is the reason for advocacy, both for faster cures and for better care.

Barry Munro, a wheelchair-using advocate from the Canadian Spinal Research Organization, reminded the scientists that people living with SCI are a readily-available resource, with thousands of years of knowledge about this injury to contribute. What if we could get inside those silos, not once a year or for one panel, but every day? What if we could routinely help direct the course of research to lead efficiently to better care and faster cures? Now that would be disruptive.

Resources

Videos of SCI2020: Launching a Decade of Disruption:
- First Day, videocast.nih.gov/summary.asp?Live=30194&bhcp=1
- Second Day, videocast.nih.gov/summary.asp?Live=30198&bhcp=1
I wanted to write about the overly-medicalized stereotypical images of caregiving a lot of people carry around in their heads, so I entered the word “caregiver” into a search engine and then clicked images.

Sure enough, nearly all the stock pictures that popped up were of young women taking care of old women. The young women were almost always dressed in medical scrubs and the old women were usually wearing robes or pajamas, as if they never left their bedrooms.

No surprises there. That’s how most people see caregiving — a female medical professional taking care of a female shut-in. Nobody on the receiving end is young or active, and very few of the people on either end are men.

So I entered “caregiver man” into a search engine and up popped a whole bunch of images from porn videos. Yep, apparently there is an entire genre of porn videos known as old man/caregiver. I guess I shouldn’t have been surprised to learn this.

I watched a few of these videos for research purposes because that’s what journalists do. (You’re welcome.) Or maybe I should say I watched a few of them long enough to get the gist of the stories they tell, which wasn’t very long. Videos of this genre seem to follow a specific plot structure that begins with a buxom young caregiver arriving at the home of an old crippled man. I won’t tell you what happens from there so I don’t spoil anything. I’ll just say that although they’re all pretty much the same, some of the videos have deeper, more elaborate plots that involve sponge baths.

This cinematic discovery had me curious as to what else might be out there. So I entered “old woman caregiver” and “young man caregiver” into a search engine, but no porn video images there. I guess it shouldn’t have been a surprise to learn this. I think it’s because porn video producers assume there’s no market for that kind of junk.

Another thing I noticed is that the male leads in these old man/caregiver videos don’t look very crippled — almost all of them aren’t in wheelchairs and they have all of their limbs. I guess Hollywood casting directors aren’t the only ones who always cast uncrippled actors to play crippled characters. Porn casting directors must also assume that no cripples are properly equipped to handle starring roles.

However, it did appear that the protagonist in one of these videos might actually be crippled. He had that actual-cripple air about him. He didn’t have a quad belly or bony legs, but his wheelchair wasn’t one of those clunky models you only see at hospitals and airports. A woman wearing nothing but a nurse’s cap with a red cross on it sat on his lap and a caption on the image showed where the complete video could be found. I went to the website for research purposes, because that’s what journalists do. (You’re welcome.) This site calls itself the “ultimate handicap hardcore sex site” featuring "handicaps, amputees and all kinds of freaks!” And the people getting it on in the images are wheelchair users or amputees or amputees in wheelchairs.

I wasn’t sure what to make of all the stereotypical imagery I’d Googled for research purposes until I went to that site, but after going there I was truly offended. Yeah, it’s true that all those playing the roles of amputees appeared to be actual amputees, but this site sunk to a new low. It made me feel demeaned and degraded. I always feel that way when somebody still calls us handicaps.
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Bart Kylstra, 52, was a mechanical engineer, living and working in San Francisco for nearly 27 years where he came to found Rio Mobility in 2006 and proceeded as the principle engineer and CEO. Rio is a mobility solutions company, most noted for the “Firefly” full power handcycle attachment that turns any lightweight manual wheelchair into a powered mobility device. Bart dedicated the majority of his career to helping others find affordable mobility solutions and was described by his friends and family as a natural born problem solver.

Bart Kylstra is missed daily by his friends, colleagues, customers, girlfriend, and family. His company Rio Mobility is still being operated by family, friends and colleagues.

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Before retirement, I was a college professor and did brain research. One night, to treat my research team, I ordered pizza and since my lab was tricky to locate, gave instructions for the driver to meet me at the end of the breezeway.

When I went to meet the pizza driver, I watched as a vehicle circled a few times, but never stopped. When no one else showed, I had to go all of the way back to the lab to call, as we didn’t have cell phones then. Again, I went outside and watched as the whole scene repeated.

I called back a third time and the exasperated order taker said, “The driver is here now. YOU can talk to him!” The driver’s excuse? “I drove around twice but nobody was there to meet me except some lady in a wheelchair!”

“Do you think I have to eat pizza standing up?!” I responded.

In the end, most of the team had to leave before the cold pizza was finally delivered. Looking back, I could kick myself for paying.

Oh, that’s right, I can’t kick either.  

Crustfallen, Ph.D.

BRA HUMBUG

After being injured in 1995 and wrapping up nearly a year of rehab, I finally ventured out alone. I renewed my driver’s license and could manage my chair pretty well, so I decided to start Christmas shopping at the mall. A ride on the Macy’s elevator took me to the second floor and dropped me off right in the middle of the Women’s Intimates section. The aisles were tightly packed to accommodate all the Christmas displays and I brushed up against most of them as I passed.

As I cleared the lingerie section and purposefully rolled in the direction of the men’s department, I heard a woman’s voice call out, “Can I offer you some assistance?”

“No thanks,” I said. “I am all set.”

“I really think you could use some help,” she responded.

“No, I’m good ... really,” I replied, wheeling away.

Then she said, “I don’t think so. Look behind you.”

I turned around to see several bras and their hangers caught up on my chair’s handles, backpack and folding bars. Oops. The saleswoman, smiling and trying to suppress her laughter, quickly disentangled them while I just sat there, getting redder by the minute. When finished, she gave me a hug and said I was good to go. We wished each other a Merry Christmas and I continued on my way.

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