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Cover and Contents Photos by Loren Worthington
Amadeo Garcia Garcia might as well be the last man on earth. He lives in the village of Intuto, Peru, on the banks of the Amazon, and he’s the last survivor of his tribe — the last native speaker of his first language, Taushiro [“Thousands Once Spoke His Language in the Amazon. Now, He’s the Only One” — nyt.ms/2pzV1fH]. When he dies, no one will be left to speak his language. Now, while he lives out his final years, he may be the world’s loneliest man.

Imagine if no one spoke your language. The profound connection we have with our native language is lost on most of us who are American-born English speakers. Every day we hear our language spoken wherever voices can be heard, in snatches of public conversation, on radio, TV, movies, computers, cell phones and a host of electronic devices and recordings. But Amadeo no longer hears his own language. When he speaks, his words fall on silence — and no one responds. Does that ring a bell?

In the United States, we hear many different languages spoken, but our first allegiance, our primal identity, our ability to communicate with others, is inextricably linked to our first language, whether it is English, Spanish, Italian, Japanese, Chinese, Vietnamese, German, Russian, Swedish, Dutch, Hebrew, Arabic, Swahili, Samoan, or one of countless other languages that make up our uniquely diverse nation. And some of us also speak a distinctly unique dialect of a particular demographic group.

Those of us with severe disabilities, for instance, speak Disabledese. Certain words or expressions yield their complete meaning only to others like us who also speak Disabledese. When we use words like “wheelies” or “crips,” their connotations transcend the literal meaning of the words or phrases. These words are rich with innuendo and shared meaning. But the fullness of their meaning is only appreciated by other members of our cultural tribe. The great majority of inhabitants of this nation have never spoken Disabledese, nor will they ever.

It is no doubt a monumental stretch to compare our sense of isolation with that of Amadeo Garcia Garcia, but we do share certain characteristics that make true communication with others outside our tribe difficult and, at times, seemingly impossible. Our specialized vocabulary is at once unifying and divisive. At best it creates a sense of community among us; at worst it erects boundaries that separate us from the mainstream.

Like Trump’s proposed wall on our southern border, purpose is everything. If our purpose in speaking Disabledese is to enforce borders, it will have an isolating effect. On the other hand, if we make a real effort to translate our specialized dialect into friendly terms and make it more easily understood by others who do not speak it, we break down the great wall, and we invite others into our world, our personal space, our lives.

Now is a critical time for those of us with disabilities to reach out to people who so often misunderstand and unconsciously limit our participation in the evolving national culture. Are we willing to help them understand and appreciate our uniqueness as part of the greater “we,” not the marginalized “them?”

“Our specialized vocabulary is at once unifying and divisive.”
An actor, director, educator and writer, Regan Linton is also artistic director and acting executive director of Phamaly Theatre Company in Denver. She was recently honored with the True West award for Colorado Theatre Person of the Year 2017. She has performed professionally with Oregon Shakespeare Festival, Mixed Blood, La Jolla Playhouse, Pasadena Playhouse, Big-I, and Phamaly, among others. She is a leading voice for diversity and inclusion throughout the national theater community. She is also an adaptive swimmer, golfer and yogi, and enjoys traveling, new adventures and challenging the status quo. Visit her website at reganlinton.com.

Mark Mathew Braunstein became a T12 paraplegic from an unskillful dive in 1990. Lucky him, his injury and recovery were made into a short TV documentary (youtu.be/96EhHzN6RoI). After 30 years as an art librarian and art curator at Rhode Island School of Design and then at Connecticut College, he retired to contemplate his navel as well as other people’s art and literature. A frequently published photographer, he is shown here photographing the ramp at Vermont Studio Center. You can view his nature photography and read his eight previous articles for New Mobility at MarkBraunstein.org.

Cindy Otis served with distinction as a CIA security analyst and manager between 2007-2017 on some of the top U.S. national security priorities, including a tour as an intelligence briefer at the White House. Prior to the CIA, she worked as a public affairs officer for the U.S. Army. Since leaving the federal government, she has written on important political and national security issues in publications like The New York Times and Teen Vogue. She holds a master’s in international relations from Boston University and a bachelor’s in international politics from Brigham Young University.

Want to contribute to New Mobility? Please send queries and manuscripts to Ian Ruder: iruder@unitedspinal.org
"One topic that is not discussed (and should be) is emergency evacuation of wheelchair users."

What About Emergency Evacuation?
This is a great article and well-resourced ["The Unfriendly Skies,” December 2017]. One topic that is not discussed (and should be) is emergency evacuation of wheelchair users. Current procedures are based on a study conducted in a B727 in 1977, an airplane that is not in service any longer. In 40 years much has changed — from the number of passengers crammed into airplanes to increasing numbers of people with disabilities enjoying air travel. And aircraft seating configurations today have much less space between rows, making rescue challenging for anyone, irrespective of mobility issues. I hope to raise awareness that current procedures are woefully inadequate for disabled persons to have the same chance to survive an aircraft emergency evacuation. See adapts.org for more information.

Robin Wearly
NewMobility.com

No Accountability
I, too, have dealt with an airline crew’s uncaring handling of my wheelchair during my last trip. It was the same situation mentioned in the article ["The Unfriendly Skies"]. I saw the crew member lift my manual chair up and slam it on the conveyer belt. I got so heated I started banging on the window, yelling and cursing. Of course they didn’t hear me, and I also looked like a crazy person to the other passengers, but nobody understands unless it is you. Luckily, nothing was wrong, but it infuriates me because it takes so long to get a repair done. I rely on my wheelchair every day to get around. When someone doesn’t give a crap about their job or others’ belongings, it really pisses me off, especially when they are not held accountable.

Melissa Veale
NewMobility.com

Management Necessary
My partner works for American Imaging Management (now known as AIM Specialty Health), so I shared your editorial with him ["Waiting for Care, Not Management,” Bully Pulpit, December 2017].

It’s important to recognize why [health care management] company exists. Yes, of course, insurance companies are trying to minimize their costs. But also be aware that there are doctors who run practices for their profit and not for the care of the patient. Some purchase their own MRI facilities to use as money mills, sending as many patients there as possible for injuries that don’t require this testing. Also, some tests do carry risks, so it is important to be sure that they aren’t done repeatedly or unnecessarily. …

Which isn’t to say I disagree with your main point. Those who do need tests get delayed while dealing with these issues. The great majority of requests do get approval. But the number of requests has gone down by a third since companies like AIM came into being. Like it or not, fraud exists. Sadly, in the U.S., health care is a for-profit industry, and so the focus is often on dollars more than health. I wish my partner’s job wasn’t necessary, that there was no waste or greed in health care. Ideally, profit should be based upon wellness, not illness, so that everyone’s incentive is on your good health.

Vince DiFruscio
NewMobility.com

ALS Resource
Many areas have ALS Association loaner closets that will gratefully accept working power chairs to lend to PALS ["Safe Disposal of Unwanted Items,” Everyday Advocacy, December 2017]. Also, Hoyer lifts and manual chairs as well. Check out www.alsa.org/community/chapters.

Laurie Gelb
NewMobility.com

Will Miss Tiffiny Carlson
So sorry to hear that Tiffiny is no longer doing SCI Life. I always look for it when reading my copy of NM. Say it ain’t so!

Kathy Dunn
NewMobility.com

Correction: In January’s “Leaning into the Ogo” story, information concerning sales and support should read: For inquiries, demos, sales and support, Ogo has an expanding network of Ogo agents, including Living Spinal. All are listed on ogotechnology.com under Agents.
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HOW THE TAX OVERHAUL COULD AFFECT THE DISABILITY COMMUNITY

Congress passed sweeping tax overhaul legislation on Dec. 20 that could have serious ramifications for the disability community, and President Trump signed the bill before the calendar year’s end.

Named The Tax Cuts and Jobs Act, the reform contains the largest reduction in the corporate tax rate in U.S. history, going from 35 percent down to 21 percent. Supporters say the across-the-board tax cut will stimulate economic growth and boost U.S. wages. Opponents say it is a giveaway to large corporations and the wealthy. The Joint Committee on Taxation, a nonpartisan congressional committee, released a preliminary estimate that the final bill would add $1.4 trillion to the deficit over the next decade.

Disability advocates are concerned that existing disability programs and services will be cut to pay for the massive deficit. “Several Republican lawmakers, including House Speaker Paul Ryan, have said they will be looking at cuts to entitlement reform in 2018 to help pay for the bill,” says Alexandra Bennewith, vice president, government relations for United Spinal Association. “They will propose cuts to Medicare, Medicaid and welfare programs next year — programs on which many in our community rely for their survival and independence.”

The legislation also repeals the enforcement mechanism of the Affordable Care Act’s individual mandate, which compels all Americans to obtain health insurance or pay a penalty. The repeal is expected to significantly raise private insurance rates for those with pre-existing conditions.

In a letter to senators, the

GOING THE EXTRA MILE

EPIC FUNDRAISING JOURNEY

On Dec. 5, approximately 15 months after he set off from Prudhoe Bay, Alaska, Ian Andersen, 25, completed an epic fundraising effort for United Spinal Association. He cycled some 15,000 miles from above the Arctic Circle to the southernmost city in the world, Ushuaia, Argentina, to help raise more than $22,000 for the organization.

The seed had been planted by Ian’s uncle, Bret Andersen, who did the same trip in 1986. While Andersen was enrolled at the University of Southern California, his best friend, Natalie Fung, was hit by a drunk driver while riding in a taxi, sustaining a cervical spinal cord injury. Fung and Andersen both learned of United Spinal’s advocacy and support work through a mutual friend. When Andersen began to contemplate retrace his uncle’s journey, he decided to dedicate the fundraising to United Spinal, a cause he believed in.

“The money aspect was good. I don’t think I changed the course of all spinal cord research … but I think I did as much as one guy can do,” Andersen says. But the real benefit was the dialogue it opened with people all over the Americas. “It makes the experience even better when you have a reason, a story, a cause. When people ask you why you’re doing this, it opens up a whole conversation with the people you meet.”

Andersen carried all the gear he needed to live and camp on his bicycle. Being able to easily connect with people was a huge benefit on a trip where he was often reliant on the kindness of strangers to have a place to sleep each night. “Depending on which country you were in, you could ask a restaurant, family, firefighters or farmers with land if you could camp on their property, and every time they’d say yes,” Andersen says.

He’s only been back in the United States for a few weeks, recovering at his parents’ home in Minnesota, but Andersen already has his sights set on more journeys. “I’ve cycled across two continents now, and I kind of feel like I can’t stop at two. I’m in too deep now to stop, I’ve got to cycle across the other four.”

Follow his continuing adventures at: Instagram.com/ridewithian

FOR UNITED SPINAL
Several provisions in current tax law directly affecting the disability community and that had been on the chopping block in either the House or Senate version of the bill were ultimately retained. These include:

- The medical expense deduction, which allows individuals with high out-of-pocket medical expenses to deduct those costs. Current law allows deducting medical expenses in excess of 10 percent of total income, but the new law will lower that threshold to 7.5 percent.

- The Disabled Access credit, which helps small businesses comply with the Americans with Disabilities Act by removing architectural barriers, providing auxiliary aids and services, or making reasonable accommodations to ensure equal opportunity for disabled employees.

- The Work Opportunity tax credit, which provides businesses with a federal tax credit for hiring people with disabilities, as well as others, including unemployed veterans. The current tax credit for hiring a person with a disability can be as high as $2,400 for a business.

Given that many of the potential effects of this legislation are still unknown due to the haste with which it was passed, Bennewith says the disability community must keep a close eye on Congress in 2018. “It is United Spinal’s job to remain vigilant on behalf of our membership and the broader disability community whatever 2018 holds for us.”

**MARK BOATMAN: 1975-2017**

New Mobility contributor Mark Boatman died on Dec. 8 of complications related to Duchenne muscular dystrophy. In addition to writing for NM, Boatman was published in Quest magazine and built a reputation as an effective disability rights advocate. He was 42.

In 2003 Boatman began using a vent. Under North Dakota Medicaid rules, he was using “skilled nursing,” thus no longer eligible for home-based attendant services. “The only option for me was a nursing home,” said Boatman in an interview with ventusers.org. “It was hell. The nursing home told me when I could shower, when lunch was going to be, and when I had to be in bed. And ... there was just no privacy. I got very depressed.”

Fortunately he met Theresa Martinosky and Dustin Hankinson through an MD support group, and the couple moved Boatman to Missoula, Montana, in 2006. The three became roommates, with Martinosky providing attendant services for both men.

Independent once more, Boatman earned a bachelor’s degree in journalism from the University of Montana in 2012, graduating with high honors. “I had been watching his posts on social media for a while, waiting for him to graduate,” says Josie Byzek, NM managing editor. “I was impressed with his intellect and his insight on a broad range of disability issues and wanted our readers to benefit from his talent.” He became NM’s primary news writer from 2012 to 2016, when he cut back on assignments due to health problems. He wrote blog entries and features on subjects ranging from outdoor recreation to emergency planning.

Boatman also wrote “Buying a New Home” for NM, about the house he, Martinosky and Hankinson purchased and made accessible in 2015. The family and their seven pugs happily lived in their new home until this past May 16, when Hankinson passed away, also from complications of Duchenne.

“No matter how much time you spend with those you love, on the day they leave ... that time will never seem long enough,” wrote Martinosky on Facebook about Boatman’s death. “Tell your partners, family, friends and pets how you feel. Hug someone, share a smile, spread some love and when you do, think of Mark and smile.”

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

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

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.
Q. The power in my apartment building went out yesterday, for about the fifth time in the past three months. It came back on this morning, but our elevator still does not work. This building has a parking garage on the ground floor and the accessible apartments are located on the main floor above it, so people who use wheelchairs or other mobility devices need the elevator to access the main floor. The past two times the power has gone out, the elevator was out of service for about five days — trapping the wheelchair-using and elderly residents, like myself.

I have multiple sclerosis and require the use of a power wheelchair, so walking or crawling up and down stairs to access my home is not an option. We have called the building manager several times whenever the elevator has been out of service, but nothing happens for hours, sometimes for days. Because we are simply renting or leasing our apartments, we have no homeowners association to represent us formally. What can we do to expedite this repair? Who can we contact about this situation, and what can we expect to happen afterwards? Are there laws or regulations that require these types of buildings to be accessible?

— Feeling Trapped

P. Property owners receive building permits based on their compliance with state building codes and federal architectural guidelines, with the expectation that a building will be maintained in that condition throughout the life of the building. When property owners fail to maintain those features, they are obviously out of compliance with whatever law governs; in your case it would appear to be the Fair Housing Act and possibly state disability civil rights laws of a similar nature.

The ideal situation is when the property can be designed and constructed with level access to the building and dwelling units. There are exceptions made for buildings like the one where you are living that have parking or retail spaces below the lowest level of the apartments. In those cases, it is permissible to have an elevator as part of the accessible route, but obviously that route is no longer accessible if the elevator does not work.

The U.S. Department of Housing and Urban Development has the primary responsibility for enforcing the Fair Housing Act and its amendments. They count on local building officials to assure that newly constructed facilities are constructed in compliance with applicable building codes. It has been over 20 years since the Fair Housing Accessibility Guidelines were adopted, and most state building codes have been updated in line with those guidelines.

HUD takes action on complaints they receive from those who have been discriminated against for a variety of reasons, including disability. HUD has offices throughout the country that can assist with filing complaints if needed, and the complaint form is also available online. Filing a formal Fair Housing discrimination complaint is a process that can take months, and may end up in a courtroom before it is concluded. Because of that, I would recommend that first priority be given to actions that can be taken by you and fellow residents at the local level.

Whenever these incidents occur, be sure to generate a letter to the management company, preferably signed by as many of the building tenants as possible. If that doesn’t stop these incidents, file repeat complaints with HUD so they will understand the serious nature of the situation. Contact the local police chief, fire marshal or fire chief and city manager; they will understand that they need to be prepared to assist with evacuations should an emergency occur in your building. Finally, emphasizing that this is a public safety issue, let the media know too; they often appreciate human interest stories to fill in their newscasts. Good luck, and I hope your elevator stays operational.

Resources
- Department of Housing and Urban Development, hud.gov

“Whenever these incidents occur, be sure to generate a letter to the management company, preferably signed by as many of the building tenants as possible.”
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Request a free demo today at easystand.com!
Most gardeners and beach bums agree nature has a restorative effect, whether it be from plunging our hands into the soil or plunking our butts on the sand. But what if being in direct physical contact with the earth actually makes us healthier?

That’s the big idea behind grounding, also called earthing. The theory is that our wired environments’ positive electrical charge (AC) isn’t good for us, so we should connect directly to the earth’s negative field (DC). And if we can’t get outside to walk barefoot, then we can buy a grounding mat or sheets or pillow cases or any other number of similar products that are plugged into a grounded electrical outlet.

Sounds woo, but it works, says Julienne Dallara, a para since contracting transverse myelitis 21 years ago. “I tend to be cynical, but the first thing I noticed since using a grounding pad is that the swelling in my feet went down,” and she adds that sleeping with her legs on the pad seems to help her spasms.

But what made Dallara, a salesperson for the Abilities Expo, a true believer was the time she forgot to take her mat with her to a show. “I woke up feeling sluggish, looked down, and sure enough my feet were all swollen up again,” she says. “I called the Grounded Beauty company and got an emergency overnight package of a grounding mat, slept better and the swelling went down. I always thought, ah, maybe it’s the placebo effect. Maybe I believe it because I want to believe it, but that was the absolute black-and-white test for me.” Now she keeps a mat under her feet during the day and sleeps on another one at night.

“It’s not a bolt of lightening, it’s not, like, zing,” she says. “You’re sitting there and you feel like, hmm, I’m getting more energy, I feel good. It’s definitely more subtle.

Dallara believes in earthing so much that she has talked Grounded Beauty into putting up a booth at the Los Angeles Abilities Expo. “They will have some pads you can put on your hands. You can sit down, relax, and really experience it right then and there,” she says.

An introductory article that includes citations to existing studies can be found here: bit.ly/2DrFnsj.

---

**GROUNDING EXPLAINED**

**MINDFULNESS MEDITATION**

“I find having a spinal cord injury in this fast-paced 21st century can be overwhelming and exhausting to my body, mind and spirit,” says Paralympian Candace Cable in the intro to “Mindfulness Meditation,” her two-minute-long video for the Reeve Foundation. “By integrating some slow-paced practices I’ve been able to sit back, unwind and enjoy the ride.”

Mindfulness meditation is the art of focusing on the breath as it moves in and out of the body, explains Cable. When first trying it out, she set a timer for five minutes at different times of the day. Now, she meditates an average of 30 to 40 minutes, usually in the morning. Her video offers simple posturing suggestions and shares a breathing exercise for relaxation. To watch, go to christopherreeve.org/living-with-paralysis/health/depression/video-mindfulness-meditation.

Injured in 1975, Cable pioneered wheelchair racing in the ‘70s and ’80s and won 12 medals in nine Paralympic Games. Follow her blog at christopherreeve.org/blog/life-after-paralysis.

**UNITED SPINAL WEBINAR: SEXUAL SUSTAINABILITY AFTER SPINAL CORD INJURY**

Dr. Marcalee Sipski Alexander wrote the e-book on sexuality and SCI — literally. It’s called Sexual Sustainability: A guide to having a great sex life with a spinal cord disorder. The book is available for $4.99 from Amazon, but if you download it on Valentine’s Day, it’s free. “I want to share what I have learned through 30 years of research and education on the topic with as many people as possible,” says Dr. Alexander, a clinical professor at University of Alabama, Birmingham’s Department of Physical Medicine and Rehabilitation.

Her desire to share her knowledge directly with those who will most benefit from it is also why she is presenting a free webinar for United Spinal Association on Feb. 22 from 3 to 4 p.m. Eastern time called “Sexual Sustainability After SCI.” To sign up, go to unitedspinal.org/webinars.
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FEBRUARY 2018
**CRAZIEST THING I’VE DONE:** I had two guys help me go to the top of Machu Picchu in my chair. Once you got all the way up there, looking down was pretty scary.

**FAVORITE SPORTS:** I love water skiing and jet skiing, but sled hockey is my favorite. The adrenaline and the competition keep me coming back.

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**Rewalkin’ that Walk**

As a “ReWalker,” Marcela Turnage gets to do two of her favorite things. One, show off the ReWalk exoskeleton and talk about how it has changed her life. Two, travel around the country and the world.

Turnage, a T12 para since a 2002 car accident, is a passionate spokeswoman for ReWalk’s technology. “The ReWalk has done beautiful things for me,” she says. “I can’t say enough about it.” Since she first started using the exoskeleton in 2014, Turnage has enjoyed multiple benefits, including a reduction in pain and improved bladder control. Last year Turnage developed an even deeper appreciation as the ReWalk helped expedite the healing of a broken tibia. “Before I wasn’t as loud about the benefits, but now that I see the proof of how it helped me and how it really helps me to get better and heal my bones, I’m all over it,” she says, “ReWalk, ReWalk, ReWalk, ReWalk! I cannot breathe without ReWalk.”

The broken tibia didn’t stop Turnage from a whirlwind travel year that would make even the most frequent of frequent flyers jealous. In 2017 alone, she traveled all over the U.S. and visited Spain, Argentina, Peru, Germany and the Netherlands. Through her travels, she met countless doctors, researchers and dignitaries, including the Real Madrid soccer team, the president of Israel, the king and the prime minister of Spain and the vice president of Argentina.

Meeting the vice president of Argentina, Gabriela Michetti, had special meaning for Turnage, as she is also a wheelchair user. “It was incredibly meaningful to see another female wheelchair user who has risen so high in politics,” says Turnage, who is of Peruvian descent. “I got to share a meal with her and show her how the ReWalk works.”

Argentina provided a first-hand example of the difference an outspoken wheelchair user can make. “It often seems like so many nondisabled politicians pay lip service to disability issues,” says Turnage, “but [Michetti] has shown a real commitment to working with people with disabilities and advocating for a more accessible society.”

Turnage has not talked with Michetti since the meeting, but keeps up via Instagram. “I asked her if we could meet up some
other time to talk more, but she is so busy," she says.

Traveling abroad has reinforced to Turnage the need for continued advocacy to improve accessibility. "In Europe, everything seemed inaccessible," she says. "Even something as simple as going to the bathroom was a nightmare."

As life-changing as the ReWalk has been for her, Turnage's travels have inspired her to dream even bigger. After being carried to the top of Macchu Picchu on a recent trip, she dreamed of a next-level exoskeleton that would give her the freedom to explore wherever she so desires. "The ReWalk is great, but I would love to go hiking," she says. "The world is so beautiful, but there are so many places you just can't go in a chair. It would be nice to have an exoskeleton that let me do whatever I want. That would be awesome."

It will be tough to top 2017 when it comes to adventure, but now that Turnage's tibia is fully healed, she is excited about 2018. She is planning to live abroad for a month or two in the summer and hopes to keep traveling and working to help others with spinal cord injuries live their lives to the fullest.

LIFE GOALS
Helping Others Adjust

No matter how busy her travel or work schedule, Marcela finds time to be a peer mentor at local hospitals. She often shows up with nothing but a smile, a United Spinal New Beginnings backpack and an open ear.

Getting people with new injuries to talk can be hard sometimes, because they don’t always want to accept their new reality. But there is real value in hanging out with, or getting to know, people who have gone through the same things you have. When I visit, I make a point of not giving any advice at first. If you go in and are pitying them or talking all about your own accomplishments, you’re not really helping. No one wants to hear any more advice. They’re probably still grieving. They’re still mourning. So I go, smile, be positive and ask, ‘How can I help? Just let me know.’ I want to give them a good impression. My goal is to be a friend, someone who will listen. They need to know they can be happy and live their lives in a wheelchair. It’s not the end of the world.

KEY TO SUCCESS: I’ve always been an independent woman. I never think of my life as being hard, because I know it could be worse.

WHY I JOINED UNITED SPINAL: I joined because I wanted to help people with new injuries as a peer mentor. Being a member is amazing because it allows me to meet so many people around the country and to get more involved, both locally and nationally.
In Florida, five days before Hurricane Irma struck last September, home health aides stopped coming to the home of wheelchair user Felicia Jaffe, 62. After calling every organization she could think of for help, she used all of her money — money budgeted for her mortgage and other bills — to pay for private aides to stay with her during the hurricane. “I was desperate,” she says.

Things didn’t improve much after the hurricane blasted through. While the state set up multiple sites for people to apply for aid from FEMA, Jaffe was unable to take advantage. “Because of my multiple sclerosis I was unable to endure the crowds and long lines and I had no transportation,” she says. No accommodations were made or thought given to help people who were elderly or disabled, Jaffe explained. “It was a total disregard for the most vulnerable.”

Luckily for Jaffe and many others with SCI/D who were affected by one of the most devastating hurricane seasons in history, United Spinal Association was there. Jaffe applied for and received a relief grant from United Spinal. The grant helped cover the money Jaffe had used to hire emergency aides and helped her get closer to getting her life back. “I want to thank United Spinal for being at the forefront of obtaining services for all those affected, not only during the storm, but continually focusing on tangible services that directly impact the quality of our lives,” she says.

WHERE RECOVERY STARTS

The microgrants are one part of a much broader hurricane relief effort on behalf of the organization at both the national and chapter levels. Those efforts started almost immediately in the wake of Hurricane Harvey striking Texas in late August.

The disability community in Houston lost vital equipment and medical supplies, according to Rafferty Laredo, an occupational therapist and the executive director of United Spinal Association Houston. Houston mobilized several major shelters to house thousands of displaced people, and Laredo spearheaded United Spinal’s disaster relief efforts there.

“Individuals affected by disability in these shelters were in desperate need of mobility devices,” Laredo says, “like wheelchairs, walkers, and canes, as well as medical supplies like catheters and other incontinence management items. We provided over 400 donated wheelchairs to these facilities. We received hundreds of wheelchairs, thousands of medical supplies, and were supported by dozens upon dozens of volunteers.”

After watching United Spinal’s vital work in Houston, the Craig H. Neilsen Foundation, an organization dedicated to improving the quality of life for those with SCI, offered United Spinal a $500,000 grant to help people with SCI/D pay for unexpected costs.
from the hurricanes. With the grant, United Spinal was able to help Jaffe and many others start to recover from the devastation.

HURRICANE HARVEY
(Aug. 17-Sep. 1, Peak 130 mph)

Angela Wrigglesworth couldn’t have expected that she would find herself applying for one of the grants as Hurricane Harvey bore down. Wrigglesworth, 40, has a form of muscular atrophy and uses an electric wheelchair. She and her fiancé had decided to get supplies and hunker down in their home near downtown Houston. “I’ve lived in Houston my entire life, so hurricanes weren’t foreign,” she says. “No one in our area was leaving. Even though we live in an area that floods, our house has never flooded.”

The couple woke up early Sunday morning, August 19, to a river of water in front of their house. “We turned on the news and saw people up on their roofs getting rescued not far from us. That’s when we knew we needed to go,” she says. They tried to call 911, but could not get through. Other emergency management services told Wrigglesworth to get on her roof. Wrigglesworth took to social media to ask for

Every time hurricane season came and people predicted the worst, we thought, ‘That’s not going to happen.’ Forecasters always announce something, but nothing bad happens. But this time something that we could never have imagined happened. It was unmanageable: bad, bad, bad.

For over a month after the hurricane we didn’t have any way to communicate off the island and we didn’t have access to food and water. All we had was junk food and canned food. Even now, months later, I think only 40-50 percent of people have power and maybe 60 percent have water. Imagine trying to take a shower with just a gallon of water — that’s hard for anyone, but especially for wheelchair users.

For the members of our chapter who need attendants and medical or government services, for the first month there were almost no options. All they had were friends and family. Many people who needed help were forced to just lie in their houses, developing pressure sores and other problems. They had no way to get good food because they had no one to get them up and take them places.

If you didn’t have enough medical supplies on hand, there was no easy way to get more. We had to share our catheters amongst each other.

With no electricity, power wheelchair users often had no way to recharge their chairs. Some businesses and people with generators let others charge their chairs, but thing is, many people didn’t have a car to take their wheelchairs to the generator. And many more people simply didn’t have any gas to drive their cars. If you didn’t have gas to take your wheelchair to a place where there was a generator, it was very difficult for you to go anywhere. It got so bad that people were trading supplies for access to generators.

Even today, we still don’t have a consistent means of communication. Most of the radio and cell antennas were blown over or damaged. We just got power back a week ago where I live — it had been over 90 days! Thanks to United Spinal, our chapter got a number of power inverters so members could use car batteries to recharge their chairs and electrical stuff. Our members also have applied for grants from United Spinal to help them pay for the many costs they’ve incurred.

The whole experience has reinforced the need to be prepared. We need to think three to four months in advance, in terms of food and medical supplies. And manual chairs are a must — even if you don’t normally use them — because you can’t know how long you’ll be without power.”
help when water started seeping into her house later that morning.

Her post went viral. A few hours later, a team of firefighters arrived, but they determined they could not transport her and her wheelchair safely. Later, three former Marines in a canoe paddled to her house, but there was too much risk that the canoe would tip over in the rushing water. “Being medically fragile, I was worried about being transported and transferred safely,” Wrigglesworth explains. “There were these moments of relief because we thought we were being rescued, but then these letdowns when we realized it wouldn’t work.”

In all, it took six hours of trying before they were safely rescued. Two friends arrived with a snorkel Jeep that could drive into high waters and a 12-foot-long fishing boat that could accommodate her. Wrigglesworth’s wheelchair was damaged from the rain and her home is still being repaired from flood damage, but she considers herself lucky to have had so many people try to help. She plans to use the money she received from United Spinal to pay for hotel expenses she incurs while the damage to her home is fixed.

HURRICANE IRMA
(Aug. 30-Sep.12, Peak 185 mph)

Before the damage from Harvey could even be assessed, Irma became the strongest hurricane ever recorded outside the Gulf of Mexico and the Caribbean Sea. Just like Wrigglesworth days earlier, Yami Hernandez, 52, was forced to evacuate her home in Key Largo, Florida. She went to stay with her daughter further north, but had to leave her power wheelchair behind. Her power chair gave her the freedom to do things her manual chair could not, she says. After the hurricane, Hernandez returned to her home to find the entire first floor filled with three feet of water, mud, and debris from the hurricane. Her power wheelchair was ruined.

Hernandez says that if it was not for her daughter who helped clean out the first floor of her home in Key Largo, she would have had to abandon her home completely. She is still working to repair her home after the flood damage. Because of United Spinal’s grants, she was able to purchase a new wheelchair.

“My insurance really didn’t cover anything, and I can only do repairs to my home little-by-little because it’s so expensive. But I’m so grateful to have my ability to move around again with my new chair.”
**HURRICANE MARIA**
(Sep. 16-Sep. 30, Peak 175 mph)

The record hurricane season saved perhaps its most devastating blow for the island of Puerto Rico in the form of Hurricane Maria. With 175-mph winds, Maria would do over $100 billion in damage and take more than 500 lives.

In December, a team of United Spinal employees visited Puerto Rico as part of a larger community event for people with disabilities in San Juan. They handed out vital supplies, such as power inverters, food, solar lamps, and hygiene products, and helped people like Raymond Ortega Serrano fill out applications to receive grant money.

Serrano, 17, lives in a home that had been adapted for his wheelchair on the northeast side of Puerto Rico. “In the middle of the hurricane, trees began to fall on top of the roof of my house and there was a terrible noise,” he says. “Water started pouring into the house. Things started to collapse. There were a lot of cement structures that could have fallen on top of us.”

Thinking the house might collapse, Serrano and his family drove in blinding rain and battering 170 mph winds to his grandparents’ home nearby to take refuge. Serrano said after the hurricane, there were trees, posts, and cables all over the streets. “When I saw the destruction, I felt like I was in another country,” he said. Serrano has not been able to move back into his home for fear it will cave in. Like many, he still has no electricity or access to water and has not been able to attend school.

“We have not yet recovered,” Serrano says. “We have had to spend a lot of money on generators, getting basic food stuffs, health services, and other things. I don’t want to lose my beloved home that was made for my mobility needs. We got by, making so many sacrifices. My biggest desire is to return to home and have my space and my accommodations, like my adapted bathroom.”

United Spinal board member Andy Hicks was on the team that went to Puerto Rico. He said that assistance to the people of Puerto Rico has only been a Band-Aid solution, and the people who need the most help cannot get into San Juan for assistance. “One woman, who has a high cervical injury, told me she had to move up to the second floor of her uncle’s home because of the inundation of water. She has to be carried down every day to go to work. Another woman who cares for her disabled granddaughter has half a roof. She said when she wakes up, she often puts her feet into water that is on the floor from rain that night.”

To learn more about United’s hurricane recovery efforts, visit unitedspinal.org.
To get started, there are a couple of things you should know about Christiaan “Otter” Bailey. The first is that 37-year-old Bailey knew how to shred before his spinal cord injury, and he knows how to shred now. Bailey started surfing and skateboarding when he was 4 years old, and was sponsored in both sports at the ripe old age of 12. Today, just over a decade after he broke his L3-4 vertebrae while filming a video segment for Santa Cruz Skateboards, he is still a sponsored surfer and (chair) skater, traveling the world, performing at stops on the World Surf League’s World Championship Tour of Surfing and dropping into quarter pipes from California to Indonesia.

That Bailey shreds the world is cool, but what makes him unique is how much good he does in the process. For much of the past decade he’s been working with Global Mobility, a nonprofit that delivers wheelchairs to kids and adults who need them all over the world. Bailey is part of the process that helps get, not just a wheelchair, but the right, properly fitted wheelchair to individuals that likely have never had such a thing, offering a key step toward independent mobility. In addition, he founded and runs Ocean Healing Group, a nonprofit that brings kids with physical disabilities to a surf camp in Costa Rica, using adventure to help families transcend the rehab mindset and develop skills and confidence to last a lifetime. For Bailey, adventure is about a whole lot more than just having fun.

WHAT’S IN A NAME?

The second thing you should know is that Bailey feels fortunate to have the nickname “Otter.” Why this is so goes back to the time and place he grew up: Santa Cruz, California, in the late 1980s. It was a childhood that underpins the hard-charging style that, paralysis or not, Bailey brings to his life’s myriad of adventures.
“Santa Cruz back then was gnarly. Unless you’re a surfer from Venice back in the ’70s, I don’t think you can really compare it to any other place in California. It was cold water, big sharks, and even bigger waves. If you did well and you showed the proper amount of respect, then, as a kid out there, eventually you’d be invited to The Point [where the best surf in Santa Cruz was located] and you’d earn a nickname.”

“I had a bad habit as a kid of going free-diving out at Steamer Lane and I’d go rake abalone and oysters off the reef. I’d float on my back and collect my catch and [Shawn ‘Barney’ Barron, a legendary surfer from Santa Cruz] said, ‘Oh my God, that’s the biggest fucking otter I’ve ever seen.’ The name stuck. I feel pretty fortunate to have that nickname. Most nicknames in Santa Cruz are not very complimentary, you have ‘Tick’ and ‘Flea’ and ‘Rat Boy’ and ‘Condor.’ So I was stoked to get the name I did.”

“Restless by nature” is what Bailey calls himself. His restlessness is unsurprising, given his current occupation and early life. As a teenager, he moved with his father to Paris and spent the next decade of his life traveling around Europe and North Africa. When he was 20, he moved to Morocco to help a friend run a surf expedition company that took surfers to some of the least explored waves in the world.

“A feather in the wind” is what Bailey calls himself. His restlessness is unsurprising, given his current occupation and early life. As a teenager, he moved with his father to Paris and spent the next decade of his life traveling around Europe and North Africa. When he was 20, he moved to Morocco to help a friend run a surf expedition company that took surfers to some of the least explored waves in the world.

“Imagine some of the biggest waves in California except with no crowds. Things have changed a lot in the last 17 years, but back then it was the Wild West. There were a few adventurous surfers who would go out there and want to go on these massive expeditions on the coast, and we’d try to facilitate that as best as we could. The best thing I could equate it to is kind of like Law-

**OTTER GLOSSARY**

- **Drop** – To start rolling down a ramp, so named because many ramps have a vertical top face, so entering requires a drop.
- **Gnarly** – Can be used for a variety of purposes, usually some combination of dangerous, rough and extreme.
- **Handles** – Located at the front of an adaptive surfboard, placed there so a prone surfer can better control the board.
- **Quarter pipe** – A type of ramp often seen in skate parks with the shape of a quarter circle.
- **Ripping** – To be doing something very well.
- **Shaper** – A person who custom shapes surfboards.
- **Shred** – To attack what you’re doing with skill and aggressiveness. “He just shredded that wave.”
rence of Arabia. We’d have some Land Rover Defenders and just pile ’em full of surf boards and equipment and whatnot and just strike out for a month or two. It was some of the best times of my life, a really good way to spend my early 20s.”

These days Bailey wanders the globe, surfing, putting on WCMX clinics, and often working with Global Mobility, which was founded by a longtime friend. “They’ve distributed about 150,000 wheelchairs to 38 countries, and periodically throughout the year they’ll hold seating clinics in various countries,” Bailey says.

While I was interviewing him, Bailey was helping to load a container full of wheelchairs bound for Indonesia. Included were two of Box Wheelchairs’ WCMX chairs for riders on the island of Java. Bailey will be meeting the recipients in a month or so when the container arrives to help set them up in their new rides and instruct them in the fine art of ripping. Bailey has been to Indonesia before with Global Mobility, and just last year he had an experience there that he says “truly encapsulates why I do what I do” — getting a wheelchair set up for a young boy, Raihan, who had never had a wheelchair, and had previously been carried everywhere by his family.

“Upon first glance, Raihan wasn’t quite sure what to make of it. … Then came the magical moment when he was got into his new ride and took his first push. The change in his expression, from a frown to a grin, was immediate and awe-inspiring.”

THE MORE THINGS CHANGE …

Bailey was paralyzed while skateboarding in 2006, an injury that appears to have had little more than a minor impact on his pursuits. It took exactly three days after he got out of rehab for him to make it back to the skate park.

“There’s a memorial skate contest that’s always held at Scotts Valley Skate Park [in Santa Cruz]. I was out there in my chair, an Invacare A4 with a high Jay 2 back, you know, absolutely not designed for any action or performance or skating, but I took my first little drop on a quarter pipe and kind of came to the realization that it was possible to skate.”

His return to surfing came but a week or so later, in a scene that would’ve fit nicely in Point Break. “Barney comes banging on my door at like 5 o’clock in the morning maybe a week and half, two weeks after I was out of the hospital, and I wake up out of this drug induced slumber and open the door and he’s like, ‘the surf’s pumping, we’re going out! I’m not taking no for an answer, get your suit on, asshole!’”

“So he transfers me into my chair and grabs my suit and I’m still sitting here in a turtle shell back brace. He grabs my 1978 Robert August pristine single fin off the wall and takes me out to Sewer Peak at Pleasure Point and pitches me into my first wave. From that point on I knew pretty much anything was possible.”

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Both WCMX and adaptive surfing were just in their infancy at that point. Aaron Fortheringham, the now famous “Wheelz” of wheelchair backflip and Nitro Circus fame, was taking his chair to skate parks out in Las Vegas, but he was about the only other person doing it. There were a few international paras and amputees who were surfing lying down, but hardly anyone in the U.S. For both surfboards adapted for use by riders lying down and wheelchairs capable of handling the demands of a skate park, the technology didn’t really exist.

“After that first skating session, I actually brought it [the Invacare A4] over to my boys at Santa Cruz Bicycles and we chopped the hell out of the frame, took a plasma cutter to it and just started thinking, geometry wise, what would be the most efficient design for WCMX. We welded it together, and it worked pretty good for a little while.”

It was a similar story with adaptive surfing. You could do it on a regular stand up surf board, but it wasn’t ideal. The board shapes, because they were designed to distribute the weight of someone standing up, limited the ability to ride big, difficult waves.

“When you’re lying down on a board, you can shift your weight using your handles back slightly and forward slightly, but it really forces you to start from scratch, with a blank piece of paper to address the board design from zero. You have to really think scientifically about how you’re designing the board and how to best use your weight and positioning and the abilities that you do have in order to squeeze the most amount of performance out of the board.”

As the equipment has advanced, so has the worldwide popularity of both sports. Last year’s WCMX World Championships featured athletes from across North America, Europe, Israel, and Japan, and adaptive surfing is on a path for possible inclusion in the 2024 Paralympics in Paris. The sport has been championed by and brought under the fold of the International Surf Association. Bailey has been closely involved with developing the competition system needed to make surfing a Paralympic-level sport. In 2017 the World Championships for adaptive surfing had 29 national federations represented by 109 competitors.

“I never knew adaptive surfing could get so big so quickly.”

EXHILARATING AND TERRIFYING

With the right board, there are few limits to the kind of waves that prone surfers can ride. “As long as you have a good crew, and a good shaper, and you train hard and you train right, pretty much anything is possible. There are a few waves out there that would be incredibly difficult for an adaptive surfer, but that certainly isn’t to say that they won’t happen in the future,” Bailey says.

Bailey regularly surfs his old Santa Cruz haunts, and has ridden big, dangerous, world-class waves all over the world — from Pipeline to Teahupoo’s. The kind of waves that Bailey doesn’t see himself capable of riding — Shipstern Bluff in Tasmania, and Cortez Bank in California, to name a couple — are the kind of breaks that make professional big wave riders shudder. In 2010, Bailey became the first adaptive surfer to ride Mavericks, a colossal wave just south of San Francisco that typically only breaks during cold winter swells. Depending on the swell,
it can range in size from 15 to 40 feet. If that’s tough to picture, imagine a three or four story building that suddenly breaks into a wall of water chasing you down the street.

Bailey describes riding Mavericks as, “the most exhilarating and simultaneously the most terrifying thing I’ve ever done. There’s something to be said for going down a wave at 40 mph, six inches from the water and having a mountain of water chasing you that weighs 100,000 metric tons. It was absolutely terrifying, but also absolutely, hilariously fun.”

SHATTERING PERCEPTIONS

One of Bailey’s favorite things these days is mentoring young adaptive surfers and WCMX riders, kids who’ve had a disability since birth or a very young age. Turning a young person’s self-image from a kid in a wheelchair to a surfer or a WCMXer can have an immediate and lasting impact. To that end, 11 years ago he started a nonprofit, Ocean Healing Group, with the aim of giving kids with disabilities their first taste of independent adventure.

“We have a surf resort down in Santa Teresa [Costa Rica]. Over the course of 10 days we bring kids in chairs, physically disabled kids, and we take them on an adventure. Our major focus is to give the kids a sense of independence and really kind of cut the umbilical from the parents so their accomplishments are theirs and theirs alone. We go zip lining over the jungle, we take quad rides through the jungle and up on the beach and over rivers and all this stuff. We take them surfing every day obviously, and fishing. Our volunteers are mostly comprised of ex-military, firefighters, police officers, swift-water rescue personnel, coast guard, life guards, things like that. They help us empower the kids to really take their skills and their attitude to that next level as far as not just being a kid in a chair, but being an adaptive athlete. That’s our main goal, to shatter preconceptions or expectations.”

The same thing goes with helping kids in chairs at a skate park for the first time. Teaching kids that they’re not as fragile as they’ve been led to believe is far more important than teaching them how to drop into a ramp.

“[People in the rehab world] basically treat these kids with spina bifida and some with cerebral palsy like they’re a cracked vase, and if they fall out of their chair they’re going to be shattered into a million pieces, where in reality it’s the exact opposite. A lot of these kids have gone through some incredible trials and tribulations in their lives and they’ve spent their entire life being in and out of the hospital dealing with surgeries and pain and, so they’re really a hell of a lot stronger than most people give them credit for.”

“When you get these kids involved in WCMX … within a week or two all of a sudden they’re racing up and down the hallways of their school and their parents are getting concerned phone calls from the principal.”

Bailey asks, “Would you stop a nondisabled kid from jumping a set of stairs or playing on the jungle gym? No, you wouldn’t. Don’t treat these kids any differently. They’re just having their own way of play.

“That’s one of the incredible things about the sport, there’s this rapid acceleration of maturation and growth, not just physically, but also emotionally because there’s that paradigm shift, where their perspective no longer is, ‘I’m going to fall out of my chair,’ but ‘I don’t care If I fall out of my chair, it’s all right, I can get back up and try it again.’ Reinforcing that confidence and that drive is really critical, especially for disabled kiddos in this day and age.”

ADVICE FROM AN OTTER

If there’s one thing that’s clear from talking to Bailey, it’s that for him, sports like WCMX and adaptive surfing aren’t frivolous pursuits but a means of garnering the skills and confidence to live a fuller life.

“For anyone who’s newly injured, I’d recommend occupying every aspect of every day with something different. Whether it’s just pushing down the street or doing something. Just to get out of the headspace of the could’ve, would’ve, should’ves of life. Because when you’re stationary, in one place, it becomes very easy to fall into the ‘poor me’ mindset.

“Don’t be afraid to get the hell out of your house and push your limits because that’s where the best adventures are always found. You’re not going to find any staying at home and playing Xbox.”

Besides being fun, Otter says adaptive sports like surfing and skating show that disability does not have to equal fragile.
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COUPLES WE LOVE

BY REGAN LINTON
Those of us who have adapted to a wheel-based life due to injury, illness, or other circumstances are overwhelmingly peddled the narrative that when it comes to sex and relationships our experience is somehow going to be “less than.” In movies, TV shows, magazines, books and pornography we are shown what sex and relationships are “supposed” to look like: normative bodies strolling hand-in-hand down an inaccessible hiking path with the sun shining through the trees. It’s flawless skin brushing up against rock hard abs with meticulously groomed eyebrows and genitals, and no hemorrhoidal skin tags. Phooey.

Occasionally, we get limited snapshots of what the experience as a wheeler is “supposed” to look like. The problem is, these narratives are usually written by people who don’t write from experience, but rather from conjecture. The stories are often stereotypical and limited, and rarely venture into the realities of intimate spaces. Where is the hot sex scene with the couple on a bed pad and a Hoyer lift hanging over their heads? If we never see it, then we don’t think it’s possible. But it is.

If you are a wheeling person who wants sex, or wants a relationship, it’s available to you. It might look different, but it’s there. Experiencing paralysis or using a wheelchair doesn’t diminish who we are as intimate or sexual humans. In fact, if we allow it, sex and relationships after a physical transformation can be “more than.” It can mean increased exploration, adaptation, and vulnerability. We have the potential to achieve deep and expansive intimacy in ways some non-paralyzed, non-wheeling folks will never experience.

For Gina, a 32-year-old C5-6 complete quad who lives near Phoenix, Arizona, being in a chair hasn’t resulted in any compromise or sacrifice of satisfaction. “So many people say ‘I can’t date because of my chair.’ It’s not the chair, it’s your attitude. Either you’re doing it wrong, or you haven’t found the right person.” She laments that “we have really desexualized people with disabilities — there’s a stigma to it.”

Gina was injured in a diving accident 14 years ago at age 18. She had been sexually active before her injury, and always had a strong sex drive. Following her injury, she was married for five years before divorcing. “We were just different people,” she says.

Following the divorce, “I was a slut!” she says, laughing. “I would do a one night stand and do my thing.” She joined Tinder, and was always entirely transparent about using a wheelchair. “I didn’t lead with my chair, and I’ve never had a problem [getting a date]. But then I was on Tinder looking for another hookup, and he stopped me in my tracks.”

“He” was 28-year-old Nick, her current boyfriend of two years. “First of all, he had a job!” she jokes. “And he was so funny in his profile and could communicate well.”

The feeling was mutual,” says Nick. “I was attracted to Gina the moment I laid eyes on her picture of her enjoy-
ing a cigar and scotch. To be honest I didn’t even realize she was in a chair even though it was in the picture.”

It took about two weeks for them to meet. “Instantly we had an attraction,” she says. Since he had never dated anyone in a chair, she found a creative way to start addressing questions. “I wrote him an erotic story and I outlined details like lifting me up, getting me undressed. He would write back and he could ask questions, and sometimes I would think, ‘I gotta address this.’ I recommend people writing — it’s so sexy. You’re reading a story and it’s hot.”

They were well-matched, with similar upbringings, a lack of nervousness or embarrassment with intimacy and senses of humor. “He’s hysterical, he’s got his shit together. He puts up with my shenanigans and puts up with me when I get drunk!” She laughs.

Gina’s straightforward approach appealed to Nick. “That was just the type of personality I was attracted to, the no nonsense lover of life,” he says. “I told her from day one that her chair and disability were irrelevant to me, I was attracted to her for her.”

His family immediately built ramps at their house and were intentional about including her, and they found mutual shared hobbies like cooking and playing Magic: The Gathering. “I’m a closet nerd,” Gina says.

The chemistry was just as palpable in the bedroom. “We have sex three to five times a week,” she says. It’s not the same as before her injury. “Before my injury, I would masturbate once or twice a day. And was the sensation better? Yes. Now it’s nowhere near the same sensation, and it’s not as easy.”

But she does still have sensation and sensitivity, and sex is infinitely more fulfilling than pre-injury. “Sex with someone with a disability is so much more intimate because your partner has trust in you — you have more of an emotional connection.”

There are important considerations, like counting on your partner to communicate openly, and for the ladies, using lubrication. “You need a partner who knows your body. For me, the sex is still ‘normal’, I just can’t stand up.” She enjoys a partner who has the physical ability to move her around. “We get creative. He’s so strong, and he can throw me around. I love being on top of him, and he can offer me support.” She also likes massage, “but that’s because I’m selfish!” she jokes.

As for positions, “I’m a lazy pillow queen — give me missionary, it’s so easy and it’s my favorite!” She also emphasizes the importance of foreplay. “We’ll watch porn, or I send him a naughty pic.”

When it comes to advice for others, she says people need to be open to things like toys. “Vibration can give you a different response,” she says. And for her, keeping caregiving separate from sex is a must. “He might help me get into bed, and if I need to cath [with a Mitrofanoff] he helps me with that. But morning routine? Hell no. My ex helped me every once in a while, and it screwed things up — it takes the sexy away, it takes away the mystique.”

Bedroom activities only add to their overall relationship, which Gina says isn’t in a rush. “He’s a good guy, he makes sure I’m OK,” she says. “Neither of us had a need to get married. But he’s everything.”

“Yeah, mornings take a little longer to get ready and yes, we put a lot more thought into arranging our travels,” says Nick, “but at the end of the day, I can’t imagine my life without her.”
Before Taylor became a C6 incomplete quad in a motorcycle accident, the 23-year-old Lincoln, Nebraska, resident admitted it was a bit of a “revolving door” when it came to the ladies, sometimes with a different girl every weekend. That didn’t end after his accident. “It was never a struggle,” Taylor says about his ability to connect with women from a chair. “I was realistic, and to be blunt, I could be an asshole. I just thought, GET OVER IT.”

Girls came to rehab and things would happen. During bed baths from female techs in rehab, he’d get reflex erections. And at first it was all reflex, as he had complete paralysis from the waist down. After two months, he could get some stimulation from touch, and then achieve arousal from thoughts. But it could be frustrating. He even got a prescription for a super-powered vibrator, but for the first year and a half it didn’t improve function.

“I had to put in way too much time,” Taylor says of masturbation. Within one year, he was able to achieve orgasm four times. “It was frustrating, but then I knew it could happen, and then I was more determined.” He took a use-it-or-lose-it approach. The more he did it, the more successful he was.

Enter Hanna. She was working as a tech at the rehab hospital, and was a coworker of Taylor’s friend. He was younger by five years, and she had sworn she wouldn’t date the young ones. Hanna was also more of a relationship gal — she didn’t practice Taylor’s same “revolving door” approach. But she was looking for heart and personality, traits she found in Taylor.

“I got questions like, ‘Is this what you really want?’” says Hanna. “And I thought, ‘I don’t know.’” Hanna was just getting out of a relationship, and had a young daughter. But Taylor was open to her situation, and she was open to his. She got it — he didn’t have to put his quad cards on the table. Simultaneously, he fulfilled her emotional needs. “We’re the same,” says Hanna, “We’ve just had some different shit happen.”
They continued to develop communication about everything from kids to relationship roles. Hanna “wears the pants” with bills and household duties, but Taylor plays an active role, both supporting the family with his job staffing for hospitals, and playing second dad to her daughter. “It’s just Dad-in-a-chair,” says Hanna. “Parenting happened naturally, and Taylor was careful not to step on toes.”

A focus on openness from both of them made some of their circumstances easier. “We have no problem telling each other when we’ve crossed the line,” says Hanna. She’s careful of her propensity to put on her therapist hat with Taylor. “She’s like my mom sometimes,” jokes Taylor. “I have to remember I’m a wife first,” says Hanna. On the flip side, Hanna can get overwhelmed by Taylor’s lack of a filter. “He’s an open book, and a people pleaser. Sometimes I’m like, reel it in a bit!” she jokes.

But she appreciates how his openness puts her at ease. Taylor feels compelled to be open so he can help people learn and break down walls. And together with Hanna, they maintain a focus on trying things and not being embarrassed, which includes in the bedroom. “There are lots of firsts in this relationship,” says Taylor.

“He can go for hours … it’s exhausting,” says Hanna. “And when it comes to the bedroom, quadriplegic my ass. He’s the aggressor!”

They joke that some of the time, their sex is pretty “boring.” Although, that wasn’t the case when Taylor first orgasmed with Hanna during sex. “We were trying different positions as part of a consult on fertility. Normally we could have sex for two hours with no orgasm. But that time, it was like 10 minutes. His eyeballs were as big as saucers!”

They agree that there’s a healthy, comical side to their relationship, in and out of the bedroom. And this helps their ability to work through some of the more stressful circumstances, like living with his parents and sister in his parents’ accessible house. “Our room is our escape,” says Taylor. “We hope to have our own place in the next six months.”

As they await the arrival of their second child, Taylor and Hanna have struck a good balance, with communication, authenticity, and family at the root of their relationship. “The longer you’re with someone, you learn which things you have to communicate about more gently,” says Hanna. “I enjoy watching his dreams come to a reality.”

Like humor, independence is important to their relationship. “We take care of ourselves, and work for what we want to have,” says Taylor.

It sounds like the good premise for a joke: two wheelchair users roll into a bar. Or, two wheelchair users go to Barcelona. Or, two wheelchair users fall in love, do marathons, become scuba divers, and have great sex at Disney World. But it’s not a joke … it’s Jessika and Rey.

“He thinks we first met at a support group when I had red hair, but I didn’t have red hair back then … so whoever he was hitting on, it wasn’t me,” says Jessika, a 31-year-old T2 incomplete para from surgery for a spinal tumor. Following her injury, she met Rey, a peer mentor. He had been a firefighter and EMT before a hit-and-run motorcycle accident rendered him a T6-7 incomplete para eight years ago. “At first, I didn’t like him, because he pushed me to work hard. He would tell me to get on the floor and then get back up,” says Jessika.

“I didn’t expect her to actually do it, but she did,” says Rey. He realized he was crushing on this special woman. They had mutual friends in the SCI community, and before long realized they had similar interests in being active, doing everything from 10k races to handcycling and traveling. “I loved to travel, but Rey had never been anywhere. I think he caught the travel bug from me — we just got back from Barcelona!” says Jessika.

Before meeting, Jessika hadn’t really considered dating. “It just wasn’t on my radar,” she says, because she was focusing on rehabbing and adapting to life in a chair. Having been a chair user longer than Jessika, Rey had experienced the dating world, but found it difficult. “It was very hard dating in a chair,” Rey said. “Often the other person wasn’t open-minded,
or her parents wouldn’t see me as part of her future — I didn’t feel accepted.”

Their connection was immediate. Rey was active, having played wheelchair basketball, sled hockey, rugby and tennis. He even introduced Jessika to iFLY indoor skydiving. “He’s my best friend, and he taught me everything about being a wheelchair user,” says Jessika. Their bond has grown strong over three years, staying active and sharing their passion for helping others.

And occasionally, even helping each other on a level that most couples could never dream of, including cleaning up after a bladder accident, or Rey helping with a bowel program when Jessika was sick. “I don’t mind, I’m curious about the human body,” says Rey. “I was a firefighter and paramedic. Even if she’s dealing with bad diarrhea, I don’t care … I want her to be safe and feel better.”

“I fell in love with someone who understands what I go through on a daily basis,” says Jessika.

This kind of openness and vulnerability with each other has helped them grow closer in every way, including sexually. And their sex life is, at the least, incredibly robust. “Before our injuries, things like farting during sex would have been mortifying. Now, we realize we can’t control that aspect, and we’re very open with each other,” says Rey.

“Haha, we’ve had lots of moments of disaster,” says Jessica, including one time when she thought she had farted. “I said, ‘What hole did that come from?’ And Rey said, ‘Mine!’” she says, laughing.

Their own curiosity and willingness to try things has helped them become more educated themselves. For Jessika, sex helps with spasms. Even though she doesn’t feel anything vaginally, her clitoral experience is heightened. It took a bit of trying, but after about a year of being together, Jessika eventually orgasmed from cunnilingus, which helped her feel like the arousal experience wasn’t all focused on Rey.

Rey can get aroused from stimulation, but like Taylor, he found that it took a while and he would get frustrated. After visiting the Miami Project and trying an e-stim probe, it became easier.

As a couple they explore different positioning, and with two paraplegics, “It’s always a workout!” Having Jessika on top with Rey helping to move her hips has been successful, as has having Jessika on top of Rey while he’s in his chair. “He pulls up to the edge of the bed, and I just slide across. But, we have to be careful with my legs, because one time I ended up with bruises all over them from his wheels!” says Jessika.

Cialis has also been helpful for Rey in maintaining an erection, although they joke about how the timing is important. “Sometimes it kicks in at the wrong moment,” says Rey. “Sometimes it doesn’t kick in until the next day when we’re out rolling around, and I have to be like, ‘Babe, help me cover up!’” They laugh. The Cialis also doesn’t do well with an empty stomach or with alcohol. “I drink the alcohol and he takes Cialis, and it’s a great night!” says Jessika.

While Jessika and Rey have found the physical experience to be robust and satisfying, they emphasize that the mental component helps a lot. Rey will give Jessika a massage before they get physical, or he’ll tell her the things he wants to do to her. “Although, once he just repeated what I said — it’s still a work in progress,” Jessika jokes.

Which is their ultimate conclusion about their relationship. “It’s work, you have to rediscover your body, and play around,” they say. “You get to know each other’s bodies incredibly well. But, the work is definitely worth it.”
The joy of a relationship isn’t only expressed through adventurous sexcapades. Gail, a C5 incomplete quad 44 years post-injury, and Don, C7, 37 years out from injury, find their happiness on cross-country trips together in their twin Mini Coopers. “Mine is pepper white with a black roof, and his is bright red with racing stripes,” says Gail, who lives in Arizona with her husband of 27 years.

The couple has built a partnership that reflects the kind of love that can only be formed and re-formed over years of adaptation, patience, humor, trust, and respect. “You gotta be able to stand each other,” they joke.

Initially they didn’t see each other as romantic material. “I thought of Gail as a teammate,” says Don, who first met her when they were on a quad rugby team together. “She was pretty cool, because with her injury level she could reach over, pick up the ball with both hands, and sit up.”

At a state championship game, they chatted at breakfast one morning and discovered a lot in common. They had both been dating non-chair users, and expected to end up with a non-paralyzed person. They both worked in IT and software. They had similar morals, humor and intelligence. They both wanted to achieve great things and had similar challenges. Before long, they had become best friends and more. “I wanted to be able to love someone, and have them love me back,” says Don, the self-dubbed “sensitive” one.

Over the years it hasn’t been easy, but they’ve adapted. Both were laid off at the same time, and they used the opportunity to relocate and build a fully accessible retirement home. Both have had shoulder surgeries. Gail faced cancer. Don broke both legs, and struggled with challenges of OCD.

Through it all, they found ways to support each other and never hold each other back. “He’s always there for me, I’m always there for him. You suck it up and take care of your partner … we would do anything for each other. Well, unless sports is on,” Gail jokes.

“You have to be willing to acknowledge things in yourself, and put them on the table, and dissect them,” says Don. “I would take a bullet for this woman.”

Their intimacy has never been superficial. “We are sensual, but it’s more of an intellectual sensuality. We have romance, we bring flowers, do things unexpectedly; we hold each other. We are physically, emotionally and mentally close.”

Being a strong foundation for each other and not dwelling on the drama has allowed them to achieve great things. “When I was younger I was still focused on me,” says Don. “Yeah, younger people are,” chimes Gail.

Getting past the inexperience and naiveté of youth brought a life full of accomplishments, including racing cars, scuba diving, and flying. Nowadays, their lives resemble something of a comfy holiday rom-com. Don spends time in his garage man-cave, and Gail enjoys gardening, knitting, and getting together with friends. Mostly, they keep going.

While Don doesn’t think of himself as being disabled, Gail admits that her injury will always stay with her. “I will always grieve that loss. And sometimes the grief really hits, like momentary passing sadness,” says Gail.

“It hurts me,” says Don. “I want to help, but I just have to give her space and let her work through it.”

So what’s their secret? “We have a deep personal rela-
relationship. Anyone can have that, but you have to acknowledge a few things first, and then embrace that and move forward,” says Don. “Knowing what’s important, and then moving on. If one or the other can’t entirely let something go, you can still work through it.”

And the little things. “We’re always touching,” says Don. “Not a day goes by without us saying we love each other, and saying good morning, and good night.”

NOTHING LESS

Four couples with four very different experiences. But all four are creating their own versions of relationship, sexuality, and intimacy that are robust, adventurous, and deeply connected. No matter who you are or how your body functions, sex, love, and relationships are a wide frontier waiting to be explored.

Can it be challenging, especially when you’re facing the flesh-and-blood embodiment of survivorship after some of our most intense traumas and griefs? Yes.

But the first step is knowing that your love life post-injury can be extraordinary. As Gina emphasizes, “I’ve had much more intense sexual experiences after being disabled than before.”

Our traumatic experiences are assets that make us more genuine, complex, and lovable humans. They teach us to adapt, to grow, to be open and vulnerable.

RESOURCES

• Jessika Kattah’s blog, www.jessikakattah.com
• Don Lively’s new novel, “The Social Event,” www.amazon.com/gp/product/B00KY5GW4O
• Gina’s Facebook, GinaIsOnARoll, and check out her writing with PushLiving.com.
USAA $1,000 REBATE*

VMI and USAA have partnered to offer USAA members an exclusive $1,000 rebate on a wheelchair accessible van.

Operation Independence $1,000 REBATE*

Available to disabled veterans for the first-time purchase of a VMI van with a new conversion.

vmivans.com

Talk to one of our veterans in VMI’s Veteran Advocate Center to learn about the many benefits available to help you gain mobility.

844-VAC-4VMI (822-4864) | VeteranAdvocate@vantagemobility.com

*Eligible veterans can receive up to $2,000 in mobility benefits by combining USAA’s exclusive $1,000 incentive and VMI’s $1,000 Operation Independence™ Rebate.

USAA: Membership eligibility and product restrictions apply and are subject to change. USAA means United Services Automobile Association and its affiliates. Purchase of a product other than USAA auto or property insurance, or purchase of an insurance policy offered through the USAA Insurance Agency, does not establish eligibility for, or membership in, USAA property and casualty insurance companies. © 2016 USAA.

Operation Independence: VMI and our Select or Authorized Dealer Network are offering disabled veterans a $1,000 rebate toward the first-time purchase of a van with a new VMI conversion. The vehicle purchased must be converted for wheelchair access by VMI and purchased from a VMI Select Dealer. The Veteran can receive a check for $1,000 from VMI or choose to have $1,000 taken off their invoice at the Select Dealer. Checks take 60-90 business days. Rebate is available through VMI Select or Authorized Dealers and is valid from 1/1/2018 to 12/31/2018. It is payable upon end user delivery.
There are a growing number of sexual enhancement devices that are easier to use for every body (and everybody) and adapt to your individual needs and preferences. Here’s a look at a few.

**Perfect Pleasure Cushion**
The Perfect Pleasure Cushion ($399) is a Liberator wedge on steroids. A cross between a foam wedge and a toy mount, the Perfect Pleasure Cushion was invented by a woman who lost mobility in her arm and couldn’t hold her vibrator anymore. Unhappy with existing toy mounts, she created the Perfect Pleasure Cushion. It is good for holding vibrators, sleeves, or dildos; providing support for intercourse and optimal positioning for cunnilingus. It’s waterproof, washable and when not in use for sex it serves beautifully as a backrest or lap tray! The cushion allows for adjustable, hands-free use of toys and offers a way to experiment with a variety of new sex positions due to its ability to form multiple shapes.

**The LOVE BENCH**
Advertising itself as, “The only sex furniture designed for people with short stature and those with limited mobility,” the LOVE BENCH ($3325) is the brainchild of sex educator Marylou Naccarato, Ph.D. Born with a rare form of dwarfism, she wanted to be “on top” but it was too difficult on her hips and knees, and she did not have the strength to hold herself up with her arms to compensate.

The LOVE BENCH is narrow, low, and padded, which allows creative positions like cowgirl or reverse cowgirl without putting extra strain on joints or weight on your partner. It is useful for massage and exercise too. The LOVE BENCH is custom made to fit your individual measurements. It is also good for people who have hip and knee limitations resulting from joint implants, and cleans up easily.

**Umie**
Many new vibrators have tiny little controls that are molded into the design, making them a real challenge to turn on and off, or adjust. Thankfully Tantriss has developed a new vibrator, Umie ($149), that comes with a great app. Once turned on, which takes me two hands for any of these, it automatically connects via Bluetooth with an iPhone or Android device, and the excitement starts from there. Intensity and heat can be controlled (and wow, this is a strong rechargeable vibrator), and its five modes include sound (“Hey Umie, a little faster”); multimedia, where you can choose a song or video from your library and then Umie moves to the music; and a preset that has eight different waveforms to choose from. Umie is waterproof and there is even a dynamic battery level indicator.

**Vibrators**
Fin ($75) is a small vibrator from Dame with an optional tether that slides over two fingers, making it great if you have no grip. It has a good size on/off/three speed control that you can press with your hand or even against your chin. It’s water resistant and has great power for its small size. Dame also makes Eva ($95), a clitoral stimulator, which could be set in place by you or a helper. It stays in place with the help of two flexible wings that tuck under the labia to tickle your fancy with no hands.

Tenga also makes a line of small finger vibes ($14-17 on Amazon) — the VI-Bo Finger Orb, VI-Bo Hand Orb, VI-Bo Ring Orb and the VI-Bo Stick Orb — that are all great for those with limited hand function. They share an inexpensive yet effective vibrating orb with an on/off switch easy enough for many.

**Resources**
- Perfect Pleasure Cushion, theitcollection.com
- Umie, 888/644-8643; umie.co
- Dame, www.dameproducts.com
- Tenga, www.tenga.co.uk/collections/tenga-vi-bo
Imagine keeping a medical secret from every person you’ve been with and loved — an elaborate lie that kept you from being fully vulnerable and intimate with someone. That was my reality for more than half my life. Until last summer, when at 33, I finally let my guard down and told a significant other about my colostomy for the first time.

Since I was paralyzed in a car accident at the age of 5, I’ve lived a normal life. I went to college, traveled the country, and have built amazing friendships. Like any disability, mine has provided challenges at every step (even as I write this, I’m about to head into a doctor appointment).

For all the frustrations my wheelchair causes, it has never been difficult to explain my relationship to it when dealing with boyfriends and potential lovers. In fact, it’s somewhat easy and often needs no explanation at all: I use a wheelchair. It gets me from point A to point B. If I don’t have it for any amount of time, I’m screwed. We’re a package deal.

But perhaps the most frustrating part of my disability is explaining what’s not readily visible. No one prepares you for explaining a colostomy bag and all that comes along with it. How do you explain to the person you’re dating that you shit in a bag? There’s no easy way to do it.

So I kept this part of my disability a secret from every man I’ve dated since the age of 16. As you can imagine, this has the potential to get quite awkward in the bedroom. How the hell do you hide something like that?

In the beginning, it was easy. When I had my first boyfriend at 16, I had no interest in sex. All I had to do was keep my pants on, and he was none the wiser. For three years, I never spent the night with him, changed in front of him, or let anything get close to sex. Needless to say, it was three years of things in the bedroom being “about him” and keeping him at arm’s length, physically and emotionally.

But being a person who does have a need for intimacy and sex, I figured out that just practicing abstinence was not a realistic solution. And in fact, the first time I was ever in love, at age 21, the issue was undeniable. For the year and a half we were together, I was never fully naked with him, got undressed strategically and frequently feigned having a stomach ache or said I had a bruise and couldn’t be touched on my stomach.

I was so in love, and yet so afraid that if he knew the truth, it would be the end of us. But hiding it brought about what I most feared. When we broke up, he said I wasn’t truly available and never let him in. I tried to fight for us, and tell him I would do whatever I needed to in order for us to work. But at that point, with over a year of lying to him, I knew it was already over.

THE STRUGGLE

You’d think I would have learned my lesson at that point, but I was still another 11 years from even coming close. Initially I thought I just needed to be cleverer in my deception. I found pieces of lingerie that would cover the exact right spot, or I would strategically place sheets covering that 3-inch part of my stomach. I refused to ever shower with a boyfriend, often just saying that I wanted my privacy and had no desire for him to come in with me (both lies). I even dated someone for a while who had a colostomy himself and when he told me about it, I said, “that’s cool, thanks for letting me know.” I couldn’t tell him that I had one too, and that I was tortured with guilt for not affording him the same honesty that he gave me.

I had built up this idea that the moment a guy found out about my colostomy, he would no longer find me sexy. Keeping it a secret allowed me to be in denial. In those moments, it felt like maybe I could pretend it wasn’t there, and that I was just like any other woman they would be with. There was safety in that. But knowing I was lying to people I loved and never truly becoming intimate with them kept me up at night. I would think about what would happen when he found out. What would he say? How much would my existence gross him out?

Something finally clicked when one of my best friends addressed it with me for probably the 50th time. She told me I was making too big of a deal out of the whole thing, and anyone who loves me will love ALL of me, parts that are less sexy and all. She pointed out that, “if he can’t handle this, which is so small, what will he be able to handle?” She also recommended that I tell future suitors early on, so I know if they are worth my time. I thought she was out of her mind, but that it couldn’t hurt to try. This invisible wall had been up for too long.

When I started dating a music teacher over the summer, I knew within the first hour of the first date, that this would be the guy I told. Let’s call him Ben. I liked Ben instantly, but not so much that I’d be heartbroken if he wasn’t cool with it and bailed. He made me instantly feel more at ease than any other person I have come into contact with. I had a grand plan. I was going to tell him after about a month of dating, and I was going to do it head-on in a calm, collected way.
My plans were quickly thwarted. This guy was more perceptive, passionate and inquisitive than anyone I’d ever dated. I had to come clean. Fast. He had no problem asking pressing questions early on. He’d look at me and say, “why won’t you just take off your shirt?” And, “is there something wrong with your stomach?” For whatever reason, I couldn’t stand the thought of lying to him — I wanted this to be different.

On date two, after way too much wine before he arrived, I got up the nerve and told him about my “medical device on my stomach.” I explained it as simply as I would explain the wheelchair. I wasn’t sure how much I should divulge, because part of me wanted to ease any potential fears about cleanliness. But I didn’t have to. To my surprise and relief, he was receptive and cool with it. He likened it to an insulin pump, and asked to see it, to which I told him no. Although the colostomy didn’t seem to faze him, he also didn’t portray any empathy for my situation. Telling him was a big step for me, but I wasn’t ready to make that extra leap of faith of showing it to a guy I barely knew. Which was funny, because in some ways he already knew me better than any guy I had dated previously. That scared the crap — pun intended — out of both of us.

**WHAT DOESN’T KILL YOU …**

I’ll skip the sordid details of what followed, but Ben and I did not last. While I had spent so long worrying about this one thing, convinced that I would immediately be rejected upon discovery, I never prepared for how I would feel afterwards. I was so worried about other people’s perceptions, I forgot about myself.

For the first time in my life, I was completely vulnerable and honest with someone. It was terrifying for me, and I did not handle it well. I felt naked for the first time of my life and convinced myself that it was still going to go sour. Instead of being honest about the nerves I had in that moment, I did everything I could to push him away. I was critical, unfair, and became needy and overly insecure. Now, months later, I am still incredibly embarrassed about just how unprepared I was and how poorly I handled it all. I made something fun and carefree become overly serious because in my mind, him knowing meant that things were suddenly different. And that wasn’t entirely true.

Ultimately, this whole journey was one of learning to be honest with myself, and finding out that I could be cared for and accepted regardless of the situation. I’m so glad that I was honest about who I am and what I have. I don’t know how the next man I tell will react, but I have learned how to handle what happens next in a positive, meaningful way. The confidence that has followed is palpable. I feel more comfortable with myself and the device than I ever have before, and this changes my approach to dating moving forward.

Yes, I have a colostomy bag. I’ve kind of stopped giving a damn, and it’s the most freeing feeling in the world.
Their love may sound idyllic, but their tale is the stuff of tabloids. On May 23, 2010, at her bachelorette party a few nights before her wedding was supposed to take place, Rachelle Friedman — a sort of all-American-girl type from suburban North Carolina — was drinking with her best girlfriends when one of them playfully pushed her into the swimming pool. Wherein she injured her spine at the C6-cervical-nerve level. Her injury delayed the wedding by nearly a year, but it didn’t stop it. Her eventual marriage to long-time sweetheart Chris Chapman garnered so much attention, in fact, that it became a feature on The Today Show and in People magazine, among other venues.

Now in their early 30s, Rachelle and Chris live in Knightdale, North Carolina — a leafy suburb of Raleigh with a rapidly growing population, largely thanks to its being within Research Triangle. “Before my accident,” she tells me, “Chris and I were joined-at-the-hip in love, and best friends. I
don't think we could've gotten any closer. Then the accident happened — and we stayed that way!"

Fair enough, I think, but it was obviously an adjustment, a learning experience, right? “You’re thrown into a new world,” says Chris.

It’s now nearly five years into the marriage, and her confidence in their union remains undiminished. What’s the secret? What are her tips? “A lot of people think they’re in love and someone loves them, and everything is great,” says Rachelle. “But if something goes wrong, it can end the relationship. So it turns out their love wasn’t as strong as they’d thought. … Our relationship proved to be strong. We’re just two people who love each other and can deal with each other’s flaws — love each other, flaws and all.”

“Does Chris have flaws?” I say.

“You can’t necessarily see his flaws,” she answers. “That sounded so bad. … But he has anxiety, I guess you could say, and I’m the person who calms him down.”

It’s an important point for her, the give-and-take between them. “A lot of people feel that, with an interabled couple, the able-bodied person is some kind of hero just because he’s with you. That’s messed up!” she says. Just the other day, she continues, a man at the mall tapped Chris on the shoulder, shook his hand, and said, “You’re my hero.” “It doesn’t take a hero to be with somebody,” says Rachelle. “I mean, that’s basically saying it takes an extraordinary person to deal with someone like me, when really it’s just that we’re both in love.”

It makes her feel like they’re saying she should be “so grateful” — and that Chris has all the control in their relationship. “It’s not like one of us is forcing the other. We share the power equally,” she says. “I’d never leave him, not because I can’t due to my disability or something like that. I’d never leave him because I love him. It’s not fair to think otherwise. It’s not true, not how it is with us.”

When I ask him about this, Chris says he’s insulted by such encounters, too. “I just smile and move on,” he says. “But I’m with her for me. Because I want to be. Not because I feel guilty or am doing her a favor.”

“Our love — us together — that’s what should be inspiring,” Rachelle emphasizes. “That’s what I want to get across. Someone should get inspiration from the fact that we chose love. The fact that we stay together should reflect on us together.”

From In Sickness and in Health: Love, Disability, and a Quest to Understand the Perils and Pleasures of Interabled Romance, by Ben Mattlin (Beacon, 2018). Available on Amazon.com, a.co/04PsnQr
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What if I told you there’s a resort that honors artists and writers with free vacations of room, board, and studio space? And that, at this resort, preference is given to artists and writers with disabilities — and not just any old vanilla-flavored disability, but specifically spinal cord injuries?

Welcome to Creative Access. What started in 2008 as a partnership between an artists residency center and a foundation dedicated to improving the quality of life for people with spinal cord injuries has grown into a sprawling, multi-site opportunity unlike any other.

Last year I was one of 13 lucky crips who were awarded Creative Access fellowships. The fellowships entail an extended stay, usually one month, to pursue your own artistic endeavors at one of four unique residency sites across the country. They are like art schools without final grades or summer camps without counselors. Think of these colonies as Creativity Camps.

With locations in Vermont, Oregon, New Mexico and Illinois, the sites are almost as diverse as the applicants. Last year’s fellows included painters, sculptors, filmmakers, writers and much more, all united by the fact that they had some sort of spinal cord injury. That’s one of the prerequisites set by the provider of the fellowships, the Craig H. Nielsen Foundation: Creative Access awards are for visual artists and writers living with spinal cord injury in the United States and Canada.

All the staff have already been well broken-in from hosting wheelers before us. Hence, they are knowledgeable and welcoming. And the staff are themselves artists or writers. Hence, they share camaraderie with those who are mutually afflicted by artistic callings.

While some events calendars might be tagged with studio visits, poetry readings, lectures, workshops, critiques, rap sessions, social gatherings, and even yoga classes, these are all optional. Freed from the shackles of job responsibilities and family obligations, you can fritter away your time in any way you please.

“The quest for inspiration and productivity is what brought everyone together.”

Reveca Torres

Fashion designer, illustrator, photographer, filmmaker and nonprofit founder Reveca Torres’s resume is nearly as long as her passion for the arts is deep. Torres, a C5-7 quad, co-directs the annual ReelAbilities Film Festival in Chicago and curated an online photo exhibition that showcases the lives and work of people with disabilities. She attended Vermont Studio Center in 2014 and Santa Fe Art Institute in 2017.
Yet as a 67-year-old retiree whose every day already is a vacation day, I accomplish much more living alone at home with deep woods just 50 feet beyond my window than I did in the middle of a Vermont village with the commotion of companionship and community all around me. Writing, after all, is a solitary act. Still, my time there was productive, just not as I had planned. That happened to many others, too, who laid plans to do one thing but accomplished another. Thrust into a totally new environment as though we had dropped from the sky, we hatched some new eggs.

The quest for inspiration and productivity is what brought everyone together. After all, at home few artists enjoy the luxury of a bright and spacious and well-ventilated studio with empty walls begging to be filled. So in their separate artist or writer studios, residents create their latest masterpieces, all the while enjoying the comforts of sharing up to three meals a day, of being allocated unhurried and unscheduled time, and maybe, just maybe, of being instilled with inspiration to last a lifetime.

During several hour-long gatherings, residents were invited to give ten-minute slideshows or readings to the VSC community. During each of those artistic and literary “happy hours,” you got to see or hear the works of your peers who you had been meeting around campus. And you, too, got your chance to condense your entire oeuvre into ten minutes. I am proud to say that I limited mine in nine.

Other evening events were the two-hour Open Studio visits that alternated between painters’ studios one week, sculptors’ the next week, and so on. Hobbling along on my crutches, I did not try to keep up with the Open Studio parade. Instead, I made studio visits on my own, at my own pace. All are accessible except for the second floor of the sculpture studios. Some visits I arranged in advance, others were by happenstance. If at work in their studios with their doors closed, that signified, Do Not Disturb. But open doors meant, Come On In. The studio hosts got to verbalize the artistic itch they were scratching, and I got to accost them with my unsolicited but nevertheless welcomed critiques. Those intimate one-on-one conversations were the most indelible memories of my entire Creative Access experience.

Ready to Apply for 2019?
Applications will be accepted beginning in September 2018. For the precise date, consult the Creative Access webpages on the

Javier Flores was awarded a master of fine arts in printmaking. But don’t let that diploma fool you. A T12 para, Javier also paints, sculpts and makes ceramics. Some of his artwork is blatantly political, and some more subtly immersed with symbolism. He did his fellowship at Playa right after completing his degree and used his time to paint and create multicolor woodcut reliefs. He says his residency provided him with the opportunity to devote time to his artwork without distractions.

Tony Boatright chose Santa Fe Arts Institute for its summery climate in September and in order to research his historical novel set in 19th-century frontier New Mexico. A C5-6 quad and a professional writer, Boatright has been a content copywriter, copyeditor, ghostwriter, blogger, e-book author, restaurant reviewer, ADA consultant and more. Now in his 60s, he balances commerce with creativity by writing novels and Sci-Fi. “My time at the Santa Fe Arts Institute was an experience that stretched my mind,” he says.

Catherine Peterson

Using crystals, beads, and gems, and drawing on her love of Mexican traditions, including the Day of the Dead, Catherine Peterson creates what she calls “skulplurals” — essentially painted and decorated animal skulls. A T12 para, Catherine found Vermont Studio Center a very supportive and engaging community. Her time there allowed her to think outside the box of her art and to see how others tried new techniques even if theirs ended in failure. “I now feel I can experiment with new mediums without necessarily achieving success with them.”
Alliance of Artists Communities website at artistcommunities.org/creativeaccess/apply. And remember, even if you are not awarded a fellowship, you can still attend on your own dime. If this article generates a flood of applicants for 2019, don’t despair. An overwhelming response would only confirm the need to renew and expand the program into 2020 and beyond.

**Resources**
- Creative Access, 401/351-4320; artistcommunities.org/creativeaccess
- Craig H. Neilsen Foundation, 818/925-1245; chnfoundation.org
- Playa in Summerlake, Oregon, 541/943-3983; playasummerlake.org
- Ragdale Foundation in Lake Forest, Illinois, 847/234-1063; ragdale.org
- Santa Fe Art Institute in Santa Fe, New Mexico, 505/424-5050; sfai.org/residencies
- Vermont Studio Center in Johnson, Vermont, 802/635-2727; vermontstudiocenter.org

**Elizabeth Sachs**
A failed T1 spinal surgery at 65 made Elizabeth Sachs a latecomer to the SCI world, but did little to slow her creative momentum. A journalist, editor, New York Times book reviewer and children’s and young adult author (pen name Betsy Sachs), Sachs now writes about her disability. Look for her forthcoming memoir, Late to the Dance. Her residency at VSC demonstrated just how nurturing fellowships can be, “It allowed me to gather a disjointed manuscript representing 40 years of writing into a cohesive story.”
In February 1977, the hit CBS sitcom *Maude* ran an episode in which middle-class, middle-aged liberal Maude Finley, played by Bea Arthur, is forced to confront one of her oldest friends recently stricken by a devastating stroke and in a wheelchair. After tiptoeing around this woman for most of the episode, Maude finally engages her in awkward chitchat. The friend, seeing her blatant uneasiness, confronts Maude with, “I scare you, don’t I?” Maude’s reply: “You scare the hell out of me.”

Cut to February 2018, and tune into the Comedy Central hit series *Drunk History*, whose premise is simple: A drunk narrator tells you the story of an important historical event and actors reenact that story, lip-syncing their slurry words. The story highlighted here is a seminal moment for the disability rights movement: The first mass sit-in, by 150-plus disabled protesters at a federal building in San Francisco that began on April 5, 1977, and lasted 25 days. Known as the Section 504 protest and led by wheelchair-using activist Judy Heumann — played in the video by wheelchair-using actress Ali Stroker — this comic re-creation is a raucous time, rock-and-roll on loud speakers and revolution in the air. The Black Panthers and rock mavens Jefferson Airplane show up. As our loopy narrator concludes, this was “Woodstock with wheelchairs and medical supplies.”

The distance in tone and substance between these two TV moments denotes the progress of disability inclusion in American media. You have to take a long view to realize how substantial the progress made over the last 31 years is. According to Anita Hollander, National Chair of the SAG-AFTRA Performers with Disabilities, in the 2016-17 television season more actors with disabilities had regular roles playing more characters with disabilities than in the entire history of the medium. This also held true for people with disabilities showing up in all kinds of roles, big and small. The shows are proliferating: *Speechless*, *The Good Doctor*, *Atypical*, the Saturday morning series, *The Inspectors*, a brand-new series on Amazon about kids with Down syndrome, *Love You More* — not to mention features like *Stronger* and *Wonder*. These are not one-off, feel-good cameos on TLC. *The Good Doctor*, about a young medical savant on the autism spectrum, is this fall’s highest-rated new show. *Wonder*, about a kid with a facial disfigurement, made $70 million in its first week.

Characters in wheelchairs have always been the most prominent disabled representatives on TV and in film, for two reasons. They generally aren’t as “scary” to the nondisabled crowd as the stroke survivor in *Maude* or someone with speech difficulties. And they can easily be played by nondisabled actors, usually box-office draws from Marlon Brando in *The Men* (1950) to Tom Cruise in *Born on the Fourth of July* (1988) to the much-maligned Artie in Glee (2009). For years, the joke in Hollywood has been “play someone disabled, win an Oscar.” That has held true right up to Julianne Moore playing a woman with early Alzheimer’s in *Still Alice* (2014).

There is currently a fervid backlash among Hollywood activists against this “fake” casting, branding it as inauthentic and unfair. The recent movie, *Stronger*, about the double-amp survivor of the Boston Marathon bombing, Jeff Bauman, is a case in point. The actor, Jake Gyllenhaal, was clearly chosen to play the role because first, he’s an excellent actor, and second, he’s a box office draw. Disability die-hards consider this insulting. Even with the real Jeff Bauman standing right next to him giving him cripple tips, Gyllenhaal doesn’t ‘know’ what it means to be a double amp.”

“Even with the real Jeff Bauman standing right next to him giving him cripple tips, Gyllenhaal doesn’t ‘know’ what it means to be a double amp.”

Nondisabled Jake Gyllenhaal plays double amp Jeff Bauman in *Stronger*. 
ing him cripple tips, Gyllenhaal doesn’t “know” what it means to be a double amp. More importantly, this kind of substitute casting robs talented, dedicated actors with disabilities of work. To them, it’s a life or death issue.

This situation is a classic double-bind. There aren’t enough stars with disabilities to carry such films, but if you keep giving these cherry roles to nondisabled actors, how are disabled actors ever to become stars? According to Gail Williamson, the principal agent for actors with disabilities in Hollywood, things are changing, slowly. More disabled actors are being seen for and landing smaller roles, even ones that don’t explicitly call for someone autistic or using a wheelchair. This is a concerted strategy among all committed casting directors to go small and build up. That’s where stars come from.

Current movies starring those in chairs are a mixed bag. Quad provocateur and New Mobility icon, John Callahan, will be played by actor Joaquin Phoenix in the upcoming 2018 bio-pic, Don’t Worry, He Won’t Get Far On Foot. In a recent British release, Breathe, Andrew Garfield plays a man stricken by polio in the late ’50s who beats all odds by designing a wheelchair with a ventilator.

For a real, genre-busting movie starring folks in chairs — played by folks in chairs — check out the recently-released-in-America Hungarian film, Kills On Wheels, astutely reviewed by Seth McBride in the December issue of NM. Like Snakes on a Plane, the title tells all. This caper about chair-wielding hit men was Hungary’s official entry in the Academy Awards. Made in the ever-popular Tarantino mix of comedy and carnage, the American version, no doubt with nondisabled stars, is probably being plotted as we speak.

The authentic/inauthentic argument will continue to rage in Hollywood for a long time, but look to TV to move the needle faster than movies. Why? Because TV, with its voracious appetite for talent, makes stars, while film, given the cost alone, needs stars. RJ Mitte of Breaking Bad fame really has CP. Micah Fowler of Speechless really uses a wheelchair and has a speech impairment. They are already household faces, if not names, and the pipeline is filling up fast.

Patience, unfortunately, is a bitch.

The co-host of this year’s Media Access Awards, Haben Girma, the first deaf-blind person to graduate from Harvard Law School, succinctly stated why these media representations matter. Girma has never seen or heard a movie in her life. “But just because I can’t see or hear your shows,” she told the film and TV-makers in the audience, “doesn’t mean I am not deeply impacted by them. [These stories] greatly affect how the world perceives me and perceives all of us who are disabled.” She then introduced 95-year-old Hollywood luminary, Norman Lear, the man who produced that Maude episode above, and cast the first actor with a disability as a regular on primetime TV (Geri Jewell, Facts of Life, 1980), and co-created the very same Media Access Awards in 1979 to honor those who shine a light on disability.

When Lear gave Girma a kiss on the cheek, it was as if he were passing the baton of change from the nondisabled visionaries like himself to the new generation of visionaries with disabilities who will now take over and get us all in the picture.

Stay tuned.
The theory of marginal gains states that if you take any system and improve every individual aspect by just 1 percent, you can dramatically improve overall performance by stacking the small gains into one significant improvement. This approach has proved successful in arenas ranging from business to professional cycling — and, yes, even ultralight manual wheelchairs.

The very definition of an ultralight wheelchair has dramatically changed over the past four decades. In the 1970s, an aluminum manual wheelchair approached 40 pounds, but decade by decade, weights dropped. By the late 1990s, an ultralight manual wheelchair was formally defined by insurance coding as weighing 29 pounds or less in its base configuration. However, due to never-ending marginal gains in ultralight chairs on the part of manufacturers consistently pursuing lighter weights, most now see 29 pounds as heavy in a world of sub-20-pound ultralight models.

So, what makes the latest designs in ultralight models and components so astoundingly ultralight?

What’s in a Pound?
The iconic Quickie brand has never stopped pushing the envelope when it comes to reducing weight, especially in the widely-funded K0005 class of ultralights. The newer Quickie 7RS is among its lightest models to date, weighing in at 17.67 pounds complete for a 16-by-16-inch seat size, with a transport weight of 9.88 pounds. So, how does the Quickie 7RS achieve such an impressive weight?

It begins with using 7000 series aluminum for the frame, which has a higher strength-to-weight ratio than a comparable 6000 series aluminum, allowing a very strong, light structure. From there, the Quickie 7RS squeezes out every ounce by using a minimally adjustable axle mount instead of a highly-adjustable one, and an integrated welded backrest that eliminates mounting brackets. These two areas alone not only shave just over a pound off the chair, they also increase propulsion efficiency by more directly translating the user’s energy into each push rather than being absorbed by bulky frame components. To reduce weight even more, Quickie offers an ultralight seat sling, not overlooking even the smallest weight-saving detail.

In a market where ultralight has become somewhat synonymous with ultra-expensive, the Quickie 7RS is a high-performance rigid ultralight that fits many conventional funding sources.

’T lite Keeps Getting Lighter
The TiLite TR is a bit like an iPhone — when someone says they have one, you have to ask, which version? Indeed, the TiLite TR — now on its third series — has been an industry leader in high-end ultralights for years. However, even the newest version continues receiving weight-reducing refinements, bringing today’s TR in at 16.9 pounds in a 16-by-16-inch seat size, with a transport weight of 9.3 pounds. That’s astoundingly light for also being among the toughest, strongest rigids on the market.

The TiLite TR’s ultralight weight is mostly due to its titanium frame. Its strength-to-weight ratio is higher than aluminum, so you can decrease the weight of the frame itself without compromising strength. However, that doesn’t tell the real story as to why the TR is so light.

If you look at the current TR, you’ll note that it’s not a monotube frame, but a unique swept-in box frame, meaning there are both top and lower tubes, seemingly doubling the frame material. So, how does this create a lighter chair?
In order to create strength and durability in a mono-tube frame (with one frame tube per side) thicker-walled tubing is required, which adds weight. By going to its dual-tube design, the TiLite TR actually reduces weight by creating a super-strong reinforced structure using extremely light, thinner-walled tubing. It sounds counterintuitive, but more tubing equals less weight based on how it’s applied.

TiLite hasn’t just focused on making an ever-lighter frame. Its newer “bullet caster housing” removes even more weight in this typically bulky area. To drop weight even further, TiLite offers an optional carbon fiber camber tube along with an all-titanium backrest and footplate for an unbelievably ultralight package.

The TiLite TR Series 3 isn’t the most funding-friendly ultralight. However, if you have exceptional insurance or are paying out of pocket, the weight savings warrants the steeper price tag.

Frog Legs Makes Another Leap
Frog Legs suspension forks have been the premier ultralight accessory for two decades. Although they’ve evolved and slimmed over the years, they’ve still always added bulk and weight over conventional caster forks — that is, until now. The new Frog Legs Phase-Two fork (double or single-sided) is made out of carbon fiber and is said to have twice the tensile strength of the aluminum version, with less weight. Additionally, although not yet for sale at press time, Frog Legs is introducing a corresponding carbon fiber caster that’s 33 percent lighter than its aluminum counterpart. In all, Frog Legs Phase-Two forks are a big leap in allowing the benefits of caster suspension in a compact, ultralight design.

Lightening the Load
Reducing the weight of an ultralight manual wheelchair isn’t just about numbers. It’s about practical impacts on our everyday lives. A lighter chair is simply easier to propel and transport. Saving a pound here and there on an ultralight may not sound like much. However, the marginal gains add up when correlated with quality of life via less body strain. That may be the greatest benefit of marginal gains, after all.

Resources
• Frog Legs, 800/922-2129; www.froglegsinc.com
• Quickie, 800/333-4000; www.sunrisemedical.com
• TiLite, 800/736-0925; permobilus.com

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ONE STEP AT A TIME

I'm rethinking prunes, the same way I rethought Fleetwood Mac.

Prunes and Fleetwood Mac were my two biggest emotional triggers. Encountering them in the course of life released a tsunami of hostility in me, and so I avoided exposure to them at all turns.

My prune trigger is a cripple thing. But my Fleetwood Mac trigger was just a matter of being in the wrong place at the wrong time. I lived in a college dorm when the Fleetwood Mac album “Rumours” came out. Everybody in the galaxy owned a copy of “Rumours,” except me. Why buy a copy when if I wanted to hear it I just had to step out in the hall? At any given hour “Rumours” was playing on three or four different stereos in the dorm.

It got to where I felt if I heard “Rumours” one more time I might snap and go on an ax murdering spree. That’s a terrible affliction because it’s impossible to go through life without being ambushed at some point, at a party or in the background music at a store or wherever. About the only way to avoid “Rumours” is to hide under the bed wearing powerful noise-canceling headphones, which I often considered as a lifestyle option.

Well it took 40 years, but these days I can sit through almost an entire song from “Rumours” before I start looking around for an ax. I don’t know what happened to soften me but I’m glad it did. It’s time for me to clear away old resentments. I have to make room for the new ones.

But my prune trigger came about because so many adults pushed them on me when I was a criplet. Prunes were a frequent food tray item when I was a teenage inmate at a state-operated boarding school for cripples, which I affectionately refer to as the Sam Houston Institute of Technology (SHIT). They also served us prunes a lot at cripple summer camp.

Prunes symbolized what I shouldn’t trust about uncrippled adults. Uncrippled adults always had an agenda. Everything they gave me or did for me was designed to achieve an “outcome.” With prunes, I assumed, the desired “outcome” was for me to take a crap. I didn’t know why my taking a crap was so important to the uncrippled adults or why they thought I needed their intervention to achieve that outcome. Taking a crap was one of the things I did best. I took one daily, efficiently, with no help from anyone.

So I never ate any of their prunes, and this act of defiance made me feel powerful and in control. Maybe I couldn’t boycott the therapies or counseling sessions or clinics at the cripple school, but I didn’t have to cooperate when it came to prunes. And they never put me in a straitjacket and force-fed them to me, much to my surprise.

Like my Fleetwood Mac trigger, my prune trigger remained super sensitive well into my adult life. If I passed a bottle of prune juice or a can of prunes in a store, I couldn’t help but say “God I hate prunes!” And the thing is, I didn’t really hate them. I just felt obligated to hate them and to state my disdain loud and clear. It was my subconscious way of speaking out against cripple oppression, I guess.

But recently I was snooping through the refrigerator when I came across an unmarked container. Inside the container were prunes! Yikes! I guess they belonged to my wife. Emotionally, it was like opening one of those gag cans of peanut brittle where you lift the lid and snakes shoot out. But with age comes perspective. Instead of freaking out, I paused to consider the whole phenomenon of prunes. They’re just fruit, I told myself. There’s no reason to feel threatened by them. They can’t hurt you anymore. You took them on and you won! You’re a grown man now. You don’t have to keep proving to everybody that you’re a strong, independent, in-charge cripple by reaffirming your contempt for prunes. If you want to eat a prune, eat a prune, dammit!

It was at that moment that I finally made my peace with prunes. And it felt as if an enormous emotional weight was lifted.

I put the container back in the fridge. I still didn’t eat any of the prunes. One step at a time.
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CNN’s online LoveStory series included a piece on Kristen, a wheelchair-using New Yorker who lets us tag along on a first date. See the whole video at facebook.com/LoveStoryCNN/videos/143844976208361/ and follow @LoveStoryCNN on Facebook or @hellolovestory on Twitter for more episodes.
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