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It's famously rare for wheelchair-using characters to be played by wheelchair-using actors on screens big and small, yet Darryl “Chill” Mitchell has no problem getting roles. What's his secret? It's not his talent, he tells ALLEN RUCKER, it's his personality. Also AARON BROVERMAN chats up Micah Fowler, a young actor with CP who — get this — plays a character with CP on the new sit-com Speechless.

Cover Photo by Charley Gallay/Getty Images
Contents Photo by Monty Brinton/CBS
If exclusion is a state of mind, so is inclusion. Our problem as the most disrespected minority is simple, yet daunting: how to overthrow the universal misconception that the lives of people with disabilities are less valuable, and in some cases, even expendable. But how do we uproot and destroy a negative view of an entire class of people that has been entrenched in the human psyche for millennia?

The honest answer: The best we can hope for may be incremental change. Total eradication of stereotypical thinking and discrimination is unlikely. Why? Because human beings are very good at denial, compartmentalized thinking, and ignoring the other person’s plight.

So how does real change happen? When families are confronted in a personal way with the reality of disability, their point of view begins to change — from the inside out. Suddenly those closest to the newly disabled loved one are involuntarily enrolled in a crash course in Understanding Disability.

The Ruderman family went through a similar process on their way to becoming powerful and effective advocates for people with disabilities. Jay Ruderman, president of the nonprofit Ruderman Family Foundation, explains it this way: “Our first major philanthropic investment was in Jewish day schools in Boston. As we got involved, we became aware that children with disabilities were excluded in the school system. After that, my brother had a child with autism. And then my dad, who passed away in 2011, had a disease that diminished his lung capacity and gradually weakened him. Those personal experiences made the issue of disability more real to my family.”

Jay took over running the foundation in 2008, and with his background as an assistant district attorney passionate about civil rights, he was perfectly positioned to change the foundation’s focus and “go narrow and deep” in the battle against disability discrimination. “I realized that the organizations we supported weren’t doing it like we wanted, so we started our own advocacy efforts and began doing what we call rapid response advocacy.”

He cites examples: “When Donald Trump mocked a disabled reporter, the foundation spoke out immediately and got wide coverage. When Air France refused to fly a passenger in a wheelchair, we contacted the airline right away and put pressure on them.” Then came the “disability snuff film” Me Before You, with the Ruderman Foundation calling out Warner Brothers right alongside our most ardent disability advocates.

Now comes something new: Ruderman white papers published and circulating widely, covering hot topics like police brutality (a large percentage of those killed unjustly are disabled mentally or emotionally). In our current issue, Allen Rucker cites the Ruderman white paper, “On Employment of Actors With Disabilities in Television,” written by Danny Woodburn and Kristina Kopić.

This kind of multi-pronged, immediate advocacy is starting to chip away at the most stubborn kind of discrimination that is embedded deep in the human psyche. Most encouraging, the advocacy effort is born of real commitment and devotion and is alive and well and growing — not only in the Ruderman Family Foundation, but throughout the disability community.

— Tim Gilmer
Sam Maddox is certainly no stranger to *New Mobility*, having conceived of and founded the magazine in 1989, after publishing the book *Spinal Network*, followed by *Quest for Cure* (1992), the first history of spinal cord injury research. He moved on to become Knowledge Manager for the Reeve Foundation and authored the Reeve *Paralysis Resource Guide* and is currently the Foundation’s biomedical research writer. These days he is working on yet another book, *SCI: The First 90 Days*. He is a graduate of the University of Colorado, where he taught in the School of Journalism. He lives in Los Angeles.

Born with muscular dystrophy, Carole Zoom has been involved in the disability rights movement since the 1980s. As executive director of the Coalition of Texans with Disabilities, Zoom helped organize the passage of the ADA, the Air Carrier Access Act and other legislation. She was also the international leadership exchange coordinator for Mobility International USA. In the past three years she has traveled to 25 countries and been interviewed by National Public Radio on international travel issues. Her travel and disability writing has been published in the *Washington Post*, *AARP Magazine*, and *New Mobility*.

Aaron Broverman has been a freelance journalist for close to 10 years. Based in Toronto, Ontario, his areas of focus include personal finance, entertainment and disability issues. As a young man with cerebral palsy and pop culture maven, he’s always paying attention to the way people with disabilities are represented on screens large and small. As for the new TV sit-com *Speechless*, he hopes the show proves “popular enough to warrant a spate of shows featuring true-to-life depictions of people with disabilities helmed by people with disabilities.”

A former Ms. Wheelchair Louisiana titleholder and active member of Toastmasters, Jamie Duplechine holds associate’s degrees from Bossier Parish Community College (computer information systems) and In Christ International Bible College (theology). She is a certified peer mentor and family support member of the Christopher and Dana Reeve Foundation and a member of the Louisiana United Spinal chapter. She currently resides in Lafayette, Louisiana, where she continues to be committed to advocacy and education to make our society a better place for people with disabilities.
How can anyone living on Social Security and Medicaid/Medicare afford medical marijuana?

What About Price?
Nobody seems to address the price of medical marijuana ["Medical Marijuana 2.0 — Stirring the Pot," July 2016]. How can anyone living on Social Security and Medicaid/Medicare afford it? In Arizona where I live it costs $250 a year just for the card.

Kirk Sketchley
via newmobility.com

Grateful and Happy
I really appreciated this article ["Learning to Say Yes," July 2016], especially the parts about one’s life not having to be smaller because of the injury, and the points about post-traumatic growth. I know mentally and spiritually I am different/better because of my injury, and for that I am very grateful. And happy.

Kelly McCall
via newmobility.com

Just in Time
I needed this article ["Learning to Say Yes"] as I’m a T4 para, 11 months post-injury, and recently really struggling with the changes I’m being forced to make. Thank you for sharing this!

Carissa Bennett
via newmobility.com

Right to Drive
The restrictions and costs to vehicles with adaptive driving equipment are directly related to involvement of lawyers and litigation ["Your Right to Drive is Under Attack," Bully Pulpit, July 2016]. Twenty years ago, a person who owned a vehicle modification business said he could see a day when adaptive driving controls were no longer offered due to liability costs. It seems that that day may be coming soon.

Scott Barr
via newmobility.com

Has 1984 Arrived?
The lack of hand controls on dealership rentals ["Your Right to Drive is Under Attack"] is something that has repeatedly been brought up in my SCI support group: The fact that we drivers whose vehicles are equipped with hand controls need to bring our car to the dealership for service, but are not treated the same as every other driver, in that we cannot drive off the lot in a loaner car that we may wish to purchase.

Just watch someone try and take away my right to drive my car. It will be an extremely and exceedingly bad day for him or her. Last time I checked, this country had not (quite) turned into an Orwellian state.

Beth Wiesner

Roosevelt Estate
I enjoyed reading Matther Castelluccio’s Spotlight: Hudson Valley [July 2016]. I was surprised that he didn’t mention the Roosevelt Estate in Hyde Park. I utilize a mobility scooter (I’m a post-polio survivor) and I visited the estate two years ago. While there are stairs for the front entrance, they have an accessible entrance through the basement and an elevator that takes the visitor to the various floors of the estate.

There is also a bus that takes visitors to Roosevelt’s mountain top cottage; the bus and the cottage are accessible. It is a wonderful part of history, especially since FDR was a polio survivor, and he did so much for those of us with polio.

Bob Andersch
via newmobility.com

Urologic Meds and Brain Damage
I’m 62 with spina bifida and have taken these medications off and on for years ["Anticholinergic Meds May Cause Brain Damage," May 2016]. The one I’m on now is Enablex and I have taken it for more than five years. Now I have to wonder if my absent-mindedness is just a natural part of aging or caused by the meds I’m taking. I will certainly bring this up at my next urologist appointment. That is, if I remember.

Craig Cappuccilli
via newmobility.com

NM Bias Re: DME
In many articles in newspapers or magazines, the author of the article will make a disclaimer such as “Full disclosure — I own/patronize/whatever the following product.” I have been troubled for some time about the obvious bias that New Mobility has in regards to durable medical products. In the April issue, I counted the equivalent of at least nine full-page ads for either wheelchair/mobility or seating products. I’m not saying that NM should not be advertising such products, nor should they not write about same. But, I feel that you ought to acknowledge up front that you have another vested interest, a financial interest, apart from having a disability. If you wrote a piece critical of a certain product, would they drop their advertising from NM?

Dan Mayclin
via newmobility.com

Correction:
BraunAbility has advised dealers that installing their products in a vehicle that has not been specifically approved by BraunAbility engineers for such installation will void the warranty on the lift and will require the customer to be given a disclaimer. BraunAbility has informed NM that it has not yet approved the installation in the Mercedes Metris minivan that was reported in our August issue [Motorvation: "What’s new in accessible vehicles"].
Designed from the ground up for universal accessibility, the Mobility Ventures MV-1 is built for wheelchair and scooter users who demand the safest vehicle on the market.

Visit our website to find your local MV-1 dealer and learn more about this revolutionary vehicle.
Project Value: Disability Not Worse Than Death

Founded by five prominent members of Canada’s disability community, Project Value (www.facebook.com/projectmyvalue/) counteracts the narrative that disability is a fate worse than death through a series of videos by people with disabilities testifying to how fulfilling their lives are.

“There is so much more to our lives than misery, helplessness, and pain,” says co-founder Catherine Frazee, 62. Professor of distinction in the School of Disability Studies at Ryerson University in Toronto, Frazee has spinal muscular atrophy type 2. “We want to counteract the dangerous effects of those stereotypes and the prejudice that they fuel, by projecting the energy, vitality, resilience and contribution of disabled people’s lives.”

The inspiration for Project Value came on June 27th when Julia Lamb, a 25-year-old woman from Chilliwack, British Columbia, with spinal muscular atrophy, put forth a constitutional challenge to Canada’s new assisted-dying law. Currently, only those with terminal illnesses qualify, but Lamb and the British Columbia Civil Liberties Association want that criteria expanded to include “those who are suffering with no immediate end in sight.”

The press coverage resulting from Lamb’s challenge emphasized a bleak and terrible future ahead for those with SMA, so Frazee got on the phone with a few people with similar diagnoses and they hatched Project Value.

Project Value is the latest in a series of initiatives from Dear Julianna to The Disability Visibility Project that push back against ableist sentiment. The movie Me Before You glamorizing the suicide of a fictional quadriplegic, teen Jerika Bolen’s decision to disconnect breathing assistance, the murders of 19 people with intellectual disabilities in Japan, and now this constitutional challenge — all are raising questions around the very existence of people with disabilities.

“There needs to be equal time for the other side of the story,” says Sandra Carpenter, Project Value co-founder and executive director of the Centre for Independent Living Toronto. She lives with spinal muscular atrophy type 1. “To us, assisted dying is as absurd as people without disabilities opting for death because they aren’t world class athletes.”

Adults with SMA Question Teen’s Decision to End Life

At press time, Jerika Bolen, an Appleton, Wisconsin, teenager with spinal muscular atrophy type 2, planned to turn off her nighttime breathing assistance at the end of August with the full support of her mother.

“There were a lot of tears, but then I realized I’m going to be in a better place, and I’m not going to be in this terrible pain. I’ve been working on it and thinking about it for way longer than anyone else has,” Bolen told Appleton’s Post-Crescent News.

Many adults with SMA were saddened by her decision and disturbed her mother and the media didn’t question it.

“She’s not sick, she’s not terminal, she’s just in pain. Get her some help, but don’t let her die,” said Emily Wolinsky, president of NMD United, an organization by and for people living with neuromuscular diseases. Wolinsky, who has SMA, is also the creator of Dear Julianna, a campaign in which adults with neuromuscular diseases wrote life-affirming letters to a 5-year-old child with muscular dystrophy whose mother allowed her to die when she said she “wanted to go to heaven” instead of the hospital.

Wolinsky wondered why the media hasn’t investigated Bolen’s 38 surgeries claim.

“Thirty-eight surgeries in 14 years is a lot,” said Wolinsky. She polled her friends and found the most they’d had was two before age 18.

“Maybe it’s the surgeries, not the diagnosis that’s exacerbating her pain.”

Much of the media coverage made a point of saying most don’t survive SMA past adolescence, but there are many examples of adults with SMA who have pain, but lead rewarding lives.

“I use a ventilator most of the day, a wheelchair, and a lot of services and my life (even with pain) is pretty fantastic,” said Alice Wong, 42, founder of the Disability Visibility Project, who has SMA.

Still, there’s a lot of variability in lived experience, shouldn’t Bolen...
have had the right to decide her fate?

“Some in the disability community confuse value of life with quality of life and no one, disability or not, can make a judgment on quality of life except the person living the life. The main right she needed is the right to be herself, provided that self is fully-informed and gutsy,” said Ruth von Fuchs, President of Right to Die Canada. In Canada, assisted suicide is legal for those over 18 when death is “reasonably foreseeable.” But Bolen was only 14 when she made her decision, and without action on her part, her death was not “reasonably foreseeable.”

Bolen’s lack of information may have been the problem — it’s just that no one in the media seemed to mind.

“If this was a nondisabled girl the same age who wanted to end her life for similar reasons, would we have been so quick to support it? Would the media have been as eager to cover a person’s quest to raise money for an accessible van or home compared to a community-wide effort to put together her ‘Last Dance?’” asked Wong.

As of mid-August, Bolen was still alive and efforts were being made by adults with SMA to reach out to her.

*New Mobility* was the only news outlet to interview adults living with SMA about Jerika Bolen’s widely-publicized desire to end her life, and reaction to our news story was swift and passionate. Join the conversation at www.newmobility.com/2016/07/adults-sma-question-jerika-bolen.

**SMA No Obstacle to Happiness**

46-year-old with SMA type 2 here. Virtually paralyzed and in daily pain, but equally very happily married to my nondisabled wife, living in our own home and with a supportive family and cute dog. I’d be surprised to find many people better educated, world travels and happier than me, irrespective of physical ability.

I trust nothing the medical profession tells me, so for a family to be sure of a 14 year old’s decision to commit suicide based on “expert medical advice” leaves me questioning the validity of their choices.

— Kevin Cross, Southampton, United Kingdom

**Stay Out of It!**

Jerika has one of the most known and qualified SMA specialists on her team. She went to different doctors to get second opinions and even went to a hospital that told her when first diagnosed to just take her home and love her, that she would die by the age of 2. Her mom, a medical professional, knows her best.

My 8-year-old son has SMA type 2 and has other diagnoses on top of SMA. I cannot imagine nor do I want to ever have to make this decision, but the Bolens have and it is their right. Leave them alone, they have enough to deal with. And those of you touched by SMA who have commented already — you have things to deal with, too!

— Pam Pytenberg, Little Chute, Wisconsin

**Stay and Fight**

I have a 15 year old with SMA and it would break my heart if he wanted to die. I have a lot of mom-guilt because my son doesn’t have all the abilities like most other 15 year olds, and yes, pain. But when he complains about his back, I say, “well I have to lift you and that chocolate shake you had is going to make you heavier,” and we laugh.

If he told me he wanted to die, I would say over my dead body. I have told him from the beginning that we are in this together. It may be his body that is betraying him, but I made it and I will work as physically hard as I can to make sure he is taken care of.

He asked me if there had been testing available when I was pregnant with him would I have chosen to get tested, and I said yes. The natural next question was, would I still have had him, and I said yes. If I could choose to have him without SMA, absolutely I would, but if he and SMA had to come together, then so be it!

Jerika, at 14, no matter how smart you are, and I am sure you are very, your brain is not fully developed yet. And you are not the first nor the last 14 year old that wants to die. Please do not take this as disrespect, but you need help with pain management, not a suicide plan. Stay. Fight.

— Kirstie Loudermilk, Royal Oak, Michigan

**Get Her Some Help**

When I was Jerika’s age, I had suicidal thoughts. It wasn’t just my diagnosis, it was a multitude of different factors that any body can experience no matter who they are. Jerika could easily have multiple factors contributing to her wish that may disappear if she got some help.

Pain can be eased. I completely understand it takes work, but the work can be worth it.

— Jerry Conner, St. Louis, Missouri

**It Devalues All of Us**

If Jerika didn’t have SMA, she would be getting psychiatric help and treatment and this wouldn’t even be considered an option, I guarantee it. She is not terminal and that’s the part all these supporters ignore. This sets the value for others with SMA to a low level, saying we are not worth keeping alive when we may just need proper help and guidance.

— Scott Menzel, De Pere, Wisconsin

**Call Me**

I am 45 years old, have SMA 2 and live in New Jersey. When I was born, my mother was told to leave me in an institution because I’d never be anything. I graduated from a public high school with honors in 1989. I went to St. Andrew’s University in Laurinburg, North Carolina, and graduated in 1993. I am a singer, writer, and life coach.

Jerika, you have a world of opportunities available to you. There is no reason you can’t have a happy and productive life. The world is bigger than Wisconsin.

You need to talk to other people who are dealing with the same obstacles you are facing. We have so much to offer you. You have even more to offer us. You can Google me, I’d love to talk with you.

— Kimmi Biglin, Glassboro, New Jersey
ne of the nation’s most influential disability rights lawyers, Larry Paradis, cofounder and executive director of Disability Rights Advocates, died July 28.

“Larry spent his life working tirelessly so that people with disabilities would be fully included in all aspects of American life. That is his legacy, and he will be loved and admired forever for it,” said Linda Dardarian, chair of DRA’s board of directors. Paradis was 57.

As a young man, Paradis became a wheelchair user due to disability when he was a law student. He went on to graduate cum laude from Harvard Law School in 1985 and soon after became an associate with Miller, Starr and Regalia, a powerful and respected California real estate law firm. He worked his way to a position of partnership over a 10-year period.

While Paradis was still employed at the firm, the Americans with Disabilities Act was passed. At the time, Disability Rights Education and Defense Fund was the leading disability law firm. Its director of litigation was Sid Wolinsky. “Larry offered to work pro bono for us,” says Wolinsky. “I asked if he had done much trial work, which turned out to be a silly question,” he says. “We hit it off so well, we decided to open our own practice, and that’s how Disability Rights Advocates got started.” They opened an office in Berkeley, California, and later moved to nearby Oakland.

DRA, Paradis and Wolinsky soon became known for class action and other high impact disability rights litigation, specializing in precedent-setting ADA cases involving discrimination in employment, housing, transportation, education, insurance, and public accommodations. Twice Paradis was named one of California’s Lawyers of the Year — in 2003 and 2011 — by California Lawyer Magazine. In 2004 he was voted Trial Lawyer of the Year, along with his co-counsel, by San Francisco Trial Lawyers Association. A number of DRA attorneys have been honored with awards over the last several years.

In 2010 DRA announced it was opening an office in New York City. They had done work in conjunction with United Spinal Association and other disability organizations that had national impact. Perhaps their best known case was the NYC cab lawsuit, Taxis for All Campaign v. Taxi and Limousine Commission, et. al., which resulted in NYC agreeing to make 50 percent of its cab fleet accessible. “On his first trip to New York City after the new DRA office opened, Larry couldn’t get a cab,” says Wolinsky. “I flagged down a cab, it stopped, Larry rolled out to get in, and the cab sped off.” It was then that DRA got involved in a big way in the NYC cab case. “Larry was not to be trifled with,” quips Wolinsky.

As for the future of DRA now that Paradis is gone, his work and devotion to their mission will continue to guide the organization. “Larry is irreplaceable,” says Wolinsky, “not only to the disability rights community, but to all of us at DRA. We intend to carry on his legacy in all the areas he’s been most interested in – access to technology, the sidewalk accessibility cases that began in the 1990s [Barden v. Sacramento; Californians for Disability Rights, Inc. (CDR), et. al. v. California Department of Transportation], and now similar cases involving NYC and Long Beach, California.” DRA has also been a leader in bringing about accessibility improvements in the health care industry nationwide.

In nearly three decades of disability rights litigation, Paradis did not lose a case, says Wolinsky, “at least not one I can remember.” According to Kate Hamilton, director of development and communication, DRA itself has almost never lost a case. Even more important, she adds, Paradis and DRA have always been focused on getting results for the disabled community, often through negotiated settlements. “It’s not about fees or winning. This is what makes DRA unique,” she says.

Larry Paradis will be remembered not only as a superb lawyer and champion of disability rights, but as a beloved husband and father. He is survived by his wife and two sons. A Larry Paradis Legacy Fund has been established to help carry on the work that has defined his life (more info at dral egal.org). A Celebration of Life was held August 31 at the Ed Roberts Campus in Berkeley.
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L. McCartney  Logan will be getting a new one like this in a couple of weeks. He picked Limelight for the color. We’re so excited.

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Q. I am confused about what has happened to parking spaces for those of us who drive vans and must unload from side ramps or wheelchair lifts. I have usually been able to find at least a few parking spaces in large parking lots that would allow me to unload safely without being blocked by another vehicle. That is no longer the case, at least at one of my favorite stores. Their parking lot was recently resurfaced, and in the process they restriped the lot. The “Van Accessible” signs were still there, but gone were the wider aisles that allowed me to unload without risk of being blocked. When I asked the store manager why the dimensions had been changed, he said that it was the latest requirement under the Americans with Disabilities Act.

I thought any changes to that important law would be for the purpose of making things better, not worse. Why did this happen? If every parking lot is changed, there will be limited opportunities for parking by those of us who need vans with lifts and ramps. Is there anything that can be done to restore what has been lost?

— Still Looking

Your observations of fewer wide access aisles are correct. When the ADA was reauthorized in 2009, there were several changes made in the standards. Those changes took effect in 2012. Van parking space dimensions, particularly the access aisles meant to allow space for unloading, were changed in the process. They were reduced from 96 inches wide — sufficient for unloading off the end of a ramp or lift — to 60 inches wide in the new configuration.

I checked with the federal agency responsible for these standards — the U.S. Access Board — to get an explanation. Board staff responded that when the regulations were being discussed prior to finalizing them in 2010, the board considered complaints it had received for several years that the wider access aisles were mistaken for parking spaces, so people often parked there, blocking any unloading from vehicles parked in adjacent accessible spaces. This happened to me on a couple of different occasions. In both instances I was able to contact law enforcement and the officers issued tickets. The next step was to have the vehicles towed, but both drivers moved their cars prior to the tow trucks arriving. At that time the fine for illegally blocking an access aisle in California was over $1,000, so hopefully those drivers learned an expensive lesson. However, this may not be occurring in other jurisdictions.

The good news: In the new parking configuration, a total width of a van parking space plus the adjacent access aisle remains the same as before. The 36 inches taken away from the access aisle was simply added to the van parking space. A van can park farther from the access aisle and still make use of it even if a vehicle is parked in the space on the opposite side of that aisle.

Also, the changes in the 2010 ADA standards actually increase the number of van accessible parking spaces — from one accessible van space per eight accessible spaces to one accessible van space for every six accessible spaces in any parking facility. It is also important to note that the previous configuration for van parking spaces with wider access aisles is still legal under an exception (Section 502.2), so you may see parking lots restriped without any obvious change in the dimensions of the van parking spaces.

For those who want to make a change in parking regulations, there are some steps that can be taken by advocates at the community level. The use of available van parking spaces by people who drive smaller vehicles will continue to be a problem unless state or local parking laws are changed. Local jurisdictions are responsible for parking enforcement, and could mandate a change to “Van Only” parking signage. They could also require that the words “No Parking” be stenciled as part of the access aisles, in addition to stripes. Local leaders, like mayors and chiefs of police, can also step up enforcement of disability parking laws, and advocates can make sure that the media are aware of that emphasis.

Anyone wishing to recommend or request a change to the ADA Standards can do so by writing to the U.S. Access Board at the address listed in the resources below. Their periodic board meetings are usually available via webcast, and it takes public comment at those meetings. Referring to the applicable standard by number, and with a clear statement of concerns and suggestions, will help assure that your problems are addressed.

Resources
- DOJ ADA website, www.ada.gov
- ADA Information Line, 800/514-0301 (Voice) or 800/514-0383 (TTY)
- ADAAG Technical Assistance, ta@access-board.gov
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07/16 740-01451-MKT-06
Mother to five children and married to a pastor for over 17 years, Alicia Reagan, 39, is not your average pastor’s wife. In 2009 while pregnant with her fifth child, she began to feel ill. After lying down because of blinding pain, she woke up — paralyzed.

“When I awoke, I felt weird all over. My arms felt like they weighed 100 pounds each,” says Reagan, who had contracted transverse myelitis and was officially diagnosed with C5 incomplete quadriplegia. Eventually she regained upper body function, including her fingers, and delivered her baby successfully.

Transitioning into her post-injury life, however, definitely posed a challenge. “When I first was in a chair in my community, I was so embarrassed! What helped me was seeing YouTube videos of some amazing and confident wheelchair users. I came to see the wheelchair as my freedom — not my prison.”

Fortunately, her children transitioned much more easily. “They didn’t even care a hoot about the wheelchair. I worried that they would be embarrassed or resent me, but they have not. My youngest three don’t even remember me not being in a chair.”

Her relationship with her husband also took some transitioning. “Jimmy and I decided early on that this was ‘our’ disability, because it certainly has affected his life, too, and neither of us were going anywhere. We took our marriage vows seriously. We want to be the old people that have been married for 50 years. So we don’t run when things get hard,” she says.

Now a popular blogger and vlogger sharing her life, mothering and more, her advice is helping thousands, and she couldn’t be happier. “I love being a disabled, happy voice in a world that still mostly feels that disabled voices are unhappy.”

“Nothing Can Take Down This Mama Bear

Sand’s Worst Enemy

Beach sand and wheelchairs are a notorious combination that every wheelchair user knows well. “Stay off the sand unless the sand is hard!” is what you are told, and definitely don’t scoff at this advice. Getting stuck in the sand is no picnic. However, beach access mat manufacturer AccessRec is hoping to change this with its line of sand mats. AccessRec sells four different varieties. Its AccessMat is a portable polyester roll made for temporary use, and its DuraDeck 2 beach mat is made of super strong plastic plate. The Mr. Boardwalk mat is a rollout walk-away system made from teak and plastic; and the PathMat is the least expensive, made from a rubber-like surface. Ranging in price from $10 to $33 per square foot, all mats are custom ordered in length.

See them online at accessrec.com/ada-access-mats.

Singing With Heart on Her Sleeve

Paralyzed 25 years ago in a car accident, Katie Rodriguez Bannister, a 51-year-old C5 quadriplegic from St. Louis, Missouri, has created a CD called “Beauty in the Lou: Songs and Poetry” — songs on her journey of living with a disability. You can view two music videos from her album on her site — access4all.com.
Eating Right When the Budget’s Tight

People with SCI are at risk of developing a host of serious, debilitating and potentially life-threatening secondary health complications. A nutritious diet can help prevent and/or manage many of these conditions. However, finding ways to eat well on a tight budget can be a challenge. Here are 10 tips on how to get healthy foods in your diet and save money:

1. **Make a weekly plan**
   - Make a list of meals for the week. Avoid excess buying and budget your meals.
   - Collect coupons and buy items on sale.
   - Do not shop hungry.
   - Cook more and eat out less. You’ll save more than you can imagine.

2. **Eat whole foods**
   - Many nutritious whole foods (fruits, vegetables, legumes and whole grains) cost less than fast food, chips, cookies and pop. Fast foods may fill you up, but they often lack nutrients and fiber, are loaded with salt, sugar, additives, preservatives and bad fats, and they contribute to secondary health complications, such as obesity, cardiovascular disease and type II diabetes.
   - Take a pass on prepared foods, pre-cut fruits and vegetables, frozen meals and/or vegetables in sauces. They save time but cost more.
   - Nutrient-dense whole foods (nuts/seeds and whole grains) fill you up so you eat less. Refined carbohydrates, processed foods and sugars cause cravings and overeating, which in turn means spending more.

3. **Build your main meal from whole grains and legumes two to three times a week.**
   Quinoa, whole grains and legumes (beans) are less expensive than meat and contain complex carbohydrates for sustained energy, fiber for better bowel function, protein for tissue repair and growth, and other essential vitamins and minerals that our bodies need.

4. **Buy and cook in bulk.**
   Grains and legumes can be bought in bulk inexpensively. Prepare bean salads, chili and stews in quantity and freeze in meal size packs. This makes for healthy, quick, easy meals during the week.

5. **Skip the middle aisles.**
   The middle aisles are where the processed foods are kept. Shop on the outside edges where the whole foods are located.

6. **Buy local.**
   Buy fruits and vegetables that are grown locally and in season. Farmers market foods are usually fresher and less expensive.

7. **Grow your own vegetables and herbs.**
   If you lack space, grow produce in large flower pots or balcony planters.

8. **Wash fruits and veggies well!**
   Not all produce is created and/or grown equally. Some contain fewer pesticides than others. Just make sure you wash your fresh produce well — especially spinach, bell peppers, potatoes, celery, peaches, strawberries, raspberries, apples, grapes and pears, which tend to have higher pesticide levels.

9. **Don’t throw out wilted vegetables or fruits.**
   Save them for smoothies, stews, soups. Freeze them and use later. To keep celery crispy longer, wrap it in aluminum foil.

10. **Shop off hours.**
    Shop late Saturday night or early Monday morning and take advantage of marked down prices on meat and produce.
VMI’s industry-leading interior space offers flexible seating, expansive headroom, and enough floor space to execute a full 360° turn. Even the largest power wheelchairs have room for maneuverability in a VMI van.

HURRY! LAST CHANCE TO ENTER IS OCTOBER 15

ENTER ONLINE: VMIVANS.COM

OR BY PHONE: 855-VMI-VANS (864-8267)
This is a story about neck surgery. I know, sounds dreadful and downbeat. But it’s not all sawbones and sutures. It’s full of personality and positivity. So stick around, meet the cast, and maybe if the message resonates, you’ll slow down some, take just a little better care of your body, and never again have to see the words anterior cervical stenosis with disectomy and fusion.

The story starts with Deborah Davis, who wrote a cautionary article in her website PushLiving.com last December called “Save Your Spine.” Davis, the New Mobility Person of the Year in 2014, lives in Florida, is 51, has two daughters, 26 and 24, and has been spinal cord injured since age 19; she’s a C6-7 quad but functions more or less as a para, with no balance — which means she falls. A lot. In 2014 she did a full-weight face plant on to a commode. She had a concussion; it took her weeks to stop the vertigo and to see straight again. At the time this happened, Davis already knew her spine had issues, as 18 months earlier an MRI revealed cervical nerve invasion, just not yet to the point of no return.

Last fall, Davis attended a conference in Fort Lauderdale, pushing herself across town in a wheelchair with a damaged seat and poor support for her body. A couple days later she experienced debilitating neck strain and her head felt heavy. “I thought it would work itself out, as usual. But it didn’t,” she says. “I went to see an orthopedic doctor, who sent me to a neurosurgeon. I normally hate to go to the doctor. You know me, I’m great with the van-
ity issues — my skin, my hair, my nails, my clothes. This time I realized it’s a lot more than being slim and pretty.”

Davis went in for a new MRI, where they saw clearly that her cervical spine was still degenerating. “There was a big blob of disc material herniating into the cord,” says Davis. Unless she got surgery to repair it, she faced a very high risk of becoming a higher level quad. When the doctor tells you your spine is a mess and that the blob is only going to get worse, and that if you fall again it could dramatically raise your level of disability, it gets your attention. “My doctor and I didn’t want to risk having me lose my independence. Not doing surgery was riskier than doing it.”

I did not anticipate that Davis’s marital status would be part of the story, not until she revealed to me that she got married again (number four) in December, just days before the surgery. She said she kind of “freaked out” about all the what-ifs before the operation — worrying about her daughters, her business, her affairs. She said it would have taken months to get everything in legal order. So, here’s Frank, a dating partner for a year and a half, soon to be the designated guardian. “We were not sure what we were going to do,” she says. “But we weren’t going to leave each other, so we said, ‘let’s do this.’”

Davis’s diagnosis: cervical stenosis. What that means, simply, is that the canal formed by the spinal bones to encase the delicate spinal cord has narrowed, typically because the discs that cushion the vertebrae are bulging, or because bone growth is beginning to pinch into the cord or into nerve roots. Her surgery opened the neck from the front, then moved the larynx and esophagus out of the way to get at the spinal column. Doctors exposed the backbones in the neck, removed the bloboid pieces of the damaged discs, propped the vertebrae open with fake disc material, and cut away any bone that might have been pressing on nerve roots. They tidied up by fusing the vertebrae with bone material and a titanium plate.

This type of surgery is fairly commonplace, especially among older folks. According to the medical literature, more than 85 percent of those over 60 have cervical degradation, or spondylosis, even though it might not be symptomatic. Make that 100 percent of those over 70. Why? Wear and tear on the backbones. Add wheelchair living to that, with years and years of arms being legs, and it’s a recipe for overuse and degeneration.

THINGS WEREN’T RIGHT

Now meet Erin Gildner, who runs the United Spinal Association chapter in Arkansas. She is 36, married, has two boys, 10 and 12. Gildner was spinal cord injured, T11-12 in 2002, in a motor vehicle accident. At the end of 2014, she fell hard, felt numbness and tingling, had no loss of strength but had pain in her neck and shoulders. “It was a stressful time. I gained weight and wasn’t physically active.”

Last June, Gildner fell again in a hotel room during the United Spinal Roll on Capitol Hill. It did not seem serious at first. But when she came back to Arkansas, things weren’t right. “I got more numbness and tingling, began to lose a lot of strength, especially on my left side, which is my dominant side. I couldn’t transfer into a vehicle or take my chair apart. I had a hard time gripping things. I got an MRI that showed cervical stenosis — the nerve canal in my neck was closing in on nerve roots.”

Gildner’s doctors opted to start with more conservative options — intensive physical therapy, massage, and traction, with 20 pounds pulling on her skull to relieve her spine. This worked a little. But by October, her pain increased and even her bladder function got worse. “I started to feel achy all the time. My face was bloated. I was just not myself.”

Gildner didn’t know it yet, but she would soon join Davis in a sisterhood of spondylosis. A while back Gildner had started a private Facebook page for women with spinal cord injuries. Davis, one of about 125 members, posted last November that surgery
had been recommended for her own stenosis, and does anybody have any experience with this? A couple of weeks later, Gildner responded that, OMG, I'm having the exact same procedure, for my own disc issues and bone spurs at C5-6 and at 6-7.

Gildner’s surgery was pretty much exactly like Davis’s. They came in from the front of the neck, took two discs out and put in what they call cages to keep the vertebrae aligned, used a cadaver bone paste to fuse the entire segments, then added the metal plate.

Gildner, in Arkansas, had her cervical spine redone six days ahead of Davis’ surgery, in Florida. They compared notes and sent each other get-better presents.

DID IT WORK?
It wasn’t like flipping the on switch to off, says Davis, but she woke up with no numbness in her hands. Neck pain was gone. Her head didn’t feel so leaden. She was able to go home, with some part-time home health aide, new spouse and family care during the early days. She’s had some issues with swallowing. But she’s happy she did it.

Gildner is even happier. Her situation was “instantly better” after surgery. “It was actually kind of miraculous,” she says. “I thought there was going to be a long recovery, lots of PT, I thought I would be hurting. But it was not anything like what I thought.” Gildner came home and in all, only lost about four weeks of time away from work. She still has issues with her voice (the surgery roughs up the vocal cords) but she has lost weight and is stronger and busier than ever. Gildner is even happier. Her situation was “instantly better” after surgery. “It was actually kind of miraculous,” she says. “I thought there was going to be a long recovery, lots of PT, I thought I would be hurting. But it was not anything like what I thought.” Gildner came home and in all, only lost about four weeks of time away from work. She still has issues with her voice (the surgery roughs up the vocal cords) but she has lost weight and is stronger and busier than ever.

Quadriplegics, who often already have spinal column fusions, are prone to stress on the bones, and thus stenosis, in the areas above and below the fusion, says Falci. “This can create a difficult decision. We need the area to be decompressed but we don’t want the person, who depends on neck mobility, to lose flexion and extension. People need to be able to bend their neck, so sometimes we agree not to fuse, even though in the future that area could become unstable and require it.”

Advice: If pain gets worse, if function starts to change, get an evaluation. “It doesn’t mean you have to do anything, but at least you know your options,” says Falci. Some people, at the first sign of functional loss, “jump at surgery. They don’t want to lose anything else. Others may watch as they become more paralyzed, so to speak, but learn over the years to accommodate it and modify their lifestyle. If they’re good with that, I’m good with that.”

KEEP THE NECK STRONG
Rick Mason has spinal stenosis and he’s good with it. He’s 58, a C6-7 quad, manager of a bicycle program in Sacramento, California, a 40-year veteran of the SCI club. “It causes lower back pain, which gets worse with sitting and movement throughout the day,” he says. Mason is one of those super active guys — a former competitive swimmer who’s tried it all — handcycling, rugby, tennis. “I’ve used and abused my body. My arms have been my legs, too, for 40 years, and it’s finally catching up to me.”

Billy Altom declined neck surgery for his cervical stenosis, but many people with paralysis opt for surgery because “they don’t want to lose anything else,” says Dr. Scott Falci.
Since 2012, my husband Patrick and I have traveled to 21 countries together. I use an electric scooter for mobility and a ventilator for breathing, and Patrick, who is nondisabled, is flexible and supportive. We prefer adventure-some and authentic travel experiences, so we have stayed in people’s homes from Tahiti to Iceland to Greece, that are offered through peer-to-peer lodging websites like Airbnb, VRBO, HomeAway, FlipKey and HomeExchange.

We have met hosts who offered extraordinary hospitality, and everything from delightfully wheelchair accessible homes to impossible to access toilets, houses with steps where none should have been, and monumental misunderstandings that led to unnecessary difficulties. Access is a highly personalized concept — what works for me might not work for someone who has my same disability but a different personality. So while we would not exchange our travel experiences for more accessible and sanitized touristic hotel stays, we do have minimum requirements that we have to work within. What we have learned through our extensive travel experiences is that we, as travelers with disabilities, have to ask numerous detailed questions, and we have to be prepared with plan B if a lodging turns out to be just too hard to manage.

The Good, the OK and the Unmanageable
Although it can be time-consuming, it is possible to secure accessible — or accessible enough — homes using peer-to-peer lodging sites. Following are a few of our successful experiences, and one unsuccessful booking.

We arrived in Paris midafternoon on a very hot day and strolled several blocks from the Gare du Nord to our rental, dragging our roller bags behind us. We had chosen this lodging for proximity and wheelchair access.

Upon arrival to this 19th century building, I was blocked by a small threshold at the front door. Quickly problem solving, the host offered us a large wooden cutting board to use as a ramp. Hurray! It worked. We were ushered into this impressive basement apartment featuring a glass roof, ultra modern furniture and replicas of classical sculptures. We’d never seen a home like this.

While the bathroom was a little cramped, the AC a little weak for this 100 degree day, what an experience to stay in what seemed to be an imitation of the glass pyramid at the Louvre! Even though this apartment was not completely accessible, we made it work and were rewarded with a unique lodging experience.

Similarly the apartment we rented in Reykjavik offered insights into life in Iceland. It was 40 degrees and raining outside, but since geothermal energy is provided free to every household by the government, a cozy heat steamed up from the floor to warm our travel-weary bones. The midnight sun played tricks with us at bedtime, and black out curtains had to be deployed to block the sun, which shone well past 2 a.m. The bathroom — with free unlimited hot water — proved easy to use as every modern apartment in Reykjavik is built to standards that make it useable and visitable by wheelchair users.

When we traveled to Santorini, I did not expect the picturesque whitewashed dwellings to be a possibility for me. Much to my surprise, after an extended search, we found a largely accessible typical Greek home of white stucco and blue balconies overlooking the sea. Ramps to the
One of the brightest developments in peer to peer lodging is Accomable.com. Launched in 2015 by travelers Srin Madipalli and Martyn Sibley, who both use wheelchairs, Accomable is an insightful and intuitive lodging website run by and for people with disabilities. While many lodging providers ignore the accessibility questions that travelers with disabilities need answered in detail, Accomable offers extensive check boxes for nearly all accessibility questions, and video verification so that travelers and hosts are fully informed. Accomable asks hosts detailed questions about accessibility and connects travelers with accommodations that offer the level of access each traveler specifies.

Madipalli feels Accomable offers something uniquely valuable to travelers with disabilities: “You can trust that all of our properties will have the accessible features they promise. It’s the reason we started Accomable. I have spinal muscular atrophy and use a motorized wheelchair, and while I love to travel, I grew very frustrated with arriving at an accommodation that advertised itself as accessible when it simply wasn’t. We’re trying to change that.”

“Accomable is like the Airbnb or FlipKey for people who have a disability or mobility issue,” says Madipalli. “We recently set our guarantee that all of our listings will have step-free, wheelchair-friendly access to the main entrance, bedroom and bathroom with at least one other adaptation. To do this we use video technology to verify the adaptations of each and every property that goes onto our site.”

In addition to providing lodging listings for travelers with disabilities, Accomable advocates for travelers with disabilities by creating partnerships with mainstream travel providers to document and improve accessibility. “We also work with large scale hotels, and have just signed a deal to work with the Hilton London Bankside as well as Radisson Blu and InterContinental Group, and they are extremely motivated to show off their incredible accessible rooms and facilities, and welcome disabled travellers,” says Madipalli. “We’re also working with HomeAway at the moment to identify which of their properties are accessible, so we can list them on Accomable.”
upstairs — although steep — were serviceable; outdoor seating area complete with a grapevine-covered pergola and traditional BBQ grill, swimming pool and newborn kittens rounded out our idyllic moment in Greece.

But our trip to Portland, Oregon, was a disaster in miscommunications.

After a long travel day, we checked into our rented studio. We spent a few hours setting up my medical equipment, then we got washed up and settled into bed. All of a sudden, an insistent knock came at the door. Well after midnight, it seemed this must be a mistake, but the knocking became louder and louder. “You have 10 minutes to get out of here!” the angry voice screamed.

I use a ventilator and electric scooter and cannot get in or out of bed solo. So Patrick turned on the light, put on some clothes and answered the door. We asked the irate woman to come in … but she wouldn’t enter and wouldn’t talk to me, only Patrick. She stood at the door getting more and more agitated. As manager of the building, she demanded to know how we got in.

We were confused: We had arranged through Airbnb to use our host’s apartment while he is in Germany. We had spoken to him by phone to confirm the measurements of his bathroom and doorway, the address and legitimacy of his listing. Andrea, his upstairs neighbor, gave us the keys to the apartment and told us the building rules. The apartment was a small, ground floor, centrally located studio. We thought we had hit the jackpot for our month stay as the studio was ADA-compliant with a roll-in shower, but what we didn’t know was that this building did not allow sublets.

“I don’t know how you got in, but you have 10 minutes to get out, or I’m calling the police,” the manager growled. Patrick and I looked sideways at each other. We are not the type of people who could have “snuck in.” We carry two to three suitcases of equipment, ramps, medical supplies and other disability-related items when we travel. We stand out in any situation.

Indeed the manager did call the police. Two young officers showed up right away and it was agreed we’d vacate the apartment by 10 a.m. the next morning.

We spent the following days in a whirlwind of trying to find an accessible place to move to, to get a refund on what we had paid, to get back the taxes paid separately. We also spoke to the people at Airbnb. While compassionate, they had little disability experience and fewer ideas how to help. Specific requests we made had to go up the food chain to supervisors and were generally denied. What might have worked for a nondisabled guest did not work for us: there were only a few listings identified as accessible that were available this late in the game.

Ultimately the listing where Airbnb moved us was neither actually accessible nor was it a legal short term rental.

‘We’ll Look Into That’

In addition to problems with accessibility, some people with disabilities report being screened out by potential hosts. It’s common practice in lodging networks for the host and traveler to post a profile with self-description and identifying photo. We who have obvious disabilities know that nondisabled people often make assumptions based on disability stereotypes that can lead to discrimination. This kind of visual discrimination is common on lodging websites.

“I actually had someone refuse my booking just because I asked how many stairs there were into the lodging when I could see stairs in the photos,” says Curtis Walker, 39, who walks with difficulty and has chemical sensitivities. “I have had so much trouble finding lodging that does not have chemical issues that I accept stairs when I select a place to stay,” says the Portland, Oregon, man.

As Walker found, guests with disabilities who ask specific accessibility questions to hosts before booking or whose profile photos reveal their disabilities face the same potential for discrimination as African American guests whose profile photo reveals their race. However, no one in the peer-to-peer housing industry is talking about disability or increasing disability access to listings. Despite a big push by Airbnb to become more racially inclusive, the company has been conspicuously silent on treatment of guests who have disabilities. (Repeated requests for comment were ignored by Airbnb.)

When potential guests with obvious disabilities experience disability discrimination on peer-to-peer lodging sites like Airbnb, HomeAway, VRBO and Flipkey, they find it difficult to verify whether a host was acting in a discriminatory way. When queried about this issue, companies usually assure guests by saying “we’ll look into it,” but of course nothing comes of that. Companies should have a more rigorous way to track issues between hosts and guests and eliminate discriminatory players.

Trust but Verify

Difficulty in using peer-to-peer housing websites is common for travelers with disabilities,
as Crystal Evans, 35, a wheelchair user from Boston discovered Labor Day 2015. The host had mentioned other guests who use wheelchairs, which led Evans and her husband to think the house they booked was accessible. But when they arrived in the evening, they found that it was not.

“My husband used Airbnb and got a house in Maine with a ramp, but when we arrived, there was only a ramp to the porch and a 10-inch step into the house,” says Evans, who has a neuromuscular disease. “The bathroom was not accessible — it had sliding shower doors, which are far harder than a tub with shower curtain to transfer into. And no grab bars.”

There were no nearby lodgings in this rural area and no cell phone or landline service to look into other options.

Other families traveling with them helped lift Evans and her wheelchair separately into the house, but it was a dangerous and difficult transfer that had to be done a couple times a day. They eventually found a couple of boards to make a makeshift ramp, but it was neither sturdy nor smooth and required several helpers each time. And there wasn’t a solution for the inaccessible bathroom so Evans “just did what I could.” Even the outdoor area where the families gathered by the fire pit was inaccessible to Evans due to gravel.

Evans still wonders how former guests who use wheelchairs had negotiated the steps and narrow doorway. Most nondisabled people think they know enough to list their home as accessible, but she stresses, “people don’t always know what accessible means.”

The system needs to be more detailed and interactive, rather than just taking someone’s uneducated word that a house is accessible. “The consequences are serious,” she points out, and the responsibility for clarity around access is shared between the host and the traveler.

With all of the problems she experienced, would Evans use Airbnb again? “Yes! I just know what issues to look out for next time,” she says.

Even when you ask all the right questions, problems may still occur. “Airbnb is kind of a crap shoot,” says Mike Neher, 53, a quad from Brownsville, Oregon, who uses a manual wheelchair. “I found one guy in Paris who was a wheelchair user and he had a great place. The place we stayed in London said it was accessible, but had a step in the front door. As you know, you always have to double-check when they say it’s accessible.”

CEO and co-founder of Airbnb Brian Chesky stresses the importance of building a community of trust and a sense of belonging. While people with disabilities may feel welcome at Airbnb if things go ideally between host and guest, experiences like Evans’ and Neher’s suggest guests with disabilities don’t yet fully belong to the Airbnb community and should embrace the old adage “trust but verify.”

**Knowledge is Power**

While travel with a disability may be fraught with unforeseen difficulties, understanding the culture where you are traveling may also help avoid issues. For instance, in Europe, one step is not considered inaccessible, as most people who use wheelchairs travel with an assistant.

In France most toilets are in a separate smaller closet from the shower and sink “wetroom.” Often European bathrooms have a bidet next to the toilet, making a small bathroom even smaller and wheelchair transfers very difficult. In Asian countries, hosts will not generally offer a photo of a toilet when showing the bathroom, so you’ll have to ask. In Greece nearly all showers are enclosed by glass and placed right next to the toilet, leaving no room for the wheelchair or transfer.

There’s a big world out there and lots to learn about navigating it successfully. Knowledge is power in terms of accessibility. Rather than being scared or intimidated by travel, gather detailed information, make a back up plan, and go!

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**Tip:** “Contact hosts in advance to discuss access in detail. Have hosts measure door widths and bed height. Ask about terrain in general and if there is gravel, pavement, hills or bumps in the path of travel.”

— Crystal Evans

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**Peer-to-Peer Websites that Filter for Wheelchair Access**

**EXEMPLARY:**
- Accomable.com (worldwide listings, high scrutiny of access)
- Handiscover.com (listings in UK, Europe)

**FUNCTIONAL FILTER, BUT VERIFY WITH FOLLOW UP QUESTIONS:**

Although the following websites may list dozens to hundreds of accessible homes, only one or two may actually work for wheelchair users, so it is important to verify whether the access will work for you and your situation.

- homeaway.com
- vrbo.com
- flipkey.com
- roomorama.com
- housitrip.com
- 9flats.com
- homeexchange.com
- lovehomeswap.com
- guesttogoquest.com
- knok.com
- couchsurfing.com
- misterbandb.com
- vacationhomereatals.com
- travelmob.com
- windu.com
“I took a social handicap, being black, and transferred that fight to a physical disability. But this time I got ammunition!”
Daryl "Chill" Mitchell — ex-rapper, T4 SCI, disability activist, actor, currently the co-star of *NCIS: New Orleans* — is at war.

So far he seems to be on the winning side. Nowadays he is arguably the most steadily-employed actor with a disability in Hollywood. And certainly the most steadily-employed black actor with a disability. He belies all of the pathetic statistics on the hiring of performers with disabilities in film and television. The most recent survey, courtesy of GLAAD, shows that only .09 percent of all characters on network television last season were people with disabilities. Another study from the Ruderman Foundation found that 95 percent of those characters with a disability are played by actors without a disability. We are talking even small speaking roles a la, “Can I get you another Scotch, sir?” There are no statistics on black actors with disabilities. It’s a demographic too small to sample.

Chill’s war — his metaphor — has been a protracted one that he has been engaged in most of his life. The first campaign was hip-hop. That’s where the name “Chill” came from. It’s short for “Chill-e-dawg,” a moniker given him by one of his comrades in the three-man rap group, Groove B. Chill. Along with Gene “Groove” Allen and deejay, BiLal, the group started at the bottom on their home turf of Long Island. They built their reputation by busting rhymes in front of Bronx theatres off the back of a flatbed truck — until the police showed up. It worked. They got a major record deal, cut an album, “Starting from Zero,” which led to meeting filmmaker Reginald Hudlin, which led to a role in the Kid ‘n Play movie, *House Party*.

He then decided to leave hip-hop and become a full-time actor in Hollywood, a black actor with few contacts in a place where working black actors can all fit in a corner booth at Canter’s Delicatessen. He realized he was an alien in a strange new world. He carefully observed how others behaved, learned from their mistakes, and figured out a way to do it in his own style. It was one skirmish at a time.

He got bit parts on the *Cosby Show* and *Law and Order*, a meatier role in the Steve Martin comedy, *Sgt. Bilko*, and then became a regular on two network series, a rarity for any actor. The first was *The John Larroquette Show*, a modest hit, followed by *Veronica’s Closet*, a modest miss. Battle won, right?

One day in November 2000, Chill took off on a nephew’s motorbike at a family gathering in South Carolina. Though a skilled cyclist, he missed a turn, hit some soft terrain, spent three days in a coma, and ended up a T4 para. The story begins again.

Post-accident, Chill got back on the acting horse pretty quickly, motivated, in part, by the need to take care of his family. In less than a year, he became a regular on the NBC sitcom, *Ed*, playing (what else) a paraplegic injured in a motorcycle accident. After a few more guest spots, he then jumped to a starring role tailor-made for him. The Fox series was called *Brothers* and starred Chill and...
former football great turned media star, Michael Strahan, as two estranged brothers trying to reconnect. Because of poor ratings, the show was cancelled after 13 episodes. Nevertheless, Chill gained even more recognition upon receiving the coveted NAACP Image Award for his role as a paraplegic struggling to keep a restaurant going. He cried on stage. He felt validated.

Skip ahead a few years. Chill can currently be seen weekly on the sixth most-watched TV series in America, NCIS: New Orleans. He plays Patton Plame, an “investigative computer specialist,” or more snidely, a hacker. He has given himself the nickname, “Triple P,” the third P for Perfection. He's that kind of brainiac/wiseacre. The series goes into its third season in the fall and could go on for years.

One successful actor in the performers-with-disabilities category does not reflect a trend, but it doesn’t hurt to investigate how he did it. Who is this guy? How did he pull off something so rare? Is he just incredibly lucky, incredibly talented, or what? He is quick to answer: “A little adversity goes a long way.”

Chill Mitchell often speaks in aphorisms, probably because one, he's a former rapper with a gift for pithy phrases, and two, he has his game down pretty well after all the battles he has fought. To him, they are all of a piece — learning to live and thrive with a disability.

“Being a minority, I had to do the same thing. Not only that, but being a rapper coming into acting, I had to do the same thing.” The thing he had to do was to divert people’s attention from seeing him as either a black man for half of his career, or a disabled black man for the other half.

Early on, he used to walk into a casting session and the people on the other side of the table, having seen his resume, were thinking, “Oh, no, he’s a rapper,” with all the baggage that carries (e.g., he might be belligerent, secretly hate all white people, or start trouble just for fun). How to counteract that? Don’t talk street, don’t dress street, don’t bring your posse to the reading, and most importantly, be prepared for the role at hand.

He tells a follow-up story about being a regular on the Kirstie Alley vehicle, Veronica's Closet. “I always had wardrobe bring me a suit jacket when I was on the set, even if I had on jeans and a T-shirt. You know why? Because I had to make the writers not see the street in me. I wanted them to write human stories, not rapper stories. Everyone else can be as casual as they want to be. Me, when I’m casual, I’m hip-hop. If you see me with my hat back and just a T-shirt, you’re going to see hip-hop.”

Post-paralysis, Chill applies the same logic with his disability and all of its presuppositions. (He’s got a chip on his shoulder, will ask for favoritism, or will call in sick every three days.) In essence, don’t roll in talking about your disability or in any way pointing attention to it. Roll in talking about the show you are casting for and the role you are about to get.

His attitude is playful, but he is dead serious about the work. “I’m not going in there with a script in my hand,” he says, “I’m going in there ready. I never come in the room as a disabled actor, I come in the room as an actor. Because I know they are going to look at me crazy. But when I leave, no matter how they looked at me, they’re going to say, ‘He was prepared.’”

Chill experiences the same obstacles anyone in a wheelchair experiences. He just spins them differently. He refuses to be denied. His manager, he says, taught him a powerful word: No. Meaning, “No, you ain’t gonna lock me out of this audition.”

He talks about the time, for instance, where he got to a casting session and was staring at a long staircase he could never get up. Many a disabled actor would be offended and leave. Chill called the casting person up and convinced him to come down and sit in his car and listen to his reading. “I wasn’t asking too much,” he says. “I told the guy, ‘Hey, what are we going to do?’” Just by being persistent, not to mention not shaming the guy, he had already left an impression.

From the beginning of his acting days, Chill insisted on being considered for mainstream projects, not just the occasional black-centric ones. He told his then-manager: “I know they are going to

‘It isn’t about my talent, but about my personality.’

Getting an acting job is a skill Chill has mastered and it’s not a bad analogy as to how anyone in a chair might function in the world of jobs. Here you begin with a casting session. The whole audition process is a form of acting. The more you hone your performance, the more you up your chances of scoring. As Chill says, “When you get into that audition room, you have 10 seconds to give them that vibe. Ten seconds. You got to give it to them. The minute you turn that door knob, you got to be in charge.”

But what if they are uneasy in your presence and lock in on your wheelchair and your “tragedy?”

“I’m sure they may be uncomfortable, but I don’t give them the time. I rely on my strength and my strength is my sense of humor.”

‘It’s not your physical appearance, it’s your mind.’

Winning an NAACP Image Award for his role on Brothers was a high point for Chill. He cried on stage.
treat me differently, but you go to war for
me and when I get in that room, I’ll take
over.” This kind of chutzpah is almost a job
requirement in Hollywood. There’s a fine
line, though, between being engaging and
entertaining or being obnoxious and over-
bearing. Given his track record, Chill can
apparently walk that line pretty skillfully.

In life as in acting, Chill often displaces
awkwardness with antics. That’s the “vibe”
others feel in that first 10 seconds. “I never
audition at an audition,” he says, “I show
up for work. I go in and say, ‘Let’s get this
part over, when’s the press junket?”
“Oh, my God,” they think, “This is the
attitude we like.” The joke in the room is
that press junkets are tedious affairs, ev-
everyone hates answering the same question
50 times, and it’s best to get them over with
as soon as possible and get back to the real
fun of acting. The line cracks casting peo-
ple up, plus implants the thought, “This is
what we want — an eager beaver!”
None of this is secret sauce, Chill is
quick to point out. It’s merely learning to
adapt your approach to fit the environ-
ment rather than try to alter the environ-
ment — and the whole social structure —
to fit your needs.

He carries the same mindset into every
situation. “When they called me to come
to NCIS: New Orleans, brother, I came
onto that stage like I was the chief, the
man in command. I run this whole opera-
tion: ‘Man, he comes in here like he runs
the place!’ The open-plan set is such that
he can move around freely in the chair he
dubs “The Triple P Mobile.”
“They loved the energy. This is what
they wanted. When I show up, they know
it’s going to be a party!”
Which doesn’t mean, when the cam-
eras roll, his character, Patton Plame, is
just a joke-meister. In an episode entitled
“Broken Hearted,” Plame must deal with

As Patton Plame on NCIS: New Orleans, Chill is
often seen using a BlueSky Mount ‘n Mover to
hold his tablet (mountnmover.com).

‘When I show up, they know
it’s going to be a party.’

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wheelchair is the cushion. It is your only
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the painful death of a fellow computer coder whose heart transplant doesn’t take. “If you’re a fan of Patton Plame,” exclaimed one fan site, “this episode is definitely a must see.”

Just being around someone in a chair, says Chill, has had an effect on the NCIS crew. “They pay attention to things [i.e., people with disabilities on the street] they didn’t pay attention to. It’s like when you have a new car, now you see your car all over the road. If you buy a Mustang, everywhere you go, someone is driving a Mustang.”

Chill definitely had a leg up in show business after his accident. He’d already been an actor for 15 years, had a very savvy manager of long standing, Jenny Delaney, and had some famous friends to go to bat for him. He says he feels guilty about this sometimes, as if his past has given him an unfair advantage and thus, to the non-disabled, makes life in a chair look like a breeze. Then he thinks: “Wait, I earned that past. And I’ve used it. I took a social handicap, being black, and transferred that fight to a physical disability. But this time I got ammunition!”

“Respect” is a big part of that arsenal.

Chill knows his presence has educated the NCIS crew about disability. By the way, Chill is a minority outreach spokesperson for the Christopher and Dana Reeve Foundation, among other such efforts. He also created the Daryl Mitchell Foundation to help minorities find their way after an SCI. Black people, he notes, are rarely included in discussions about disabilities.

Chill is, if anything, an expert in how to maneuver in foreign territory and be consciously aware of, and practiced in, the art of winning people over. “I speak three languages,” he says. “I speak Eb-onics,” or street language. “I speak Caucasian,” or mainstream English. “And I speak Disabled,” the language with which people with disabilities, and fellow travelers, speak with each other.

You wouldn’t speak French to a room full of Germans, right? Then why speak Ebonics or Disabled to a room full of casting agents and producers who only care about finding the perfect actor for the part. These are by and large white, nondisabled men and women who are way more interested in their success while using you than in your success while using them. Speaking different languages to different audiences is not devious. It’s smart.

Chill knows his presence has educated the NCIS crew about disability.

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“Respect” is a big part of that arsenal.

You may hate the script, but respect the
scriptwriters. Doing so, they may just listen to your ideas. Any form of disrespect will register with anyone you work with, or more important, you work for. It sounds simple, but isn’t. Especially in a place like Hollywood where people will trash someone if they think it earns them points with someone else, or just feeds their bottomless ego, being respectful to all is a learned response. And it’s also why many doors were opened for Chill after his injury.

‘I don’t care what you believe in, you better believe in something.’

Something deeper than Chill’s genuine kindness or his bag of tricks helps him keep moving forward. Growing up in New York, his father drove a bus and his mother, who worked in a civil service job, was a devout Jehovah’s Witness. Without proselytizing or reiterating a rehearsed spiel, Chill is steeped in religion but passes no judgments. He simply says, “I don’t care what you believe in, you better believe in something.”

With Chill, that’s prayer and meditation. He remembers when he first hit it big in Hollywood — fancy car, big house, the works — he still felt like he needed “to come home.” “Home,” in this sense, meant both returning to some kind of spiritual foundation and also back to the home he shares with his wife and his three almost-adult children in Sugar Hill, Georgia. He bought the home there 19 years ago because he wanted to be near the burgeoning Atlanta hip-hop scene. Doing TV series, he has spent a good deal of his time in Los Angeles. In his words, “We rolled like gypsies in my children’s youth so they are well-adjusted to the rhythm.” One of Chill’s sons is autistic, goes to a university in Florida studying video game design, lives alone, and according to his dad, “manages quite well.”

Chill fell in love with northern Georgia and now spends much more time there. NCIS: New Orleans is a double blessing. It’s both a great job and a five-hour car ride from home.

In his spiritual leanings, he never questions God. “I know why I’m still here. He gave me the strength to endure. He gave me a place to go and sit quietly and focus.” And the results, he says, are powerful. “I can now focus on the promise and stop focusing on the pain. I see better days ahead.”

Finally, how does Chill Mitchell deal with the inevitable sadness and depression that comes with paralysis?

“I won’t allow myself to get down. I won’t allow those things to creep into my brain. Uh-uh, I ain’t going there. That may be denial, but the way I see it, I got plenty of time to cry later on.”

“Right now, I got to go to war!”

Chill’s Facebook and Twitter posts give glimpses of his warm connection with friends and family.

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AAfter countless years of watching non-disabled actors play characters with disabilities in movies and on television, a bright spot is on the horizon. A weekly TV series on American mainstream network television will star an actual wheelchair user, and it promises a truly inside look at what life is like when a member of your family has a disability.

"Speechless" is a family comedy akin to "Modern Family" that premieres this September on ABC. It centers on the Dimeo family and stars Minnie Driver as that familiar crusading mama-bear and 18-year-old newcomer Micah Fowler as JJ, her non-verbal son with cerebral palsy.

Fowler's being cast as JJ is a giant step forward for television, since Fowler has the life experience and the acting experience, too. He actually made his acting debut in the 2013 romance "Labor Day" opposite Josh Brolin and Kate Winslet. He even did some work on "Blue's Clues" and "Sesame Street" when he was a young child.

Acting is a family business, too. His sister is 19-year-old Kelsey Fowler, a Broadway actress whose credits include "Mary Poppins" and "Grey Gardens".

With a major network series on the horizon, we're betting Micah will soon be the most famous Fowler in the family. But before he reaches Peter Dinklage heights, he talked to New Mobility and I quickly discovered that "Speechless" only applies to his character.

Micah Fowler: I didn’t ever really picture myself pursuing acting, but one day, after my sister performed on "The View", her agent, Ellen Gilbert, saw me in the audience and called my mom and said, “I want to represent him!” I thought it would be fun, so I figured I’d give it a try. From there, I started with an episode of "Blue’s Clues", then did a couple episodes of "Sesame Street" and eventually booked a role in the movie "Labor Day".

NM: What is it like being a person with a visible disability during an audition? Are the audition spaces usually accessible and what do you do if they’re not?

MF: I don’t audition often because I tend to only audition for disabled characters. When I do audition, I usually just send in a tape.

Once, when I was auditioning for "Labor Day", we had to go to this casting office in New York City’s Chinatown. A lot of buildings there are older and not completely accessible. We went up several floors, in this tiny elevator, and then my dad had to drag my wheelchair and carry me up the final four steps to the office. I guess it worked OK though, since I booked the movie.

NM: How did you land the role of JJ Dimeo on "Speechless"?

MF: My agent sent me the pilot script to read and my family and I thought, “This is like our house!” Just like the scene in the trailer, we could identify with people complaining we’re using an accessible spot, thinking I don’t need it until they see my wheelchair. The craziness of constantly not getting out of the house until the last minute was just like my life, too.

For the audition, I sent in a personality video, introducing myself and telling them about me. Then, in the next round, I recorded my performance of several scenes and hoped for the best.

NM: In what ways does the show accommodate your disability on set?

MF: The studio is terrific. When we arrived on set I was so excited to see they had found me this amazing trailer to use, with a large ramp on the back-end. They even set up a hair and makeup station on the trailer’s back patio and had hair and makeup come to me, since I could not access the regular one.

NM: How does having cerebral palsy help you in the role?

MF: It has helped because I’ve lived with CP all my life and many things JJ goes through, I go through on a daily basis. Watching "Speechless" and knowing that JJ is
played by an actor who has cerebral palsy allows people to get a real perspective, an inside look at what life is like living with CP. It lets them see the ups and downs, all the challenges and even the fun, humorous moments that we experience.

NM: Is it a challenge playing a character with cerebral palsy, but who is nonverbal?

MF: I love playing a character who is nonverbal, with a more severe diagnosis than myself, because it’s an acting challenge for me. I really hope I can represent the disabled community well and show us in the best light possible.

NM: Do you get to influence how your character is portrayed and the direction of his storylines on the show?

MF: Yes, from my experience the creative team is very responsive to me. I speak up if something doesn’t seem real, and they value my input. My parents have also given them some ideas from their experience raising me!

We’ve even changed some scenes in the middle of filming to make them more realistic to my life as a disabled person.

I could so identify with having a mama-bear who fights for the services I need, but my onscreen mom, played by Minnie Driver, is much more crazy, over-the-top and funny. Minnie is so nice, generous and kind and she is so loving. I really enjoy working with her.

We said at the beginning we wanted to make it real as possible. Scott Silveri, the network and the creative team were totally committed to having a disabled actor play the role from the very beginning. Scott and the team consult with professionals in the disability community for their perspectives as well.

NM: If you could give any advice to any creator looking to add a character with a disability to their next show, what advice would you give them?

MF: Make it as real as possible and cast actors with disabilities who have lived it — we are out there! Show people you do care and just try your very best.

NM: As one of the only visible people with a disability on television, do you feel a sense of responsibility to the larger disability community?

MF: Yes. I’ve been given a huge responsibility, and thinking about it stresses me out a little, but I am ready to represent them and make them proud.

I hope as people watch Speechless they get to know JJ as a very normal person, to the point that they don’t even see his disability, but his humor and personality and that they can bring that into their own lives.

One of the things I’m most committed to is showing people that you don’t have to act differently or be uncomfortable around disabled people. We are so normal. Just say, “Hi!” Look beyond the physical or other limitation and see the real person, the heart, the personality, the love and yes, even the humor.

Watch Micah Fowler on Speechless, premiering Wednesday, Sept. 21 at 8:30 p.m. ET/PT on ABC.

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As someone who has resided on wheels for most of my young life, looking up at the rest of the world has sometimes left me yearning for a bullhorn to shout, “Hello up there! Remember me way down here!”

Fortunately for chair dwellers, the development of a variety of standing and lifting wheelchairs in recent years is allowing us to upgrade to a bird’s eye view within a matter of seconds. Besides the higher vantage point, standing wheelchairs have been proven to promote a variety of health benefits including stronger bones, pressure relief, less spasticity, better digestion, increased lung capacity, and improved bowel and bladder control.

Here are five popular standing wheelchairs on the market and stories of people who own them.
“My neighbor got a kick out of watching me chase my horses through sagebrush to get them back home, seated in my wheelchair, and strapped in good,” says Robert Nedens, 65, a C3 complete quad. Nedens rides a Redman Chair Chief 107-ZRX on his Billings, Montana, ranch, and has ridden Redman chairs since leaving rehab after his injury in 2003.

“Sam Redman brought the chair to Craig Hospital and let me try it out, and I liked the looks and performance,” says Nedens. “The hospital pressure-mapped the chair and it proved to be exemplary.”

It was difficult for Nedens’ body to acclimate to the upright position at first. “I had a hard time with my blood pressure and would pass out before I got all the way up,” he says. But he pushed himself to use it consistently and has logged over 1,000 miles since his first Redman.

Nedens says he likes the variety of positional options. “I stand for long periods of time, but I also can do a combination of seating positions,” he says. “I can put my legs partially up with a small amount of recline and partial stand (blended stand), or legs straight out and full recline (a horizontal position). It also allows me to stand and recline to a bending backwards position (yoga).”

But don’t try the standing feature on a sharp incline, Nedens warns. “You get on a steep enough hillside and it will tip over. I did that, and there was no damage to the chair or me. I just had to wait for someone to set me up,” says Nedens, who uses sip-and-puff to control the chair.

Nedens values the impact the Redman has had on him in social situations. “Sometimes people in wheelchairs are ignored. I find when I stand with everyone else I am more included in the conversation,” says Nedens. “The chair is very dependable, and I’m comfortable rolling around on my own. After rehab I’ll stay in town and either go downtown or to a park, just have to let the wife know where I’ll be so she can pick me up after work.”

On the cusp of getting his third chair from Redman, Nedens says they have a long history together and almost feel like family. “I encourage getting a standing wheelchair, one that’s easy to work on, with a good support team and I have that with Redman,” he says. “In the past I have checked out other wheelchairs, and the best choice for me is still Redman.”

And he adds he is grateful for the smooth buying process. “Private insurance paid for my first one and after that Medicare covered 80 percent. Also had a trade-in allowance,” he says. “Redman handled all of the purchasing process.”

At first glance, it looks like Troy Yoho, 47, is using a Segway to zip around Hill Air Force Base in Northern Utah, but the calibration contract manager is actually scooting around in a TEK Robotic Mobilization Device. Created in 2012, the Tek-RMD is designed solely for standing, and allows paraplegics and others with good upper body strength to get out of their wheelchair,

As the Tek-RMD, MATIAROBOTICS.COM: INNOVATIONSHEALTH.COM

POSITIONS: STANDING, SITTING FOR LIMITED PERIODS
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stand and move around on smooth surfaces.

Injured in 2013 at the T12 level, Yoho decided to get a Tek in February 2016 to gain the benefits of standing during his eight-hour work day. "I stand approximately four hours a day in it," says the Air Force veteran. "It keeps me off my back side from sitting all day and hopefully with less break down of my body."

Yoho says he has seen many improvements to both his health and well-being and his social interactions with colleagues. "What's amazing about it is the ability to be up vertical for long periods of time and having eye-to-eye communication with my coworkers," he says. "My core strength has also improved, and I have been able to stretch my leg muscles, hamstrings and hips."

On the flipside, Yoho, who has good upper body strength, says it is difficult to transfer into the device. "I have improved my technique, but my pants ride up when I get in and it's near impossible to get them pulled down by myself," he says.

He also wishes the device had more storage options for everyday items like papers and pens. "I can put some things in my pocket, but I'm limited on carrying stuff."

The Tek can only be used independently by people who have upper body strength, hand dexterity and a good grip, but the company says quads can use it if they have assistance.

Unfortunately, because it is so new on the market, Tek does not currently have a Medicare reimbursement code, which is needed for Medicare, Medicaid and many other private insurances. "It bums me out so bad," says Yoho, who bought the chair with his own money. "My insurance would not pay anything. It stinks because the health improvement is so beneficial, especially the lower chance of pressure sores and improved circulation. I just don't understand why they won't approve."

**PERMOBIL F5 CORPUS VS**

As creator of beyond-disabilities.org, Steve Ferreira, 27, has spent the past 12 years speaking to over 500 regional high schools, colleges, churches, graduations and other venues to educate the public on the disabled population’s unrecognized talents and inspire others with disabilities to realize their own potential. But working to encourage others left the Seattle native neglecting his own health and long overdue for a new wheelchair.

"I received my old wheelchair about 15 years ago when I was in middle school.
Needless to say, it was falling apart and I needed a new one,” says Ferreira, who has cerebral palsy. “I had been having back problems from my old chair, and my therapist thought the ability to stand would improve my overall health, as well as help me to reach things when I worked.” Ferreira decided on a Permobil F5 Corpus VS, which has four power seat functions — tilt, recline, power leg rests and a seat elevator — plus the ability to stand.

Although he has only had the chair for a few months, Ferreira says it has been a game changer for his health, independence and busy career. “The sit-to-stand feature gives me the ability to stretch my legs. It’s also great for weight bearing and breathing,” says Ferreira. “When I go to a restaurant with a high table, I can now raise up to it. Also, while speaking, it’s great to be able to face an audience and look them in the eye.”

The only downside? Because of insurance obstacles, Ferreira says the process of getting the Corpus VS was a nightmare and took two full years.

“We had to have a physical therapist write a letter and also needed a doctor’s prescription before submitting the request to insurance. I’m covered under Regence from my mother’s office and Medicaid is my secondary insurance. Both insurances only approved part of the wheelchair. We were denied the sit-to-stand feature as well as other parts of the chair like the footrest and recline,” says Ferreira. Their appeal was denied and eventually his mother became frustrated and self-paid the last portion. “I finally received my chair in March. We paid for about $9,000 toward the $45,000 chair.”

Overall, Ferreira says the chair’s many benefits overshadow the frustrating purchasing process. “If someone is on the fence, I would say go for it,” he says. “The chair is truly life changing.”

**LEVO C3**

Tobin Boenig, 43, credits using a standing chair soon after his C4-5 incomplete injury two decades ago for his increased movement and function.
“My physical therapist thought it would aid in my efforts to potentially walk again,” says Boenig, an attorney from Houston, Texas. “While I never was able to walk in my ‘everyday life’ routines, I was able to use a walker with forearm platforms for about a quarter of a mile. I am convinced that regularly standing in my wheelchair helped with that effort.”

Boenig has had an older model Levo standing chair since 2002 and reflects on the milestones the chair has helped him conquer. “I have used my standing feature to deliver speeches, dance, exercise, and even to exchange my wedding vows with my wife,” he says. “I think it has helped me to stay healthier, both mentally and physically.”

Wanting an upgrade, Boenig is getting ready to purchase the latest C3 model. “The tilt function is something I am looking forward to for pressure relief,” he says. “This old Levo of mine doesn’t handle well on rough terrain, but the new Levo that I tried handles it much better.”

The Levo C3 power chair features dual drive, meaning both the front and mid wheels are powered. It’s built to take on outdoor terrain, but only in the sitting position — the standing function should only be employed on solid, flat, level and obstacle-free surfaces. In a seated position, the C3 is also able to climb up to 4-inch curbs allowing the user to bypass many curb cuts completely.

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As for whether his insurance will cover it, Boenig is crossing his fingers. “I should know in a few weeks. I am going through the insurance process as we speak,” he says.

ELEVATE YOURSELF WITH A QUANTUM REHAB ILEVEL

Quantum Rehab’s iLevel is not a standing chair, but it is an elevating chair that allows you to drive around at normal speeds while elevated, and that’s exactly what Florida native and former police officer Rich Pollock, 36, wanted.

“I enjoy going to Disney with my family,” says Pollock, diagnosed with ALS in 2014. “When I started using a scooter, I constantly had to keep asking my wife where my daughter was. I couldn’t see her because I was below crowd level. This was not acceptable to me.”

Knowing a standing chair would not be feasible for his progressive disease, he decided to purchase a Q6 2.0 with iLevel adjustable-base power chair from Quantum Rehab. The iLevel elevates up to 10 inches and moves 3.5 miles per hour while elevated, but should not be used on rough terrain — it’s best used indoors.

In addition to elevating, Pollock appreciates the iLevel’s recline position. “Using this feature is a godsend because my legs and feet begin to swell and it allows me to elevate my feet while lowering my upper body. The head rest and associated neck support are also excellent, because I have lost strength and function in those muscles.”

Pollock also appreciates the impact the iLevel has on his emotional health. “I am no longer down at kid level. I have also always been the ‘cook’ in our family and in a regular chair that wasn’t possible,” he says. “When you are diagnosed with something such as ALS and you know that you are going to progressively lose the ability to do everything, this is a bright spot in the midst of that darkness.”

Jeanne Allen, 61, of Sonoma, California, had an “aha” moment when she saw an elevating wheelchair at local abilities expo in 2014. Desiring a seated chair that lifts up to standing height, Allen, whose MS is progressing, opted for Quantum Rehab’s Q6 Edge X lifting base chair, an older version of the company’s iLevel base.

“MS fatigue is one of my symptoms and the tilt/recline allows me to rejuvenate by getting myself into a comfortable resting position, even napping in my chair,” says Allen, founder of incredibleACCESSIBLE.com. “I also have edema in my feet and the tilt/recline allows me to lean back and raise my feet above my body to reduce the swelling.”

Like others who use standing or elevating wheelchairs, Allen credits the Edge with improving her social life. “When I’m in the elevated position, my husband can put his arm around me and give me a kiss,” she says. “I can be in a standing crowd and see what everyone else is seeing, or browse through the clothing racks at hanger height. I’m no longer sitting while everyone else is standing.”

Jeanne Allen has elevated her cooking and her social life with her Quantum Rehab chair.
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MY TAKE
Louisiana is packed full of history and rich in culture, and I am grateful that I have had the opportunity to experience both the northern and southern regions; however, it seems as though my heart has led me back south to the Cajun Heartland of Louisiana. It is definitely the one place that I can be myself, eat some of the best food there is, and do what the Cajuns do: “Laissez les bons temps rouler!” (Let the good times roll!). Living here is quite entertaining and lots of fun, especially being able to access the majority of festivals and events. Unfortunately, transportation is not great in the Lafayette area, but if you are able to get to where you want to, access is available.

PLACES TO GO
Due to the almost year-round warm climate in Louisiana, if you are into outdoor sports, you can definitely find yourself fishing, boating, or taking advantage of an exciting swamp tour on the beautiful Atchafalaya Swamp, only 15 miles from Lafayette. Make sure that you call in advance to schedule your tour to assure availability of an accessible tour boat. If the weather is nice and you would like to learn a little more about the Cajun people and what living was once like, you should visit Vermilionville for a tour of an Acadian-style village and a nice relaxing time listening to a local band. Everything here, including the historic homes, is accessible.

Only 135 miles away is New Orleans, an experience one must have at least once in a lifetime. Begin your day with a visit to Café du Monde for some delicious beignets (fried French donuts) and a delightful cup of café au lait (coffee with milk), but make sure you have your walking shoes on as you stroll through the French Quarter browsing through shops and enjoying the artful atmosphere. Enjoy the Audubon Experience when you visit the Audubon Zoo, the Aquarium of the Americas, the Audubon Butterfly Garden and Insectarium, and finally the IMAX theater. There are several different options of tours that are available in the New Orleans area: more swamp tours, plantation tours, and even cemetery and ghost tours.

AVAILABLE HEALTH CARE
Louisiana is home to LSU Health Sciences Center’s hospitals and clinics. There is one located in Shreveport and one in New Orleans. I have personally utilized the Shreveport facility whenever I lived there and received great care. The clinics, as well as the hospital, are awesome. If I am in need of hospital care here in Lafayette, I utilize the Lafayette General Health system.

GETTING AROUND
Transportation here in Lafayette may be a bit difficult if you are traveling as a wheelchair user without your own vehicle. Most of the streets here are accessible, especially the downtown area, where most festivals take place. Most of the city buses are also accessible. However, they run on a schedule and are not always available. There are several para-transit systems here, but, unfortunately, they are not so “wheelchair friendly” — unless you are elderly and only plan on visiting the doctor or doing some type of grocery shopping at the local grocery store or Walmart.

SKINNY ON THE CITY
Lafayette is the fourth largest city and home to the second largest university in Louisiana, University of Louisiana at Lafayette. It is known for many things, but has been nicknamed “Cajun Heartland” for its French heritage and Cajun traditions. It is known worldwide for its mouth-watering food, upbeat French music, outstanding festivals, and enthusiastic, fun-loving people.

MUST SEE, MUST DO
Avery Island: Only 30 miles from Lafayette, you can enjoy a delightful and accessible tour of the Tabasco plant to learn how the famous Louisiana hot sauce is created. After the tour, you can either have a meal at the restaurant or a packed picnic lunch across at Jungle Gardens, a 170-acre botanical garden and bird sanctuary where you can relax and enjoy the beautiful wonders of Louisiana wildlife. The gardens are quite accessible — you can drive through in your car. You can get out whenever it is convenient and take advantage of the chance to see many birds native to Louisiana, alligators, and maybe even deer.

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Louisiana: Combining Communities to Broaden Reach

Many of United Spinal’s 40-plus chapters started as independent organizations before affiliating, but the Louisiana chapter’s origins separate it from many of its sister chapters. The Louisiana chapter started in 2004 as the Brain Injury Association of Louisiana, aiming to serve the state’s community of people with brain injuries, their family members and care providers. Last year, recognizing the overlap in communities and needs, BIALA joined up with United Spinal.

“It has been wonderful for our organization because it allows us to help more individuals in our state,” says Kimberly Hill, the chapter’s director of outreach and resources.

Hill is one half of the chapter’s new leadership team. Instead of having an executive director, the New Orleans-based chapter switched to employing two part-time directors earlier this year. Hill handles most of the day-to-day operations while her co-director, Kathleen Mulvihill, oversees development and fundraising. Both are uniquely suited for their positions. Mulvihill brings a long track record of advocacy and fundraising for nonprofits, while Hill’s personal and professional lives both seem to have prepared her for this role.

Hill is a recreational therapist and a certified cognitive therapist with a long history working with brain injuries. On top of that, a family member sustained a brain injury, and her son had a spinal cord injury two years ago. Both have enjoyed what Hill deemed “miraculous” recoveries, but the traumatic personal experiences gave her added insight that she now uses daily.

“Because of everything, I bring an understanding of the therapy side of working with brain and spinal cord injuries and also an understanding of the caregiving side,” she says. “Obviously, I don’t understand what each person is going through, because it’s all different, but at least I can speak to my experiences.”

One of the chapter’s signature offerings and one of Hill’s primary responsibilities is applying that understanding and experience to the organization’s 24-hour brain injury hotline. Hill carries the hotline phone with her wherever she goes and says she averages about 30 calls a month. The calls, which can come from a direct local line or the Brain Injury Association’s national hotline, run the gamut topically.

“People call looking for resources, support groups, what to do,” she says, “I have some individuals who call once a week just to check in and talk. It’s been incredibly rewarding to do that because sometimes a parent calls not even knowing what they’re looking for, and it ends up they just need someone to talk to.”

The hotline is just one aspect of the chapter’s growing offerings. While BIALA doesn’t directly offer support groups, it does work with state support groups by offering resources and grants. Hill says the chapter is working to bring the state’s nine support groups together for a joint event next year.

The chapter has also built a reputation for its annual conference. This year’s conference focused on “Technology in Brain and Spinal Cord Injury Rehabilitation” and drew great crowds in addition to a number of sponsors and exhibitors. The conference was highlighted by speeches and a number of presentations on the future of technology as it relates to brain injury and SCI. PDFs of the presentations are available on the chapter’s website, www.biala.org.
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“OK Ginger, come over here,” I say, slapping the side of my chair. She calmly walks over and stands next to me. I don’t want her near the muzzle of the rifle as I prepare to shoot.

“Now sit there.” She sits down right next to me, paying full attention.

“I’m going to shoot now,” I say. She half closes her eyes in anticipation of the bang.

I am out hunting rodents with my new adventure buddy. She is only 11 months old, and it is amazing how quickly she took to hunting. It seems that it must be somewhere in her genetics. As soon as she knows that we are going hunting, she transforms from a bouncy-nearly-uncontrollable puppy to an adult who seems to be fully trained. Ginger will automatically walk right beside me and not get in front.

Some of you probably read my story a while back about losing my old yellow Labrador retriever, Nakoda, about a year and a half ago. Pet lovers will understand that she was so much a part of my life, that she left a huge hole when she passed. For the last few years we knew it was going to happen one day, and my wife Terry and I had talked extensively about getting another dog. We had owned dogs for over 20 years and decided that we would enjoy embracing our freedom for a while and see how it goes. When Nakoda finally passed, it was devastating. Recalling our newfound-freedom plans, I decided to talk to my wife for verification about our decision. Our lengthy in-depth conversation went something like this:

“So do you think you want another dog?” I ask, bottom lip out.

“Nope,” says she. End of discussion. She was right. We wanted and planned for our freedom and now it was our chance. Heck, we could travel with not much more than an overnight bag and a minivan. We could leave the camper for hours on end in hot weather and be out late without worrying about having to get home for a dog. We could stay in any hotel room, not just the pet-friendly low-budget dives with the obligatory air of ashtray-and-spilled-booze, right? We’d be free … free at last … and our expenses would be way down, right? We would not have to pay
vet bills anymore. It would be so nice and quiet and blissful! Oh how happy we’d be with no responsibilities to hold us back … how happy!

Fast-forward four months.

I have come to a few realizations. Walks with the dog are no fun without a dog. Hanging on to the dog’s leash while walking is a real drag without a dog. Talking to the dog looks really strange to other people when there is no dog. Playing fetch with the dog is a one shot deal when there is no dog. You get the idea.

We were successful in making it about four months without even mentioning the subject of getting a new dog. Secretly I was really missing the companionship. Then one day while wandering a resort town, I noticed a young golden retriever tied to a bicycle, the owner inside the coffee shop. I had some time to kill so I wheeled over and said hi to the dog, who looked right at me with those kind eyes. I reached down and she slowly licked my hand, so I started to pet. She gently put her head on my lap and then crawled up so that I could reach her better. About then my wife came out of the store she was in and smiled as she noticed the dog.

“If we ever get another dog, I think this is the one,” I said.

“So did you talk to the owner? Would they sell her?” she replied, half sarcastically.

“No I didn’t, I can’t imagine anybody selling this dog.” I said.

While we carried on our day and toured around, trying not to give much more thought to the subject, it was hard to get that beautiful dog out of our minds. We were torn between having our freedom and also having a loving pet like the one we had just seen.

A few days later I received a Facebook post. It was a picture of a golden retriever — a newspaper ad: puppies for sale. The message was from my wife! Before I could respond, the door burst open to my man-cave. Terry pulled up a chair and sat down.

“I want a dog,” she said. “What do you think?” No sense in beating around the bush.

I was absolutely elated. I missed our old dog terribly and really wanted another one.

“I love the idea! The only reason I was hesitant about a dog was the extra workload, and I realize that the work is more on you than me. If you want a dog, especially a golden retriever, I am game for that!” I was thrilled.

The order was placed, and as soon as Ginger was old enough, we made the 300-mile drive to pick her up. So now we have a new adventure buddy. She is about a year old now, such a part of the family that we can’t imagine being without her.

Back to the present day.

I gently squeeze the trigger and the gun fires. I look up from the scope — one less rodent to dig holes in the lawn. Ginger looks to me for the “all clear” before standing up and moving around.

“OK Ginger,” I say, swinging the gun around so it is not pointed in front of me. “Let’s continue our walk!”

More dog adventures. I love it! It is one of the true gifts of this life.
T
here is a catchy term being dropped at all the best Hollywood parties these days — cripface. It’s not a new coinage but is now entering the zeitgeist and will soon be so overused as to become trite and boring. “Cripface” is the act of using nondisabled actors in film and TV shows to play characters who are disabled. Get it? It’s just like blackface back in the dark ages of show business when Al Jolson donned black paint and a black patois to sing “My Mammy.” Can you imagine that happening today? No, you can’t. Ted Danson, in a joke that went terribly, terribly wrong, showed up in blackface at a Friar’s Roast and nearly got tarred and feathered. He could have shown up in a wheelchair, faking the gestures of a C5 quad, and no one would have batted an eyelash. “Oh, that Ted,” they’d say, “Cute wheelchair bit. If only it had been funnier.”

“Cripface” is not just a goofy pun. Nondisabled actors playing disabled parts is a big problem in the entertainment business. See the advantages to producers? No close-in parking spots, no ramps or lifts to build, no double-wide porta-potties, no chairs being run over by heedless gaffers, triggering a costly lawsuit. Who needs the hassle?

The word is purposely impolite and borderline offensive. I’m sure some PC bore got all huffy and suggested “disability-face” or “mobility-challenged-face” and was asked to leave the room. “Crip” has zing. It’s punchy and memorable. In fact, I propose that crip-based words should become part of a new, specialized vocabulary, a grab bag of peppy euphemisms for all occasions, especially when someone out there bugs the hell out of you, which, in my own case, is often.

Stealing from current socio-political jargon, here’s a start:

CINO. Meaning, “Crip In Name Only.” These are people who are technically disabled but want nothing to do with anyone else in the same boat. They avoid fraternizing with other crips for fear it will sully their status in the ambulatory world. Personally, I think they should be drummed out of the club. I put forth the name of one CINO in particular to blackball: the Governor of Texas, Greg “Spine of Steel/Heart of Stone” Abbott.

COREO. A derivation of OREO, meaning black on the outside and white on the inside. In our case, it means crippled on the outside and cynical on the inside. In public, these disgusting hypocrites profess to be dedicated activists, while in private they think most people with a disability are crybabies and government moochers and should just shut up. When it comes to giving money to the cause, they’re like the guy who always forgets his wallet when it’s time to pay the tab. If they are rich, they fit the category, LIMOUSINE CRIPERALS.

NEO-CRIP. A neo-conservative believes in a super aggressive foreign policy which dictates boots on the ground and nukes in the air anytime another country calls us “The Great Satan.” A neo-crip advocates a super aggressive disability police force whose job is to hassle all the CINOs, COREOs, and anyone else they don’t like.

CRIPTOAMOROUS. Here’s something to cheer about. Like polyamorous but better. A chair user who is available for sex anytime, anywhere, with any one of any gender of his or her choosing. Could be a spicy new series on Netflix.

CRIPTOPHOBIC. Fear of saying the wrong thing or making the wrong helpful gesture to a person in a wheelchair, getting a withering tongue lashing, and being left feeling you are a callow, insensitive dolt.

KRIPTONOMANIA. People in chairs who compulsively shoplift.

CRIPTOGYNIST. A man who is deathly afraid of any woman with a disability and covers it by calling her bossy and a man-hating CRITCH.

CRIPWACKO. A disabled person at a David Duke rally.

LYING, DISGRACEFUL, STUPID, DISGUSTING, VERY UGLY CRIP. Donald Trump’s phrase for any disabled person who doesn’t vote for Donald Trump.

Please memorize these terms, practice saying them in a mirror, and then make up a few of your own. It’ll be our very own private code language and a guaranteed ice-breaker at your next cocktail party, hopefully hosted by an attractive hunk or siren who is avidly criptoamorous.
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A few years back he went to the doctor to check on his scoliosis. “They put two and two together and figured stenosis was the likely cause of the pain.”

The docs recommended surgery in the lumbar spine area; they said it was at a place where the spine bends, which might trigger inflammation and narrowing of the canal that hosts the cord. He said no. “It’s hard to say if the pain has progressed over the years, hard to say if it’s worse than it was. I have sensation of hot and cold, and touch, and didn’t want to risk losing that. I’m able to manage the pain. I am able to get relief with rest and relaxation. I’m going to try riding it out.”

Billy Altom, who has cervical stenosis, plans to ride it out, too. He is executive director of the Association of Programs for Rural Independent Living in Little Rock, Arkansas. He’s 35 years into the club, the result of a motor vehicle accident at C5-6, and L1-5. “I’m like that cartoon, you know, ‘Lost, male dog, has one eye, mangled left ear, paralyzed hind leg, crooked tail. Answers to the name, Lucky,’” he quips. With SCI, it’s always something. “I’ve broken every bone in my right leg, it kills me all the time. My hands are atrophied, arms and elbows hurt, they’re beat to death.”

Recently Billy got 10 weeks out of circulation for third degree burns on his butt cheeks, from a heated car seat. He’s had chronic pain “forever,” and his medical chart says he has multilevel spondolytic disc issues, narrowing at C4-5, abnormal signal at C7. “They recommended surgery. No. I saw more potential for harm than good.”

Can people with SCI head off stenosis? Hard to say, says Falci: “I don’t know how to tell people to stop using their upper body. Stop using the arms? Use an electric chair? Don’t live life to the fullest? I don’t have a good answer. I do recommend that people stay as fit as possible, keep the neck strong.”

Gildner and Davis recommend the obvious, that you don’t fall. Don’t smoke. Keep your gear in good shape, take vitamins A and D. Drink a lot of water. Gildner went off carbs and feels better. Davis loves massage.

They both told me they take better care of themselves and are more mindful of technique and ergonomics.

“Please heed our warning,” says Davis. “Learn from our shared experience, monitor, and do not create undue strain and disc degeneration or herniation on your cervical or lumbar spine. Take the best care of the body you have been given post-injury, and preserve your quality of life for as long as possible.”

**RESOURCES**
- Questions and Answers About Spinal Stenosis, www.niams.nih.gov/health_info/spinal_stenosis/#spine_b
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Allergan: The LLS (Lower Limb Spasticity) Approval press release is at the link: www.allergan.com/NEWS/News/Thomson-Reuters/U-S-FDA-Approves-BOTOX-onabotulinumtoxinA-for-the

Astellas Pharmaceuticals, www.astellas.us, 800/888-7704

Asterias Biotherapeutics: Now enrolling. Take a look! www.scistar-study.com

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For more information on how you can support United Spinal and become a business member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

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CRIP BUZZ

THE BEST OF DISABILITY BLOGS AND BANTER

WE CARRY KEVAN

“My philosophy is to just keep moving,” Kevan Chandler, 29, told CNN in March. Then, he and three of his friends were raising money to backpack across Europe with Chandler, 65 pounds, carried in a backpack-like contraption they invented so he could explore the sewers of Greensboro, North Carolina, with them.

Calling themselves “We Carry Kevan,” and alternately, “There is no I in Kevan,” the friends raised $36,575 on GoFundMe. No doubt the stories about Chandler, a sound editor with spinal muscular atrophy, appearing on CNN.com, HuffPo and other web outlets helped them surge past their $35,000 goal.

The friends spent three weeks touring Ireland, England and France this August. Catch up on their adventures at www.facebook.com/AOLLifestyle/videos/1055133937905598/.

HE’S FAMOUS … KIND OF

“Being in a Wheelchair is (Kind of) Like Being Famous,” wrote Brian Grubb for Uproxx.

Here’s a taste of his excellent logic:

The first way being in a wheelchair is a little like being famous is that people really don’t want to say “no” to you. Famous people get this treatment for business reasons (keep the famous people happy so they keep coming and normal people will want to come to be near them) and/or personal reasons (“Guyssss Jennifer Lawrence called me ‘sweetie’ when I told her the coffee was on the house. Do you think I should ask her out?!”), whereas I get it, generally, because people do not want the person in the wheelchair to be sad. This is a problem for a couple reasons:

One, because I spent 23 years before my spinal cord injury as an able-bodied doofus who was filled to the brim with bad ideas. People told me no constantly, and justifiably, to the point that I came to rely on it as my check against doing something stupid. Without it, I’ve had to start relying on my own judgment and moral compass to help sort the good ideas from the bad. This is not a sustainable option. If I know anything about myself, it’s that I can’t be trusted.

Read it all at uproxx.com/life/being-in-a-wheelchair-like-being-famous/.

BMW PARALYMPIC CHAIR

“This chair was built for breaking things,” intones the voiceover of a BMW commercial featuring field and track Paralympian Josh George wheeling down a deserted highway, “like rules, stereotypes and world records … to remind us ‘limits’ is just a little word that makes a swooshing sound when you pass it.”

This understated, powerful video featuring the chair BMW built for the U.S. Paralympics that take place this month in Rio de Janeiro can be viewed atyoutu.be/6IlgxHJ8b3Q.
Use CEO-TWO® Laxative Suppositories as part of your bowel program. These unique CO₂-releasing suppositories allow you to control your bowel function and prevent constipation and related problems, such as autonomic dysreflexia. Regain confidence in social and work situations by avoiding embarrassing accidents with CEO-TWO!

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Jen Goodwin
Permobil user since 2013