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COVER STORY
THE PARENTING ISSUE

Kids grow up fast, and whether parents use a wheelchair or not, they need all the help they can get to keep up. SETH MCBRIIDE, STEPHANIE ARRACHE and TEAL SHERER break down the early years of raising children and share how they — and their kids — have adapted to parenting with a wheelchair.

FEATUERS

16 COMIC ON THE RISE
You may not think of Indianapolis as a hot bed of comedy, but Lucas Waterfill is working hard to change that perception. CHRIS RYAN reports.

34 CALLAHAN ON FILM
TIM GILMER reviews the new film Don't Worry, He Won't Get Far on Foot, weighing in on how director Gus Van Sant captures former New Mobility contributor John Callahan’s famed memoir.

34 ROLL ON CAPITOL HILL
United Spinal’s Rolling Revolution took over our nation’s capital for three days in late June, and IAN RUDER delivers a firsthand report.
This past Sunday, 35 of my closest friends and family got together to celebrate the 20-year anniversary of my SCI with an event my parents and I titled, “Surviving and Thriving: Celebrating 20 Years.” My folks rented a lovely venue, we planned a brunch to end all brunches, ate and drank way too much and had a phenomenal time.

Between old stories, humorous anecdotes and sincere tributes, there was plenty of fodder for reflection after the event was over, but what stuck with me the most was a comment from the nondisabled partner of one of my friends. He pulled me aside and said that the idea of celebrating surviving 20 years “seemed kind of morbid.”

I hadn’t thought of the party that way, but I could see where he was coming from. I told him how 20 years ago to the day, two weeks after my injury, my mom was in a hospital elevator coming to see me when she heard a code called to my room. I relayed how the doctors told my parents to plan on me relying on a ventilator for the rest of my life. And how, when I finally came down from the cocktail of drugs I was on almost six weeks later, the idea of being alive in 20 years — much less having a blast with so many people I cared about — was damn near impossible to fathom.

At the time, not being able to see a lengthy future didn’t seem morbid, or fatalistic. It seemed realistic. I saw a murky fate, characterized by uncertainty and obstacles like moving home, hiring caregivers and finding meaningful work and relationships.

Now that I’m on the verge of turning 40, the future is brighter — thanks in large part to the people who attended Sunday’s party: a caregiver who helped me figure out long-distance air travel, another who showed me what I needed to do to live independently, a friend and wheelchair user willing to listen to my wheel-complaints and figure out what to do. The majority of the people in attendance were people I never would have crossed paths with had I not been injured, but just as much, they are people I cannot imagine my life without.

Not only have I figured out most of the obstacles that seemed insurmountable, the process of doing so has been rewarding and often even fun. That’s not to say things have been easy — they haven’t. Figuring out how to balance on what sometimes seems like an impossibly thin tight rope between the good and the bad is a lifelong quest.

“Figuring out how to balance on what sometimes seems like an impossibly thin tight rope between the good and the bad is a lifelong quest.”

out how to balance on what sometimes seems like an impossibly thin tight rope between the good and the bad is a lifelong quest. That my work with New Mobility is focused on that same quest, and helping others to hopefully navigate it better, has proved to be an unexpected blessing.

That’s why the celebration was so important to me, and why I was oblivious to any sense of attached morbidity. Good and bad, surviving these 20 years made me who I am and has opened my eyes to a future I can dream of. That to me is worth celebrating.
DEANNA FIKE

Deanna Fike is the production manager for New Mobility and graphic designer for United Spinal Association. She has been with the company for seven years. Deanna holds two degrees: one in graphic communication, the other in art history. Her passions can be described as "old things," like houses, furniture and cars, as well as reading, traveling, exercise and nutrition. She is mom to Eliot, her 1-year-old son, and has been happily married to her husband, Erik, for six years. Deanna and her family live in a 1925 bungalow outside of Philadelphia with their two dogs.

CHRIS RYAN

Chris Ryan is an MFA candidate at Butler University and a freelance journalist with a focus on sports, politics and culture. His stand-up comedy career was aborted a decade ago after one terrifying attempt. He now spends his time, when he’s not chasing his toddler around the house, hanging out in comedy clubs, watching safely from the back of the room. His work has appeared in Indianapolis Monthly and NUVO.

STEPHANIE ARRACHE

Stephanie Arrache is a criminal defense attorney by day and blogger/writer by night. She splits her time between Southern California and Wyoming with her husband, toddler son and two dogs. She was born with a tumor on her spine that ultimately led to her paralysis in August 2013. In her free time, she’s either in the gym, in a karate dojo or on her couch watching really bad reality TV. You can follow her on Instagram and YouTube (@Paraplewhat) or on her blog, paraplewhat.com.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
Great Guy, Great Guitarist
Excellent article (“Eric Howk. The Man,” June 2018). Eric is a trailblazer and a hell of a guitarist. I’ve had the pleasure of his company quite a few times, and I love his humor and attitude.
Bill Baldwin
Newmobility.com

That Extra Spark
Fabulous article (“Eric Howk. The Man!”). Eric has that drive, that something extra that has propelled him to the top ... very few people are lucky enough to have that extra spark combined with God-given talent! Well done, Eric!
Jessi Cotter
Newmobility.com

Beyond National Parks
I so appreciate your insight and experiences (“Nature’s Sublime Wonderlands: Grand Teton and Yellowstone National Parks,” May 2018). I’m a T6 para and was an avid camper before my accident 18 years ago. With my kids now grown up, I’m planning my escape. These trips will be weeks, if not months, at a time. I have been researching everything it is going to take for me to get back out there with just my truck, and teardrop campers have won me over.

There are dozens of types, but I have broken it down to just two or three that will allow me to either camp at an RV park as I see the U.S., or what I am really after — camping in the “boondocks” off the beaten path with no electricity, water, bathroom facilities or dining facilities. You must be a very strategic planner and up for the known and unknown challenges. This is right up my alley.

Despite the challenge, these places can be some of the most scenic, solemn beautiful places in the U.S. — far away from the crowds. There are literally millions of acres of Bureau of Land Management land at $0 to minimal cost per allocated stay, usually 14 days at a time, but it varies. These savings extend the amount of time I can travel, as staying at hotels or RV parks every night is cost prohibitive.
Robert Garza
Newmobility.com

Daughter of the Year
What a wonderful story (“Rolling With Dad,” June 2018). Even in the midst of an accident that was painful and debilitating — this wonderful time happened for the both of you. What a great daughter you are!
Sharon Blackwood
Newmobility.com

Hybrid Chair Wonders
I use a Spinergy ZX-1 Power Add-On that very rapidly attaches to my TiLite ZRA (“Portable Power Chairs,” May 2018). It is easy for a quadriplegic to use and weighs only 82 pounds.

I get around the house in manual, and most times when I drive my car, but I can go out easily in the ZX-1. No transferring between manual and electric is a major bonus for me.
Colin Johanson
Newmobility.com

Portable, Really?
I love the concept of these travel chairs, but what I don’t get is how they get out of and into the trunk of a vehicle (“Portable Power Chairs,” May 2018). Fifty pounds is not trivial, even when its broken down into component parts. I have a 20-pound Ti wheelchair and that’s heavy for a couple of the people who have assisted me. What am I missing?
Patricia Bissey Greaves
Newmobility.com

Bathrooms Lack Access
My teenage son uses a wheelchair, and one of the most frustrating things we encounter is accessible bathrooms with stalls so small a wheelchair cannot fit into them (“Small Town ADA Violations: Building a Group Case,” May 2018). He is forced to use a cover drape and sit in the open to cath where anyone entering the bathroom will see (and the doors leading to the outside rarely have a lock). It seems as long as a rail is placed inside the stall they can get away with slapping a wheelchair access sign on the door.
Monica Turner
Newmobility.com
Life is unpredictable...
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A large portion of the general public had at least heard of Krauthammer — appearing multiple times per week on America’s highest-rated cable news channel will do that — and his influence on modern conservative thought is considerable. What a much smaller percentage knew was that he was a wheelchair user, as he had been living with quadriplegia since a diving accident at age 22 while attending Harvard Medical School.

Both his national prominence and the public ignorance of his disability are of Krauthammer’s own design. He was intensely ambitious, having graduated on time and with honors from Harvard after his accident. During the very brief time Krauthammer was engaged in the field of psychiatry, he won a prize for excellence in psychiatric research. But he quickly grew bored with the profession, and turned his considerable intellect to politics. With next to no experience, he was hired as a speech writer for Vice President Walter Mondale during the Jimmy Carter reelection campaign of 1980. “History is shaped by its battle of ideas, and I wanted to be in the arena,” Krauthammer reflected in 2003.

He rose quickly among the commentariat, taking a job with the influential magazine, *The New Republic*, before becoming a columnist with *The Washington Post* in 1984. Krauthammer began his writing career as a “liberal Cold Warrior,” and is credited with coining the term “the Reagan Doctrine” for the policy to provide military support to anti-communist groups throughout the Americas. Later, he wholeheartedly identified as a neoconservative, arguing for robust military force to combat terrorism and leading the chorus of voices arguing for the 2003 invasion of Iraq.

In Krauthammer’s rather lofty “history-shaping” mission, he initially saw his disability as an impediment, not because it in any way affected his professional abilities — thinking, writing and talking — but because of the way people would view him. “That was the one thing that bothered me very early on,” Krauthammer said in a *Washington Post* interview in 1984, the first time he spoke publicly about his disability. “The first week, I thought, the terrible thing is that people are going to judge me now by a different standard. If I can just muddle through life, they’ll say it was a great achievement, given this.”

“I thought that would be the worst, that would be the greatest defeat in my life — if I allowed that. I decided if I could make people judge me by the old standard, that would be a triumph and that’s what I try to do. It seemed to me the only way to live.”

**Hiding in Plain Sight**

To anyone who has lived with a visible disability, personal experience would tell you that Krauthammer’s concerns were valid. Regardless of your ambitions or abilities, it can be difficult to be taken seriously in a world where simply living as a wheelchair user — getting out of bed in the morning, going to the store, let alone holding any sort of job — is often seen as an act of courage and perseverance. This was even more true in 1975, when Krauthammer was first seeking to make a post-disability life for himself.

Krauthammer’s general policy regarding his disability, at least professionally, was to pretend as if it didn’t exist. He didn’t write about it, he didn’t speak publicly about issues relating to disability. The only reference to be found regarding Krauthammer and the ADA, when searching both *The Washington Post* archives and a broader Google search, is a speech he gave for the American Dental Association in 2015.

For the most part, the media complied with his wish to have his disability hidden, or at least framed in soft focus in the background. On Fox News, he appeared from the chest or shoulders up,
wheelchair invisible beneath the scrolling news ticker. Most photos appear with a similar crop or shot from an angle that shows only the barest hint of his chair. A 2014 Newsweek photo shows Krauthammer sitting at his desk wearing a black turtle neck, a whisper of a push handle camouflaged against his shirt is the only visible piece of his wheelchair. In the photo, his right arm is visible, atrophied forearm leading to a hand curled into a loose fist. It’s a fitting illustration of the way he presented himself in the media — his disability is visible, but only if you go looking for it.

Of course, Krauthammer is not the first public persona to ablewash themselves. Franklin D. Roosevelt is the most obvious and prominent example — public figures with disabilities who claim their careers are not about their disability and so choose to hide it from view. That these are most often ambitious white men from privileged backgrounds should not be overlooked. Krauthammer came from money, and enjoyed the kind of mobility where, on a whim, he could switch from studying philosophy at Oxford to enrolling in medical school at Harvard. After his accident, he sued the builders of the pool he dove into and won a settlement around $1 million, which he said, “rights the scales a bit,” referring to the extra costs of living with SCI.

The Road Not Taken
None of that is to say Krauthammer rose to the summit of his chosen profession solely because of his privileges — it’s not possible to do anything as well as he did without uncommon talent, creativity and work ethic — but his financial stability allowed for whatever medical care, supplies and assistance he needed.

It would be unfair, perhaps, to have expected Krauthammer to use his public platform to advocate for social services, universal health care or an expansion of disability insurance. His political leanings, especially in his later years, precluded any of that, while his chosen lifestyle left him disconnected from the needs and day-to-day reality of most in the disability community. But irrespective of politics or policy specifics, Krauthammer could have made a world of difference in societal perceptions of disability by simply being more open about the whole of his life, wheelchair and all.

The few times that he did write or speak about disability, he did so with eloquence and wisdom. In the 1984 article where he first spoke publicly about his disability, he offered this analogy: “The people who probably understand me best are political refugees in exile.... They have to go to a new country where they have to speak a language they have a lot of trouble with. Now, they can express themselves but they never have that wonderful elegance they have in their native tongue.”

As a writer, Krauthammer possessed a rare gift: being able to shift people’s perspectives with the power of his words. Jacob Heilbrunn, the editor for the prominent foreign policy journal, The National Interest, said that Krauthammer, “crystallized conservative thought and exerted influence by setting the terms of public debate at key moments in the nation’s political life.”

This was a man who helped to successfully convince a sizable portion of the U.S. that the regime of Saddam Hussein was a direct and imminent threat to our country and way of life. Persuading the American public that people with disabilities are a valuable, integral part of society, deserving to be seen and treated as everyone else, should have been a rather simple task, comparatively.

Krauthammer was obviously concerned with societal perceptions of disability. We’ll never know what impact he could have made had he chosen to confront those perceptions directly instead of hiding his disability from view.

— Seth McBride
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GOOD NEWS

UNITED SPINAL PARTNERS TO IMPROVE PHOTO REPRESENTATIONS OF DISABILITY

Are you continually disappointed by images of people with disabilities in the media? Tired of seeing inauthentic depictions of wheelchair users or photos that reinforce outdated and inaccurate stereotypes?

United Spinal Association is excited to be a part of a new effort to address that problem and improve the representation of people with disabilities in the media. On May 17, United Spinal joined 16 other member organizations of the National Disability Leadership Alliance alongside Oath and Getty Images to launch The Disability Collection, a repository of images that break stereotypes and more authentically portray disability. View the initiative online at www.thedisabilitycollection.com.

“One of the hardest things we face, day in and day out, is discovering authentic images to run alongside our stories and on the web,” says Ian Ruder, editor of New Mobility and United Spinal’s point person for The Disability Connection. “There is an obvious need to cultivate better images and make them more accessible, and The Disability Connection has the potential to do just that.”

While some 15-20 percent of the world’s population have a disability, Getty found that only 2 percent of stock photographs depicted disability. At the same time, its own data showed a huge spike in disability-related searches, with terms like “wheelchair access” and “disabled worker” jumping 357 percent and 254 percent respectively on GettyImages.com between 2016 and 2017.

The project invites photographers to portray disability as a natural part of someone’s identity, instead of something that needs to be “cured,” “fixed,” or “overcome.” Furthermore, guidelines are provided to ensure effective and appropriate communication onsite and on set, including avoiding using nondisabled models pretending to be people with disabilities and highlighting a whole person instead of only the disability. Since the launch, both established and aspiring photographers have uploaded photos that can be viewed online via the Getty website at bit.ly/2JmoyOB. Once submitted, entries are screened to ensure they meet the guidelines established by Oath, Getty Images and NDLA members. Selected photos will then become permanent fixtures of the Getty stock image collection. To sign up or find out more about the project visit oath.com/accessibility/getty-collection.

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What does world traveler and renowned blogger Cory Lee Woodard of Curbfreewithcorylee.com fame eat when he’s spanning the globe?

Not meat, says Woodard, 28. “Back in September 2017, I watched a movie called What the Health? on Netflix and as soon as I finished, I decided to go vegan immediately,” says Woodard, who has spinal muscular atrophy. “I have not eaten meat since then and I’ve only had dairy a handful of times when I’m traveling in other countries.” He says it was tough to be vegan in Spain and Morocco, “so I was more vegetarian for those couple weeks.” Vegetarians abstain from meat, but may eat eggs and dairy, and vegans do not eat any meat or meat by-products.

What about protein? As Woodard points out, the average person only needs about 40-50 grams a day, and how you get there is up to you. “A serving of beef has about 20 grams, whereas one cup of soybeans has about 60 grams,” he says. Beans, lentils, peas, and many other plants also pack in the protein.

Woodard feels great on his diet and says it’s even alleviated disability symptoms. “I’ve definitely noticed an increase in energy, and I feel more aware of what’s going on around me,” he says. “Also, for the first time ever, my lung function has increased! When my pulmonologist told me it went up instead of down, I knew I was doing something right.”

If you’d like to give it a go, Woodard has the following advice: “Try it for just 30 days. During that time, watch documentaries, do research, join vegan related Facebook groups, and try lots of new recipes.”

MARISA HAMAMOTO’S INFINITE FLOW

If you live in Los Angeles and are interested in dance, Infinite Flow may be for you — whether you have a disability or not. “Everyone can dance and we’re not just about people with disabilities, we serve everyone,” says founder Marisa Hamamoto. “It’s all about inclusion.”

Hamamoto experienced a spinal cord infarction during a contemporary dance class in 2006 that resulted in quadriplegia and a doctor telling her there would be no recovery. However, in her case, she walked out of the hospital two months later. Because of this experience, she realized what gaps exist for people with disabilities in the world of dance. She is also sensitive to the fact that most people do not recover full mobility.

“Sometimes I feel like people try to steer me toward rehab and health and focusing on ways to do dance therapy, but no, dance is dance, and the benefits of dance are going to come regardless,” she says. Also, her approach is different than many other similar companies. “What we do is about mainstreaming. I ask the question, how can I impact a broad general audience, not necessarily an artsy crowd?” After all, there’s a reason why shows like So You Think You Can Dance are so popular, she says.

Her approach is catching on, as she was one of 15 selected from hundreds of applicants nationwide for Red Bull Amaphiko, a launch pad for grassroots social entrepreneurs making a positive difference in their community. Follow her at Infiniteflowdance.org, Facebook, Instagram and Twitter.

TWO BOOKS FOR YOUR HEALTH


Six Seasons: A New Way with Vegetables: This handsome book by Joshua McFadden with Martha Holmberg is literally “editor’s choice,” as New Mobility editor Ian Ruder recommended it to fellow editor Josie Byzek, who loves it. Some recipes include meat ingredients, but most can be adapted, and it will change how you view vegetables — and probably when, where and how you purchase them, as well. Ruder especially recommends a salad of farro and roasted carrots.

Both books are available from Amazon.
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As an SCI researcher and a person with a spinal cord injury, Alexander "Sasha" Rabchevsky sees "both sides of the story" when asked to reflect on how SCI research has evolved over the past three decades. He's learned his unique position can be an advantage and a source of frustration, but he is dedicated to improving the quality of life of his fellow wheelers.

As an SCI researcher and a person with a spinal cord injury, Alexander "Sasha" Rabchevsky sees "both sides of the story" when asked to reflect on how SCI research has evolved over the past three decades. He's learned his unique position can be an advantage and a source of frustration, but he is dedicated to improving the quality of life of his fellow wheelers.

Passion for Science

Rabchevsky, 52, has been a research scientist and a professor of physiology at the University of Kentucky since 1997. A T5 spinal cord injury between his sophomore and junior years in college set him on the path to his career. He wasn't focused solely on a cure, but says, "If there isn't a cure for spinal cord injury, I want to be in a room of authoritative people and have them tell me why not."

With that in mind, Rabchevsky headed for medical school and chose the research route instead of working to be a practicing physician. "I felt like I'd help more people by doing research," he says.

Today, Rabchevsky teaches medical, graduate and undergraduate students, with a focus on neurophysiology and neuroendocrinology. Most of his research is SCI-related, much of it using rat and mouse SCI models. He carries out experiments to improve ambulation, but is more passionate about his research that could improve day-to-day quality of life for people with SCI, focusing in particular on spasticity and autonomic dysreflexia.

"While we're waiting for a cure to walk or use our hands, I want to be able to pee and poop and have sex," he says. He focuses on autonomic dysfunctions, including unregulated cardiovascular and metabolic syndromes that frequently develop with a sedentary lifestyle.

He thinks the research community's focus on a "cortically driven" approach to regaining volitional, complex movements may have diverted attention and funding from proven approaches that could help people with SCI do more. One such area is functional electric stimulation. Rabchevsky has been a vocal advocate for FES implants since 2002, when he received one that enabled him to stand up with a walker and ambulate — albeit with strenuous effort.

"We could've been improving upon the FES put into me 16 years ago!" he says. "I know I'm an anomaly, but I often wonder why the heck aren't there more SCI folks being implanted with upgrades?"

"If government and private foundations had spent significant money — like that directed to the stem cell research field or other more 'sexy' genetic approaches — into technologies to improve FES that have already been proven to work functionally, then I think that researchers might not be so hastened to develop 'usable' exoskeletons," he says.

UNIQUE REMEDY: I take a very low dose of oxycodone under medical supervision to help relax my bowels so that I don’t have to go every day, which also affects bladder spasticity.

CAN'T LIVE WITHOUT: No Barriers co-founder Mark Wellman’s adaptive climbing aids are so incredible that even if you’re not a climber, with some innovative rigs and nondisabled friends you can tackle some of the craziest sheer rocks.
“Everybody who is willing to work hard to get a known functional outcome would be getting FES implants.”

As you can probably tell, Rabchevsky isn’t shy about sharing his two cents. He takes pride in representing the SCI community as the lone wheelchair user in many scientific discussions and is aware that makes some audiences more receptive to his ideas and thoughts.

“Sometimes I think I get the benefit of the doubt because I am a wheelchair user,” he says. “But I also claim that I don’t know the answers. There are a lot of times when I’ll scrutinize other people’s plans and they’ll say, ‘Well, if you know, why don’t you tell us?’ My response is, ‘I’m not saying I know. I just know that’s not right.’”

Rabchevsky’s efforts to educate the general public about SCI and to involve advocates with SCI go beyond his research and professional role. In addition to his work with No Barriers USA (see sidebar), he co-founded the Kentucky Congress on SCI, and works with a nonprofit called Independence Place Kentucky that helps get people with disabilities back into society and into the workforce.

CRAZIEST THING I’VE DONE: Myself, another para, a man with no arms and blind adventurer took chairlifts up a mountain and “rolled” down an incredibly steep trail of switchbacks in order to go 30 mph down a 3,000-foot Alpine slide in Winter Park, Colorado.

WHY I JOINED UNITED SPINAL ASSOCIATION: Rabchevsky is a new member of United Spinal, but has crossed paths with the organization in many endeavors, including his work with the National Spinal Cord Injury Consortium, of which United Spinal is a member. “So, in a way, I am intimate with United Spinal,” he says.

Sasha attended his first No Barriers Summit in 2007, joined the board in 2010 and hasn’t missed one of the events since.

“"In 2007, I went through a divorce and was depressed as I prepared to go to the second No Barriers Summit at Squaw Valley, and I asked myself, ‘What in the hell am I doing here with all these incredible adventurers who’ve lost limbs and even sight?’

Within a day of being there, it changed my life. I was climbing mountains. I scaled a 100-foot cliff. I got to go geocaching ... I bought what No Barriers was selling hook, line and sinker.

I fell in love with these folks. They were a fledgling organization, basically, with testosterone-laden guys with disabilities who were doing amazingly crazy things. I joined the group and it became like family.

I’m excited about this year’s summit, October 5-6 in New York City. It’s the first time we’ve had it in a big city, and that presents a whole new set of opportunities ... and obstacles.

Any time there’s a crisis regarding accessibility, I’m one of the guys the board or staff calls. It’s not like I have all the answers, but, as a wheelchair user, I do have a history of being able to work through things."
t was a Saturday night in Indianapolis, and Morty’s Comedy Joint was at capacity for the finals of Trial by Laughter, the club’s annual stand-up competition. The field, which once featured 30 up-and-coming comedians from all over the Midwest, had been narrowed to eight, with the winner of the $1,000 cash-prize to be decided by a panel of judges, plus an aggregate audience score.

Chris Bowers, the owner of the club and that night’s emcee, was on stage making fun of his purple sequined jacket, keeping the crowd warm in between sets, while two comics worked in the shadows to set up a ramp on stage. Bowers got their thumbs-up, nodded to the cameraman in the back of the room — the show was being filmed by Comcast for their on-demand service — and fell into his announcer’s voice:

“Alright folks, let’s keep it going for your next comic!” He waved a purple arm in the air to signify how much more noise he needed. “LUUUUCCAAS WATERFILLLLL!”

There was a small commotion off to the side, and then a wheelchair user was lifted over the lip of the wooden ramp. With a smile as wide as the curtains, Lucas Waterfill rolled onto the stage and into the spotlight.

More Than a Pipe Dream
I met up with Waterfill a few weeks prior to his performance at Trial by Laughter, at a bar in Broad Ripple, a trendy neighborhood on Indianapolis’ northeast side. It was a Tuesday night, and the club across the street, Crackers Comedy, was hosting its weekly open mic, which meant the bar was full of local comics loosening up before the show. Waterfill, who has cerebral palsy, is one of the best comedians on the scene, an ascendant talent, a guy with a real chance of making it in the world of comedy. He is the type of guy people want to rub shoulders with, and as we made our way to a seat, he was greeted with head nods and back slaps and hey-buddy’s.

We ordered drinks, beer for me, vodka-Sprite with an extra-long straw, for him, and settled into what I planned on being a one-drink, half-hour conversation. The first
thing he told me, almost apologetically, was that he wasn’t as funny in person as he was on stage. Which is true. In private, Waterfill is far removed from the loud, profane, laugh-making machine who apologizes onstage on behalf of the disabled community for Japanese internment camps (“That was our fault,” he says on stage, pausing a beat to see how many people get the Franklin Delano Roosevelt reference) and breaks down the “Four Levels of Crippled,” yelling in faux-anger about “active cripples” and how, “those smug sons of bitches make being crippled look easy!”

In person, Waterfill is quiet and low-key — a polite, thoughtful alter ego of his stage persona, someone who isn’t afraid to talk seriously about the craft of making people laugh. That’s not to say he isn’t funny. Despite his best efforts to respond earnestly, he couldn’t help but test out some material when I asked about the difficulties of getting booked out of town by club owners who weren’t familiar with his disability. “It’s kinda like trying to pick up women,” he said, cracking a sly, sideways smile. “A lot of my life is convincing people what I’m capable of.”

We talked about 2017. It was a good year for Waterfill — there...
was no debating that, although we quibbled a bit on how to define it. A breakthrough, is how I tried to frame it. Progress, is how he saw it. Either way, after nearly four years of hustling to pay his dues — taking the bus back-and-forth to open mics, hanging around on the alt list, doing shows in dive bars for three people and no money — all the hard work and sacrifice was finally starting to feel worth it.

Earlier this year, Waterfill won the highly-competitive Funniest Person in Cincinnati contest, embarked on, and survived, his first tour — a nine-city, five-state DIY adventure with two other local comics — and found himself in the penultimate slot on the main stage at the Brew Ha-Ha Comedy Festival, featuring for the festival’s headliner, former Saturday Night Live writer Brooks Wheelan. It was a nerve-racking experience with over 1,000 people in the audience, but Waterfill killed, absolutely slaying the largest room he’d ever played. It was the highlight of his summer, he said, a turning point, the moment he realized this comedy thing might not be such a pipe dream after all.

Despite all the success, however, Waterfill emphasized he wasn’t satisfied. It’s nice to win competitions, validation is always good — sometimes desperately needed — and going on the road was a great experience. But it was all in the past. Same thing with Brew Ha-Ha. It was a thrilling, confidence-boosting 15 minutes, but it was in the rearview. “Comedy is a young man’s game,” he explained, noting that his 27th birthday was coming later that month. “Every comic has this internal clock, where you’re like, shit, I’m 27, I’ve been in three years and nine months, I should be here, I should be here, I should be here.”

I asked whether the clock was starting to tick a little louder for him and if it added another layer of pressure to an already pressurized situation. He admitted that it had, but in a good way. It’s inspired him to up his game, he said, get more professional, write new stuff; stop sitting back waiting to be seen, and go get himself discovered. “[The pressure] is motivating,” he said, leaning over to take a long pull of his vodka-Sprite. “It’s put a fire under my lazy ass.”

The Thrill of the Tension

“So the other day I was rolling down the street and I stopped at a crosswalk …”

There’s a moment during every comedy performance, in the seconds between a comic’s introduction and the punch line of their first joke, when the room fills with a nervous, uncomfortable energy, a collective feeling in the audience of oh God, please, please be funny. There is nothing more awkward, no more painful experience as an audience member, than watching someone up on stage who shouldn’t be up there, telling jokes that aren’t funny. It actually causes a physical reaction in some — a reddening of the face, a tingling of the skin, an undeniable urge to cover the eyes and run from the room. The comic up on stage feels it, the weight of that expectation, and for the vast majority of people who ever attempt stand-up comedy, it’s that pocket of pressure that crushes their dreams, turns them back into accountants and teachers and data analysts.

When Waterfill takes the stage, that tension, the enormous responsibility of making people laugh, is intensified by 10 times. Nobody, not even the meanest of drunk hecklers, wants to watch a guy in a wheelchair bomb. “This woman comes up to me, and she says, ‘May I pray for you? ...’

Sitting in the showroom at Morty’s for the Trial by Laughter competition, I felt that tension firsthand. I had seen Waterfill before, so I knew what to expect. But crammed into the packed showroom, surrounded by people just checking out a random comedy show on a Saturday night, I could actually sense the crowd get stiff — pucker-up, as the comics like to say — when Waterfill started into his first joke. It was as if everyone had taken a deep breath all at once and was holding it until the guy in the wheelchair could make them stop feeling so damned uncomfortable.

“I said ‘sure’ ... thinking that she would pray, you know, AWAY FROM ME!”

And with that, the crowd fully exhaled. Shoulders loosened, drinks were brought to lips; the tension in the room evaporated and was replaced, just like that, by a buzz of excited energy, one that just kept building and building throughout his set, seven-minutes of frenzied, pointed absurdity that by the end had the audience on its feet, leaving no doubt in anyone’s mind who the winner of the competition would be.

“I love the tension,” Waterfill said, leaning his seat forward when I brought it up at the bar. “I take full advan-
tage of it, blow it up. I like embracing that awkwardness, having them feel like that, and then being like, OK, he’s in control of this situation. He knows what he’s doing.”

It’s one of the reasons Waterfill said he was drawn to comedy, the reason why he’s constantly seeking out stage time — the power he has up there, that level of control, it’s a high, and it’s something he doesn’t get a lot of in his day-to-day. It’s not the only reason, of course. As his mom, Missy, put it, with a laugh, when I spoke with her on the phone from the family’s home in Plainfield, a small town on the outskirts of Indianapolis: “Lucas is a person who loves attention. ... It’s just his personality,” she explained, noting that he fronted a hardcore straight-edge band back in high school.

It’s a characterization that he acknowledges, and fully embraces: “I want to be famous,” he told me at the bar, without apology. “I want to have Netflix specials, go on tour, be a pan-dent on Bill Maher.” He paused and leaned down to take another drink. “I want to give Bill Maher shit,” he said, flashing that half-smile again. “That’s a goal of mine.”

The Disability Advantage
Logistical issues like inconsistent stage access, not being able to hold a mic, and having to write and store jokes entirely in his head are daily realities for Waterfill, but he believes his disability is an advantage. As he sees it, while having a disability can make it harder to advance in many systems, in comedy, all the added adversity gives you a different perspective and more material to work with.

“I think comedy is a good vehicle for us,” he said, as the comics in the bar — almost all bearded white guys in their mid-20s — began to head across the street to the
“There’s something inherently funny about looking different, or limping, or using a wheelchair, or whatever, and I don’t think it’s bad to lean into that.”

It’s not just the material, though, or the different perspective. From a young age, because of his disability, Waterfill was very aware of what people thought of him, and it forced him to confront those perceptions, to accept or reject those notions of himself, much earlier than his nondisabled peers. At the age of 12, for instance, angry at people who kept telling him he’d be able to walk one day, Waterfill adopted a motto, which he later had tattooed on his thigh: Crip 4 Lyfe.

It’s that attitude, a defined sense of self, that Waterfill brought with him to the stage when he first started, and it translated immediately in his comedic voice, imbuing him with a personalized authenticity that most good comics take years to develop.

When you get right down to it, in fact, the biggest conflict that Waterfill’s disability creates for him on stage is internal — how much should he talk about it? How should he talk about it? It’s an issue he came back to several times during what turned out to be a three-hour, multi-drink conversation. Waterfill was a political science major at Indiana University-Purdue University Indianapolis, interned for U.S. Sen. Joe Donnelly (D-IN) while there, and had hopes of becoming a political organizer after graduation. It didn’t work out — Indiana isn’t exactly a hotbed for liberal activism — and so he traded the bullhorn for the microphone with the idea that maybe he could help bring some of those issues into the mainstream through comedy.

There’s a fine line though, he said, between saying something, making a statement, and being a “cheesy liberal social justice warrior guy who wants to change everyone’s mind.” It’s something he’s continually trying to balance. His goal, he said, as the waitress plopped down our second drink, is to “talk about being disabled the way [comedian] Patrice O’Neal talked about being black.”

“I just want to make it that out-of-control, and that ridiculous.”

That’s what comedians do, the good ones anyway — they take what’s personal to them, something that’s unique to their experience, and they exaggerate it and make it so outrageous that it somehow becomes relatable to all. It’s a cathartic process for Waterfill, whose initial emotional response to many of society’s interactions with disabled people isn’t good humor, but frustrated anger. He can’t help it — half of him, he says, just wants to have a good time and laugh everything off, but the other half is “so fucking pissed.” Comedy bridges that divide. It allows him to take a negative emotion, something that could fester into full-blown bitterness if left internalized, and turn it into something positive, a sharable, laughable, example of the absurdity he deals with daily.

Waterfill cited his opening joke, the one about the lady who prayed for him, as the sweet-spot. The joke blossoms from the initial punchline into a piece of performance art in which Waterfill pretends to be healed by the woman’s prayers. “I knew I was pissed about it … but I needed to make it funny, so people could understand how ridiculous it is for someone to pray for you in public. If I went up there and said, ‘somebody prayed for me in public,’ [the audience] would go, ‘ah, that’s sweet, that’s so nice.’ I have to demonstrate how absurd that is. If someone did that to anyone else, they’d be like, ‘What the fuck? Get off me,’ but because it’s me, someone in a wheelchair, it’s socially acceptable.”

That’s the needle he’s trying to thread, juxtaposing how
people perceive his situation against the reality he experiences, and doing so without getting up on his soap box, or worse, having people feel sorry for him.

“I never want to be the corny crippled guy, the made-for-TV movie crippled guy. That’s my biggest fear,” he said. “Well, not my biggest fear.” He cracked another sideways grin. “My biggest fear is failing and having to move back into my parents’ house.”

**Go Big or Stay Home**

The future is still unfolding for Waterfill, and what it reveals is anybody’s guess. 2018 has been even better than 2017 — not only has he climbed another rung of the ladder, establishing himself as a steady feature act around town, but he had a killer showing at Laughing Skull in Atlanta, one of the most prestigious comedy festivals in the country. It’s more progress, there’s no doubt about that, and that’s great, but the success has brought him to a crossroads, one that every legitimate comedian from the Midwest has to face at some point — does he stay in Indianapolis, working his 9-to-5, hitting the road on the weekends in the hope that somebody, somewhere sees him, or does he start saving his money for a move to one of the coasts, where the dream can become a reality in an instant (or crushed just as quickly).

It’s a Catch-22 for Waterfill. In order to make a permanent move to Los Angeles or New York City, he needs to go on the road to make more money, but the road is not economical. The Crippling Egos Tour he went on with his two comedian buddies required meticulous planning, special accommodations, and the agreement among the three that they would tell everyone they “broke even” when they got home. It was fun as hell, but the road-life is simply not practical for Waterfill. Neither is making a temporary move to New York or LA, crashing on a buddy’s couch for a couple months to find out if he sinks or swims.

That’s why Laughing Skull was such a big deal. Not only was it one helluva confidence-booster, just getting the invite — what he refers to as “fuel” — but the festival is famous for its industry showcases, where dozens of television bookers, casting agents, managers and talent scouts show up to find the Next Big Thing. It’s the kind of situation where, if the right person just happens to catch your act on the right night, it can make your career. And this year they saw Waterfill. They approached him after the show, handed him business cards and told him they’d be in touch. It was exactly how he’d played it out in his head, the kind of break he’s been dreaming of. But he doesn’t want to dwell on what could be. He has jokes to write, bits to iron out, more festivals on the calendar. He knows he can’t get complacent, no matter how well things are going, or how bright the future seems.

“I won’t be satisfied until my second buddy-cop movie,” he told me that night at the bar, after ordering a round of tequila shots. He was smiling that sideways grin of his, and I laughed out loud. Both of us knew he wasn’t joking.

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Kelly and I didn’t even have a name picked out before he was born. After eight months of waffling, Ewan and Micah were the boy-name finalists. Choosing a name that he’d carry through life seemed like a big responsibility.

Then out he popped, all wrinkles and cries and vernix and monkey toes. Ewan, I thought. That’s Ewan. “What do you think?” I asked Kelly.

“He’s beautiful,” she said.

I smiled. “Yes he is. What about his name?”

“Ewan,” she said.

I smiled again. Guess it fit.

Of the many unknowns that awaited us on the other end of Kelly’s pregnancy, Ewan’s name was the first to be resolved. Like all first-time parents, we had a thousand questions.

My concerns about being a parent with a disability weren’t related to anything existential — like, what will he think about having a dad in a wheelchair? Or, what will his friends think? I knew enough fathers through wheelchair rugby to understand that to a baby, you’re not the wheelchair guy, you’re just dad.

But some of those dads could also count the number of times they’d changed a diaper on one hand. I have C7-8 motor-complete quadriplegia, which manifests in weak hands and poor trunk stability, and that was where my concerns were: How long was he going to tolerate my floppy-fingered fumbling with a diaper? How would I carry him around and get him into and out of a car seat?

Kelly would be going to back to work full-time after a few months of maternity leave, and I would be on my own with Ewan for eight to 10 hours at a time. I didn’t have the option of trying to change a few diapers, and saying, “this isn’t working, maybe you should just do it.” And I sure wasn’t going to sit inside with him all day. I’d have to figure out how to do things my own way, but I had no idea how Ewan would respond. I shouldn’t have worried. Adaptability is something we often have to relearn after a disability. For babies, it comes naturally.
First Diapers

I didn’t actually get a diaper all the way on the first time I tried to change Ewan. But I didn’t get peed on either, so I took it as a win. He was a week or two old, and I decided I needed to get to it. Diapers are one thing, but everything else, from getting him up onto the changing table to unbuttoning his onesie, was terra incognita for me as well.

By the time I figured out how to get him on the changing pad (on the shoulder first, shimmy forward under the table, then lay him down), he was already starting to get a little fussy. After a few failed attempts, I figured out how to use my right thumb (my most functional digit) to pop open the buttons on the bottom of his onesie. At this point, he was starting to yell a little and landing some solid kicks to my face. In between blows, I was trying to settle the situation with my calm authoritative voice, “Ewan, we will not be driven by fear into an age of unreason. . . .”

OK, maybe the Murrow impersonation was more in tone than content, but either way Ewan wasn’t buying it. Neither was Kelly, who’d appeared in the doorway to watch the commotion. “You want some help?” she asked.

I did. Kelly came over, got the new diaper on, and Ewan calmed down with ease. I put on my grumpy face.

A few attempts later, I did get pee and poop on me, and Ewan burped milk all over himself — but I also got both of us cleaned up and a fresh diaper on, so I took that as a win, too. It took a few weeks for me to actually get comfortable changing diapers. We were using a combination of cloth and disposable, and each variation required a slightly different technique to get the closures tight enough for the diaper to hold more than a few drops of pee.

Once I got comfortable with the process, so did Ewan. He could sense nervousness and would pounce on it like a tiger. The only way to keep him from getting wild was to be confident that I was actually in charge of the situation. I still took two or three times as long as Kelly did to complete the process, but as soon I was comfortable enough to actually project the authority that I was trying to imitate earlier, he calmed right down with me. He’d have gotten agitated if Kelly took 15 minutes to change his diaper and clothes, but with me, he just seemed to understand — dad’s slower than mom, and that’s just the way it is.

“Adaptability is something we often have to relearn after a disability. For babies, it comes naturally.”
Everything is Better Outside

The motion of being walked is calming to infants, a steady bouncing rock that is evolutionarily ingrained to calm them down. A pushing motion in my wheelchair was definitely not the same thing. Ewan would fall asleep in a few minutes when Kelly put him in a carrier, nestled against her chest while we strolled the neighborhood. When I tried, he’d last a few minutes and then start wriggling and fighting like the carrier was a strait jacket. After a number of unsuccessful attempts, we decided to reevaluate.

Ewan wasn’t going to sleep while on me, but he loved being outside. The fix was to just flip him around to face forward. If we were going to be outside, he wanted to see the world, not my chest. We had a forward-facing Baby Bjorn carrier that had clasps my hands were capable of operating. I could take him out wandering as soon as his neck was strong enough to keep his head from flopping around. Up until Ewan was 5 months old or so, he didn’t weigh enough to really throw off my balance. As he got heavier, and more functional, I loosened the straps so that he was basically sitting on my lap. That way he was supported, but the whole of his weight wasn’t pulling me forward.

Going outside was damn near a magic trick for anytime Ewan started to get fussy. Didn’t matter if it was snowing or 45 degrees and raining, as long as there was open sky and we were moving, he was happy.

That realization was the key to my first year of daddy day care. Ewan is relatively chill as far as babies go, but his moods during year one were a mystery to me. Being hungry pissed him off. Being tired pissed him off. Those I understood and could fix. But there were other things that pissed him off that were entirely invisible to the world in which I resided. Whenever those imperceptible agitators started to tickle his angry bone, I’d take him outside to wander around and, generally, all would be forgotten (see sidebar, page 26).

The Great Expanse Beneath Your Wheels

Another key component of my being able to take care of Ewan while Kelly was at work was being able to get him off the floor. I didn’t want him to be stuck on my lap, and once he started to get more mobile, I couldn’t leave him on a bed or couch and expect him not to wiggle off. Plus, what if I dropped him?

Of course, I did drop him. Once off my lap, which was downright terrifying for both of us. Twice I flipped over backward while holding him. That was less scary for me as I was cradling him and knew that physically he was fine, but it still freaked him out. A practical tip: If you have adjustable center of gravity, move your axle forward to remove some tippiness from your chair before your baby gets strong enough to really wriggle and kick.

Anyway, parenting failures included, there are plenty of reasons I’d need to get Ewan off the floor. But lacking functional back extensors, I can’t sit up from being bent over my lap while holding anything, and Ewan didn’t have enough neck skin to do the tiger cub trick. A friend of ours through rugby — a guy with less function than me who did change his kids’ diapers (sorry C6ers, no excuses!) — had a sling that he’d received from another quad dad when his first was born. It was basically a big oval of fabric, with straps on
either side. He gave it to us before Ewan was born and the sling worked so well that I ended up having two more sewn. With the sling, I could get him off the floor with little more than wrist extensors and biceps.

I have other friends who swore by overalls for the same principle — they function like a luggage handle for your kid. With overalls on, I could pick Ewan up by simply sliding my hand under the shoulder straps and lifting. But there were drawbacks. First, overalls were difficult to put on, and though baby ones have snaps at the legs so that you can change a diaper, I couldn’t get them snapped back up while he was in them so a diaper change meant taking them all the way off. Second, depending on the cut, when his full weight was on the straps, the front of the overalls would start pressing up into Ewan’s neck, giving him a bit of a choke. Not ideal.

We wound up with a number of pairs, and after some trial and error, I figured out the ones that fit the best for lifting purposes. The absolute best was a pair of Patagonia fleece overalls. They had some stretch and a V-cut neck, which meant that I could lift him wherever I needed and he stayed comfortable. Alas, Patagonia doesn’t appear to sell these anymore. But if you find something similar, get them.

The Real World

Given their difficulty to get on, overalls weren’t a daily wardrobe choice. I reserved them mostly for when Ewan and I were venturing out in the car. First, let me say that for someone with my function, getting a baby into and out of a car seat sucks. There’s no easy way to do it. Lifting him out away from my body to bridge the gap between my chair and the car wasn’t doable with both hands holding Ewan. Every time we needed to go somewhere, I wriggled the overalls onto him so that I could stabilize myself with my right hand and swing him over into the car seat with my left.

Once he was in the seat, there was usually a good five to eight minutes of fumbling to get him situated, the straps untwisted and the buckles done up. The first few times, he got rightfully pissed. He was used to mom doing it — slip in the seat, click, click, done. But like the diaper changes, he quickly got used to my painfully slow process and would
maintain far more patience than he ever would for Kelly.

For that first year I felt like I was continually swimming upstream against my function — trying, failing, adjusting and trying again. The thing about being a new parent is that I was so afraid to mess up. But it’s impossible not to. It’s a learning process, and learning involves messing up. Babies don’t judge you for it. (That’ll come later.) When I was figuring out how to do something new, Ewan would sometimes yell and kick and cry for a while, but then he’d get over it.

People always ask me if having a kid is any different than I expected. Looking back on the first year of the Ewan experience, it was more difficult than I ever would have thought, but it was also way more fun. You’re learning to care for a very needy little being that has no way of expressing his needs other than through crying, and you’re doing it on very little sleep. But you’re also laughing and singing and playing and getting to act like a goon.

Whatever your level of function, to your kid, you’re their normal. Just do what you do, however you need to. To Ewan, it doesn’t matter how I do things. As long as I keep him fed, take him outside, love him, play with him and don’t drop him too often, he thinks I am pretty great.

Baby Gear Hacks
Kelly and I both need to get our bodies moving most every day to feel normal, but finding the time to work out is tough with jobs and an infant. Kelly could run with Ewan in the stroller, but I couldn’t push faster than a stroll with Ewan on me in a carrier.

The first solution was an adaptation for my handcycle that Kelly’s dad rigged up while we were visiting in Ohio. We’d bought a Thule Yepp Mini (see photo below) front bike seat off Craigslist, but at 3 months, Ewan wasn’t yet stable enough to sit upright in it. Her dad fabricated a rack that clamped on the frame of my Top End Force CC handcycle. The Yepp seat then clamped onto that rack at a more reclined angle than it would on a regular bike. Ewan could lie in the seat, strapped in and secure while I rode him around.

He loved it from the first ride. When we got back to Portland and Ewan and I were home alone during the day, a morning bike ride was guaranteed contentment for Ewan and a great way to get the blood flowing for me. That was definitely a win.

The world opened up to us a little bit more when Ewan got to 5 months and started to get some sitting stability. Until then, unless Ewan was in the carrier, I had been rolling around with him laid down on my lap, head at my knees. It worked in the house, but I had to hold onto him with one hand and push with the other, switching back and forth to go anywhere. Outside, on any sort of slope or uneven terrain, it simply didn’t work.

When he was more stable, but before he could sit on his own, I started putting him into a molded rubber seat called a Bumbo seat (see photo, page 23). I’d set the Bumbo on the table and lift Ewan up into it, then wheel under the table and pull the seat down onto my lap. He would kick his tiny little legs in excitement as soon as we rolled outside to head down the block. Realizing how much he liked it, I bolted a webbing strap with sewn loops at either end to the front of the seat. I’d pull the straps taut around the sides and slip the loops over my backrest bar. That kept the seat secure enough that I could wheel at normal speed all over the city, and he stayed stable on my lap.
My son, Henry, took his first real steps on Easter Sunday 2017. He saw his cousin, who was two months older and toddling all over, and thought to his little baby self, “Hey, if he can do it, so can I!” From then on, it was nonstop.

One of my biggest worries came from not knowing how mobile Henry would be. Would I be able to keep up with him in my wheelchair? Would he still progress at normal stages because he didn’t see me walking? My greatest fear of all was that he would take off into traffic and I wouldn’t be able to stop him.

One day, my son and I were in the front yard of our house when my husband was taking groceries inside. At that exact moment, Henry took two steps down the driveway. My imagination instantly flashed forward to a speeding car driving out of control and hitting my baby. Even though we live on a quiet street in a gated subdivision where neighbors generally drive slowly, at that moment I was certain he was going to be hit.

I shrieked my husband’s name and he came running out of the house, no doubt expecting to find dismembered limbs or some major catastrophe. My son stopped and looked at his mama to see why she was yelling like a crazy person. And that was when it hit me: I am his mom and, for the most part, he listens to me because I’ve taught him to. That’s when I realized I was going to be OK with the whole toddler stage.

So here are some tips and tricks I picked up from that moment forward that helped with this critical phase of his life.

“Would I be able to keep up with him in my wheelchair? My greatest fear of all was that he would take off into traffic and I wouldn’t be able to stop him.”

The author worried most about keeping her son safe during the toddler stage.
The Wheelchair Walker

We bought our son several walkers to help him learn to walk, but none of them rivaled my wheelchair, a TiLite ZRA that has a large bar across the back. Henry would grab onto the bar, pull himself up and push me around the house. We would spend a couple of hours a day walking laps around the house, no exaggeration.

I loved him using me as a human walker for two reasons. First, it was a really special bonding time for us. I had been concerned I would be left out of the hands-on experience of his learning to walk, but now I was an integral part of it. Second, I could control how fast he went and help him navigate things like turns and walls. When he used his other walkers, he would often crash.

While I encourage him to learn things the hard way, I also encourage safety. My being able to control speed and obstacles meant he was able to focus on the walking basics. As he got more accustomed to walking, I allowed him to borrow my chair to push around the house when I wasn’t in it. Yes, our walls are now worse for wear and will require some touch-up paint, but he is really good at maneuvering and will have lots of practice if he ever gets into demolition derby driving.

For the record, or in case your kid doesn’t like pushing your chair, of the walkers we bought, my son’s favorite was the Little Tikes Light ‘n Go 3-in-1 Activity Walker. He could sit and play with all the fun cranks, twists, buttons and lights. He could stand and play with the activities. Or, he could just hold the handle and walk with it.

Controlling a Toddler in Public

Going into public with a toddler is when things start to get especially tricky. When my son was a baby, I used a Moby Wrap to secure him to me. I liked that I could make him as secure as I wanted, and we weren’t confined to a carrier that came in a predetermined size. As soon as Henry was big enough to sit up on his own firmly, I used the Moby Wrap to tie him to my lap.

From about age 1 on, if we were out in public, I would sit my son on my left leg and wrap the Moby Wrap around us about two or three times, with a knot behind my back. At home, he was very good at balancing on my lap, and I could alternate wheeling with one hand while supporting him with the other. But in public, I didn’t want to risk hitting an unexpected bump, hole, rock or anything that could interfere with my casters and possibly send him flying. He was always very secure, and I was able to smell his baby shampoo. Win-win.

From 20 months to 2 years old, my son stopped wanting to sit on my lap in public. At our local mall, after I parked in the structure, I would get him out of the car and attach a leash to his left hand. The other end attached to my right arm. We explored a harness leash, but he did not care for that one. The hand leash he tolerated. I liked the mall in the mornings because it gave us a quiet place to explore where he was also confined. Running became a new hobby of his, and he always wanted to be on the go. At the mall he would just do laps.

While he was learning to stay near me, we used the leash not only at the mall, but also at any parking lot when Henry and I were on our own. We did get some odd looks from people, but my son’s safety is more important to me than opinions of strangers.

We only used the leash for a few months and maybe only a dozen times. He caught on quickly that he needs to stay close to me at all times when we are in parking lots or crossing streets. In fact, people often comment on how he stays right next to me while we are walking. I am still vigilant and remind him while we are near moving vehicles that he needs to stay by my side.
Using Games to Control Running and Wandering

When we are in a store and my son gets antsy and wants to take off, I distract him with “find something blue,” or “find the number nine.” He loves letters, numbers and colors, and when he is interested in something, he forgets about wanting to run all over. I can keep up with him when he runs off, but in places like grocery stores, it’s hard to pull him out of the way of a cart and control my chair at the same time. I’ve nearly spun out numerous times, trying to stop him with one hand and my chair with the other. People aren’t usually expecting a runaway toddler to dart out in front of their shopping cart, so it’s up to me to try to keep him from being smooshed.

If Henry stays close to me, then I reward him with letting him lead where we go (within reason) for a few minutes. Our grocery store has a big red metal truck that moves around the store for various displays. I bargain with my son and tell him that if he stays close to me for a few aisles, then we can go see the truck. This usually works. Recently, we stayed in a hotel, so I made a deal that if he stayed with me while we checked in and went to the room to leave our stuff, we could explore and he could lead the way. We went up and down the hallways and explored every floor in the hotel. Again, I love confined spaces where he can have some freedom and where I can easily keep up with him.

When it comes time to load up and leave, it’s time for another game. Where we live, the temperature reaches well over 100 for half the year, so in a hot parking lot I load the car first, then load him. To keep him close while I’m busy, I allow him to stand on his own while I put things away, as long as he stays in the blue striped section next to the accessible spot. He isn’t allowed to cross the blue. I sometimes give him something light to hold so he feels like he has a job. When it’s just the two of us, I normally just have to put a bag in the trunk when we shop or his backpack in the car after school. Making it a game helps. If he stays in the blue, he is safe. If he crosses, he is out and loses a treat.

Most of All, Have Fun

I have found that if you get overly stressed out, your kid will pick up on it, so why not have fun when you can? My son loves racing me in my wheelchair (I usually let him win). When we are walking on the sidewalk into his school, we race. I only do this when he’s running in the direction I want him to go and when there’s no threat of him getting run over (by carts or cars). He likes it when I do wheelies and calls them my “jumps.” If we have to wait somewhere that I feel isn’t safe, and I want to keep him distracted so he doesn’t dart into danger, we do jumps and see how high we can jump or how many times we can jump.

I thought the early baby stage would be the most worrisome as a parent in a wheelchair, but I’ve come to realize that the mobility stage is equally nerve-wracking. However, I think that’s just the way parenting is in general, a common thread among all parents, no matter your physical abilities. The important thing to remember is that your child will listen to you if you are firm enough and make things fun when possible. So, enjoy the crazy ride.
My 3-year-old son, River, sat in my TiLite wheelchair, pushing around our house. He’s becoming a good driver, crashing into walls and furniture less and less. As I cozied into our couch, River asked me, from across the room, to help him reach his monster truck that fell off his lap onto the floor. I told him if he wanted help, he’d have to bring me my chair. “Momma, just walk,” he replied. When I told him I couldn’t, he encouragingly replied, “Try harder!” I chuckled and explained that I already tried hard, but my legs don’t move. He got quiet, wheeled toward me, and asked, “Why?” I hesitated.

Even though I had answered this question a hundred times, to strangers at Starbucks and to kids at the supermarket, explaining my disability to my child felt different. My instinct told me to be straightforward, so I told him that I had been in a car accident and hurt my back. Because my legs don’t work, I use a wheelchair. He had a lot of follow-up questions, so I threw in some details, like I had been taken to the hospital in a helicopter ambulance, which he thought was cool. Content, he climbed down from my chair, pushed it to me and said, “Momma, let’s play Legos.”

I thought about our interaction for days. River has only ever known me to use a wheelchair, it’s his norm. When he comes in our room in the morning to wake me up, he doesn’t say, “Momma, get up.” He says, “Momma, get in your chair.” But now that he’s getting older, he’s starting to understand what being in a wheelchair means.

As parents, how we frame these conversations can have a lasting impact on how our children perceive disability and how they interact with other people with disabilities. In talking to fellow parents in chairs, I learned they had similar advice when it came to discussing disability with their children.

Honesty is the Best Policy

At the top of the list is the simplest advice: Be honest. Don’t try to hide or sugarcoat your disability, keep it simple, and explain what they can understand. Yasaman Best, a C7 quad who lives in Vancouver, British Columbia, has a 3-year-old son named Alex. Like River, Alex recently told his mom that he wanted her to stand up and walk. “The comment seemed to come out of nowhere while he was standing on my footplate washing his hands in the bathroom sink,” says Best. “I looked in his eyes and said, ‘Love, that’s not possible. Mommy can’t walk or stand. Mommy also needs help with a lot of things because Mommy’s
hands don't work well. But Mommy loves you very, very much, and you and I make a great team. We are gonna have so much fun together.” Alex smiled and hugged her as she kissed his forehead, and they continued to wash their hands and laugh.

Keith Polischuk, who lives in Marietta, Georgia, has three boys that are 5, 3, and 5 months old. His oldest son is really into science and robots, so Polischuk, a C6 quad, explained his spinal cord injury in a way he could relate to — by comparing it to the wires in a light bulb. “I told my son that if those wires were cut or damaged, the electricity wouldn't be able to get through to turn the bulb on,” he says. “And how, in a similar way, the brain sends messages through the spinal cord to tell different parts of the body what to do, and if the spinal cord gets cut or damaged, the signals can't get from the brain to the rest of the body.” Polischuk also found the Dr. Seuss book Inside Your Outside helpful. “It's a fun book about the human body and how it works,” he says. “And there's a page about the spinal cord.”

Recently, Polischuk and his family were at a cousin’s birthday party when a little girl asked him why he used a wheelchair. “My son jumped right in. He told her about my spinal cord and how messages don't get through anymore,” he says. “It was really funny.”

Polischuk has also explained to his sons that he may do things differently because of his injury. For example, Polischuk uses his teeth to help him open things and pull apart Legos. “I noticed my son was also starting to pull apart Legos with his teeth,” he says. “I explained to him that he should use his hands, and why I did it the other way.”

Priscilla Hedlin, a L1-2 para and the voice behind “The Wheelchair Mommy” blog also has three boys. Hers are 13, 10 and 7. “They’ve always known I was in a motor vehicle accident that left me unable to walk,” she shares. “But it’s never been a big deal and not something they just asked me about one day out of the blue.” Hedlin thinks it’s important to be open to your children about the realities of your disability. “My feet swell, so I sit on the couch and put my feet up,” she says. “I explain to my boys what I’m doing and why. They see the swelling and see how putting them up helps. They always see my transfers and even help put my chair into the van.”
Share the Positive

Recently, River asked me to stand up and do jumping jacks with him. When I reminded him that I couldn’t stand, he looked disappointed and started pulling at my legs to help. I explained to him that even though I don’t stand, I can still do jumping jacks. I just do them differently. Then, I began to bounce my upper body while I swayed my arms together and apart. River smiled, started to giggle and joined in.

Polischuk, who in addition to his three boys, has 19 nieces and nephews, also thinks it’s important to share the positive when talking about your disability. “With all of the kids in my family, I get asked questions about why I use a chair a lot,” he says. “I explain that even though I can’t walk, my wheelchair helps me get around, and there are so many other things I can do.”

Kristina Rhoades, a T5 para and life coach who lives in New Mexico, said that her 6-year-old daughter, Kamryn, gets asked questions like, “What happened to your mom?” from other kids. “Often she’ll answer the questions,” says Rhoades. “But sometimes, when they ask about my wheelchair, she does something else that is pretty clever. She’ll say to me, ‘Hey, Mama, pop a wheelie!’ or ‘Show them the lights on your wheels!’ In an instant, kids go from being nervous about my differences to thinking I’m pretty dang cool, and they’re back to playing.”

Coping With Obstacles

The toughest thing I have had to explain to River about my disability is why I can’t do something with him. Recently, we were visiting family who live near the beach, but to access it you have to go down a steep hill. River really wanted me to come, but I had to stay up at the top. As I watched him playing on the beach below, I felt sad and left out. But then I saw how much fun he was having, and that made me smile. Polischuk has experienced something similar. He has a swing set in the backyard, but the terrain around it is rough and he can’t get to it. “My son will ask me to push him on the swing,” he says. “It’s really hard, because I wish I could.”

“The great thing about kids is that they are so adaptable and amazing,” said Best. “Alex and I were playing hockey in the living room, and I wasn’t fast since I couldn’t grab the stick and it kept falling from my hand. I nodded to my husband to come and play with him, because I felt bad. Alex grabbed the stick and gave it back to me and said, ‘Wait your turn, Daddy!’ I love that he is so close to me and accepts my limitations and tries his best to make it work.”

Something Special

I recently came across the children’s book Mama Zooms by Jane Cowen-Fletcher. Written in 1995, the book tells a story of a mom who uses a wheelchair and her son. Because of her “zooming machine,” they go on lots of adventures together. Sitting on his mom’s lap, they become a racecar, a train, a ship at sea and finally, on the last page, “Mama zooms me right up until bedtime. Then Mama is just my Mama, and that’s how I like her best.” I get teary-eyed every time I read it because it beautifully captures the special bond that I feel parents with disabilities have with their children. A bond that will influence them for the rest of their lives.

“One of the most meaningful parts about being a parent with a disability is Kamryn getting to be a part of the incredible disability community I’m so lucky to be connected with,” says Rhoades. “She’s able to see I’m not different from everyone else, but that diversity is normal and wonderful. She learns so much about the human spirit by watching people like us do things every day that most of the world thinks is impossible. She doesn’t look at us like we’re broken or vulnerable. It inspires me so much to know that she will go out into this world with that outlook and understanding for others.”

One night, as I tucked River into bed, he told me his favorite part of the day was when his friend, Tara, came over to play. He talked about how they ran in our front yard and made sandcastles out of dirt. And then, he very factually declared, “TARA’S MOMMY DOES NOT USE A WHEELCHAIR.” Amused by his observation I replied, “Yeah, not all mommies use wheelchairs.”
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Don’t Worry, He Won’t Get Far on Foot

When the news broke that Gus Van Sant was finally going to make a movie about cartoonist John Callahan, I knew my friend, who died in 2010, would have been elated that his 1989 memoir survived the long journey to the screen. But would it be the movie he wanted? Would disabled moviegoers excoriate Van Sant for casting yet another nondisabled actor — Joaquin Phoenix — to play a quadriplegic? Many in the disability and mainstream communities feared the final product might be forced into the “inspirational cripple” stereotype that the movie industry too often relies on — and that Callahan despised.

Van Sant got out in front of the expected backlash by declaring in a press release video that a nondisabled actor was needed to play Callahan in his pre-SCI years. He added that at first Callahan wanted Robin Williams to play him. When I interviewed John for a 2007 NM story, he liked Phillip Seymour Hoffman for the role. Clearly, a nondisabled actor was not an issue for either the subject or the director.

Phoenix, 43, had the difficult job of portraying the politically incorrect cartoonist from the age of 20 until his mid-30s, focusing mainly on his post-injury-wheelchair-user alcoholic journey. He does a credible job of capturing the soft-spoken Callahan, whose real-life facial expressions and iconoclastic wit could easily be misinterpreted or missed altogether. In the few instances where Phoenix seems not quite convincing, the problem lies with the dialog or the situation — in other words, the script. His portrayal of Callahan’s C5-6 paralysis is authentic, right down to the increased level of dexterity in his right hand.

Moviegoers will form their own opinions about Phoenix’s portrayal, but he gradually won me over, and so did the movie. Don’t Worry, He Won’t Get Far on Foot is well worth seeing, marked by strong acting performances, a story that builds emotionally, and a bittersweet, satisfying ending.

The Real Disability
In the first half of the movie, Van Sant uses smash-cuts and nonlinear sequences to reflect Callahan’s chaotic life before and after his paralyzing car crash. The early dramatic story is difficult to watch, at times even uncomfortable, yet mostly true to the pre- and post-accident experience. Catastrophic spinal cord injury has a way of ripping a life apart, leaving two violently separated remnants dangling. We are rewarded at the movie’s midpoint when Callahan begins to patch the two halves together. From the moment of epiphany forward, the movie is a pleasure to watch, especially as we share in the development of his unique cartooning talent.

Rooney Mara plays Annu, Callahan’s love interest. She befriends him in the ICU — his body and head immobilized in a circle bed. She appears at just the right moment, like a dream, her pretty face a life-saving contrast to Callahan’s predicament. Throughout the movie she reappears, always fresh, their relationship eventually intimate, somehow always free from conflict. In contrast, Callahan’s memoir limits Annu’s real-life role to the hospital. He never sees her again after he leaves the ICU.

Without a love interest (and considering Mara is a two-time Academy Award nominee), the movie might not have been made. If we want literal truth, we need a documentary. For a commercial movie, it is to Van Sant’s credit that the story never sinks to the maudlin paralyzed-quad-battles-insurmountable-odds default mode. And that is the key to the movie’s success: It focuses on Callahan’s real disability — his alcoholism.
success: it clearly focuses on Callahan's real disability — his alcoholism. His battle takes place in his soul, where he is consumed with the single most important fact he knows about his mother: She abandoned him, giving him away to a convent shortly after birth. Months later, he was put up for adoption and raised in a family where he felt like a faux sibling.

Jonah Hill plays Donnie, Callahan’s sponsor once he reluctantly enters Alcoholics Anonymous. Hill’s performance is surprisingly nuanced and convincing, and much of the emotion we feel as the movie nears its resolution comes from how much we have invested in Donnie’s journey as well as Callahan’s. Throughout the movie we see him as a strong and reliable sponsor with a quirky philosophy built on equal parts Lao-Tzu and broad tolerance for any individual’s choice of a Higher Power — as long as it derives from faith. The conflict between Donnie and Callahan is built upon Callahan’s denial of his deeper problem — obsessing with being abandoned.

Callahan’s cage-rattling cartoon drawings, so critical to his recovery, often come to life as moving images, spicing the weighty story line with funny-satirical moments.

Donnie’s job is to patiently lead his disciple to the higher ground of sobriety and inner equilibrium while making certain he knows it will remain a lifelong struggle. Callahan’s journey to redemption eventually leads him back to the movie’s beginning and Dexter, his drunken-driver-friend-for-a-bender (Callahan had passed out in the passenger seat at the time of the crash). Jack Black seems made for the role, doing an excellent job transforming from immature wild-eyed party animal to middle-aged man with a soul full of shame.

Book-to-Movie Dilemma

Adapting an autobiographical book for the screen is — among other challenges — a dilemma in reductive editing. What parts must be deleted while staying true to the main story? In his book, Callahan doggedly searches for his mother at a time when Oregon law protected the birth mother’s identity. He runs into multiple dead ends before unearthing the hope-killing revelation that she died in a car crash years earlier. His biological father is dead as well. Callahan sinks into despair, but eventually recovers and finally finds the next best thing to a real relationship — photos, remembrances, testimonials. The woman who abandoned him was pretty, intelligent, and had a sense of humor. The kind of mother he would have wanted.

Van Sant’s version of this all-important search plays like an incomplete summary. The onscreen Callahan never finds out the whole story about his birth mother. For my money, more screen time could have been spent on Callahan’s quest to find his mother and less on group therapy scenes.

Callahan’s cage-rattling cartoon drawings, so critical to his recovery, often come to life as moving images, spicing the weighty story line with funny-satirical moments. Danny Elfman’s edgy jazz score, while sparse, sets a fitting tone. In the closing credits we are given an unexpected gift worth waiting for — Callahan’s pure voice singing “Texas When You Go” from his 2007 CD, Purple Winos in the Rain.

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In the final analysis, Don’t Worry succeeds largely because we see Callahan’s real struggle is much like Donnie’s — which is revealed in the last few scenes — and we feel included. Each of us is unique, yet we are alike. We all have our disabilities, and many of them manifest themselves from the inside out.
Georgia advocate Kim Harrison’s eyes lit up while she was meeting with an aide from one of her state representative’s offices during this year’s Roll on Capitol Hill.

“Out of the corner of my eye I recognized the actual representative was about to walk by,” she recalls, “I instantly thought, ooh, score for us!”

With the nimbleness one would expect from a four-time veteran of the Roll, Harrison, her husband, Brian, and fellow advocates quickly circled their wheelchairs around the representative as he tried to make his way into his office.

“It’s kind of like going to the doctor,” she explains. “You learn to box them in and make sure they answer all the questions. Even though he felt sick, he took the time to stand and talk with us, he could have very easily just ducked into the office.”

Scenes like this played out throughout the halls of Congress as more than 120 members of United Spinal Association took over Washington, D.C., this June 24-27 for the seventh annual Roll on Capitol Hill. Wheelchair users, clinicians, partners and other disability advocates from 33 states plus Washington, D.C., and Puerto Rico, gathered to fight for greater access to quality affordable healthcare, community integration, disability rights, assistive and rehab technology, veterans’ benefits and air travel protections vital to people with spinal cord injury/disease.

Roll on Capitol Hill is United Spinal’s signature annual policy event that supports key advocacy priorities for its membership and the broader disability community to en-
sure that legislators include wheelchair users and all people with disabilities in policy debates on Capitol Hill.

“We believe wheelchair users should be involved in creating disability policies. That’s why our members must help educate policymakers about the needs and rights of people with disabilities,” says James Weisman, president and CEO of United Spinal Association. “We’re not just here to fight for a seat at the table. We’re here to fight for a seat at the head of the table.”

Pennsylvania member Katie Smith was one of more than 40 first-time attendees and says she came away revved up and eager to take the skills and information she learned back to fight in her local community.

“It was great to connect with people from chapters all over the United States and see how pumped up everyone was about advocacy,” she says. “I learned a lot, and then to be able to put all of that knowledge into action in meetings with legislators was incredibly empowering.”

A full day of over 200 meetings with representatives’ offices on June 26 was capped off with an awards reception to recognize members of Congress as well as grassroots advocates for their outstanding service to people with disabilities and veterans. Awardees included Senators Johnny Isakson (R-Ga.) and Tammy Baldwin (D-Wisc.) and members

Kim Harrison, her husband Brian, and fellow Georgia advocate Vincenzo Piscopo gained viral fame for this photo and an accompanying video showing Brian’s scooter at the helm of their wheelchair train. “We brought his scooter along to help him get from place to place, as he had back surgery, but at one point we realized we can make our appointments and not feel stressed,” says Kim. “It was fun because people were commenting and we’d yell out, ‘That’s how we roll’.”
Gretchelle Dilán, who received the 2018 Outstanding Community Service Award for her hurricane relief efforts in Puerto Rico, and Texas member Earle Powdrell and his wife, Kathy, who received the 2018 Finn Bullers Advocates of the Year Award. Emotional speeches by Dilán and the Powdrells capped off an inspiring night (see next page for an excerpt).

For members like Harrison, the annual event has transformed her from feeling like a nervous outsider to a fierce advocate.

“I was very intimidated the first time I came here and I wondered what someone like me was doing here,” she says. “Now it’s not ‘who am I?’ but ‘watch out for who I am.””
‘I HAVE A VOICE’

EARLE POWDRELL’S ACCEPTANCE SPEECH

United Spinal Texas member Earle Powdrell captivated a packed ballroom at the Roll on Capitol Hill congressional awards reception in Dirksen Senate Office Building. Speaking via a voice synthesizer that read a speech he composed using eye tracking software, Powdrell, 65, an aerospace engineer, explained how his advocacy work with United Spinal has changed his life since he suffered a brain stem stroke nine years ago that left him with “locked in” syndrome.

Thank you for this award. My wife, Kathy, and I are truly honored.

In 2009, I was permanently and catastrophically disabled due to a brain stem stroke. I was left voiceless. I often say that I did not choose the stroke; the stroke chose me. But in so many ways it has brought us blessings.

I have to thank my hero, my wife, my daughters Kristen Huff and Lindsey Bachman, who are also grass root advocates. I am joined by my grandchildren here tonight. At home in Houston there are so many people who make my continued recovery possible.

Seven years ago, Rafferty Laredo, the president of United Spinal Association’s Houston chapter gave me, a voiceless disabled American, my voice back. United Spinal transformed my purpose and added to my quality of life. Today I speak. Today I am not voiceless. I am so thankful to all of you for this award.

We truly stand in the shadow of all of you. We have met so many of you through the years and we have been inspired by you and your stories. The tireless work of United Spinal serves the nation and those who roll with the highest standards a national association should aspire to. The staff, the delegates and the grass roots advocates — United Spinal’s organization serves the nation’s wheelchair community on many levels.

In a special way, we accept this award on behalf of all disabled persons and their caregivers and advocates. Without everyone here, I would not have been inspired to persevere. I am locked in.

It is a challenging journey.

Viktor Frankl, the Jewish psychiatrist who labored in four different concentration camps during the Holocaust said: “It did not really matter what we expected from life, but rather what life expected from us. … Each man is questioned by life, and he can only answer to life by answering for his own life; to life he can only respond by being responsible. … When we are no longer able to change a situation we are challenged to change ourselves. … Everything can be taken from a man but one thing: the last of the human freedoms ... to choose one’s attitude in any given set of circumstances, to choose one’s way.”

Seven years ago, when Kathy got a call from Rafferty, our lives changed for a second time.

Finn Bullers was a fellow advocate, an editor who set a standard of what advocacy looks like. Finn put the face of a family on disability advocacy. This is an honor I never dreamed of. This is an honor that I am not worthy of.

For all disabled persons and their families, we have a unique understanding of what a changed life due to disability looks and feels like. We understand what it means to hope. We understand what it means to have courage. And, most of all, we understand what it means to have the right attitude.

As we say in my business of aerospace — failure is not an option.

Our advocacy work must continue. We have so much work to do. We must make air travel accessible and protect the ADA at any cost. I know that one voice can make a difference, but as Rafferty Laredo says, “Many voices can shout down the walls, because together we are one.” After Hurricane Harvey, United Spinal Houston served so many who had been flooded and lost their homes. Rafferty is the real hero here.

Thank you for a seat at the table. I will continue to advocate and work to share the mission of United Spinal Association: Nothing about us without us. This is a moment I will never forget.
If you want to know where disability has made the biggest impact in any form of American media, check out the live theater listings in New York City, Chicago, Cleveland, Seattle and maybe your town, too. Long a fountainhead of innovation and inspiration for film and television, the “thea-taa” — actors, playwrights, musical dramatists and the impresarios who pay for it all — has gradually been introducing characters and plot lines featuring disability experiences since The Miracle Worker first opened on Broadway in 1959. Just in the last two to three years, though, the pace has greatly accelerated. Performers with disabilities have gone from cast members to known quantities and even stars, while productions about disabilities have gone from small notices in the back pages of The New York Times to major award winners.

Even if you have never seen a live production of a play and get your regular entertainment fix from film and TV, you should be jumping for joy, at least figuratively. Theater is busting through roadblocks and upending clichés. This stuff will spread. Success in American show business is contagious and cross-fertilizing.

Let’s start with the most heralded such success of this very noteworthy theater season. This year’s Pulitzer Prize for Drama was awarded to playwright Martyna Majok for Cost of Living, her drama/comedy about four people — two couples alone in two apartments in New Jersey. The play focuses on Ani, recently paralyzed at a high level from a car accident, and her estranged husband, truck-driver Eddie, who desperately wants to reconnect. Then, in alternate scenes, the main couple is John, rich and bright but in need of personal assistance due to cerebral palsy, and Jess, his just-hired caregiver. Both Ani and John are in wheelchairs for the entire play. Ani is played by double-amputee Katy Sullivan, and John is played by Gregg Mozgala, who has CP.

The play intertwines the struggle of intimacy and loneliness within the lives of these two couples. It is searing, darkly funny, unsentimental, subtly sensuous — “My mind’s a great lover,” Ani says — and perhaps most importantly, as one review notes, “slams the door on uplifting stereotypes.” Disability is not a topic here, nor a flag of protest or exclusion. It’s a reality that informs and impacts the lives of everyone involved and links up with the most human of experiences. “In both stories,” says critic Jesse Green in The New York Times, “the biggest handicaps are the universal ones: fear and disconnection.”

“If you don’t find yourself in someone onstage in Cost of Living,” he concludes, “you’re not looking.” Sullivan, aka Ani, “the hilariously foul-mouthed New Jersey terror,” as Green describes her, is a legitimate star in this new world of the theater of inclusion. She is riding high. For her role in Cost of Living she has been nominated for the highest theatrical awards — the Drama League, the Outer Circle Critics, and the Lucille Lortel — and she recently won the Theatre World Award.

She is having, in her own words, “her victory lap.” Like most actors who make it, disabled or not, Sullivan is a decades-long overnight success. A Paralympian who didn’t compete until age 25, she got a degree in theater at Webster College in St. Louis and worked her way up, first in Chicago, then New York and Los Angeles. Born with no legs below the knees, she mastered prosthetics at an early age and has played both disabled and nondisabled characters on stage. In a long skirt, she says, she can pass for any long-legged

Ani and Eddie struggle to regain intimacy in Cost of Living.
lass. In Cost of Living she plays a character who is a combined quad/amp, has the use of only one hand, and needs a caregiver, a role Eddie yearns to fill.

“We are seeing the needle move in theater,” she says, and as is often the case, “theater leads the charge, and Hollywood follows.” Her agent, Gail Williamson, also the agent to a number of other actors with disabilities flourishing on stage, adds that “theater people are the most receptive and inclusive people you can find.” Their interest in the lives of people with disabilities is not out of an abnormal helping of do-goodness, she says, but because of the creative possibilities these stories invite.

Williamson is riding the same wave of success as Sullivan. Her other clients include a Tony Award nominee — Lauren Ridloff, for the deaf lead in the Broadway revival of Children of a Lesser God — and three out of six Theatre World Award winners, including Ridloff, Sullivan and Jamie Brewer of American Horror Story fame for her role in the play, Amy and the Orphans, among others. Brewer is also up for a Drama Desk Award, as is Mozgala. Another off-Broadway production featuring four performers with disabilities, The Artificial Jungle, got its share of award nods, as did Evan Ruggiero, a tap dancer with one leg.

You get the idea — actors with disabilities are hot. Why is this happening? Actress/amputee Anita Hollander, herself an established success with her long-running, one-woman show, Still Standing, tracks performers with disabilities for the Screen Actors Guild-American Federation of Television and Radio Artists and sees a slow evolution, then a big blip. She says the picture started to change in 2015-16, coming off the Broadway success of Deaf Theater West’s revival of Spring Awakening, including the notable performance of Ali Stroker as the first wheelchair using actress to appear on a Broadway stage. Already in 2018, there are 11 different theaters in New York featuring performers with disabilities. In Cost of Living, Hollander points out, even the two understudies for the roles of Ani and John were disabled. That’s a sign of genuine inclusion.

Back to Sullivan: Eager to expand her horizons with an upcoming feature role and create her own television vehicle, she says it all comes down to the love of acting and “an insane amount of ‘I can do that!’” Theater is a great place to start, in your own backyard or your local children’s playhouse. Start young, keep at it, go to acting school, hone your craft and think big.

Today — as never before in history — actors with disabilities have every reason to dream of taking a curtain call on Broadway.

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Innovation can be defined as a process. In the world of mobility products, that aspect is vital to recognize because so many innovations that improve our mobility aren’t complete product revolutions, but evolutions. In this way, to maximize our mobility, it’s often important to hone in on the small innovations that make a huge difference. You might say that innovation is often about taking a proven technology and ... yes ... improving upon it.

Indeed, when we look at the latest round of mobility innovations, they’re not cataclysmic shifts. However, they’re each an incremental improvement that can dramatically enhance one’s life. Sometimes the most impactful innovations really are found in the finer details.

**A Folder that Tricks the Eye**

If you saw the new Quickie Xenon 2 FF roll by, you’d swear it was of the ever-popular Q7 rigid series — and it is. Well, sort of. While the Xenon 2 FF carries the 7000-series aluminum frame and caster housings of the Q7, there’s a secret distinction hidden under the seat: it folds.

Rather than using a box frame design, the Xenon 2 FF draws on a rigid lineage, from the mono-tube side frames to the seemingly one-piece footplate, all weighing in at 19.4 pounds. Yet, with a tug, it folds. It’s a rigid ultralight without the rigid limitations, increasing transportability.

The Xenon 2 comes in three versions: the FF mono-tube, the Hybrid dual-tube (300-pound capacity) and the SA (with swing-away leg rests). Many designers over the decades have tried to create a “folding rigid,” but the Xenon 2 series is among the most successful designs.

**Expanded Positioning Possibilities**

Permobil's most emblematic feature, rightfully, is its Corpus seating system. After all, it remains the original ergonomic power chair seating system, designed by renowned Swedish ergonomist, Bengt Engstrom, over two decades ago.

However, as revered as Corpus seating remains, Permobil realized that it wasn’t an end-all solution. While Corpus seating has some adjustability, it’s an all-encompassing seating system that, by its nature, limits adaptability. Sometimes this prevented power chair users with custom seating needs from using a Permobil.

But now, the newest model in the Permobil lineup, the M1, allows the adaptation of highly-custom seating.

Looking at the M1, you might have difficulty telling it apart from the best-selling Permobil M3 (or M300) mid-wheel power chair. And that’s by design. While there are a few differences between the M1 and M3 power bases — 5 mph versus 6 mph, for example — the biggest difference is in the seating. The M1 forgoes Corpus seating for a highly-adaptable system that accepts virtually all aftermarket seating components.

The M1’s seating starts with 1-inch tubular back canes, to which aftermarket backs — from Jay to ROHO to ADI — mount. Additionally, a custom molded back can be fitted. From there, the seat features a universal track system for mounting positioning components, such as thigh guides, knee adductors, positioning belts and so on. Of course, all cushions are compatible, and Permobil has their well-proven flip-back arms. The seating is available in static or tilt-only versions, so multiple power functions, such as lift and recline, are unavailable (although there is a manual recline option).

With seat sizes from 14-by-14 to 22-by-22-inch, the M1’s seating covers a wide range of chair users — especially when its versatile custom seating is figured in.
Smoothing out the Bumps

Quantum’s Edge series has provided an industry-leading power chair since its introduction eight years ago. While the unmistakable “edge” aesthetics remain, it’s now on the third generation, the Edge 3.

The biggest distinction of the Edge 3 is its use of automotive-grade suspension components, known as Smooth Ride Suspension technology. SRS uses coil-over shocks with dampening to improve both comfort and performance.

The real key to the Edge 3 and SRS technology is in the dampening. Power chairs have long used spring suspension, and while it has worked, its downfall has been a somewhat bouncy ride. By contrast, adding dampening smooths and equalizes the movement of components, such as drive wheels and caster arms. Rather than “chattering” over lumps and bumps, the Edge 3 with SRS has more of a gliding effect over rough spots.

A common understanding of suspension is that it’s for comfort. However, in the power chair world, suspension is equally vital for reducing spasticity and aiding those who require the smoothest ride characteristics and those who drive with specialty controls.

Wheels for the Wilderness

Make no mistake, high-floatation, knobby tires make a big difference when propelling an ultralight wheelchair through the rough stuff. However, there has long been a trade off. While off-road tires offer all-terrain advantages, they have traditionally been mounted on heavy, wire-spoke wheels. To reduce the strain of pushing with extra rotational weight, Spinergy has developed its Outdoor Wheel Package, which offers off-road performance on a lightweight wheel set.

The Outdoor Wheel Package consists of Spinergy’s Light Extreme “LX” rims, with PBO (polyphenylene benzosoxazole) fiber spokes, paired with an anodized hand rim and Kenda Nevegal mountain bike tire. The result is a gnarly all-terrain wheel that’s all but indestructible and exceptionally lightweight. The Spinergy Outdoor Wheel Package comes in 22, 24, and 25-inch sizes. The key is to size down, as the large tires create a larger total wheel diameter than high-pressure sizing dictates (for example, a 22-inch Outdoor Wheel is equivalent to a 24-inch standard wheel).

The Spinergy Outdoor Wheel Package comes with quick-release axles, so the wheels can be easily swapped as needed with everyday wheels. If you want your chair light and tough, these wheels are up to the task.

Resources

- Permobil, 800/736-0925; permobilus.com
- Quantum, 833/745-3835; quantumrehab.com
- Quickie, 800/333-4000; sunrisemedical.com
- Spinergy, 877/291-4540; spinergy.com

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- Quickie, 800/333-4000; sunrisemedical.com
- Spinergy, 877/291-4540; spinergy.com

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Editor: NM discloses author-product relationships when appropriate. Accordingly, Mark E. Smith is the general manager of public relations for Pride Mobility/Quantum Rehab.
Every time I go to Costco, I always conduct a social experiment.

There’s an employee posted at the entrance, and that person says welcome. And then every entering customer flashes their Costco membership card. It’s an unspoken ritual.

I wonder what the job title is for that employee. Greeter? Card-checker? I suppose if someone without a membership card demands to be let in, it’s that employee’s job to grab them by the collar and throw them out. So maybe their job title is bouncer.

But anyway, when I enter, I always just stroll right by the friendly bouncer without showing my card, as if I don’t have a clue what’s going on. I try not to make eye contact. If he or she says welcome, I say thanks. I always have my card strategically tucked in my side pouch where it can easily be whipped out and flashed if they should ask to see it. But they never ask. They always let me slide on by. Every single time.

What does this social experiment prove? Hell if I know. I guess it proves that Costco bouncers are somehow intimidated by my crippledness. Thus, they give me special treatment. But should I be insulted by that? I’m probably not intimidated in the good way. They’re probably overwhelmed by my frailty.

Maybe to them I’m a fledgling, newly-hatched baby chick. Or maybe they think I’m deaf. Or maybe there’s a perceived language barrier — they don’t speak cripple.

Or maybe they’re afraid that if they card me, I’ll burst into tears. Or maybe it’s the opposite. Maybe they’re terrified that I could be one of those bitter scofflaw cripples they see on the news protesting about who knows what. And if they ask to see my membership card, I might say, “Screw you, you ableist jerk!” And then they’ll be placed in the unenviable position of deciding whether or not to grab me by the collar and throw me out. If they do throw me out, surely somebody will capture it all on their cell phone and the video will go viral. But if they don’t throw me out, their authority will be permanently undermined. It’s a no-win situation. Better for them to leave well-enough alone and just pretend they don’t see me.

Or maybe it really is the good kind of intimidation, like when people are intimidated by how smart you are. Maybe when the Costco bouncers see me they think of Stephen Hawking and they are rendered speechless by a lightning bolt of star-struck awe.

There’s one sure way to test all these hypotheses. The next time I go to Costco, I’ll make it a point to be accompanied by a vert (which is what I call people who walk). Maybe I’ll dress that vert in a nurse’s uniform or surgical scrubs, so they’ll look like my keeper/translator. And we’ll both stroll in cluelessly, like I do when I’m alone. And we’ll see if the bouncer says to the vert, “Excuse me. Does he have a membership card?” Like when a cripple and a vert go out to a restaurant and the server takes the vert’s order first and then points to the cripple and says to the vert, “And what will he be having?”

If that happens, then I’ll know that the vert was the variable that led to me suddenly being recognized, and therefore I should be offended by my previous special treatment. It was rooted in the bad kind of intimidation. I’ll hunt down the manager, present him or her with the findings of my social experiment and demand that from now on I be carded like everybody else. I could demand that all Costco employees receive cripple sensitivity training as compensation for my humiliation, but I’ll settle for a free lifetime membership.

The one thing my Costco social experiment proves conclusively is that I am a sad man with too much time on my hands. Why can’t I just automatically flash my membership card like a good citizen? Why do I feel compelled to passive-aggressively taunt the bouncers, read all kinds of stuff into their reaction and then get all worked up about it? What have those poor mopes ever done to me?

I really need to get a hobby or something.
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