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¹Interior volume and entryways vary depending on adaptive equipment purchased and installed by upfitter. ²Please visit fcausautomobility.com for full program guidelines and adaptive equipment reimbursement details. ©2017 FCA US LLC. All Rights Reserved. Ram is registered trademarks of FCA US LLC.
There’s more to independence than simply being able to do everything for yourself. IAN RUDER talks with quads with caregivers to see how they define independence and how, and if, their definitions have changed since they were injured. What are the components of independence as a quad, and how do you learn to balance them to live your life to the fullest?

Cover Photo by Summer Harper

**CONTENTS**

- **VOLUME 28**
- **NUMBER 289**

**FEATURES**

17  **A FORCE FOR GOOD**    Jennifer Longdon wants to be an Arizona state legislator for all the right reasons. Will the voters see her for who she is? MARY TOLAN tells her story.

32  **ADAPT’S MOMENT**    Not since protestors occupied the federal Health, Education and Welfare building in 1977 has the nation felt who we are. Then came ADAPT. BY JOSIE BYZEK.

37  **TECH TITAN**    Talk about tech cred. Todd Stabelfeldt was part of Nintendo’s R&D program as a boy. Now some call him “the quadfather of tech.” BY KENNY SALVINI.

**COVER STORY**

**REDEFINING INDEPENDENCE**

There’s more to independence than simply being able to do everything for yourself. IAN RUDER talks with quads with caregivers to see how they define independence and how, and if, their definitions have changed since they were injured. What are the components of independence as a quad, and how do you learn to balance them to live your life to the fullest?

Cover Photo by Summer Harper

**DEPARTMENTS**

- 4  BULLY PULPIT
- 5  CONTRIBUTORS
- 6  LETTERS
- 8  NEWS
- 10  EVERYDAY ADVOCACY
- 12  SCI LIFE
- 13  EAT WELL, LIVE WELL
- 14  HOW WE ROLL
- 42  INNOVATIONS
- 44  RAISING A RUCKUS
- 47  CLASSIFIEDS
- 48  CRIP BUZZ
Recovery from paralysis: What does it really look like? We are seeing more and more examples of people with SCI experiencing varying degrees of “recovery,” but almost all of them will still be dependent on wheelchairs. To some degree the improvements we are seeing are due to new rehab protocols made possible by technology — functional electric stimulation, treadmill walking, exoskeleton use, etc. Some proponents of exercise therapy claim that hard work is the key to recovery. But the truth is recovery of function is almost always related to some degree of incompleteness of injury.

Having been paralyzed for more than 52 years, I have met and interacted with hundreds of SCI survivors. I have interviewed and written stories about hundreds more. Add to that nearly 17 years of corresponding with NM readers with SCI on a daily basis and the number is well over 1,000. That constitutes a large sampling of SCI survivors. They all have their unique personal stories, but the one thing they — we — all have in common is damage to our spinal cords. And the key to realizing true recovery potential lies in understanding the incredible complexity of the spinal cord, and how no two injuries are exactly alike.

SCI can best be understood as a continuum. Cord damage ranges from mild and temporary — when survivors spontaneously regain motor and sensory function within weeks or months — to very severe — when the spinal cord is damaged beyond repair and no useful nerve impulses can reach beyond the damaged area. The great majority of survivors lie somewhere in the middle, where varying degrees of incompleteness exist. Many injuries are incomplete anatomically, yet functionally complete. A smaller number are anatomically and functionally incomplete — meaning enough critical nerve fibers or tracts are spared to facilitate some degree of recovery.

Those survivors who fall in this range are the fortunate ones. With timely intervention, proper therapy and hard work, as well as access to the latest rehab technology, time and money, they can experience some degree of functional return. But most people in this group will still remain dependent on wheelchairs.

Let’s be honest. Recovery is a misnomer. A better word to describe our ability to regain partial function is to “reclaim.” Reclaiming means to retrieve or recover something that has previously been lost. With SCI, unfortunately, mainstream thinking considers “walking again” as the Holy Grail. But reclaiming goes well beyond walking. In fact, walking is a small part of living, and it is possible to reclaim all or nearly all of the best that life has to offer — love, companionship, happiness, fulfillment, a sense of purpose, belonging to a community, faith, hope, gratitude, compassion for others, dedication to a cause or passion — without ever standing or taking another step.

This does not mean that it is fruitless to work hard at trying to reclaim control over our physical bodies. Indeed, unless we try, we can never know for certain how much we might be able to take back.

But we will never take back the past. Better to live our lives in the present.

— Tim Gilmer
Mary Tolan is a journalist and fiction writer who also teaches journalism at Northern Arizona University in Flagstaff, Arizona. Her work has been published widely throughout the Southwest, in newspapers — the Arizona Republic, Los Angeles Times, Albuquerque Journal, Santa Fe Reporter, and High Country News — and also in Arizona Highways, Teaching Tolerance, Matador, Trail Runner and Horizon magazines. She also writes a monthly column in the Arizona Daily Sun, “The Long and Winding Road.” Her interest in writing about disability issues comes from her father having had multiple sclerosis.

Kenny Salvini describes himself as a semiretired adrenaline junkie turned writer. He became a C3-4 complete quad from a snow skiing accident in 2004. Living in Sumner, Washington, away from a major population center, he found it difficult to connect with others who have SCI, so he started Here and Now, a social support network for paralysis survivors and their families that draws its members from all over his state, but is mostly concentrated in the Seattle-Tacoma area. You can follow his adventures by reading his blog, “Typical Guy, Atypical Situation” at kennysalvini.com.

Our managing editor Josie Byzek’s dedication to disability rights is deep-rooted and enduring. She cut her teeth as a reporter for the advocacy publications, Mouth and Ragged Edge, is vice president of board development for the Center for Independent Living of Central Pennsylvania, and a candidate for the Susquehanna Township School Board. She and her spouse have raised two children and are currently raising a third, her nephew, Tony. In February she will commemorate her 20th year of being diagnosed with multiple sclerosis.

Megan Lee, national sales manager for United Spinal, has been working directly with clients who advertise in New Mobility for the past 10 years. She also works across all marketing channels for United Spinal, including the development team, where she helps with fundraising and corporate sponsorships. She lives in Scranton, Pennsylvania, with her adopted chihuahua/terrier, and her boyfriend. She enjoys traveling, hiking, shopping, cooking, and spending time with friends and family. She stays active by playing ultimate Frisbee, kickball, and football in a co-ed league during the week.
Kudos to all who are able to see the positive!

SCI Anniversaries
Great, personal stories! [“SCI Anniversaries: Why Do We Celebrate Them?” August 2017]. My SCI was 39 years ago and I truly believe I’m a better person today because of that event. Kudos to all who are able to see the positive.

Susan Babcock Peters
via newmobility.com

Who I Would Have Been
Obviously everyone is different, and I think it’s great that people find ways to be positive, but I can’t even imagine celebrating a death. And make no mistake, the 18-year-old girl that I was died on that day [“SCI Anniversaries”]. Who I am today is not who I would have been. That’s not to say one is better than the other, and I have certainly had a very blessed life despite my SCI, but I still often wonder who I would have been if I had not broken my back.

Carol Arachne Hollfelder
via newmobility.com

No Need to Look Back
I just wanted to share that I am 23-plus years post-injury and rarely think about the day or [anniversary] date. I certainly don’t mark the occasion with any type of remembrance. My accident happened, I moved on with my life and have little need to look back at the event that changed the course of my future. Maybe I could look at it similarly to how I look at schools; I don’t take time or think about graduating from high school or college.

James Jones
Richmond, Texas

RV Freedom
I met my partner eight years ago. She is a quad and explained how she had seldom traveled [“Finding Athena,” August 2017]. It just took so much to pack supplies, a Hoyer lift, plus stopping to do her care every four hours. I got the idea of modifying an old RV while thinking up a “mobile care center.” I got a 10-year-old unit and stripped the interior out. The price of a lift was more than what I paid for the RV, so I designed and built my own. I also designed and built a track lift that runs the length of the RV and installed two hospital beds that can lock together or slide apart to do care. We lived in it for three years (not easy in Vermont with minus 30-degree temperatures) while we built an accessible house. You can see pictures of the project at mcele.shutterfly.com/2299. We use the RV all the time — sometimes just for a day trip, sometimes for a month at a time. It has truly given my partner and me tremendous freedom.

Michael Csele
via newmobility.com

The Only Way to Travel
I have an SCI as a result of a transverse myelitis attack 12 years ago. I too, need a power chair. Our requirements for an RV were similar [“Finding Athena”]. Long story short, my husband and I worked out the bugs, refined our requirements, then bought a 2015 Newmar Ventana built to our specs. We love it. We haven’t gone all that far afield, but it is the only way we would be able to travel.

Mary Dodson Knight
via newmobility.com

Physical Therapy and Shoulders
The author’s experience [“Shoulder of Fortune,” August 2017] was as bad as I feared it would be. Last year I was really panicked because I thought I’d be going through the same surgery. I was even looking at shoulder replacement, as the recovery is supposed to be easier. But my doctor said surgery would be the last resort, and he sent me to physical therapy. He said I had bursitis and gave me a shot of steroids as well. I wasn’t the most diligent exerciser, but one day about five months later, I realized I was doing things (almost) pain-free! Both shoulders will flare up if I do too much, and I’m restricting my activities a bit to prevent that. But I’m now a firm believer in PT first. With a big tear, it may not help as much, but someone might be able to manage living with a smaller tear if the muscles surrounding it are strengthened.

Kathy M. Stice
via newmobility.com

Funding for Accessible Mods
I live in Massachusetts and they have a program called The Home Modification Loan Program [“Paying for Home Access Modifications,” August 2017]. You don’t have to be low income, you can get a loan for work needed, and it doesn’t have to be paid back until you sell your house.

Kerry Trementozzi
via newmobility.com

Service Dog Training for Public
In Denver we have Domino Service Dogs, a nonprofit organization that puts you and your dog through a two-year training program [“Rescue Dog,” Outdoor Tracks, August 2017]. First thing is public behavior. We ride buses, light rail, go to restaurants, grocery stores, even the slide on a children’s playground in case your dog ever has to do an emergency evacuation from an airplane. My Hershey picks up anything I ask her to, pushes door opener buttons and pulls the door closed when we leave our apartment. I trained her to do these things one step at a time, just as the article mentioned.

Joe Beaver
via newmobility.com
Life is unpredictable... your power wheelchair shouldn't be

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CMS Clarification: Medicare Covers Maintenance Care

After years of legal battles, the Centers for Medicare and Medicaid Services issued a clarification on August 28 that Medicare coverage for skilled nursing facilities, home health and outpatient therapies is to be determined based on a person’s need, rather than their potential for improvement.

The clarification is the final step in a corrective action plan prescribed by a federal judge earlier this year, as a result of CMS’ failure to properly implement a 2013 judicial settlement over their coverage policies. The lawsuit, Jimmo v Sebelius (2011), came about as the result of Medicare denying coverage for maintenance care — nursing, home health and outpatient therapy — for those with chronic disabilities because they were not showing improvement in their prognosis. The plaintiffs argued the federal guidelines mandated that Medicare was required to cover skilled care for those who needed it to maintain their current level, or to slow a decline in their health or function.

The judge agreed, and in 2013 a settlement was put into place that required CMS to eliminate the “improvement requirement” and to make this policy change explicit to providers, beneficiaries and contractors. For years afterward, many people were still being denied access to maintenance care and therapy.

According to the Center for Medicare Advocacy, which filed the lawsuit, “Lawyers for the Jimmo plaintiff class requested further action from the court when it became clear that too many people were still being wrongfully denied Medicare coverage — in part because many health care providers had not been adequately educated, and in part because many providers were still skeptical that Medicare would alter its coverage practices.”

Advocates hope that this court-mandated clarification will be enough to convince providers that they will be reimbursed for providing maintenance services for those living with chronic disabilities.

“People living with MS, Parkinson’s, Alzheimer’s, paralysis and other long-

People in the News: Tony Jackson Jump-Starts ParaSports Live

A new webcasting service for adaptive sports, ParaSports Live, launched in early 2017 and will begin broadcasting sporting events this fall. The service, founded by Tony Jackson, will feature live streaming with commentary and play-by-play announcing for adaptive sports competitions across the country.

Jackson, a graduate of the Walter Cronkite School of Journalism at Arizona State University with a focus on radio broadcasting, plays power soccer and has been active in broadcasting power soccer tournaments, including commentating for the 2017 World Cup. He says that interest and positive feedback from the power soccer webcasts he’s done are what motivated him to start an adaptive sports broadcasting service with a wider reach.

At first, ParaSports Live looks to cover wheelchair rugby, track and field and sled hockey, as well as power soccer competitions. “None of those sports are really being shown outside of maybe the national championships or the Paralympics, so you don’t really see or hear about them,” he says. “There are tons of competitions that are happening all over the country all year long, every year, and none of them are being shown to anybody.”

Jackson aims to change that. His first broadcast will be from the Rugby Rampage, a wheelchair rugby tournament held October 21 and 22 in Durham, New Hampshire. While the primary goal of the service is to increase visibility and access to adaptive sports, he also hopes to grow the coverage enough to provide a platform for others with disabilities to gain experience as broadcasters.

“A lot of people who want to be radio broadcasters start out in smaller markets, and smaller markets mean small towns, and often times small towns don’t have the resources to make it easy for people with physical disabilities to thrive or even survive,” he says. “I want ParaSports Live to be big enough that I can’t go cover all the events myself. Then I’ll have to go out and find other people with disabilities who aspire to work in radio or TV or sports and give them career opportunities to pursue their goals.”
term conditions have waited long enough for this relief,” said Judith A. Stein, executive director for the Center for Medicare Advocacy, in a press release. “We hope that the new CMS education and information, which can be found at CMS.gov and printed out with the CMS logo, will help convince providers that Medicare really is available for people who need this critical maintenance care.”

**Tobii, Microsoft To Add Eye-Tracking to Windows 10**

On August 1, Microsoft announced that it will be adding support for eye-tracking technology to its Windows 10 operating system. The technology can serve as a technological lifeline for those with severe neuromuscular disabilities such as ALS and CP.

Microsoft partnered with Tobii, an industry leader in eye-tracking technology, to develop the new functionality for the Windows OS. Tobii’s Eye Tracker 4c will be the first device to support this feature and allow users to control both keyboard and mouse with their gaze.

“Adding native eye-tracking support to Windows 10 is a key milestone in our mission to make this technology part of our everyday devices,” said Henrik Eskilsson, CEO of Tobii, in a press release. “Through integration with Microsoft’s operating system, it becomes possible over time to realize robust eye-tracking implementations that add a range of user benefits. This collaboration clearly shows the value of eye gaze input and is a big step forward on the long-term journey to drive high-volume adoption of eye tracking.”

Eye-tracking technology has been around since the 1980s, but due to cost, was often unavailable to those who needed it until 2001, when Medicare began covering eye-tracking devices for those who had no other option for communication. Presently, dedicated eye-tracking systems can cost $10,000 or more.

Tobii’s Eye Tracker 4c is part of its gaming division, which adds head and eye-tracking functionality to immersive video games, and retails for only $149. The hope is that integration of eye-tracking accessibility features into such mainstream platforms such as Windows will have the effect of driving down costs and increasing access to the invaluable technology.

“Technology is basically a link to life for people with ALS,” said Alisa Brownlee, the clinical manager of assistive technology at the ALS Association to Slate.com. “As the disease progresses, a lot of folks become isolated due to the fact that it’s such a burden to even get out the door. Our members rely on the internet for everything: to do their shopping, get on social media, and see what their families are up to.”

Microsoft says that the eye-tracking functionality is currently in beta-testing. Those interested in testing and providing feedback can enroll in its Windows Insider program.
Q. For the past couple of decades I have owned a home located on a steep hill in a semi-rural area, but changes caused by my quadriplegia now make it more difficult for me to travel locally for shopping, recreation and social events. The isolation has been peaceful but not always conducive for travel to work for my personal care attendants, as my home is quite a distance from the nearest transit stop. The steep grade on nearby streets and sidewalks also makes it dangerous to travel in my wheelchair, and impossible when snowy or icy. I have progressed from using a manual wheelchair to needing a power chair and want to move closer to shopping, transit and more level ground so I can use nothing but my wheelchair to shop and socialize.

Such a radical change should also provide me with an opportunity to realize a longstanding dream regarding the type of housing I will be seeking. I have always wanted to live in more spacious surroundings like the open-space loft where Tom Hanks lived in the movie *Big*. If I had that type of space, it would provide me with all types of options regarding the layout as long as there was an elevator.

I’m sure I’m not the only one to consider such a change and would appreciate some thoughts about the pros and cons of such a move. My home has increased in value so I will have a decent down payment if I decide to purchase instead of rent. Hopefully I can also figure some way to minimize moving costs if I do make that change. Does this sound feasible?

— Seeking level ground

You are right — there would be many benefits to living within rolling distance of local businesses, work and friends. But that presents a couple of challenges. The first involves finding another property that would not break the bank when it comes to making it accessible. Since you already have several years’ experience in the wheelchair world, it sounds like you know what types of modifications you would need. Because building owners and managers have been less than proactive in creating accessible properties, it still takes quite a bit of imagination and pressuring of the owners of multifamily housing in order to find something that is truly accessible.

The second challenge may be finding someone to buy your accessible home. Marketing your current home as a property for “lifetime living” should appeal to buyers who know that their situations are likely to change as they age. They should also understand that it could take a bit longer for you to get relocated, so they may be more flexible when it comes to setting the closing date.

If you don’t find something you like in multifamily housing, it may be time to expand your search. Those lofts like you saw in the movie can be extremely expensive. One bold but potentially gratifying step would be to purchase and modify an old commercial building, firehouse, school building or church located in a convenient location. Check with a mortgage broker or your preferred lender to assure that financing for such properties would be available to you. With a large floor plan there might be room to create separate space for attendants or tenants, thus providing you additional options for income.

Have a commercial realtor start hunting on your behalf, and make this one big adventure. You can explore the areas where you would like to relocate, then check into storefronts or garages that have closed due to the current economy. Be sure the zoning allows live/work or residential housing. Challenging your friends and family to keep their eyes open for potential options near their favorite haunts may result in some surprising and affordable choices that would assure you have more contact with them.

The local affiliate of Rebuilding Together may be willing to construct any necessary ramping or other accessible features at no cost. Just type the organization name into your web browser; their members are usually retired individuals who have worked in the construction trades and want to focus on accessible home modifications.

Being able to have construction or modifications completed before moving is most convenient, but many hotels are accessible and offer long-term rates that are reasonably priced. You might even find a hotel that offers free breakfasts and cocktail hours to help you relieve some of the stress of the relocation.

If finances are tight after the purchase and remodeling, don’t overlook local civic clubs for help with the actual move, using their members and rental trucks. Some reality television shows have focused on unique properties that people have remodeled, including old factories, grain silos, and even service stations. If things go well, perhaps we will see you there one of these days.
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Since its inception, photography has had the ability to awaken the senses of those who become its most passionate fans, and you can include David Corbin, a C5-6 quadriplegic from Rochester, New York, as one of them.

After his injury in 1996, he went into a state of denial. “I was a passenger in a car that was hit by a bus on the New York State Thruway, and I held fast to a firm belief that my injury was temporary,” he says. “But nothing got better. There was no Rocky-like movie montage where I started getting better.”

Then one day about six weeks after his accident, his physical therapist took him aside and told him he’d never walk again. “That was the first time someone told me straight-up the full scoop on what happened to me.”

He soon became a passionate fan of film photography. “I love black and white 4x5 film. The grain of the film is gorgeous and the process is very hands on.” He uses a 4x5 camera on a tripod and usually needs an assistant. “It’s a huge pain in my ass, but I love it.” Corbin’s work has been shown in galleries in the Rochester area and his current project on self portraits can be seen at his website: davidcorbin-photography.com.

SCI LIFE

Reach That Highest Cupboard of All

A full kitchen remodel is not necessary to reach all of the cupboards. Rev-A-Shelf, the makers of organization cupboard systems, offer a pull-down shelf to bring your cupboard to your level with the press of a button. You can purchase a Rev-a-Shelf pull-down shelving system on Amazon. Prices vary but often are under or around $300. Check it out for yourself by searching Amazon for Rev-Shelf-SPD-24CRN-Pull-Down-Shelving.

A Wheelchair That Lifts

Getting in and out of one’s wheelchair is never an easy task, especially if you use a lift for transfers. But a wheelchair prototype from Spain, the Rois Transfer Chair, may change the lift industry as we know it.

Outfitted with a small incorporated crane mechanism, the chair allows a caregiver to transfer you from your wheelchair onto any surface, and the lift is hidden in the backrest. Those with increased hand dexterity could also use this wheelchair independently. A remote control is used to operate the lift.

This innovative chair is also nice for travel since you no longer need to bring a separate lift. You can use the Rois anywhere you may have dreamed of being transferred — the movie theater, onto a friend’s couch, even into a backyard chair. The Rois Transfer Chair is a project by students at Parque Científico UMH.

Follow its development: roismedical.com.

“After constant nagging from my dad to try photography, I gave in. ... I was hooked and wanted to create again.”

Drawn in by the Lens

A Wheelchair That Lifts

Reach That Highest Cupboard of All

Drawn in by the Lens

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After his injury in 1996, he went into a state of denial. “I was a passenger in a car that was hit by a bus on the New York State Thruway, and I held fast to a firm belief that my injury was temporary,” he says. “But nothing got better. There was no Rocky-like movie montage where I started getting better.”

Then one day about six weeks after his accident, his physical therapist took him aside and told him he’d never walk again. “That was the first time someone told me straight-up the full scoop on what happened to me.”

She told him he had a choice — deal with it and learn that he could still live a full and happy life — or he could give in. Corbin, now 41, decided to give his new life a shot. “I was an art major at college when my accident happened,” he says. “But soon after that, he lost all interest in art, or almost. Then he found photography. “One day after constant nagging from my dad to try photography, I gave in and tried it. I was hooked and wanted to create again.”

He soon became a passionate fan of film photography. “I love black and white 4x5 film. The grain of the film is gorgeous and the process is very hands on.” He uses a 4x5 camera on a tripod and usually needs an assistant. “It’s a huge pain in my ass, but I love it.” Corbin’s work has been shown in galleries in the Rochester area and his current project on self portraits can be seen at his website: davidcorbin-photography.com.
Shortly after our August article made a connection between avocados and testicles by way of the Aztecs, a lawyer (with a good sense of humor) contacted us and proposed that we balance the genital scales of justice. How? By doing a similar article on a female friendly fruit. Well, no objections, counselor. With all things being fair and equal, here it is.

Exhibit A: The Pomegranate

Fruiting plants and humans both have reproductive organs called ovaries. Pomegranates bear a striking anatomical resemblance to an ovary when cut in half, but even more remarkably, they function similarly.

The Evidence

This juicy, ruby red fruit contains a hormone called estrone that is structurally and functionally similar to one found in mammals. In fact, pomegranates contain the highest known source of estrone in the plant kingdom. So what does this have to do with SCI? More than you would think. Following SCI, many people experience hormone imbalances, so the powerful estronic properties of pomegranate can help support your endocrine system. Furthermore, we all know that people with SCI are at high risk of developing osteoporosis, and this risk increases for women with SCI whose estrogen levels start to decline during perimenopause. Estrogen helps bones absorb calcium. The hormone estrone, which is produced by the ovaries, is the major source of estrogen in women who have gone through menopause. So this amazing fruit can naturally help support estrogen levels and bone health and it does not exhibit carcinogenic potential associated with synthetic or bio-identical estrogens.

As if this good news isn't enough, let the evidence show that pomegranates have the highest antioxidant value of all fruits. A glass of pomegranate juice has more antioxidants than red wine, green tea, blueberries and cranberries, which means it helps support the cardiovascular system — and cardiovascular disease is more prevalent in people with SCI than ever before due to longer lifespans. Some sources say heart disease is the leading cause of death for people with SCI. Moreover, this multi-seeded tart fruit helps lower cholesterol and blood pressure and inhibits platelet aggregation, all of which contribute to heart disease.

Closing Argument

Ladies and gentlemen of the jury, let the evidence stand that the ovary fruit is beneficial to your health — and a delicious way to enjoy them is over ice! We rest our case.

Pomegranates Over Ice

2 cups pure unsweetened pomegranate juice
1 lime (juice of)
½ cup ice

Combine in glass and enjoy!
ADVOCATE TURNED POLITICIAN
Willis Washington

Despite a lack of political experience, Willis Washington decided to run for state office last year in Oklahoma. Working in his local SCI community, he saw a need and wanted to help address it. He didn’t win, but the experience was far from a losing one.

Getting the Political Bug

Politics had never been a thing for Willis Washington. In fact, just a few years ago he likely would have told you he despised politics and the smoke and mirrors politicians used as they abandoned the principles they ran on. Yet last year Washington, 44 and a T11 paraplegic, found himself going door to door, raising money and calling voters, trying to convince them to elect him to represent District 97 in Oklahoma’s House of Representatives.

Washington got his first taste of political involvement through Oklahoma’s now defunct chapter of United Spinal. He credits Teresa Tisdell, a local OT and advocate who founded the chapter, with giving him the push that started his journey from skeptic to candidate. “She would tell people, ‘Willis is going to become our next senator,’ or she’d call me Senator Washington. It was just an inside joke for her, but in time I saw the need for things to be done for our community and what I could do.”

Working as a peer mentor for people with new spinal cord injuries, he found out about a looming state budget cut that would have reduced how many catheters Medicaid recipients could receive. “I met with a medical advisory committee along with a few of my peers. Eventually they decided not to go through with the cuts,” he says. “That success showed me I had an opportunity to make my voice heard and help people.”

That led to Washington attending United Spinal’s inaugural Roll on Capitol Hill. Empowered by meeting so many dedicated fellow advocates, Washington continued to grow his involvement and heard more and more voices calling for him to run for office. He met with stakeholders and supportive politicians and considered running for state senate before deciding on the House seat for District 97.

He ended up losing in a crowded race but says the experience was highly beneficial. “I knew even if I didn’t win this, I could learn something from the experience and possibly run for my senator’s seat in the future,” he says. Two of the biggest lessons Washington learned were to start early and never assume people know your story. “I think the thing that probably didn’t get me elected is not enough people knew me,” he says. “People

IF I COULD CHANGE ONE LAW:
I’d change the income cap limitations we have in Oklahoma, so that people like me could have time to adjust and transition back into the workforce without the fear of losing healthcare coverage.

ADVICE I’D GIVE MYSELF POST-INJURY:
You’re still alive, so keep living. You have the ability to conquer this challenge and possibly help someone in the process. You’ll never know what’s going to happen unless you try.
knew me in the disabled community, but not necessarily in the general public … I’ve learned that if people don’t know you, they won’t vote for you because they won’t trust you.”

He also learned the importance — and difficulty — of fundraising. “I was given some good advice by my current senator. She said if I didn’t feel I had the ability to raise about $40,000 to $50,000, I shouldn’t do it. I thought it would be a little bit of a challenge, but to be honest with you, I really thought I knew the people to do it. I did, but not everybody gave, and some of the people that I knew that could back me lived in other districts. So, some of them gave me money, but some of them said, ‘I’d love to support you, but you know, I’m also supporting somebody in my area.’”

Since the election Washington has turned his focus to addressing the accessible housing crisis in the area but hasn’t given up on another political bid. “I don’t rule out that I might run again, but right now I’m in a different space and I want to get this done,” he says. “Then I’ll see where I’m at.”

Washington has a busy agenda that includes forming a non-profit to help raise money to address the lack of affordable, accessible housing in Oklahoma. He also runs his own consulting business, A-Daptive Solutions and Consulting, LLC (www.a-daptivesolutions.com).

I want to eventually be in a position where I can obtain some properties to manage for people with a low or fixed income. They deserve a good quality of life and by having control of some of these properties, I would be able to adjust to their income and make these properties affordable. Prior to becoming injured, I had my own home repair and remodeling business, so I understand residential construction and property management. I’m also taking a course so I can be a Certified Aging in Place Specialist.

I’ve been meeting with a group to see if they would be interested in partnering up. They have the finances set aside to do a project, so it’s just a matter of whether we are on the same page. If that works out, that will be a great starting point.

WASHINGTON conducts an accessibility assessment for a new building.

**FAVORITE WAY TO RELAX:**
I love fishing. Fishing is so peaceful and relaxing, and it gives me a chance to just get away from life and the day-to-day grind.

**WHY I JOINED UNITED SPINAL:**
I didn’t feel like I had a voice, and then I was asked to represent the state of Oklahoma and be a voice for my peers. I realized many others faced the same struggles and I thought I could help and make a difference.
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P poised for action in her ultralight wheelchair, Jennifer Longdon prepares to dash through the summer rainstorm in Phoenix, Arizona. “Every woman for herself!” she calls out, challenging a reporter who is also going for it. We make it through the light monsoon rain, she on wheels, and the reporter — me — on foot, both wiping our eyeglasses dry on our clothes when we get to shelter.

Longdon, 57, is giving me a tour of Ability360, a huge, state-of-the-art independent living center — complete with gym and fitness facilities — for people with disabilities. Longdon is communications coordinator/editor for Ability360 and LivAbility Media, which publishes a quarterly magazine about independent living. She is also a gunshot survivor — and a candidate for a House seat in the Arizona Legislature.

“This is going to sound extremely corny,” she says, “but after that incredible act of evil — someone deliberately pointing a gun at my fiancé and me, and firing it, I’ve always felt this weird need to offset that violence, that evil.” The shooting happened 13 years ago, piercing her spinal cord at T4, leaving her paralyzed from mid-chest and below.

“Currently there is no one out and proud and representing people with disabilities in our state,” she says of the Arizona Legislature. “I really want to be there — at the place where it makes the most difference.”

Longdon has entered a place of rarified political reality: running for office as a wheelchair user. There are no stats available to describe this distinction, but a good guess is she belongs to a group that makes up a fraction of a percent at best.

THE BIG CHANGE

It was November 15, 2004, when Longdon’s life — and her then-fiancé’s — were upended through gun violence. They were driving in his pickup in Phoenix, talking about wedding plans, when another truck sideswiped theirs. Her fiancé stopped his vehicle and gunshots rang out. He reached for his own handgun but was shot in his head, and another bullet ripped through her spine. She was in the hospital for five excruciating months. He is now in long-term care with a brain injury. The two are no longer together, and the shooter was never apprehended.

Everything changed that day. She went from being a respected woman to a wheelchair user who is often ignored because of that chair. “Before my injury, I was 6 feet tall, had some affluence, a great job, great house, great zip code. If I went into a store, I got service. If I went into a restaurant, I got service. If I asked to speak to the manager … the manager took that very seriously,” she says.

In her previous life she was a massage therapist building a resort-destination massage practice. “I had privilege, and I didn’t fully recognize it. I worked hard and thought that’s why I had all these things. But after I became paralyzed, people stopped seeing me: as a woman, as a white woman, as an affluent person. They started seeing me as a wheelchair. Referring to me as a wheelchair. Not even a human. As a wheelchair.”

She mimics the voices that wheelchair users know too well: “‘There’s a wheelchair in aisle three that needs help.’ There’s a wheelchair needs seating. Can anyone
help the wheelchair over in Bed Two?’ That was very, very hard for me.”

On top of it all she fell and broke her leg, and ironically, suddenly, people were engaging with her again. Because of the break, she now had a leg that was elevated in a cast, in her wheelchair. She was back to being just anybody. “So I’m out doing my shopping with my leg up. And suddenly, people are talking to me again. Because I have a broken leg … I’d be in line at the checkout, and someone would go, ‘Skiing accident? Car accident?’ And cashiers would look me in the eye, put change in my hand again.”

But as soon as her leg healed and she put it down again and went out to the same places as simply a person in a wheelchair, the cashiers stopped paying attention to her. “They’re looking at my companion, asking them, ‘What does she want? What does she need?’ They’re no longer putting change in my hand again.”

“And that really pissed me off.”

BECOMING A CANDIDATE

As her awareness grew over 13 years at chair level, Longdon served on the Phoenix Mayor’s Commission on Disability Issues, the Phoenix Mayor’s Neighborhood Advisory Council, the Statewide Independent Living Council and several other commissions and boards.

She’s been an activist with Arizonans for Gun Safety and helped organize with law enforcement a controversial gun-buyback program.

On the Mayor’s Commission on Disability Issues, Longdon helped create a non-discrimination ordinance amendment that supported the disability community, and she also worked to codify protections for the LGBTQ community in terms of employment and housing. Before the code changes, she says, “It was not illegal for someone to say, ‘Oh, you’re gay? You can’t rent this apartment. Oh, you’re gay? You can’t work here.’ We changed that. That’s one of the things I’ll always be very proud of.”

As a gun-safety and background-check advocate, she has met both Arizona Senator John McCain and President Barack Obama in Washington, D.C. (and cherishes a selfie she has with Vice President Joe Biden). She admires both Obama and McCain and believes in a bipartisan approach to solving complicated social issues.

“The last time our country was this fundamentally divided, we went to war,” she says, referring to the Civil War. She isn’t predicting another such war, but she sees the extreme rhetoric in the nation’s capital and across the country as harmful. She believes in building coalitions to tackle problems.

“Watching how the rhetoric changed in our country, seemingly overnight, was horrifying to me,” she says. As a Democrat, she believes the negative, harmful language began with Donald Trump’s election. “But still, I am willing to work on policy. I’ve always said that policy is political but doesn’t have to be partisan. And so from a policy standpoint, I want to be able to work with anyone.”

Longdon has the support of a former Arizona mayor, who praised her “ability to be strong in the face of what happened, to be resilient in the face of such tragedy.” Sara Presler served two terms from 2008 to 2012 as Flagstaff’s first woman mayor, and the youngest.

“I see Jennifer as someone who could do a very great job reaching across the aisle and finding common ground to move the state forward,” says Presler, now a Phoenix-based attorney. She met Longdon through the Mayors Against Illegal Guns program. “Jennifer’s also somebody who has earned the respect of people in the private and public sectors. That really matters for making public policy.”

So what really moved her to run for office? A few things: The Arizona Legislature, which leans conservative, almost killed a law that Longdon believes is of utmost importance. “They nearly gutted Shannon’s Law, an 18-year-old bipartisan
gun-safety bill. No one has ever claimed to be maliciously prosecuted as a result of Shannon’s Law, but someone took gun-lobby money, and just decided, what the hell, let’s get rid of this. And I was, like, I’m really fed up. I can’t take this any more.”

Also, after Trump’s election, organizers of the Phoenix Women’s March put out a statement of their priorities and included a list of past civil-rights activists. Longdon was shocked that there was nothing about disability rights, and no heroes from the disability-rights movement.

“So the legislature has completely pissed me off, and the women’s march has made it clear that our lack of representation is going to continue and leave people with disabilities vulnerable. At the same time, a seat in this legislative district opened. And while I’ve thought about running in the past and always figured I’d make a great policy advisor for somebody, this time it was like, ‘Nope. I’m running. I’m running.’”

Also, her 2016 trip to the White House — when she joined President Obama on stage the day he announced his executive recommendation on gun safety — crystallized her desire to run for public office.

“Prior to my visit to the White House, I know my name had been floated once or twice to be considered to run for office, but it didn’t float very high because people were, like, ‘Do you think she’s too fragile?’ I know there’s a segment of the population that makes assumptions about me because I use a wheelchair. And those assumptions aren’t always flattering, right? As I’ve watched other nondisabled candidates do their campaigns — because I’ve worked on other campaigns — I’ve sat back and said, ‘Now how could I do that as a wheelchair user? How would I manage these things?’”

And then there was the awe she felt the day she wheeled down the same wheelchair ramp used by Franklin Delano Roosevelt, the 32nd president of the United States.

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system works. It touches disability and being LGBTQ, disability and being undocumented, disability and being black or brown, disability and being poor, being uneducated, being whatever else that made you ‘other.’”

Her employing caregivers 18 hours a week to help with some of her daily physical routines has also put her in touch with a segment of the population in a way that she wasn’t before the shooting.

“Once you start recognizing marginalization in one group, you see how other groups are marginalized. I’ve relied on caregivers the past 13 years, and those caregivers end up being the domestic women that they talked about in the Women’s March platform: white women who are undereducated, new immigrants, women of color who weren’t getting other jobs.

“These women come into my life and become part of my life, sometimes for days, sometimes for months and years, and you develop a very intimate connection. Because they’re caring for my body. And in this process, we’re not co-workers like with someone in your office. We’re eating together, we’re cooking together, we’re cleaning together, we’re laughing and crying together.”

She feels their marginalization on a daily basis and has learned that disabilities can cause poverty and poverty can increase the chances of disability. As evidence of disability causing poverty, she cites the lack of employment of disabled people, the cost of retrofitting homes and vehicles and the possible need for full-time care. On the flip side of poverty leading to disability, she points out how poor people often live in old housing plagued with lead, for example, that can impact children’s brains.

“I think that my own marginalization, my own minority status, gives me a point of view that some of the other candidates might not share,” she says, citing her understanding of the importance of fighting for a wide variety of civil rights. “It’s all interconnected. We’ve got to work together to get solutions.” Like the need for jobs. “By helping individuals reach their full potential in terms of productivity and their ability to contribute to the community, so they then pay taxes. They’re contributing, they’re using less resources.”

A mother of a son in his mid-20s who is a college graduate, Longdon also has strong feelings about the importance of excellent education — for everyone. “Why would we not ensure that all our young people were as educated as they could be so they become vital members of a thriving workforce rather than building widgets at minimum wage?”

**AN INDEPENDENT LIFE OF SERVICE**

But it is her work on gun control that has brought Longdon the most — and sometimes, worst — attention. She has been harassed and threatened by extremist gun lovers [see sidebar]. In time, however, she pushed forward beyond the negativity. And
THE WEIGHT OF PUBLIC LIFE

After being shot and paralyzed in 2004, Jennifer Longdon was harassed and threatened by gun-rights extremists in 2014. Much of this came after an article focused on how women advocating for responsible gun use and for background checks are targeted and mistreated by gun-rights activists.

The 2014 Mother Jones article reported on an incident that happened after Longdon, who is now a candidate for the Arizona Legislature House, took part in a press conference with Everytown for Gun Safety (formerly Mayors Against Illegal Guns). The event coincided with the national National Rifle Association convention in Indianapolis. Longdon’s image, striking with long brown hair and proud posture, was included in news reports about the protest.

Later in the airport, a gun-loving zealot saw Longdon on the television news, and then again, right in front of him. He walked over and spit in her face. After the Mother Jones article revealed that incident, gun-rights extremists jumped out of the woodwork and onto the internet, claiming that Longdon was a fraud, that she didn’t even need a wheelchair, and threatened her with rape and death. And her home address was published on the internet.

She told her friends and her son to stay away, because some of the threats were aimed at people she loved.

“It turned into such a nightmare that I was basically quarantined in my house,” she recalls. “The death threats were so horrific that it was really bad.”

And this was not the first time she’d received threats due to her gun-safety advocacy.

Longdon returned home late one night in May 2013 after working with a Phoenix gun-buyback program that she helped coordinate with local law enforcement. She wheeled herself from her van to her front door. A man with a gun emerged from the darkness. Menacingly, he pointed the gun at her and pulled the trigger — soaking Longdon with a spray of water.

“Don’t you wish you had a gun now, bitch?” he asked, before disappearing into the night. Longdon, a gun owner who actually supports the Second Amendment, called the police, but the perpetrator was gone.

Like many gun-violence victims who experience PTSD, Longdon was briefly catapulted back to the terrible night nearly a decade earlier when she and her fiancé were shot.

But time passed, she sucked it up — and went on with her life.
she set up her life to live independently.

She made her home accessible. In addition to widening doors, lowering countertops and installing a roll-in shower, she added an automated environmental system. Now, via her smartphone, she can see who’s approaching her home, she can turn on lights and lock or unlock doors remotely and control the house temperature — whether she’s in bed or across the country.

Until last year she had the assistance of Pearl, a service dog who knew her every need and mood [Pearl died in November]. Now Longdon’s live-in presence is Porter, a big mutt whose “super power is shedding,” she jokes, though it turned out he was not suited to be a service dog. Still, he is attentive and loving — 110 pounds of caution.

The outspoken, gritty and sometimes irreverent Longdon, who does not shy away from colorful language, including the f-bomb, is anticipating a strong campaign, and a chance to improve the policies of the state of Arizona. As a legislator. And as a disabled person.

“I’ll put my community service up against anyone else who’s going to run,” says Longdon, whose campaign website includes an illustrated profile of her leaning forward in a wheelchair, ponytail flying back, headed toward whatever comes.

Currently there are five candidates, including an incumbent, for two Arizona House seats in District 24. The primary election is scheduled August 2018, and the general election November 2018.

“I like my odds. I think I have a good message. I honestly think that I have as good a chance as anyone else. They’re all good men,” she says of the other candidates for the Arizona House seats.

“And I think I’m really tough,” she adds. “To become independent with a significant disability requires toughness, requires advocacy, requires a lot of problem-solving.”

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If inspiration is the most overused “I” word when it comes to talking about spinal cord injury, independence comes in a close second. And just as what is inspiring for one person may be insipid for another, the dictionary definition of independence is open to interpretation.

In the days after I was paralyzed, I can still remember some medical professional assuring me that despite my C5 vertebra being obliterated, there was a good chance I would eventually be able to live independently. I think that I understood I was paralyzed, but being high as a kite from a potent cocktail of IV drugs, I was totally unaware of what the nurses meant when they kept telling me I was a “quadriplegic.” In my dreams, I pictured my independent life as a quadriplegic having the chiseled upper body of an American Gladi-ator, swinging from room to room like a graceful gymnast navigating an elaborate set of monkey bars. Of course I was going to be independent! Hell, I was going to be the paralyzed version of the Six Million Dollar Man — rebuilt better than ever before.

Almost 20 years later, my initial vision of independence has not materialized. No monkey bars, no chiseled muscles. I have yet to swing anywhere, much less transfer myself or shower myself alone. I rely on attendants to help me, but I have found independence. It’s very different from how I conceived it before I was injured, and to be honest, it’s very different from how I think most people would conceive it, but it works for me.

For this article I spoke with a handful of fellow quads, all of whom require some degree of personal care assistance, to see how they define independence. How have their definitions changed since their injuries? How do they balance the many components of living independently to find the mix that allows them to live their lives to the fullest?
FORGET THE DICTIONARY

Alex Jackson, a C5-6 quad from Charleston, South Carolina, is used to the puzzled looks he gets when he explains his conception of independence to school groups, or even his friends. Many of them get hung up when Jackson, 30, shares that he needs assistance getting bathed and dressed and into his chair in the morning, yet doesn’t hesitate to say he lives independently. It makes perfect sense to him.

“I am totally independent from getting out of the house and driving and going to work and doing whatever else outside of the house. The majority of the time I am on my own and independent,” he says.

Accepting and embracing this disability-community definition of independence requires a major paradigm shift for many. Take Dave Pierson, who was injured in 2011 when he was a software engineer raising a growing family. With all the responsibilities that come with marriage and three young kids, his idea of independence was pretty traditional. “I think before my injury, my idea of independence was just doing everything on my own,” says Pierson, a C6-7 quad. “You don’t want help from anybody.”

Then his injury turned his world upside down. “It felt like I had very little control over anything,” he says. “Your body decides when it wants to go to the bathroom, and there’s definitely a feeling of loss of independence and loss of life in general. You feel like everything is kind of dictated to you by outside factors other than your own.”

Rethinking his ideas on what it is to be independent helped him regain a sense of control of his life. “For me, the definition has changed considerably,” he says. “Now, independence is dictating life rather than life dictating to me. It’s more about doing what I want to do when I want to do it with whatever help I need — and knowing I am able to get that help.”

Pierson’s definition was one of the most succinct among all the people I spoke with, while also coming the closest to summing up what everyone seemed to be saying. But just having a new definition for independence was only one piece of the puzzle. How do people get to their new understandings of independence, and how do the definitions differ for people with different needs? What are the components of quad independence?

RETHINKING ATTENDANT CARE

For many of the people I spoke with, moving away from family played a big role in figuring out a new independence. Brook McCall sustained a C4 injury during her undergrad studies at University of California, Santa Barbara in 2002. After rehabbing at Craig Hospital, McCall, 37, worried she would never be able to return to her independent college lifestyle. Her family wanted to build her an accessible residence near them, but she rejected their offer. “I didn’t want to get stuck in a small town, and I was worried I’d be there forever,” she says. She eventually moved to San Diego and started hiring attendants. “It was scary, and kind of crazy, but once I got back to school, I started to feel ‘independent-ish,’” she says. “I had attendants, but I was living my life, not my parents’ or someone else’s.”

Reveca Torres, 36, a C5-6 quad and the founder of Backbones, a national SCI organization, also experienced one of the more profound realizations that shaped her ideas on independence when she moved out. “Moving away from my family helped me figure out that I could be independent living alone, without thinking that I
Smart-Tech: The Game Changer

From smart phones to smart homes and a handful of other “smart” inventions, quads have been one of the prime beneficiaries of accessible technology’s rapid rise, and the result is increased freedom. “Texting was literally so difficult for me that I never texted,” says Josh Basile. “But then all of a sudden, iPhones and iPads came out and it changed my independence to access the world.” Improvements in voice recognition software have also made Basile’s work as a lawyer much more manageable. “I use Dragon Legal and I can type as fast as I can speak,” he says.

Basile now manages almost all of his shopping online via Amazon.com, saving him trips to the mall. He bought a condo last year and has set it up so he has maximum independence. “Every single light in my condo, I control,” he says. “I control the thermostat. I control the TV with my voice. The disarming device. There are so many cool things that you can do with technology these days. For a high-level quad, they’re a game changer.”

Brook McCall echoed Basile’s comments, citing her computer as one of the biggest keys to her independence. She is puzzled when she meets other quads who are hesitant to fully embrace what technology has to offer. “I do get pretty frustrated when I meet people with similar injuries and they are unwilling to learn Dragon or they don’t go on the internet because they don’t want to figure it out,” she says. “I don’t know what I’d do without those pieces.”

THE BALANCING BEGINS

Once you’ve accepted that caregivers are going to be a part of your new independence, the big question becomes just how big a part are they going to play? The lower the level of injury, the trickier it can be to decide when your independence is best served by pushing yourself to try to physically accomplish something versus asking an attendant to do it. On the one hand, a task that seems impossible today may eventually become doable with repetition, but on the other, that repetition takes time — something that is already at a premium as a quad.

A recent return visit to work with an OT highlighted this conundrum for Torres. After almost 20 years without any OT, she was hopeful there’d be new devices that could help her accomplish some specific tasks more independently. As part of the intake evaluation, the OT tasked Torres with taking her shoes and socks off, something she normally gets assistance with.

“I was curious if I could do it after so many years. I was able to do it, which was cool, but at the end of it I was tired,” says Torres. “There’s that fine line of do you have the energy to do it, and if it’s going to take a lot of time, is it worth it? For me it came down to time. My routine in the morning can take anywhere from an hour to two and a half hours, so I’m not going to do something if it’s going to take me another 20 minutes.” (See sidebar, “Improving Time Usage,” page 28.)

Torres points out that her system for deciding whether it’s worth investing the energy to undertake a difficult task changes when she is alone. As an example, she shared her somewhat complex routine for picking up objects that fall on the floor. “It could take me a couple of minutes or it could take me 10 minutes, but I have to decide, is it worth it to pick that thing up? Do I actually need that right now, or can somebody just pick it up later? It depends on my energy levels. A lot of times it comes down to ‘do I have to do this?’”

Torres’ decisions work for her and her approach to independence, but might not work for others. Less than six years after his injury, Pierson is known among his friends for constantly pushing himself. Like many quads with lower cervical injuries, Pierson can almost taste attendant-free living and hopes that with continued efforts it will become a reality. “I get some help
in the mornings and help in the evenings right now,” says Pierson. “But I’m forever trying to work, and I’ve gotten to the point where I don’t need help in the evenings.”

MORE THAN JUST PHYSICAL
As much as Pierson desires the physical freedom that would come with not having to rely on caregivers, there is another component of his pursuit that he values nearly as much: financial independence. Pierson receives help from his family, but even with that, at one point he says he was spending around $1,500 per month on caregivers. As he has gotten more physically independent, he has been able to reduce that substantially, but he still feels his overall independence being affected. “When you can’t do things yourself, it becomes expensive quite quickly,” he says. “Say for the $700 a month I’m spending on caregiving now, that alone is a reasonable car payment. And $1,500 a month? Now you’re starting to approach rent on a two-bedroom apartment or a really nice car.”

State and federal benefit programs can help ease the financial burden, but for many they bring up more tough decisions about what matters when it comes to independence. Can you feel independent if you are relying on aid? Christian Budney, a C5 quad from Scranton, Pennsylvania, believes you can, but he still made finding work a priority after his injury. Budney, 29, was injured during his senior year in high school in 2006. Post-injury he focused on getting his college degree so he could find work. Just over a year ago he finally started working full time as a social worker at his local Center for Independent Living.

“[Having benefits] helped me during college and when I didn’t have a full-time job. Having that assistance was amazing,” he says. “But personally, working gives me more of a sense of fulfillment, knowing that I’m not reliant on that.”

On his path to fulfillment, Basile prioritized education and finding a job after his injury. He finished his undergraduate studies, got his law degree and now works as a trial lawyer. He says each step has helped him feel more independent and better understand what independence is for him.

Also, along the way he has shifted his conception of independence away from the physical aspects to focus on the mental. “I think in the beginning, I’d say the first four years, independence was probably 70 percent physical, 30 percent mental for me. Then it got to the point where
it was like 50/50. And then I started law school and it ended up being 80 percent mental, 20 percent physical.” Basile added that he would like to shift the balance back towards a more even split, but acknowledged that the new balance has helped him feel the most independent he has since his injury.

“STAYING STRONG
With all the pieces of their own personal definition of independence in place, even the most confident quads are likely to struggle with second guessing their formula. When almost everyone around you has a different understanding of independence, there can be an unspoken pressure to conform.

As a 13-year-old young woman coming out of her initial rehab, Torres, now 36, distinctly remembers feeling pressure to be as physically independent as possible. “It was like you had to do it for yourself,” she says. “It was good to be ambitious, but it also created this mentality that I had to do all these things for myself and it made me feel like a failure when I didn’t.”

On the flip side, Torres remembers the role a high school teacher’s unwanted pressure played in helping her figure out her independence. At the time, she attended class in a manual chair, even though she was unable to get around independently. She had a power chair but thought it made her look “more disabled.” The teacher told her he wouldn’t hire an assistant to help her just because she was stubbornly refusing to use her power chair.

“I was so mad at him, but then the next year I did start off school using my power chair and it was awesome,” she says. “It was awesome to not have someone around me all the time. Instead of feeling more disabled, I felt less disabled, I felt more independent.”

“I had an abdominal belt made to get my quad belly under control,” he says, lifting his shirt and showing a support garment somewhat like what workers wear to ease back strain. “And I discovered that when I take these straps and tighten them up fully and I lean over, I pee, and I pee fully. I have a special leg bag with an air bulb on it, and I depress it and it creates suction, so when I pee, it gets sucked into the bulb, and then I depress it again and it will set up another suction. But it takes me about half an hour to do the leaning and the belt and peeing and everything, so it’s a lot of work.” (Excerpted from “Sam Sullivan: Still Reaching,” August 2006 NM).

On his way to becoming mayor of the third largest city in Canada, Sullivan created five nonprofit organizations. The first drew its inspiration from Sullivan’s need for custom-made adaptive devices to improve time efficiency and independence. The Tetra Society of North America, an organization of volunteers who make one-off adaptive devices for people with disabilities, is still active, with 45 chapters across Canada and the United States. For more information, visit www.tetrasociety.org.
McCall. “They’ll say stuff like, ‘Oh my God, your life must be so hard!’ or compare their situations to mine. I try to laugh and say, ‘No, I’m sure you don’t like your life more than I like mine.’”

Comparing abilities and independence with other quads is common and can also lead to questioning your approach to independence. Budney catches himself comparing his situation to others but tries not to because he knows it is futile. “I’ve never met a C5 that has the exact same injury as me, but it can still be disheartening to see a C5 who’s living on their own, pushing a manual wheelchair,” he says. “That could play a mental game with you and get the best of you.”

Pierson often finds himself comparing his function and independence with others, but he comes back to the same thought. “We’re all different, and no spinal cord injury is created equal, even if it has the same classification. So, at the end of the day, I’m able to relax and accept that my level of independence might not be the same as another C6-7 because we’re actually quite different as far as the amount of function.”

A PERSONAL DEFINITION

Over the years, as Jackson has honed his speeches on quad life for school kids and people with new injuries, he has also been honing his own understanding of independence. Today he can show his audiences how he drives independently, how he uses a camera independently and how he does many more common tasks on his own. He does so with the confidence of someone who has found the right balance of the many components that make up independence. His definition of disability, like his injury, is unique to him, but the approach he used to discover it has more universal application. “I think it’s the same for anyone with a disability or not, you just sort of choose what you think is reasonable
The Chair Choice

When it comes to maximizing independence, a quad’s choice between a manual and a power chair might seem like a no-brainer. If you can push, you push a manual chair. If you can’t, a power chair is the route to freedom. Right?

If only it were that easy.

With no movement of her arms, Brook McCall seems like an obvious candidate for a power chair. She’s tried them, though, and would beg to differ. “I really do feel like my manual chair has in some ways made me more independent,” she says. McCall, a C4 quad, relies on an attendant to push her around wherever she goes, but points out she would need someone around regardless of her chair choice. She enjoys the increased access of the manual chair’s smaller footprint and says she struggled to navigate in her power chairs. “I felt pretty uncomfortable in my other chairs. People didn’t really see me,” she says. “Two times in the same day somebody called me a dude. People were like, ‘Excuse me sir,’ like they just didn’t see anything but the chair. I was a thing. I wasn’t a person.”

Reveca Torres, a C5-6 quad, shared the same worry about being engulfed by a power chair. She used a manual chair for the first four years after her injury largely for that reason before making the shift to a power chair. She says she felt pressure to stick with the manual chair. “There’s that sense from manual chair users with lower injuries that it’s the worst thing in the world to be a quad and to have to use a power chair,” she says.

Alex Jackson was injured before he was a year old, so he grew up constantly facing the decision between manual and power. A C5 quad, he used a manual chair set up for him to push using only his stronger side until he was around 10. As he grew, he found it limited his independence. “It wasn’t conducive to my independence for me to continue to push one handed that way,” he says. After some time in a power chair he decided it was the way to go. “Power was definitely more user-friendly on my body, just more feasible for accessibility.”

Christian Budney’s chair journey went kind of the opposite way. Coming out of Kessler with a C5 injury, he decided to go with a power chair because he wasn’t able to effectively propel his manual chair.

“By problem is my right side is vastly stronger than my left, so I end up doing a lot of circles.”

“I went to power with an idea that I would work myself into a manual,” he says. Eleven years of quad life have changed his perspective. “I think I’ve come to a realization that for my maximum independence, a manual chair isn’t going to be suitable.”

As a C6-7 quad, Dave Pierson spends a good amount of time in both his manual and power chairs. He regularly gets out for long pushes in his manual chair with friends and can be found ripping down some of Portland, Oregon’s, steepest trails in his power chair.

“I look at my chairs as tools to independence,” he says. “I use whatever tool seems to fit the situation the best. If I’m going into an unknown area that includes a lot of hills and areas that I would have a hard time navigating in my manual chair, then I tend to use the power chair. If I’m going to known places that are navigable in a manual chair — any kind of social thing downtown, restaurants, that kind of thing — I would prefer my manual chair because it’s a little easier in big groups of people.”
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The whole nation watched as ADAPT activists, from Washington, D.C., to Fairbanks, Alaska, staged sit-ins, die-ins and other protests this past summer, often being arrested. Images of wheelchair users being dragged out of our elected officials’ offices chanting, “No cuts to Medicaid, save our Liberty!” flooded social and mainstream media alike. The power of the images by themselves was electrifying, and the message was communicated in a visceral way.

Disabled rights protestors were the first to focus media attention on the Senate bill that would have reduced Medicaid funds by 53 percent. More than 80 percent of those on Medicaid are disabled, elderly and children — and block grants allowing states to decide who gets what would have pitted these populations against each other for dwindling funds or forced states to raise taxes, either of which would have been destabilizing, at least.

The Affordable Care Act is imperfect — markets must be shored up, premiums lowered. But its vital protections for people with disabilities who use Medicaid-funded long term care services were at risk.

The grim threat was blocked by disabled advocates, especially ADAPT, and the media took note:

On June 22, Sen. Mitch McConnell introduced his health care bill that called for deep cuts to Medicaid. Then, he instructed the Capitol Police to remove the ADAPT activists who were protesting in his office. That set off a media firestorm as CNN ran live coverage of disabled people being carried away from the halls of Congress.

“Blood on the floor outside of Leader McConnell’s office,” tweeted an ABC News reporter, referencing a cut National ADAPT organizer Bruce Darling sustained to his head while being arrested.

A widely-shared photo of another ADAPT organizer, Stephanie Woodward, shows her arm held at an odd angle while she is carried off by the police. “Generally, Capitol Police don’t arrest in offices unless the legislator asks them to, so it’s pretty clear McConnell didn’t care to talk to us because he ordered those of us in his office to be arrested,” said Woodward to Democracy Now. “I don’t blame them. They had a job to do, and so did I. It just so happens that our jobs conflicted.”

That evening, The Rachel Maddow Show, which is the highest-ranking cable news show in the nation, ran a 21-minute-long story focusing on the history of ADAPT and the fight to save Medicaid.

“It felt like a breakthrough to a lot of us,” says Darling. “There was really a collective response to the piece, people suddenly felt validated, like, we’re now real.”

Darling was especially impressed — and relieved — at how careful Maddow was to show ADAPT’s long history of disciplined, spectacular demonstrations. “It’s a testament to the work our community has done for 30 years that we had people trained up across the country ready and able to do these demonstrations. We worked really hard on message discipline: The point is that they’re slashing Medicaid, we’re going to die, not how the police are treating us.

From this first day until the night of the final vote, the media kept a spotlight on ADAPT and other disabled activists. continued on next page
Disability Advocates Forcibly Removed From Senate Protest Say It Was Worth It: ‘We Have the Right to Live’

Why Disability Rights Activists Stormed McConnell’s Office

ADAPT, a national disability rights organization, organized a protest to fight back on the health care bill
Families take a risky road trip to save their health care

Holy hell THEY ARE STILL THERE — 22.5 hours (!) after arriving, ADAPT activists keep up sit-in @ Sen. Gardner’s office over TrumpCare

Wheelchair Sports Camp MC Kelin Heffernan joins an ADAPT protest demanding Cory Gardner vote against the Republican-led repeal of the Affordable Care Act.

Community members stage sit-in at Sen. Murkowski’s Fairbanks office

Protest of the Senate health care bill outside @SenToddYoung’s Indy office.

If You Celebrated the Health Care Should Probably Thank a Disability
Families take a risky road trip to save their health care

Disability-Rights Activists Are the Real Heroes of the Health-Care Fight

They put their bodies on the line to save Medicaid and Obamacare.

By John Nichols

Vote Last Week, You y Activist

Disability-Rights Activists Are the Real Heroes of the Health-Care Fight

Protests Erupted Across America

By June 26, ADAPT protests had spread out across the nation, including places not normally seen as hotbeds of unrest, such as El Paso and Indianapolis. Activists used the media spotlight to tell how important Medicaid is to their ability to live independently in the community.

“Medicaid funds the life-or-death services I need to live in my home with my husband,” said Melva Iris Flores, a quadriplegic from Indianapolis. “We can’t tolerate the Senate healthcare bill’s attack on our freedom to live in our own homes,” said Melva Iris Flores, a quadriplegic from Indianapolis. “Medicaid funds the life-or-death services I need to live in my home with my husband.”

Denver activists held a die-in at Sen. Garner’s office that ended up lasting 55 hours, until the police arrested them. “They said they’d rather go to jail than die without Medicaid,” reported a local TV station. “And that’s where they are tonight.”

There was even a demonstration in the furthest corner of the United States — Fairbanks, Alaska — in front of Sen. Lisa Murkowski’s office. “Disability isn’t about politics,” explained Doug Toelle, who has MS and is the advocacy director of Access Alaska, to a local media outlet. “Disability is an equal opportunity minority group, everyone is welcome to join — at any second — but with this hyper-partisan atmosphere in Washington, there is no way to avoid the partisan nature of this bill.”

Teisha Simmons, a quad also from Fairbanks, has a master’s degree and a job, but says without Medicaid-funded personal assistance, that would all be at risk. “If I were to not have caregivers show up, not only would I not be able to go to work, but I would not be able to volunteer in the community. I also have a 12-year-old daughter,” she says. “When I came across legislators in the past, they’ve said, ‘Well family needs to step up and do that.’ If my family were to step up and do that, then we are asking my sister to quit her full-time job and put her family into poverty.”

Medicaid is Saved — for Now

“It was all hands on deck,” says Darling about the grueling work of organizing actions across the nation. “We’d go into a day knowing we’d have a certain number of demonstrations and then a bunch would just spontaneously happen. People would call up saying, ‘We’re at the location,’ and we said, ‘What location?’ To see how it played out all across the country was an incredible thing, it was watching history happen. I was lucky to see it.”

The protests raged on, a crescendo of chants leading up to the final vote on July 27. The bill failed when Republican Senators Lisa Murkowski, Susan Collins and John McCain joined with the entire Democratic Caucus in voting no.

With this vote, Trumpcare officially died and Medicaid was saved. Although disabled activists were not the only ones protesting the bill, many in the media believe it was their dedication and sacrifice that made the difference.

“We have been prepared for this fight for decades,” said Amber Smock, an ADAPT organizer from Chicago, in Elle Magazine’s Aug. 1 article, “If You Celebrated the Health Care Vote Last Week, You Should Probably Thank a Disability Activist.” “People with disabilities have been organizing for our lives since the 1960s, if not before. … I think the new thing is that others are now seeing us in a way they did not before.”
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odd Stabelfeldt is a busy man these days. When not traveling all over the country delivering powerful speeches like “Convenience for You is Independence for Me” — at Apple’s Worldwide Developers Conference in San Jose last June — he’s also CEO of C4 Database Management, a small business focused on maintaining digital records for hospitals all over the country from his home in Port Orchard, Washington.

We caught up with the entrepreneur and computing technology expert on a particularly frenetic day in August. C4 had just gone live with a new software portal being tested at a couple of hospitals before being released to the rest of his clients. In between taking phone calls on one of the two iPhones attached to his chair, he zips in and out of his office, a technological fortress with a very unique flavor to its design.

As he pulls up to his desk, the dual screens of his desktop are dwarfed by three 40-plus-inch TVs hanging on the wall to his left. The top two flash IP addresses and other hieroglyphs only programmers understand, while the bottom is a constant rotation of the security cameras in and around his home. You can hear the slight hum of server racks from inside their custom-designed, climate-controlled closet behind him. On his right, a contraption that vaguely resembles early PCs from the ’80s looks extremely out of place. “My keyboard emulator,” he says, biting the mouthstick and tapping away at the greenish screen.

It’s a fascinating juxtaposition of high and low tech, where he has learned to balance consistency and sustainability, while also testing the limits of emerging technologies on a regular basis. It speaks volumes for the measured approach that was developed over years of trial and error by a true pioneer of assistive technology.

NO STRANGER TO THE CUTTING EDGE
Paralyzed at the C4 level from an accidental gunshot in 1987, then-8-year-old Todd had an interesting form of therapy as an inpatient in Seattle Children’s Hospital — adaptive video gaming. Along with a few other patients at Children’s, he became part of Nintendo’s research and development for the NES Hands Free Controller, an adaptive controller that consisted of a chin-switch joystick and sip-and-puff that gave young quadriplegics the ability to play their favorite games just like their peers.

Within a couple of years, he became the face of the system and was flown all over the country modeling it and giving live demos. “My face was on the manual inside every box. It was a lot of fun.”
Now three decades later, you see a man who took those initial seeds of innovation from his formative years and built his entire world around it. Today’s drive controls aren’t all that different from the Nintendo controller, but the functionality of it has been profoundly upgraded over time.

“I grew it as the technology changed,” says Stabelfeldt, recalling the relative dark ages of assistive technology. Long before we all had smart devices preloaded with maps, internet access, and flawless voice recognition permanently attached to our palms, he was teaching himself computer programming — one tapped out character at a time — and hacking into his drive controls to make his world a little more accessible. Garage door remotes were re-wired to operate doors; infrared switches were drilled into the ball of his joystick.

At some point, he had more switches than he could make use of, though not for a lack of trying.

What was missing in both his personal and business life was the ability to communicate independently when not at his desktop. He’d tried dozens of phone modifications but never found the perfect solution to his problem. “I wanted to text to my wife or email a colleague without having to ask someone else to do it for me.”

**BRIDGING THE GAP WITH SWITCH CONTROL**

That all changed in late 2013 when a friend tipped him off to Switch Control, a feature buried deep within the accessibility settings of the iPhone iOS 7 update. Built directly into the iOS platform, it allowed access to nearly every feature in the iOS with as little as a single switch. Through automated scanning or the use of programmable switches, a blue box moves up and down the list of apps on the home screen and around every clickable link inside the majority of the apps themselves.

Paired with Bluetooth-enabled assistive devices like Komodo Labs’ Tecla Shield DOS, Permobil’s iDevice, and Komodo’s forthcoming tecla-e — each turns a wheelchair user’s existing drive controls into recognizable switches. Switch Control becomes an immersive portal into the 21st century for a section of the paralysis community to finally harness touchscreen functionality. Double-click your designated “Select” button and a menu comes up giving you the option to go to the home screen, scroll, and a whole slew of gestures like flick, hold and drag, and pinch.

It didn’t take long after his initial trial for Stabelfeldt to recognize the value it would bring to his and others’ lives. This was the solution he’d spent years looking for, so he took the idea to his nonprofit, The Todd Stabelfeldt Foundation.

**A NEW PURPOSE — SPREADING THE WORD**

Originally formed in 2008 with vague aspirations to advocate for individuals with accessibility needs, TheTSF now had a much more specific and actionable focus. The foundation acted fast, securing a grant that allowed them to outfit nearly 20 high-level quadriplegics in and around Washington state within 18 months.

One of the first recipients was Ian Mackay, a C2 quadriplegic and good friend of Stabelfeldt’s living in Port Angeles. “It’s made my life more fun and opened up the world to me,” says the avid birdwatcher and all-around outdoorsman. Having a fully accessible phone gave Mackay the means to get back out in nature by himself for the first time since his injury. These days he spends hours out on trails all over Washington, logging up to 30 miles a day to raise awareness for accessible trails in the state.

With Mackay helping Stabelfeldt spread the word around the Pacific Northwest, a tightknit group of Switch Control users were able to work together and learn to master all of its features with the help of the manufacturers. Both Tecla

### USEFUL SWITCH CONTROL DEVICES

**Tecla Shield DOS:** A second-generation device from Komodo Labs designed to turn up to six independent switches or a wheelchair user’s existing drive controls into Bluetooth switches that can be recognized by phones, tablets and computers.

**Permobil iDevice:** Sometime in 2014, the forward-thinking folks at Permobil recognized the power of Switch Control and developed a Bluetooth switch system of their own that plugs right into their newest lines of wheelchairs. Chairs purchased prior to 2014 only need an upgraded power module to harness Bluetooth capabilities.

**tecla-e:** The newest iteration of the Tecla now boasts the ability to connect to up to eight Bluetooth devices at once, which works well with Switch Control’s latest update feature Platform Switching that allows the user to seamlessly swap between each device while using the same switches. Stabelfeldt showed us just how easy it is to jump from his iPhone to an iPad to his Apple TV and back again.
and Apple were very proactive with technical assistance and soliciting feedback to help further the development of the technology. “I was blown away by their responsiveness,” says Stabelfeldt.

Four years later, the system has continued to grow with each iOS update. Features like Recipes — which lets users dedicate actions to your switches to use in specific apps — help users keep pace with the rest of the world’s digital progress. For example, you can create a recipe to turn pages in iBooks or control an action in a game. There is even a Facebook group called “Hands Optional,” where nearly 200 members swap tips and techniques for maximizing Switch Control’s skills.

“It was a huge game changer for me,” says Tyler Shrenk, also a C2 quadriplegic from Woodinville, Washington, who recently took over as executive director of Stabelfeldt’s foundation. Under Shrenk’s direction, the foundation has given out 25 phone system set-ups to wheelchair drivers from Chicago to Florida to Germany. “It’s allowed me to come full-circle,” says Shrenk. “I’ve gone from being helped to giving others help.”

THE QUADTHEDRAL — BUILDING A HOME OF (AND FOR) THE FUTURE

Stabelfeldt’s mastery of technology is also apparent in his everyday living space. In 2014, he and his wife, Karen, broke ground on their dream home. Dubbed the Quadthedral, the approach to the design was as meticulous as Stabelfeldt’s attention to the syntax of his database codes. “We built the house with technology and the future in mind,” says Karen, who thoroughly enjoyed the process of planning a home from the ground up.

The first major hurdle was infrastructure, not just for an automated home, but for C4 Database Management as well, which was rapidly expanding at the time. Even in the age of wireless connectivity, they chose to run miles of cable before the sheetrock went up. “Whenever possible we ran wire for redundancy. It’s all about consistency,” says Karen.

In the case of a power outage, there is a propane-powered backup generator hardwired into the house that will automatically fire after it senses the loss of electricity. But seconds off-line can leave miles of digital wreckage to clean up after the fact in the IT business, which is why he made sure to protect all crucial circuits with uninterrupted power supplies.

When it came to picking home controls, the Stabelfeldts found themselves in the weird middle ground that comes with an industry trying to figure itself out. Similar to the Betamax versus VCR and Blu-ray versus HD DVD battles of decades past, the home automation industry was still in its relative infancy, so the landscape...
was flooded with options that weren’t always compatible. Multiple developers with matching proprietary apps made it hard to marry the systems early on.

Fortunately, tech giants like Amazon, Apple, and Google began to release their home automation platforms so that homeowners could group products together without having to overload their devices with endless single function apps. Todd and Karen naturally went with HomeKit because of its compatibility with Switch Control and Siri.

The options for grouping and customization can only be limited by your imagination as well as your pocketbook. You can get as detailed or as broad as you want, programming every individual light in the room, or designating all-encompassing scenarios like “Lights Out” (that locks the doors, closes the shades and turns the lights off) — all with a single voice command.

Even with their highly futuristic home as it is, the Stabelfeldts know that they have just scratched the surface of what their home will become. With that in mind, they decided to test door openers and automated blinds in a few areas instead of dropping a ton of money on tech that could be out of date by tomorrow. “We purposely left gaps where we believe technology will go,” says Karen.

**HOME AUTOMATION MUST-HAVES**

**HomeKit Compatibility:** Apple’s always-expanding collaboration with third-party products make home controls much easier to group together for seamless home automation.

**Lights:** Combining Phillips Hue LED lightbulbs with Lutron Caséta switches and wall plugs makes for an infinitely customizable lighting package, allowing users to pre-program not just the brightness of their lights, but the colors as well.

**Door locks:** Schlage Connect and Sense deadbolts feature illuminated keypads that can store up to 30 different codes so family, friends and caregivers can each have their own. There is also the option for temporary codes that are only usable during a pre-scheduled timeslot, which is great for visitors coming in from out of town for the weekend.

**Blinds:** Lutron’s Serena Remote Controlled Shades work well with HomeKit. Just tell Siri what percentage you want the blinds opened to, and the motorized rollers respond right away!

**RTI:** At the time of the build, there were still a few gaps in HomeKit, so Todd and Karen Stabelfeldt reached out to Theater One, a local home automation company, to get a few extra controls like NABCO automatic doors and DSC Power Series. “We chose RTI because it was the most Switch Control-friendly of all the apps,” says Todd.

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LOOKING TO THE FUTURE … WHAT’S NEXT?
The future is difficult to prognosticate, especially since it almost feels like we are already outlining the science fiction of our childhoods week to week. Stabelfeldt points out that progress is inevitable and will be fast. As the population ages, a much larger cross-section of the populace will need further accessibility, and these technologies will become more and more universally used. “That, and lazy people are good for us, too,” he quips.

Asked what features he’d like to see come about in the future, he recalls a recent trip to Mount Rainier with Ian Mackay and a bunch of friends in wheelchairs and pointed out a tiny gap in his foresight. “I wish that Siri could have looked at my calendar and seen that I would be out of cell service, and would have given me a reminder to download my playlists and podcasts.” Basically, he wants to turn his phone into a full-fledged personal assistant.

Mackay, for one, has no doubt that Stabelfeldt will be able to make it happen. “His willingness to experiment and explore these things has really made him a trailblazer on behalf of the rest of us.”

RESOURCES
• The Quadfather (Apple video): www.youtube.com/watch?v=4PoE9tHg_P0

Switch Control resources
• Switch Control: www.apple.com/accessibility/iphone/physical-and-motor-skills/
  • Tecla DOS: gettecla.com/products/tecla-shield
  • Permobil iDevice: permobilus.com/product/bluetooth-idevice-module/
  • tecla-e: gettecla.com/products/tecla-e-pre-order
• Hands optional FB page: www.facebook.com/groups/1331209543597872/

Home Automation Resources
• Apple HomeKit: www.apple.com/shop/accessories/all-accessories/homekit
  • RTI Controller App: www.rticorp.com
  • Theater One: theaterone.com

Lights
• Phillips Hue bulbs: www2.meethue.com/en-us/
  • Lutron Caseta light switches/wall plugs: www.casetawireless.com/Pages/Caseta.aspx

Locks
• Schlage Smart Locks: www.schlage.com/en/home/keyless-deadbolt-locks.html

Blinds

Security
• DSC Power Series: www.dsc.com
  • NABCO Automatic Doors: nabcoentrances.com

What will Stabelfeldt figure out next? Mackay doesn’t know, but can’t wait to find out.
Every few years in the fall, new technologies from multiple mobility manufacturers launch simultaneously and the world of wheelchairs reaches yet another level. This is one of those extraordinary seasons.

**Invacare Turns on the Power**

In 2012, Invacare entered into a consent decree to stop manufacturing and designing FDA-regulated custom power chairs in the U.S. until it addressed its quality control systems. This summer, Invacare was declared free of the consent decree and given the green light to begin full operations. As a global player in complex rehab power chairs, Invacare has remained active in Europe, both in design and manufacturing, so once the consent decree was lifted, new products were ready to be introduced to the U.S. power chair market. This fall’s launch of the TDX SP2 marks a big return to high-end complex rehab power chairs for Invacare in the United States. In fact, it’s their most advanced power chair to date. Specifically, the TDX SP2 is the next generation of the once industry-leading TDX series — and it lives up to its legacy.

The TDX SP2 features all that users loved about the preceding TDX models, including its terrain-hugging SureStep suspension that keeps all six wheels on the ground. However, where the TDX SP2 makes leaps in innovation is in its LiNX electronics. LiNX is built around refining the drive experience. Rather than using a traditional numerical “programmer” to tailor driving characteristics to the user, a Bluetooth tablet programmer allows real-time programming adjustments via a graphical interface. An image of the power chair appears on the tablet with corresponding lines. By swiping the screen, the drive lines are moved, adjusting such parameters as acceleration, deceleration, turn speed, and so on. What’s more, via LiNX programming, motor compensation — which dictates how a motor performs on various terrains — can be fine-tuned for a user’s specific environments. LiNX also has the capability to log diagnostics data and upload it through the user’s cell phone with an app to the cloud for analysis by Invacare or a provider. Lastly, although no launch date was given at press time, LiNX features the first power chair hand-control touch screen option, allowing power chair operation very similar to that of a smart phone.

There’s a lot to LiNX as a system — and it is a creative advancement in power chair electronics.

**Quantum Moves Toward the Forefront**

Front-wheel drive power chairs have been a staple in Europe for over four decades, but less so in North America. There has been only one major player consistent in the front-wheel drive market, with little to no competition. Quantum seeks to change that with the launch of its new 4Front front-wheel drive power chair.

The 4Front introduces two notable innovations to the front-wheel-drive market. First, the 4Front features exclusive intuitive CASE (caster angle sensor encoder) technology. CASE technology allows more fluent, predictable driving.

Secondly, the 4Front features true automotive-grade suspension. The “diamond suspension” system, described based on its geometry, features gas-charged coll-
over shocks that provide absorption for comfort and dampening for performance just like on a car. The result is four-wheel independent suspension that not only provides among the softest rides in the industry, but optimizes stability, right down to the equivalent of control arms.

Between the driving technology and true suspension, the 4Front handles straight, smooth and stable.

**Ki Creates a New Seating Axiom**

Ki has taken the ultralight wheelchair world by storm, and now it has introduced a complete cushion line that’s derived from a culmination of seating science and cutting-edge technology. Ki worked with renowned rehab engineering think-tank, Georgia Tech, to best apply anthropometrics — the science of measuring the human body and its proportions — to evolve its cushion technology. Specifically, Ki’s Axiom cushion line is based on “pre-contouring.” Among the most effective seating is that which is custom-molded to your shape. It approximates the least pressure. However, it’s impossible to do with an off-the-shelf cushion. Axiom addresses this with extensive science-based pre-contouring. An Axiom cushion is formed to anatomical parameters, so rather than sitting on a flatter surface cushion that presses back, most users are encapsulated by the Axiom’s pre-contoured shape. The result is enhanced support and immersion, decreasing pressure.

The Axiom line features five versions, from a basic general use cushion all the way up to a full skin protection and positioning cushion for complex rehab use. Surfaces range from molded-in relief to a visco foam insert to a HydroLite fluid bladder. All Axiom cushions feature a premium four-way stretch Lycra cover with exceptional attention to details — like a stylized zipper and accessory handle.

Axiom may be a new name in cushions, but it’s hard to forget once you’ve seen the quality of the product.

**Innovation Fosters Innovation**

Innovative seasons like we are seeing this fall are both inspiring and intriguing because when we see individual manufacturers raising the bar of mobility technology in specific areas, it means that others are soon to follow.

**Resources**

- Invacare, www.invacare.com, 800/333-6800
- Ki Mobility, www.kimobility.com, 800/981-1540

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The thing about this wheelchair business is that it is forever full of surprises, but rarely the “You just won the Publishers Clearinghouse Sweepstakes” kind of surprises. Often, they can be injurious, like the time I turned to check out a pretty woman and rolled right off a marble landing, down three marble steps, and on to my hind side. It was both seriously embarrassing and produced a hip wound that took two years and a surgery to heal. The lesson: keep your eyes on the road, pervert.

Often, the upshot of one of these surprises is simply that everyone standing around sees you as, how would you say it, pathetic. At my own sister’s funeral, no less, during the viewing of the casket ritual, my 9-year-old grand-niece came flying at me to give a hug and flipped me over like a buttermilk pancake. The reason I sustained no injury is because we were in a funeral home, and all funeral homes have plush, mile-high, Saxony carpeting to soften the blow. If you are prone to falls, you might want to move into one.

But sometimes the surprise can chill you to the bone, even the ones you can’t feel.

A month ago, on a normal Tuesday night, I slipped into bed for another night of dreaming of hitting a walk-off home run to win the World Series. My wife was two feet away. It wasn’t a comfortable sleep, but it rarely is with my contractured body. Just as the morning sun hit the window, I awoke to a true nightmare: thousands of black ants crawling all over my body, stem to stern. They were scurrying in and out of every crevice, an ever-shimmering black mass, nipping at my flesh, no doubt signaling for more tribesmen to join in on the fun.

Remember that unholy screech in Psycho when Tony Perkins leaps into the shower and slices poor Janet Leigh up with a carving knife? I heard the same terrifying riff as I desperately tried to slap, push and wiggle away from this creepy horde. The screaming woke up my wife, who, of course, had nary an ant on her. I was the sole prey.

I’m a T12 para, which means anything from a random spec of blood from a knee scrape to slight traces of other bodily by-products can apparently sound an come-and-get-it ant alarm all over West L.A. We never found what drew them. Maybe they just like flesh that seldom moves.

The Attack of the Night Crawling Ants has now joined another strange story — the time a brain-addled patriot drove my chair like a snowplow through a crowd at Starbucks because he thought I was a war hero and deserved a free coffee — as part of my ice-breaking repertoire at house-warmings and bar mitzvahs.

See, paralysis is good for something — semi-amusing, gasp-inducing anecdotes where you are always the butt of your own joke.
EMPLOYMENT OPPORTUNITY

Job Title: Americans with Disabilities Act (ADA) Coordinator (Part-Time)

Description: The Americans with Disabilities Act (ADA) Coordinator will build upon and administer the ADA accommodation program from start to finish. The position will also be involved in the Light Duty/Return-to-Work program. Other duties include but are not limited to the following: Identifies and performs outreach to employees possibly requiring accommodations; educates management and employees on the rights and duties under the ADA; coordinates with management and employees to develop and provide employees effective and reasonable accommodations; develops written materials and other informational pieces regarding the ADA program; develops and maintains internal measures to track ADA status and compliance and maintains and documents records of all disability and accommodation issues ensures compliance with applicable laws, regulations, and policies; assures that workers with disabilities are provided effective and reasonable accommodations allowing them to work productively and safely; assure Township-Sponsored activities, Township Facilities and events address accessibility and accommodation concerns.

Requirements: Bachelor’s degree in social sciences, human resource management, business administration or related field and two years of personnel administration experience are required (or a combination of education and/or training and/or experience which provides an equivalent background required to perform the work of the class); a minimum of eighteen (18) months of experience in a position that involved evaluating and administering reasonable accommodation issues subject to the ADA or §504 and completion of a course on barrier-free design or ADA accessibility guidelines which was sponsored or approved by the New Jersey Department of Community Affairs or a department which oversees the Uniform Construction Code in any other State, the American Institute of Architects, the Paralyzed Veterans Association, or the United Spinal Association, within twelve (12) months of hire.

Salary: DOQ

Hours: Part-Time, three days weekly (not to exceed twenty one hours per week).

Apply: Send resume or application to: Ms. Braedon Gregory, HRIS Coordinator, Human Resources Department, Township of Montclair, 205 Claremont Avenue, Montclair, New Jersey 07042 or email: bgregory@montclairnjusa.org

Closing Date: Job posting will remain open until position is filled.

The REV UP Campaign aims to increase the political power of the disability community while also engaging candidates and the media on disability issues.

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That Feeling You Get When …

YOU'RE FINALLY RECOVERED ENOUGH TO WASH YOUR FACE AND HAIR AND SIT UP IN YOUR WHEELCHAIR.

Ben Tansley posted this photo to Instagram on Sept. 11, happy that he's progressed enough at Addenbrooke's Hospital, located in Cambridge, United Kingdom, to be able to sit in a wheelchair for the first time. He has a T4 injury after a motorbike accident in August. His user name is tano_hg if you want to follow his journey on Instagram, and maybe offer him some encouragement.

YOU FIND OUT YOUR FRIEND AND FELLOW-WHEELCHAIR USER HAS BEEN RESCUED FROM HURRICANE HARVEY-RELATED FLOODING.

In the midst of the terrible news coming out of Texas in the wake of Hurricane Harvey, NMD United’s Emily Wolinsky was relieved to be able to post this photo of Angela Wrigglesworth being rescued with her power chair, partner and pet dog. The most dramatic rescue of a wheelchair user is probably the one seen in the widely-spread image of a Coast Guardsman hoisting up a wheelchair into a helicopter, where its owner is already on board.

YOU APPRECIATE THE EFFORT PUT INTO ACCESSIBILITY YET THINK THERE’S ROOM FOR IMPROVEMENT.

Tim Vermande set off resounding rounds of “doh!” when he posted this head-scratcher to his Facebook page on Aug. 27. Vermande, a communications specialist for disability concerns within the Methodist church, found the photo while looking for portable ramp set-up ideas, and was able to track it back to the blog, disabledaccessdenied.wordpress.com. Meanwhile, Vermande’s friends had a lot of fun with the pic. This was our favorite comment:

Jasen Taylor: “Mom! Dad! I got a job!”

“What’s that, son?”

“I move a Keep Clear sign out of the way whenever someone in a wheelchair needs to use the ramp!”

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