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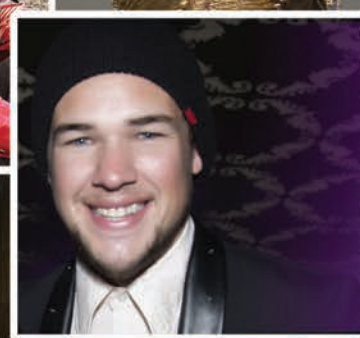
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CHINA'S Boxer w/ CP

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Whew, I have been super busy with my Ashley Fiolek MX School. I wasn't sure if I wanted to teach at first, but it's been fantastic. I also find it inspirational to work with so many different people who, like me, are excited to ride.

My friend, Ryan, and I decided to load up my truck with our dirt bikes and my dog, Bambi, and head to Florida to ride, teach classes, and visit my family. It was a crazy trip because we wanted to drive nonstop. With three bikes and a pooch, it would have been hard to get everything unloaded; into a hotel room for the night; and then reloaded back on the truck the next morning. So, Ryan and I took turns driving, while the other rested.

As you can imagine, we got pretty silly along the way, taking Snapchat pics of each other sleeping. My parents kept texting us to take breaks, but we pushed it! We made it to Florida in about 36 hours—not too shabby—even though we had to keep stopping here and there to let Bambi out to handle her business.

Once we were back in the Sunshine state, Ryan and I rode at a couple of tracks near my home. We also went over to Croom Motorcycle Area at Withlacoochee State Forest. It's so much fun there, with miles and miles of forest; you can ride through it and encounter all different kinds of obstacles, which makes it a cool challenge. We even took a little break from the bikes, and met my mom and brother down at a Disney water park.

So after our mini vacation, Ryan flew back home, and my friends Kate and Ashley J. arrived to help with the drive back to California. They also assisted with my MX clinics along the way. I had six of them in different states: Georgia, Alabama, Louisiana, Oklahoma, Texas and Colorado! That's a lot of road tripping!

Of course there were some funny things that happened along the way. When I was doing my class in Louisiana, Kate, went into the portable toilet. It was an unforgettable experience for her. Apparently, she thought her phone had fallen in, so she panicked, and wound up falling into the toilet herself! I could hear her screaming to Ashley while I was teaching my class:

"Where is some water? I need to wash off *NOW*!" she yelled. Now she's scarred for life!

Late one night, Ashley and I were driving to Colorado, we were starving and had no wifi signal to search for a restaurant. When we'd almost given up on finding food, we came up on a Sonic. We ate and continued on, but then had to stop for gas.

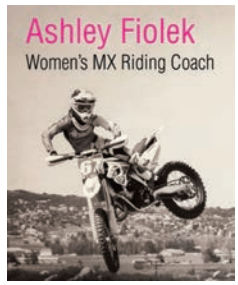
I opened up my door to get out, when a can of soda fell out and exploded all over my legs! I turned to look at Ashley, who was busy scouring the truck for something.

"Oh no, where's my credit card?" she said. That's when we realized that we'd left it at the Sonic, and had to trek all the way back. Luckily the guy who waited on us had the card.

That morning we made it to our hotel and got a few hours sleep before my class. We were headed to the track when we got a flat. When I contacted AAA, they came out but didn't have the right tool, so they had to tow me to a shop. The man who put on my new tire asked my name and why I was in town. " Oh yeah, I know who you are," he told me, "my son is taking your class this morning!" Talk about a small world!

The whole trip was crazy and wonderful and an amazing way to spend a summer month! ■ ABILITY

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The interaction of human beings has always fascinated me. It's funny to watch the reactions of some people when they meet someone who's disabled. Most of the time, people are normal, but there's always a few that seem a little uneasy. Sometimes, it's hard to get direct eye contact from them. Maybe they think, "I better not get too close, I might catch what he's got." Some are afraid if they asked a question, the person with a disability would answer in grunts and hand gestures while they stood there, dumbfounded, trying to figure out what the other person is saying. "Is this what you want? A bottle of water? A tissue? A chicken?"

There have been times where people feel pity for the person who is disabled. They talk to them in a soft whisper, "You'll be okay. God loves you." I'm glad folks tell me that. Who would've ever thought that God could love the disabled people of the world? I thought He only liked the lepers and the chubby lady who sings in church. I've had religious believers come up and pray over me. They've even tried to stand me up for a miraculous healing. When it doesn't work, they claim my faith is weak. I disagree. I tell them I had the utmost faith that this "healing" wasn't going to work. They don't bother me. Bless their little hearts for caring. Besides, a guy like me can use all the prayers he can get.

I've noticed some people are scared to talk to the person who is disabled. Maybe they just don't know what to say. Maybe they're afraid they might offend the person. Maybe they think the person will blurt out something and spray slobber on them. I don't know. It's tough to say. Everybody's different. One time I was on a date in a restaurant and the waitress took the order from my date, and then, without looking at me, asked her, "And what would he like?" My dating companion huffed, "I don't know. Why don't you ask him?" So she turned to me and politely asked, "And what can I get you?" I blurted a series of babbling moans and groans as drool dripped down my face. I know… it was wrong, but I just wanted to make a point.

On the flip side, there are those folks who won't stop talking to you. Many times I've gone out to a bar to enjoy a beer and, I don't know what is, but the wheelchair attracts the drunkest guy in the room. He staggers over and usually starts out with a "wannabe funny line," referring to my wheelchair, something like, "What kind of mileage does that thing get?" Before I can give him that fake, insincere, forced chuckle, the lush is cracking up at his own joke and telling his friends what he just said. Then he has to rephrase it to me several times to make sure I get it. "Do you get better mileage in the city? When's the last time you had it in for a check-up? You know you should take it in every 10,000 miles." Yes, he's laughing after each line. No, I'm not laughing. I've heard the routine over a hundred times. It's lost its

punch. And no, I don't get better mileage in the city. I can tolerate these intoxicated buffoons. They usually feel sorry for me and buy my drinks. Who's complaining?

Sometimes, people approach me and I guess they want to feel empathetic.

"I know what you're going through," they'll say, "I had to spend some time in one of those wheelchairs."

"Oh really," I reply, "What happened to you?"

"Well, I had pretty bad infected ingrown toenail and was laid up for almost a week."

I sympathetically nod, "Well it must've been hell on ya, buddy. Damn, I only broke my neck." At least I can get a pedicure.

The old ladies are sweet. I think they feel the pain of the disabled. Whenever I talk to one, they pat me on the head like a dog. I usually jump out of my chair and start humping their leg. Maybe we don't threaten them. They probably figure they could kick our ass if we tried to steal their money. When you're in a wheelchair, people tend to park you around the one person who nobody wants to talk to; the gabby grandmother, the drunken uncle, or the annoying neighbor who always stops by unannounced. I guess the thinking is, "well, if you're just going to be sitting there, you entertain the misfits." Maybe the thought is that the disabled guy is lonely and this will be a treat for him. Yes, I am lonely, but no one ever parks me in front of the stripper. I get Uncle Ted telling me about government conspiracies and how the aliens scan us with blue ultraviolet light beams.

People react differently to a disabled person. Some are cold. Some are warm. Some will ignore the person. Some will go out of their way to do everything they can for the other person. "Can I get you anything? Do you need me to push you anywhere? How about a nice neck massage?" These folks are kind and wonderful. They help me to get back to my lazy roots where I'm most comfortable. I try not to take advantage of them, but let's face it, who can turn down a neck massage? If I can help you to feel better about yourself, I'm there. We're a team. Your hands and my neck. Sometimes folks want to be so helpful that they'll come up and push my wheelchair up a hill and into a building. I appreciate their efforts. I never have the guts to tell them that I was going to go into the building across the street. So now, I have a longer wheel.

Others can be overly cautious. These apprehensive individuals are not exactly sure what to do. Should they offer you any assistance? Will they insult you if they ask if they can assist you? Is the word "assist" even okay to use? I have a lot of sympathy for these individuals. They certainly mean well. They want to do well, but I'm sure in the back of their minds they have a scary vision of some overly sensitive, irate, uppity disabled dude snapping, "Keep your grubby hands off of me! I can do it myself!!" Sadly, there are some of those "pissed-at-the-world" people out there. But my advice is, it never hurts to ask. Remember, if it comes to a "throw down" you got the upper hand. Just make sure to always try and get positioned behind the wheelchair. It's where they're most vulnerable to choke hold.

Sometimes people just don't know how they should act around a disabled person. It's understandable. We're odd creatures. There was this one time when I came out of a Starbucks and I was just sitting there, enjoying the sun beating on my face, when a man walked by me and put a five dollar bill in my cup and said, "Keep your chin up, big guy." I didn't realize how pathetic I looked (I've got to learn to match my shirt with my pants.) Giving me money? How rude. I was flabbergasted, so I stayed out there the rest of the day and made two hundred bucks. Luckily, nobody asked me to sing a Blues song. All in all, it was a good payday.

Often times, people will view me as non-threatening, which means that I'm somebody they can open up to. They spill their life problems on me like I'm the "shrink on wheels." Don't get me wrong, I like a good juicy story, but I don't really need to know that your husband dresses up in woman's attire. I just can't help you on that one—although you should take pictures for divorce court. I'm not licensed to give professional advice, but I typically do for my own enjoyment. But please remember, I have no power to absolve you from any sins. They usually tell me that I'm really easy to talk to—and I haven't said a word. I'm trapped listening to their problems. A lot of times you can get away with quick sentences like, "I feel your pain, dawg." Or, I'll huff, "Men are so clueless." My favorite is, "You go, girl." I haven't ruled out the possibility that it could also be the wheelchair. They understand I can't escape quickly from their boring stories, so they know they have a captive audience. I'm always like, "Excuse me, I gotta go… Ummm… sheer the sheep… out in the barn… cause I was supposed to do that yesterday… or the sheep get mad at me and then… I have to… get the mileage checked on my wheelchair…. But you'll be okay I promise… you go girl."

You never know how an individual will react to the disabled. There have been times where people have yelled at me, called me names, and even spat on me—which is why I don't spend Christmas with the family anymore. I joke. Hey, you're alright. If there is an upside to being disabled, it is that I do see a lot of good in people. Many are kind, caring, folks offering assistance to me if I need it. Do I take advantage of that? You bet your sweet boots I do. I'm just in a wheelchair, not stupid… actually, not completely stupid. I deserve a break every now and then. Look at some of the people who I've had to put up with. ■ ABILITY



by Jeff Charlebois



My sweet kitty, Harry, is in process of transitioning with cancer. By the time you read this, he'll likely have crossed over to the other side, free of pain and suffering, and onto cavorting with all my other kitties who have crossed over during my lifetime—far too many to mention here.

No matter how many times I go through the pain of losing a fur baby, however, I know I'll do it again. Not because it gets easier, but because of the unconditional love and joy that pets bring into my life.

For as long as I can remember, I have dealt with losing these four-footed friends who have become a part of the family. When I was a kid, these pets were my best friends, and as an adult they're my children.

Very rarely do our pets outlive us. In fact, a friend of mine suggested that I consider getting a parrot next time, given that they have long lifespans—longer than most humans. For some people, that may be an option, but I've never bonded with a bird, with the exception of a parakeet named Pepe, and also Big Bird.

For those of you who have never had a pet, it might be a little difficult for you to relate to "bonding" with them. But it's no different than bonding with another human. Love is love, and for the sake of love itself, I've cherished every moment that I've been graced with Harry's presence.

I adopted him when he was 10, and knew that there was the possibility that he might acquire health issues. But from the minute I brought him home, I fell hard for this adorable love bug. He was already an adult when I got him, so all the toys that we'd buy to amuse a kitten were of no interest to him. (With the exception of a red light pen; he chased that beam all over the place!) So, without the diversion of toys and with his lack of interest in catnip, we became close even more quickly than I ever bonded to a new kitten.

Harry made up his mind within the first day that I was his new Mommy. From that initial night, he slept with me under the blankets, and I felt as if I'd known him forever. I believe we had been together in many lifetimes before. It's entirely possible, given that cats have nine lives.

After a mere three months, he developed his first health issue, supposedly after he ate a spider, and it poisoned him. He was inconsolable, cross eyed, and kept losing his balance. I remember the vet telling me, that this was possibly neurological damage, and that even if he lived, Harry might be like this for the rest of his life.

In a kind of numbed shock, I said, "So what you're telling me is that I may have a cat with cerebral palsy now? Then I said, "Well, the doctors told my parents the same thing about me, and they didn't put me down."

At that point Harry was transferred to intensive care and on an IV for three days. I rang the doorbell of the hospital on this third night at about 11, and asked if I could see Harry. A little reluctantly, they let me in to be with him.

He recognized me immediately, even though he was still cross eyed, and kept falling down when he stood up. I sang to him and told him I loved him, and that whatever his fate, I would support him. But he also needed to know that extended hospitalization was expensive, and that my employment was sporadic. I prayed for all my spirit guides and fur babies on the other side to help him with whatever his little soul chose to do.

The next morning the hospital called to tell me that I could pick up Harry, and that his maladies had all disappeared! That was almost three years ago! I feel so blessed that I didn't lose him then, and since then we've thoroughly enjoyed our time together.

Now as he struggles with cancer, we both know that our days together are coming to a close. As painful as it is, however, we trust that we'll see each other again.

"Harry Houdini" will escape from cancer, but he has no desire to escape from love. He'll live forever in my heart. And yes, my furry son, I would do it all again. Thank you, my sweet loving Harry, for spending one of your lives with me! ■ ABILITY

by Geri Jewell

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CHINA'S FIRST PROFESSIONAL BOXER WITH CEREBRAL PALSY

Born in 1985 in Tianjin, China, Wang Qiang is China's first and only professional boxer with cerebral palsy (CP). His life, he says, began in the boxing ring with days of rigorous training, competitions, and a multitude of seemingly insurmountable challenges. Although it took years to achieve, his dream of being a great Chinese boxer was finally realized when he participated in his first international and national professional boxing tournaments.

On September 13, 2014, Wang Qiang jumped into the ring to participate in a match on "Gladiator Night" at the

Fourth International Boxing Tournament in Shangai. After Wang Qiang's name was announced, he faced the audience and showed several quick boxing moves. The audience roared, cheering him on.

As a bright yellow light lit the ring, the two boxers engaged in three long, fierce rounds. It was an evening in which the sport of boxing was vividly on display: waves of cheering fans surrounded the boxers, who showed amazing physical strength, their body's glistening with sweat and the unpredictable urge to fight.

Although Wang Qiang lost the match, the winner reached out to give him a big hug at the end. Wang Qiang was excited and raised both hands high in victory, as if he'd won the match. He kept repeating, "I'm ok. I'm ok." It was a legitimizing moment for the 29-year-old boxer.

Wang Qiang had waited nearly 17 years for this experience: his first opportunity to participate in an international professional boxing match. This was also the moment he became the world's first professional boxer with CP.

A Long Road to the Boxing Ring

Wang Qiang had been born prematurely and suffered from multiple illnesses early in his life: a cerebral hemorrhage, an intestinal obstruction, and bouts of jaundice and pneumonia. He was six years old before he could stand, walk, or speak.

His childhood was difficult, to say the least. He suffered at the hands of bullies, who called him names, chased and mistreated him. In an effort to protect him and improve his physical strength, his father, a part-time boxing coach in the Tianjin Armed Police Corps, introduced him to boxing when he was 12.

Despite the strenuous training, Wang Qiang was determined to become a great champion. Gradually, his body became more flexible; he learned to ride a bike and do housework. During his spare time, he organized a blog called "Patients" for people like himself who had physical challenges. He also volunteered as a boxing coach for a local, special-needs school.

But he remained deeply frustrated because no professional boxers wanted to fight a boxer with a disability. Since the Paralympics didn't have a boxing category, Wang Qiang could only participate in amateur matches with able-bodied boxers. But each time he registered for an amateur match, his disappointment deepened. Although he signed many waivers, the organizers believed he was not suited to fight because he had CP.

Instead, coaches invited him to help train other boxers, but this was unsatisfying to him. His mother, in particular, felt sorry for him. "My son is very naïve," she said. "He has nose bleeds after sparring."



But his dream proved more resilient than his physical limitations. Wang Qiang was determined to face his challenges no matter what; boxing, he believed, was his fate. He simply had to continue pursuing his dream.

In 2006, when he was 21 and had developed excellent boxing techniques, he was officially hired as a coach for the Tianjin Elong Boxing Team. With his father's help in 2007, he opened a boxing club after he graduated from a vocational school. Two years later, after his club became well known, he challenged the Olympic boxing champion Zou Shiming online.

Zou Shiming refused to fight Wang Qiang, but did invite him to attend the First National Boxing Tournament match. The Olympic champion spoke encouragingly to the young boxer: "Brother Wang, you're strong and brave. You inspire me! I believe we are boxing athletes with strong fists who will lead great lives!"

A National Win

In early 2014, the famous Chinese boxing coach Han Hongqiang was so impressed by Wang Qiang's story that he decided to make an exception and coach the boxer without pay. Finally, Wang Qiang was close to reaching his dream. On December 21, 2014, Wang Qiang participated in his first National Boxing Association match. Before the match, audience members chatted eagerly about him. He felt content and full of hope. After winning the match, he became China's first 124-pound champion with a disability. His dream, he said, finally became a reality. ■ ABILITY

by Feng Huan

This story is part of a series of articles published as an exclusive editorial exchange between *China Press for People with Disabilities & Spring Breeze* and *ABILITY Magazine*.

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Spring Breeze
A monthly magazine focusing on social and humanitarian issues



China Press for People with Disabilities
A monthly resource for individuals and their caregivers



The Journal for the Blind
A trusted source for the blind, distributed monthly

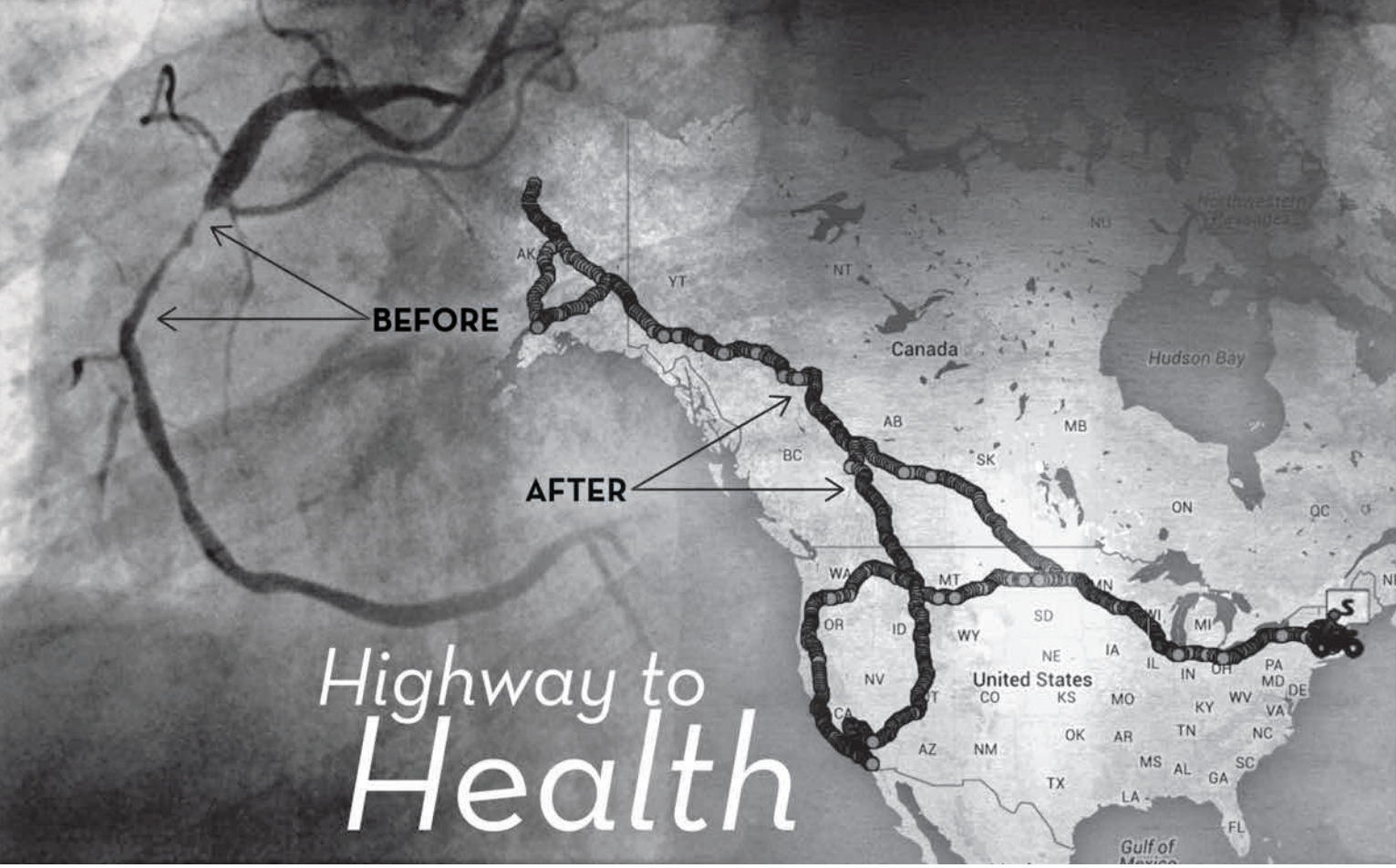


数据库查询

China's Largest Disability Publisher and Website



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悦读
公益行动
摄影人手记
文化季风
绿色通道
记者行动
博客
人道观察
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Highway to Health

It was a simple text, yet it was the start of a life-changing experience. "*Hey Paul, do you want to speak in Anchorage or Fairbanks?"*

I'd been receiving invitations to speak at events in California as part of a West Coast tour this past June, but riding my bike to Alaska had been on my must-do list for over a decade. It remained the only state on the continent I had not visited by motorcycle. It was hard to believe the message was real. I kept dreading the call saying that riding my motorcycle 4500 miles from my home in New Hampshire to Anchorage was not approved, but the call never came and my *Wheels Out West for MS Tour* now included Alaska!

I had two months to prepare for this once-in-a-lifetime adventure, and I was equally excited to be sharing my story with hundreds of people living with multiple sclerosis (MS) in eight different cities over the three-week period. I had five days to make the trek to Anchorage, then six days to find Las Vegas. From there, I would visit the Southern California cities of Escondido and Beverly Hills. The following week I would head north, visiting San Luis Obispo, Visalia, and San Francisco, and then up to Eugene, Oregon before heading home.

I spent many hours planning my routes and making sure my Yamaha and all my gear were up to the challenge. After all, just the base route alone was about 13,500 miles and that was a lot of miles for one month—*even for me!* I turned the event into a fundraiser and had people try to guess my final miles for the month of June.

I try very hard not to think about how MS can foil my plans, whether they are just to walk around the block or ride across the continent.

The surprise wrench in my travel plans, however, was not MS related and really caught me off guard. A mild chest pain I had been experiencing for about a week would normally have been ignored, but realizing I would be riding in some very remote areas without services, or even the ability to call for help, gave me reason for concern. Realizing the pain seemed to happen more often during strenuous activity finally sent me to my primary care physician one week before I was supposed to leave on my monumental adventure.

I've never had heart issues or very high cholesterol. I eat well and work out regularly. I'm not overweight, and I don't smoke, but I do have a family history on both sides of cardiac disease. An echocardiogram showed some abnormalities, and a stress test was ordered. I wasn't in cardiac arrest, so I was sent home with the instructions, "If it gets worse or happens more often, get yourself to an emergency room right away." My health insurance company authorized a test scheduled for the following Wednesday, the day before I was supposed to leave for Anchorage. I explained that I needed to find out what was going on sooner, so it could be taken care of because I was not canceling my trip. While my insurance company hemmed and hawed, I came up with my own plan.

On Sunday, five days before I needed to be on the road







to make the Anchorage event, I mowed the lawn, packed my bike, swapped my tires, and showed my wife Elin where all the cash was hidden. I then explained to her that I was going to INDUCE myself by running up and down the stairs, and that after my chest pain materialized she should drive me to the emergency room. I calmly explained to her that they would have to admit me, do the stress test on Monday, fix me on Tuesday, and release me on Wednesday, just in time to start my trip to Alaska. My wife is an amazing woman and probably wanted to rip my heart out and beat me over the head with it at this point, but reluctantly she followed along.

The plan worked flawlessly. I experienced the chest pain, she drove me in, and I spent my first night since my birth in a hospital. I failed the stress test the next day and needed to undergo a catheterization to determine which artery was clogged, and how they would go about fixing it. I was scheduled for Tuesday morning. My only concern remained, "Will I be able to go to Alaska on Thursday?" I was told flat out "No" and "Probably not" by everyone in a white coat, but I remained confident I would still be able to hit the road. I was about to embark on the trip of a lifetime, and I wasn't going to let anything keep me from going, so when I asked the lady bringing my lunch if I should take a trip to Alaska, and she said "why not", I counted that in my favor. For the three days I spent in the cardiac ward, I tried not to think of the work that went into organizing the tour for me, or the repercussions of having to cancel it. I was sure I might never be asked to speak again, and I would never get the chance to ride to Alaska. Canceling my trip was just not an option I could think about. Even if I had to zip-tie an IV pole to my motorcycle, nothing was going to stop me!

Tuesday morning, while they were wheeling me down the hall for the procedure, I joked that they better not remove the wrong leg. A doctor passing us laughed quite loudly. "The wrong leg, now that's funny," he said.

Moments later, I officially met my cardiologist, Dr. Fink, for the first time. The procedure was mere minutes, but they found my right coronary artery was 99 percent blocked. Two stents were inserted end to end to open up the vessel and restore blood flow to my heart.

When Dr. Fink stopped in later that afternoon to check on me, I asked how soon I would be able to travel, as I was supposed to leave for Alaska in two days. He said if I did not have any complications or issues in the next couple of days, he saw no reason I could not travel. "Take it easy, no driving for 48 hours, no heavy lifting for a couple of days," and as he was walking out he added, "Your stents won't be detected in those metal detectors either. Enjoy your flight."

They do say riding a motorcycle is the closest thing to flying, so..... ■ ABILITY

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Next issue: Part Two - Clogged Arteries to the Arctic Circle



High Concepts

Jenni-Juulia Wallinheimo-Heimonen

When I first speak with artist and activist Jenni-Juulia Walinheimo-Heimonen in her native Finland, she has a small admission to make: "When we set this up, I forgot it was my wedding anniversary!" When I suggest we reschedule, she says no, that she and her husband have already spent a lovely day together. Walinheimo-Heimonen is a busy mother of two, with an active career as a textile artist, who also makes edgy art videos, gives provocative public talks, and works with disability organizations. She's a powerful change agent who uses her art and activism to dismantle old paradigms about people with disabilities and to spotlight taboo subjects, such as the high rate of abuse women with disabilities face. She also has osteogenesis imperfecta (OI), commonly known as brittle bone disease, a congenital bone disorder characterized by fragile bones that are prone to fracture. Although Finland is revered as a "Nordic paradise" for its stellar educational system and universal health care coverage among other attributes, Walinheimo-Heimonen speaks openly about its rigid, one-size-fits-all approach to people with disabilities. During our conversation, she's articulate and impassioned, speaking rapidly at times, about her creative process, about how assistive technology should be more personalized, and about her efforts to change the attitudes that keep people with disabilities from full inclusion.

Paula Fitzgerald: You're a textile artist and an activist. How do these two intersect?

Jenni-Juulia Wallinheimo-Heimonen: In Finland I use the term "political disability art", but I'm not at all political in the traditional way. My art does not represent any political party or political trend; it's about human rights. Nowadays, I'm also making videos and giving performative speeches and doing more conceptual art. I like to create new terms in the disability field. In small countries, such as Finland, it's quite easy to get new terms accepted among people with disabilities. I work with several disability organizations, so I have many opportunities to share these new terms. Happily, I've noticed that people use them. It's kind of an art game.

Fitzgerald: You say it's easy to get people with disabilities in Finland to adopt new vocabulary. Why? And what are some of the new terms you've introduced?

Wallinheimo-Heimonen: I think it's largely because of the size of our country. We have only five million people, and there are several large disability associations, and most people with a disability belong to at least one of them. The field of persons with disabilities is quite small here. We all know each other. We know who's active in the organizations. When you give speeches, other people adopt your words, your sentences, and so on. I also think this is a way to do the art, because it's very important what kind of words you use when you talk about disability.

And this is the tragedy, that we are speaking English now, because I cannot play with words because my English is not that strong. But here, I'm always trying to find the positive words, the ones that demonstrate our potential, and not talking about long-term patient care, or this kind of traditional medical disability talk.

Fitzgerald: I know translation is tricky, but can you give me a few examples of terms you've created?

Wallinheimo-Heimonen: My best-known term is "kiltteysrasismi," which translates into "kindness-discrimination". I wrote about it in 2005, and I've recently seen it used even in some mainstream blogs and columns. With the term, I mean situations in which we are not given honest critical reviews because of our disability. Or, we are protected against alleged failure or embarrassment without getting a chance to try. Situations in which kind people, with protection in mind, actually deny us the opportunities to grow and develop. Kindness-discrimination makes it difficult for us to move forward in life or to work because we can't trust the feedback we get. People think they are doing us a favor with "kindness-discrimination", but it is a form of subjucation and pity wrapped in smiles and false praise. My latest term is "onion-explanations." These are answers we get when we demand our rights. We get several layers of explanations, which are often weepy and strange and do not tell the real reasons for denying us something.

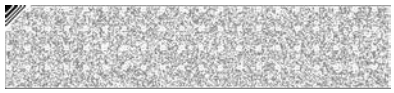
Fitzgerald: Those are insightful and right on! So how long have you been an artist?

Wallinheimo-Heimonen: I was born into an artistic family. My mother was a graphic designer, so I was making art even before studying art. I graduated with a degree in textile art in 2002 from Helsinki University of Industrial Arts, but I started almost immediately creating conceptual art. I was lucky in that 2003 was the European Year of Persons with Disabilities, so the European Union was supporting many projects by persons with disabilities from all around Europe. And in Finland we had a big project, which was a big gallery in the city center. We were given five-minutes on the morning news shows. We got a lot of attention from the public and the media, and the art world became more interested in what we were doing. I had just graduated, so I jumped into this field. It was kind of pioneering work back then, even though it was only 10 years ago.

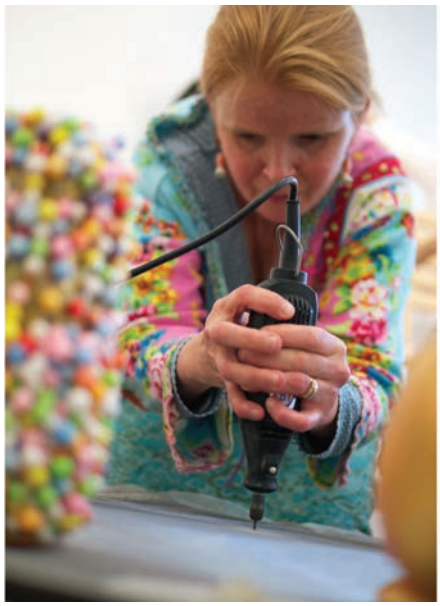
Fitzgerald: It sounds like the timing was just right for what you were doing.

Wallinheimo-Heimonen: Exactly. But when I read about what is happening in Great Britain or the US, you all started this in the '60s and '70s, so we're coming a bit late to the disability art world in Finland.

Fitzgerald: We still have a ways to go!









Wallinheimo-Heimonen: (*laughs*)

Fitzgerald: Tell me more about your family. Did you grow up in Helsinki?

Wallinheimo-Heimonen: Yes, I grew up in Helsinki. I now live 25 kilometers away. My mother was young, just 19, when I was born. My parents worked all the time, so we had a happy family life. Since my mom was a graphic designer, I would play under the light table in the '70s and '80s as she worked on a layout for a newspaper. I had all the materials and all kinds of colors to play with. That was really how I started. And then came computers, and all this paper and all that stuff was taken away, but I was also much older by then. My father was a car mechanic; he would bring us really nice stuff to play with, too. (*laughs*)

Fitzgerald: Did both of your parents have brittle bone disease?

Wallinheimo-Heimonen: My mother has brittle bone disease, and she's a second-generation. Her father had it, because we have some color photographs of him where you can see the blue sclerae in his eyes, and we also have his letters from all kinds of health spas—the places where you go to improve your health. They are really funny, because he wasn't diagnosed, he was just sent there to get fresh air and to get stronger. He would write to his parents, "I'm doing well, but my leg still hurts a bit." He was the first mutation, and then my grandfather had two kids, my mom and her brother. My mom inherited it, and then after my mom, both my sister and I have it. My sister has two children with OI, and both of my children have inherited it. The majority of my family—seven out of eight—were born with the condition.

Fitzgerald: It sounds like everyone lives a very full and active life, yes?

Wallinheimo-Heimonen: (*laughs*) Exactly, yes! My sister is a nurse, and my mother is still working. It has never stopped us from doing anything. We have been thinking we have some sort of OI spirit, which helps us to persevere. I didn't grow up with a model in which disability was about limitations. My mom told us, "Clean your room," and we did. That was the normal thing to do. I wasn't protected or told to avoid things because of my condition.

Fitzgerald: So you did everything other kids did, participating in school activities?

Wallinheimo-Heimonen: The only thing I didn't do was ice skate, which is popular here in the schools during wintertime, but I did everything else. I went swimming when others went ice skating. I cannot imagine doing anything different. I didn't need to use any assistive equipment. My condition didn't show so easily, only the teachers knew, and my schoolmates were told only to be careful with me and not to push. I love to do crafts and small things with my hands, so I wasn't very active. My sister had many more fractures than I did because she was the wild girl, and I was the calm one, sitting, sewing and painting. So I didn't break limbs so much as a child. But I think I'm now paying the price for that, because when you don't use your body so much, now that I'm getting older, I have broken some bones—stress fractures on the small part of my spine. This happens when you don't exercise enough. But my sister is much stronger now, because she was always taking better care of herself through therapy and gymnastics and these types of things. I never did. But I wasn't treated any differently.

Fitzgerald: Your mother sounds very smart in how she handled the condition with you and your sister.

Wallinheimo-Heimonen: She didn't have a choice. I also think that she was young and disabled, and she and my father didn't have much money, so we had to keep life going. Smart, yes, but it was also survival techniques.

Fitzgerald: You gave a thought-provoking talk on the topic of ugly for CreativeMornings, in which you

gradually removed all your beauty enhancements—your fake eyelashes, hair extensions, etc. Why this topic and approach?

Wallinheimo-Heimonen: The topic was actually given to me. All around the world, the topic of ugly was the theme for January. I was a bit surprised that they wanted a disability activist to talk about ugly, because I usually don't combine ugly and disability, so it was a really difficult topic. That's why I was trying to play with norms. Nowadays, so-called normality may be abnormal, like the beauty industry and wearing fake eyelashes, which I take off during my talk and used to show how difficult it is to be a person with a disability in this world because of these beauty ideals, where all the time you're supposed to try to look better. And I was playing this game, too, when I was younger. I believed that I should all the time be doing something to make myself look better.

Fitzgerald: How did you get past the body image issues that so many women deal with?

Wallinheimo-Heimonen: I was really thinking hard about this issue just this morning. It's funny that you're asking, because I was joking with my husband that nine years ago I almost cancelled our blind date, because I didn't like blind dates. I didn't have anything to wear, and I thought he's not going to accept me anyway; I don't look pretty enough and all that. And then I put on a corset from China, to make my pants fit better, which made me feel very uncomfortable during the date, and then this morning I thought, "Oh, my God, nine years later and I'm going through the same thing, talking about ugly and showing the public all these kinds of fake things."

Fitzgerald: This refusal to wear the mask and to the play the beauty game—what's this about for you personally?

Wallinheimo-Heimonen: I don't know if it's motherhood or age. It's as if I don't want to play this game if I'm talking about disability issues. I cannot play the beauty ideals game where the beauty belongs only to people with perfect health or perfect looks. I don't know how it happened or what happened to me. I was accepting of myself, maybe, but that sounds so cliché. I just realized that nothing bad happens if you do your grocery shopping just as you are in the morning. I just decided that I can do it, because as a person with a disability I have done even worse things, if I think about the medical procedures and all these kinds of really ugly things. Why do we think that it's ugly to wash away our makeup?

I was also playing with my own courage. I can do it, and nothing bad happens. Actually, only good things happened. (*laughs*)

Fitzgerald: Do you think having a disability made you less inhibited?

Wallinheimo-Heimonen: Kind of, yeah.

Fitzgerald: In the talk, you share that both of your children inherited brittle bone disease and that you were secretly happy about that. Could you elaborate?

Wallinheimo-Heimonen: I was hoping that maybe if we had kids, I would know what to do if they had brittle bones. I know how to read and play and draw and work with computers—all the arts and crafts things. This feels safe to me. And a kid with normal bones feels a bit unsafe. Even if they don't break bones. This is really difficult to explain, but I was talking with a mother who is blind, as is her husband, and she also said that maybe it would be easier to have a child who is blind rather than one who is fully sighted, because then you would share the same world.

Fitzgerald: That makes sense. It's the world that you know, so you don't have to worry about them hurting themselves or doing something dangerous.

Wallinheimo-Heimonen: There are people who've asked me, does that mean I want my kids to suffer? But I know that people with OI don't suffer all the time. It hurts when you get a fracture, of course, but there is good medication. The casts are lighter and more flexible than when I was a kid. Based on all the research, these kids study, live a normal life, and marry and have children. It is not the end of the world.

Just three weeks ago my son broke his leg for the first time, and today we went to the children's clinic in the morning, but they didn't take the cast off because it hadn't healed properly. He was disappointed. Okay, so we got some ice cream, and we had quite a good day around the city and all this celebration. I don't think he's suffering. He could have a much worse condition than brittle bones. I would think differently if it were something more serious. Brittle bone disease is not. But if you look at the Internet, you might think that this is the most terrible thing in the world, that you break your bones all the time. Yeah, you might, but you still live. (*laughs*)

Fitzgerald: You talked about an "ugly experience" you had with your doctor. You told him that you didn't want more children, and he suggested that if you wanted another child, he could screen an egg without the genetic mutation. Does this make you nervous about bioethics, the ability to screen out undesirable characteristics?

Wallinheimo-Heimonen: It makes me nervous because, for example, we have fewer and fewer people with Down's syndrome, which is easy to screen. Also, OI, the most severe types, which are Types III and IV, are almost disappearing because the characteristics are easy to see in an ultrasound. This is really tough. I'm not against prenatal screening, but I think it's not fair that when doctors find something "abnormal" or not right, they give you a huge list to read about this condition, which is only from a medical viewpoint, and they don't

tell you anything about life with that condition. In Finland, we have this very light pressure to terminate these kinds of pregnancies. I find this very unfair, because I feel brittle bone disease is like a rare plant. I don't think there is just one type of human being. We should have variations, and why are rare diseases not accepted as just variations, like eye color? Why is it something that we should get rid of? I think it's important to have people with disabilities, because most able-bodied people will join us later in life, when it's much more common to become disabled. Those of us born with a disability can give others courage and teach them about our culture. We can be very empowering to help them survive. But I think the world wants it the other way around, in order to save money, that we shouldn't exist, and that it's acceptable only if you become disabled later in life.

I think the information given to parents is not right. It's not right that the doctors are telling about disability, because it's not about a medical problem, it's about participation and how the society is working, about education, and about financial things. It's not at all about, "am I breaking a bone or not?" I have to speak a bit about this Finnish system. In many places around the world, in the global South, they think this is a Nordic paradise where everybody is taken care of, because we still have some sort of welfare, which is not at all as good as it used to be when I was a child.

Fitzgerald: Yes, I've read that Finland has a good public healthcare system. But you're saying it's not as good as what's reported?

Wallinheimo-Heimonen: We have benefits for people with disabilities. But you can barely live. You get enough money for food, but you're going to be poor the rest of your life if you're only living off these benefits. You get your assistive equipment for free. The healthcare is quite cheap. We have free education. We have all these good things, but it's all based on this medical view that we have to all of the time report everything about our bodies and apply these services, and then the parliament, the politicians and the social workers decide how we should live, how they can save money so they don't have to give us individual services. They don't allow us to choose anything, because then it gets too expensive. So they want to solve this disability issue and decide what is good and what is not for us.

This is what I'm fighting against. Of course, I like that it's not very expensive to be a disabled person who requires treatment, but it is not fair that we're treated like paper doll cut-outs from real society and given special services that are inflexible with a normal life.

Fitzgerald: Is public transportation one of the big issues for people with disabilities in Finland?

Wallinheimo-Heimonen: It's still a very big issue in Helsinki. Finland hasn't ratified the UN Convention. We've signed it. But public transportation during the winter is not accessible. The subways are accessible, yes, but there's still lots of trams and buses where you cannot get on because they're not accessible. If you need to move around, you only get 18 drives per month, which means nine times somewhere to and fro. If, for example, you go to the grocery store twice a week, then you have only one more per month. If you want to visit a friend or your mother or go to a library, it's quite difficult to manage. The funny part is, I can drive a car, and I have a car, so I also get the 18 taxi drives per month, but I cannot give them to anyone else because I have a car. So I don't even need those taxi trips, but we all get things equally.

Fitzgerald: So you're able to drive?

Wallinheimo-Heimonen: Yes, I drive, because we are not living in Helsinki, so we have to drive.

Fitzgerald: You mentioned the subway is fairly accessible for people with disabilities. How well is that working?

Wallinheimo-Heimonen: It's working quite well. But I've heard from people who are blind that the platforms were not designed with the visually impaired in mind. Also, only a part of buses and trams are accessible. Last week we had a very successful demonstration against our national railway system. Last year they bought 24 new restaurant cabins for long-distance trains, and they initially said that they would be accessible, but they were not at all. There is one accessible door, but there is a handrail that you can't get past in an electric wheelchair. Simple changes such as the removal of this one handrail would help, but after a year of negotiations, the national railways still refuses to make the change. So we arranged to have a demonstration, and it was really funny. We had only seven people who tried to travel in a restaurant cabin from Helsinki to Tampere, which is only 150 kilometers away, but we couldn't even get in.

We were told that the only accessible door to the restaurant was closed because "it had some creaking sound," and the staff refused to make exceptions or even try to let us in. We were told that we were allowed to use only the wheelchair seats instead of going into the restaurant because "people must be able to move around in a restaurant cabin." The national railway imagines that they've solved the accessibility problem with a special permit, allowing the train staff to take food and alcoholic drinks to wheelchair seats in the train. As if we want to eat and drink alone in another cabin! This proposal shows their inability to see us as members of the community, friends, co-workers or family who want to eat and drink together with their travelling partners. We've been negotiating with the national railways about this handrail for one year. This is how I spend my free time. It's crazy, but it's so much fun.

Fitzgerald: So you have demonstrations often to spotlight issues?

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Wallinheimo-Heimonen: Well, we don't have them very often, but I like to participate when we have disability issues. Sometimes we have 20 to 50 people involved, like we did for our so-called "high-heel" demonstration, where we were marching so that Finland would ratify the Istanbul convention (to prevent and combat violence against women and domestic violence) and make shelters for women who are abused more accessible. We dressed in high heels or tied them to our clothes, chairs, crutches or wore them as jewelry. The ratification process got stuck again, but after the demonstration three more shelters improved accessibility. So now we have six accessible shelters for women who are abused in Finland, but none are in Helsinki, which is the capital.

Fitzgerald: A high-heel march—what a great concept. Do the demonstrations typically get media coverage?

Wallinheimo-Heimonen: It depends, usually not as much as last week. The train issue did because the law changed on the first of January of this year, saying that we should be able to get into every public place like everyone else. That's why we got the attention, and because they made a mistake by not letting us in. If they'd let us in, probably we wouldn't have received any media attention, because seven people traveling is not news. But because we were kicked off, it was.

When I talk to them about this issue, most people say "Who wants to go to a restaurant cabin? That food is not good. Why can't you eat in your own seats? You can ask the people working in the train to bring you a drink in the wheelchair seat." We were fighting against this because we don't want to sit in the wheelchair seats. We want to go to the restaurant with our friends and colleagues and families to enjoy ourselves like everyone else. But most people said they didn't understand why. "What is the problem?" This is the situation here, because these are First World problems. We are not beaten. The state is treating us like—how could I say? We're treated like stereotypical paper dolls; I don't know how what else to call it.

Fitzgerald: It's a deeper issue, what you're after. It's normalizing people with disability.

Wallinheimo-Heimonen: Full inclusion. This is the problem. These people don't understand inclusion, because they think that the problem is "us", that we have some pathological things in our bodies, and that's why it's kind of a law of nature. "You can't get everything because you can't walk", or "you can't get everything because you can't see, so it's not our problem, it's your problem".

Fitzgerald: Which makes your work all the more important. I wanted to find out more about your focus on domestically abused women with disabilities experience, which I've read is globally two to four times higher than for women without disabilities. What is Finland doing about it?





Wallinheimo-Heimonen: Yes, we brought up this topic in 2013 when the women's working group in the Finnish Association of People with Mobility Disabilities thought about violence towards women with disabilities. It's considered a taboo subject. People think that we are protected against abuse, which is absolutely not true. According to Canadian researchers, the number is two to four times more likely. We have done only one research study in Finland, and I think only about 25 women participated, and it was done by a university, and they found that it's 10 times more likely in Finland.

Finland is one of the leading countries in domestic violence. We have lots of the European Union and other committees that have given Finland feedback that it's not doing enough to protect women against domestic violence. So it's a big issue here, but Finland is not actively doing anything about it. I think it's about the darkness, the alcohol and other terrible things. I want to bring this out in the open, because when I'm talking with people, they always think that this doesn't affect women with disabilities. They don't see us as women. They don't consider that someone would hurt a disabled person. That sounds crazy.

We have a brand-new women's hotline that opened. The line is open Monday through Friday, from 4-8 pm and on the weekends from 12-4 pm. We still have a lot to do here.

Fitzgerald: Many of the issues you've talked about are critically important social issues. Have you ever thought about going into politics?

Wallinheimo-Heimonen: (*laughs*) No, no, no. I'm an artist. The problem is that if I were to go into politics, I wouldn't be able to tell a story about a specific disabled woman's experiences in a subjective, emotional and critical way. I would be just talking this political talk. As an artist, I can go to their side, and I can tell stories, which doesn't matter in the world of big politics, but does really matter to many people with disabilities, and I can get people to listen. I can get the stories out of real people.

Fitzgerald: Yes, there's tremendous power in storytelling.

Wallinheimo-Heimonen: I have to hide the names sometimes, and I'm combining several women's stories together—they don't want to be identified. This is a small country. But no, never do I want to be in politics!

Fitzgerald: I understand. Can you talk about your art process and what inspires you? I know you have a studio.

Wallinheimo-Heimonen: I have a funny process. There are always times when I don't work on my art and instead work in disability associations for a few months, because I get the best inspirations when we are sitting around the coffee table and I'm witnessing the current issues. What's happening in disability advocacy right now? What is it about? I have this funny waking up in the middle of the night when I see weird things, so I write them down. Nowadays, I'm interviewing and videotaping people about their art pieces. In the beginning, I was writing their stories myself, but now I'm asking more and more people to speak in their own words.

Fitzgerald: And they're all people with disabilities?

Wallinheimo-Heimonen: Yes, people with disabilities. I think that disability art has to be done by a disabled person. It should tell about our life stories. The thing is that now, with two kids, I usually wake up quite early, and

we have time with my husband. But usually I'm sneaking out before my kids wake up, so then he takes the morning shift, gets them dressed and takes them to kindergarten and day care, and then I stop work around 2:00 or 3:00 in the afternoon, so the kids only have, like five or six hours in school or daycare. And then my husband works late in the evening. So I become a full-time mother, usually, in the afternoons.

Fitzgerald: It sounds like you have a nice balance between home and work.

Wallinheimo-Heimonen: Yes. But I have to thank my husband. It's just that we have different natural rhythms. I'm a morning person, and he can write till 2:00 am. I think I get my best ideas around 5:00 or 6:00 am. This year we have been extremely lucky. Finnish people typically don't like to talk about themselves, but I think I'm the first artist in Finland who's won a four-year grant for making political disability art. This is quite amazing, because I can spend time at home with the kids, who are just two and five. Right now, in 2015, I get a monthly salary to spend time with my friends who are disabled, planning their stories, going to demonstrations, making videotapes, and publishing. I think it's quite amazing, because the money is coming from the same state that I'm criticizing. But there have been artists with disabilities getting money in Finland, and I think for the first time the government really wants to support this type of art.

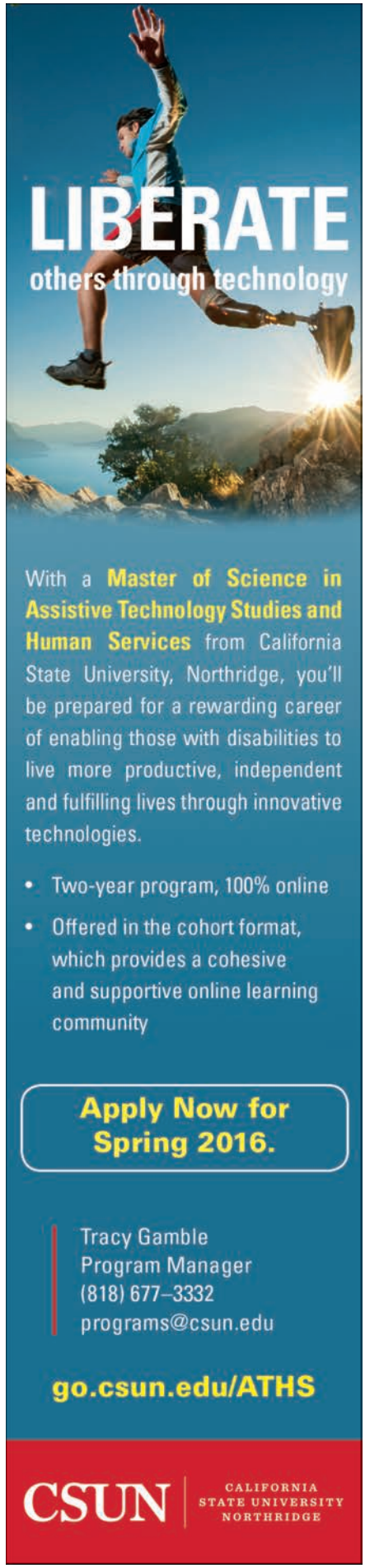
Fitzgerald: I want to ask you about your work with the Threshold Association, a human rights organization for people with disabilities. You mentioned that they did drawings of models with disabilities. Did you pose, draw or do both? And what was that like?

Wallinheimo-Heimonen: I did both. In the beginning it was kind of my idea that we should try live drawings of models with disabilities. I was working at the Threshold as a designer, and we have a volunteer who gives accessible art courses. We were talking that they should really do this, because we need more images of disabled people. Unfortunately, our first brave model passed away a few years ago. I drew her a few times, but I was also working, so I couldn't attend the course all the time. Then, when I was seven months pregnant with my son, we decided to offer the course at the CrossOver Festival, where most of the participants were without disabilities. We had a model booked, but she canceled at the last minute. We were in shock. What should we do? We had even advertised saying, "Now you can come here to draw a disabled body." (*laughs*)

People were staring at me as if to say, "It's your fault, so get undressed." And then I decided ok, I'm pregnant; I can hide behind my huge, pregnant stomach. So I posed. I'd studied life drawing in college, so I knew exactly what it was about. But I hadn't been on the other side before. It was empowering when, after 5 or 10 minutes, I forgot that people were staring at my body. It was fun. I'm not an exhibitionist; in fact, I'm very shy. I thought it would be just a once in a lifetime experience and nobody would ever know about it, but a local newspaper came by and shot a photo. A few days later, my husband's relatives called and asked what his wife was doing. (*laughs*)

Fitzgerald: Oh, how funny! But it sounds like it was therapeutic and rather self-affirming.

Wallinheimo-Heimonen: Yeah. I was also thinking that it strengthened my body image. Most of us have been visiting doctors and physical therapists that often stare at our bodies, criticize and measure them. I won't say that all women with disabilities have a negative body image, but many women







say they feel very uncomfortable. It varies. Some people think it's very uncomfortable to undress, and some people stop caring; they feel like their body is not connected to their mind or true self, so when they have to show their body to doctors, they hide inside their mind, and they don't even feel their bodies, so they're not present in that moment. So I was thinking that maybe for some women it's easier to pose as a model, because they have this trait. I do feel my body in that situation.

Fitzgerald: You're passionate about assistive technology. You've said that international conventions on human rights will never remove the low status of people with disabilities as revolutionarily as top design. What's your vision for how equipment of the future should look?

Wallinheimo-Heimonen: Have you seen Viktoria Modesta's music videos, and the posing she's done with her prostheses? She has some high-tech prostheses with crystals and music and all kinds of amazing features that can make non-disabled young girls envious of having such great legs to wear. I'm waiting for the day when disability enables you to have better features than other people. If we get assistive tools that help us do something better than a normal body part, it will raise interest in disability. We will become inspirational. For example, a person with prosthetic legs may be able to run through flames and save another person from a burning building, or maybe people with impaired hearing might have hearing aids with simultaneous translation capabilities. I could speak Finnish, and your hearing aid would translate everything for you.

Fitzgerald: Oh, I want one! That actually sounds like something everyone could use. It's futuristic, but I wouldn't be surprised if it's in the works.

Wallinheimo-Heimonen: Yes, these are still futuristic, but maybe in the future, we can have this kind of assistive equipment that makes us superheroes. Maybe soon our clothes will measure vital functions, send messages, protect against cold weather, etc. These things exist, but so far smart textiles and integrated computers are used more in art or in space clothing or for athletic wear. They are not yet available, at least not in Finland. You cannot get this kind of equipment from the state. I have a passion for searching for these innovations around the world on the Internet, but I don´t know how to get them here. It's a good thing that assistive equipment is free for us in Finland, but it has led to a situation in which we are left behind in terms of equipment development because municipalities and hospital districts don´t want to spend money on us. Equipment has to be cheap here because we don't pay for it ourselves. So there are no markets here.

Fitzgerald: Have you found companies that are doing anything close to these futuristic designs or, say, making incredibly beautiful ergonomic wheelchairs, for example?

Wallinheimo-Heimonen: There are so many. I don't have my list here. There's a lot of Japanese innovation, but I don't speak Japanese. They are working on electric wheelchairs, for example, and there are even more modern ones that you can adorn with lights and music, and they can talk to each other. Sophie de Oliveira

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Barata is one of my favorites. I think she's now the top prostheses maker. She makes them for people with disabilities or just for art. If you cannot wear prosthesis, then you can buy one and hang it on the wall. I think that's quite amazing when we're talking about assistive equipment, that it can be an art piece. I also think that 3D printing will change the field a lot. I'm really hopeful for that in Finland, because if we get free wheelchairs and crutches, maybe we can get 3D printers and create something personal and powerful. I think this possibility is very close.

Fitzgerald: So it would be like wearing a prosthetic leg that you've designed; it's a part of who you are and says something about your identity.

Wallinheimo-Heimonen: Yes, exactly. That is so important, that you could show who you are, and your ideology. Nowadays, you just have to accept what is given to you. You cannot just say, "I'm a green person. I want my wheelchair or crutches to be from recycled materials." You can't even say you don't want to have plastic or a certain material because it's against your beliefs. You just have to take what's available.

Or even the personalization that you should have something for women, something for men. OK, they always tell me that there are pink wheelchairs, but I don't need a pink wheelchair. I need, for example, a wheelchair designed for a mother. It's different. It's not about color. It's about how you carry the kid there, or how you push your trolley, or where you put your groceries or is there a place for the bottle?

Fitzgerald: Yes, you need equipment that's tailored to your specific needs. So what's next for you?

Wallinheimo-Heimonen: I'm super busy. My next exhibition will be in March with a disability poet, Sanni Purhonen, at the Klaukkala Library's Gallery Toivo. It's about violence against women with disabilities, and it's called "A Calf at a Glass Cabinet and Dependent Relationships." It's like a seven-course meal flavored with ignorance of gender, economic abuse, otherness in family services and refused assistance, mixed with tastes of physical, emotional and sexual abuse. After that, I'll be preparing for summer performances with a group of students with disabilities.

Fitzgerald: Sounds very interesting! You were a pleasure to speak with.

Wallinheimo-Heimonen: Thank you for saying it was a pleasure. I'm honored. ■ ABILITY

finnishdesigners.fi/portfolio/jenni_juulia.wallinheimo_heimonen
youtu.be/_3Toudui5Tc
http://youtu.be/Leebdl66ACQ

Temple Grandin

ON PREPPING PEOPLE WITH AUTISM FOR WORK



Temple Grandin, PhD, took the stage as the special guest of honor at a recent Los Angeles benefit for Autism Works Now. She's an extraordinary author, professor, animal expert and speaker. Also on the bill: actor Ed Asner, whose son and grandson have autism. A multi-Emmy award-winner, he works as a tireless advocate for people along the spectrum. The night also featured rocker James Durbin, who was diagnosed with Tourette and Asperger syndromes at a young age, and went on to compete on *American Idol*. Behind the scenes at the Temple Grandin and Friends event, several people with autism worked on the production. *ABILITY*'s Stan Hoskins caught up with Grandin and Jane Sparango, Publicist, amid the festivities.

Stan Hoskins: This is a wonderful evening.

Temple Grandin: It is. These students are all working in a real venue, not a classroom. They're getting to see how it feels to be professionals. I'm really concerned about people on the autism spectrum not getting into the workforce.

Last week I was at Fermi National Accelerator Laboratory, where you're gonna have people with Asperger's who are hi functioning and undiagnosed, while on the other end of the spectrum you've got people who can't dress themselves. People with autism tend to be good at one thing and bad at something else. There's too much emphasis on the deficit, and not enough on building up the thing that a person is good at. For me it was art. That became the basis of the work that I did in cattle-handling facilities. Designing is art.

Hoskins: Tell me about your formative years.

Grandin: I was lucky to get early educational intervention, because I had no speech until I was four. Also growing up in the '50s, social skills were taught in a much more rigid way, and not just to kids on the spectrum. You were taught table manners and "Please" and "Thank you." You learned how to take turns at games… That ended up helping me. A lot of smart kids today haven't been taught how to shake hands correctly; they don't know how to shop and don't have basic skills.

My mother had a really good sense of how to challenge me: When I was 13, she set up a little sewing job in the neighborhood. When I was 15, I cleaned horse stalls. I'd go out to my aunt's ranch and take people on trail rides. I waited tables. I'm seeing too many kids on the spectrum who graduate high school, maybe even college, but have never done a single job. Learning work skills needs to start way before they graduate, I'd say by 13. In some states, Project Search has been successful: Students get job training for a whole year before they graduate high school. For instance, they may set up instruments for surgeries in a hospital.

Hoskins: You're talking jobs that teach skills and give a sense of purpose.

Grandin: Yes. We need to find "paper-route substitutes," since the paper routes themselves are all gone. How about walking dogs for the neighbors? How about setting up chairs at the community center? When they're 16, give them a little job at a grocery store. Now, unfortunately, there are people who think that if somebody who's on the spectrum is really smart, that collecting shopping carts should be their whole career. No, it should not be a career, but a summer doing that teaches discipline and the responsibility of work. They've got to learn that.

Hoskins: Do you think this education needs to start at home?

Grandin: I'm saying, in general, that we've got to stretch these kids. There's a tendency to baby and overprotect. I see too many situations where parents do all the talking for the kid. I've been in meetings where the mom starts in, "My son has a question," and I go, "Wait a minute, your son's gonna have to ask the question. Here's the wireless mic," and I get the child talk to the whole group. That's when he finds out that he's able to do it.

Another problem that we've got now in the schools is

that they've taken out art, sewing, woodworking, cooking, theater, music... How're you gonna find out if you like a musical instrument, if you never try one? I had a recorder when I was a child. I was a real dud at it, but I had access to it. I found out playing an instrument was not for me. But art was for me. And that was always encouraged. If I hadn't had art when I was in elementary school, I would've hated school altogether. That made it worth going to. Art was the basis of my design work in the cattle industry.

Hoskins: How so?

You have the industrial design side of a product like an iPhone, for example, and then you have the engineering side, to make the inside of the phone work. At Fermi Lab, the physicists were talking about a lot of stuff that I didn't understand. But then I went down to the drafting department—these are the people who create the drawings for the equipment—and I understood what they were saying. I went to the machine shop. Without the drafting people and the machine shop people, they wouldn't have any equipment. That's an example of different minds working together.

Hoskins: What do you think is the next step in getting more people with autism into the workforce?

Grandin: You have to talk more specifically about the person's level of functioning. This is the problem with autism. With dyslexia, socially you're usually good. You may have trouble with reading, but other things are pretty much okay. If you have ADHD, that's a much narrower spectrum. But the problem with autism is we're going all the way from artists, Einstein, no language till age three, to somebody who can't even put their clothes on and is completely nonverbal. All that is considered to be autism. So let's start the "paper-route substitutes" around 13, 14 years old. Let's look at the level of function. Can this person dress himself or herself? Do they talk? Can they read at the level of *USA Today*? If you can read at that level, you can do most jobs.

There's gonna be different levels of jobs, but at around age 13 we've really got to start thinking about having these young people work outside the home. Volunteering does count, as long as it's on a schedule: Every Thursday night you've got to set up chairs. At 6 in the morning, you've got two dogs to walk for a full 30 minutes every day, rain or shine. And then, when they're 16, let's get them into retail. Let's get them into the real economy in some way.

Hoskins: Like a job.

Grandin: Right. We could be getting a lot more creative with this. I've found that working in the construction industry for 20 years has affected the way I think. I would design a job, supervise the construction, start it up, and make it work. It's all about getting the job done. And on the high end of the spectrum, I'm seeing too many kids graduate from college—sometimes with honors—but they've never held a job. Those job skills need to start way before then.

Hoskins: How do we get the workforce to open up to people with disabilities?

Grandin: If someone has a nice portfolio to show, we have to tell him or her that presentation matters. I just looked at a portfolio … last night; it was beautiful artwork. She could start showing in galleries right away, but I said: "You've got to do better at presentation." Her artwork was on a piece of paper ripped out of a notebook. I said, "You didn't even cut the holes off before you photographed it. Get dollar-a-sheet paper, buy some frames for about 10 bucks, and your work is worth $500 a pop." I learned the hard way: I showed some messy stuff to some people, and they were not impressed.

Jane Sparango: Temple says, "Carry your portfolio in your phone."

Grandin: Yes, your portfolio now needs to be in your phone, because you never know where you're gonna meet someone who needs to see it. It could be your programming work. It could be math. You could have your music on your phone. I know a phone's not the greatest thing to listen to music on, but when somebody comes by who can open a door for you, you've got to whip out that phone and show it to them, and maybe let them listen to it, if it's music.

Sparango: And Stan, what Temple says is that a lot of times our kids fall down in that interview process. They've got to have that phone.

Grandin: We've got to bypass that [conventional interview process]. What I did when I talked to potential customers was whip out my big drawings. I had articles from the *Beef* magazine out there. I just put it all out on the table.

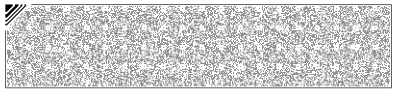
Sparango : And they were like, "Whoa!"

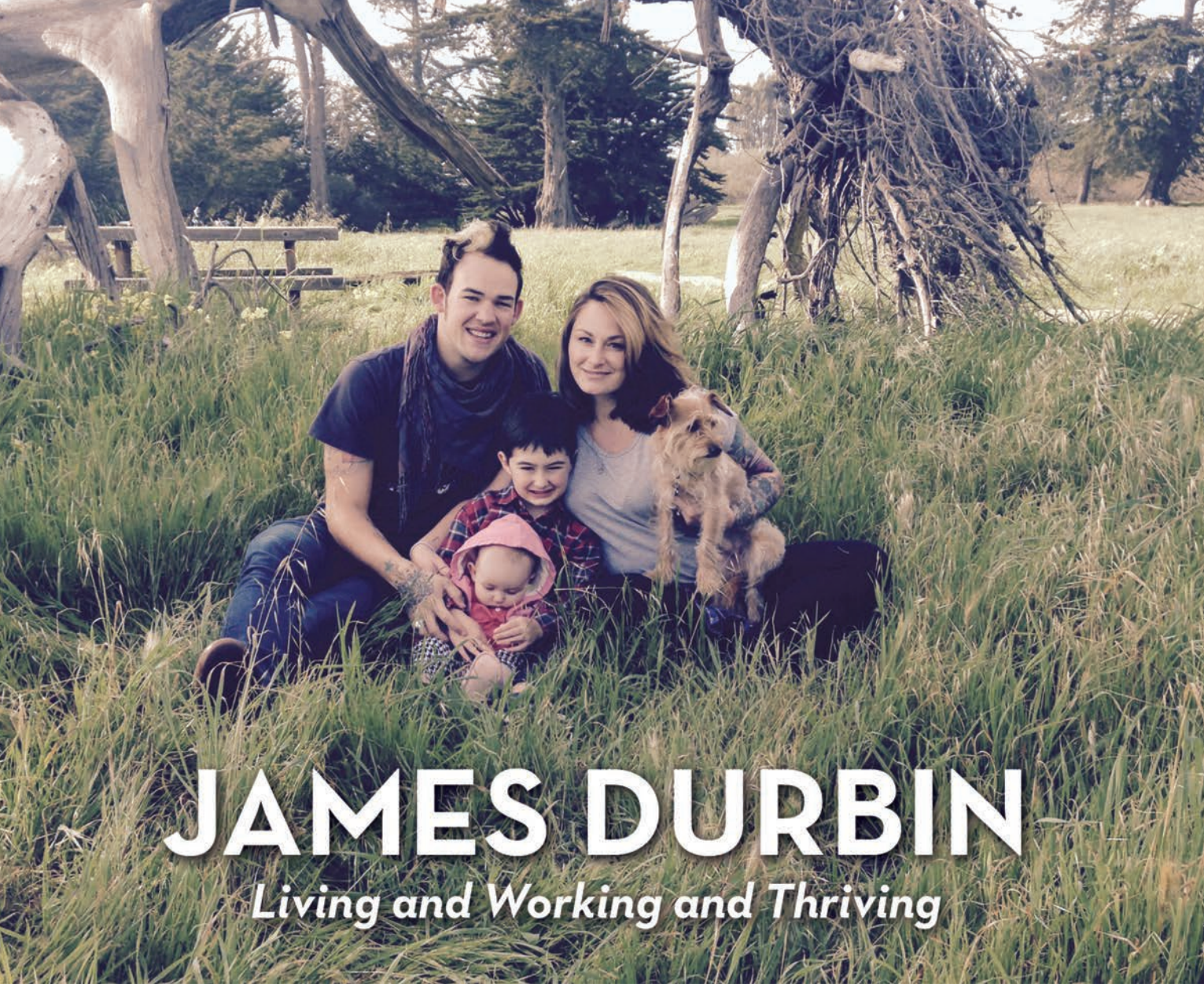
Grandin: Yeah, people didn't want to talk to me, because I was too "weird," but when I whipped out the drawings, I got respect. If you put examples of your work on your phone, you may have to wiggle it around to show it. But that's fine.

Hoskins: It's portable.

Grandin: Yes. We didn't have these phones in the '70s. I had to carry a notebook with me. Now we've got back doors to show what we can do, and we've got to find more of them. ■ ABILITY

autismspeaks.org/site-wide/autism-works-now
templegrandin.com
projectsearch.us
durbinrock.com





JAMES DURBIN

Living and Working and Thriving

At the recent Temple Grandin and Friends benefit for Autism Works Now, former *American Idol* contestant James Durbin lent his time and considerable music talent to the proceedings. Backstage, he spoke with *ABILITY*'s Stan Hoskins about finding his way into the music business, after being diagnosed with two challenging conditions at a young age.

Stan Hoskins: Can you talk about what obstacles you faced in becoming an artist?

James Durbin: In 1999, when I was 10, I was diagnosed with Asperger's and Tourette's syndrome. A year earlier, my dad passed away from an overdose, so it was an emotional and stressful time. When I'm stressed, my tics and behavior—my syndromes, as I call them—act up. It was really difficult for my mom and my two older sisters.

I had been getting teased and bullied. So finding out that there was a name for what I had was both good and bad. I got diagnosed at Stanford University's children's hospital by a neurologist named Ching Wang. "Thanks, Dr. Wang!" I'm still finding new ways to get around autism and Tourette's, and just when I think I've grown out of one of them, or it's gone away, something happens, and I'm like (*snaps his fingers*), Nope, there it is again, sneakin' up on me!

Hoskins: What made you get involved with this benefit for Autism Works Now?

Durbin: It's to help people with autism get jobs, which is an ongoing problem. It was a problem for me growing up. That's probably why I picked music, so I could work for myself. Now I make the rules. If I have any sort of legacy, it's that *American Idol* gave me a platform, not only for myself, but so that kids with autism or Tourette's could say, "Hey, that guy's just like me… Everything's gonna' be okay." Today, I'm married and have two kids. I'm physically able to work, even though I have some limitations, but I get the job done.

Hoskins: Let's talk about American Idol. *I imagine that*

you were constantly feeling stressed during the show. How did you cope with the pressure?

Durbin: It was really high stress. Now I'm a much more comfortable speaker than I was when I was on the show. I said things that maybe I shouldn't have said then, but I had never done any interviews before *Idol*. I got to one of the rounds, and I was having a real struggle with producer Jimmy Iovine. I wanted to sing "Heavy Metal" by Sammy Hagar, and he was like (*in a New Jersey accent*), "No, you're gonna sound like a Sammy Hagar wannabe, and be out of this competition tomorrow..." I said, "Jimmy, I disagree with you. If I'm gonna go out of this competition, I'm gonna go out the captain of my ship." That's where I came up with the whole "Give Metal a Chance" thing. I started a revolt, and Scottie (McCreery) and Casey (Abrams), who had let Jimmie change their songs, went back and recorded the songs they really wanted to do.

That same week, I got a call from the Make-A-Wish Foundation that a little boy named Cole Kwapich, who has Tourette's and Asperger's like me, and who'd had a double kidney transplant, wanted to meet me. I think he was seven or eight at the time. Suddenly, what I was doing on the show wasn't about me any more. It wasn't about Jimmy, or the competition… It was about what I'm doing for people, how I'm a voice for the voiceless, for people who are too afraid to speak up, or who can't maintain eye contact.

A lot of the fans I meet, who are on the spectrum, have a hard time looking me in the eye. I sit with them and I'm like, "It's okay. It takes time and practice. We have a developmental disorder. But you have to focus on making today better. It's for you and for your growth as a human. Don't worry about tomorrow, next week, or how you're gonna be in a year. Focus on right now. Slow things down. Live your life to the fullest today, because you don't know if tomorrow will ever come. We're focused on going so fast: How fast can we get information? How fast can we drive? How fast can we answer the phone, answer a message? I was having breakfast with my wife the other day on our seventh anniversary—

Hoskins: Congratulations.

Durbin: Thank you. We were sitting next to this couple, and the mom was on her phone, the Dad was on his phone, and the kid was on their phone, and I turned to my wife and said, "Honey, I'm not on my phone that much."

Hoskins: It's tough these days because you can use your phone to do virtually anything.

Durbin: Yeah.

Hoskins: I was looking at a Facebook post of a full-page, Radio Shack ad from 1990; it had all these different things on it. These days the typical phone can do everything on that page.

Durbin: Play music, tell you what time it is, tell you the date, record, "write" a note on a notepad hands free.

Hoskins: Now that you've been in the music industry awhile, are you able to surround yourself with people who keep you grounded?

Durbin: Not at all! (*laughs*). If I'm starting to get uppity, I'll call my attorney, and she'll yell at me, which humbles me. The music industry—any industry, for that matter—is not a good place to be if you're on the spectrum and don't like stress. As I've found out, it's all stress. It's hardly any music. That's the love-hate relationship I have with the industry.

But I think that what we're doin' here, and what Dr. Temple Grandin's doing is phenomenal. If we don't use our voices for speaking out and speaking up, then what are we doing? My wife and I have a baby girl, and she's amazing, absolutely beautiful. She's starting to talk, and the other day she woke my wife up and said, "Yo, Mama!"

(laughter)

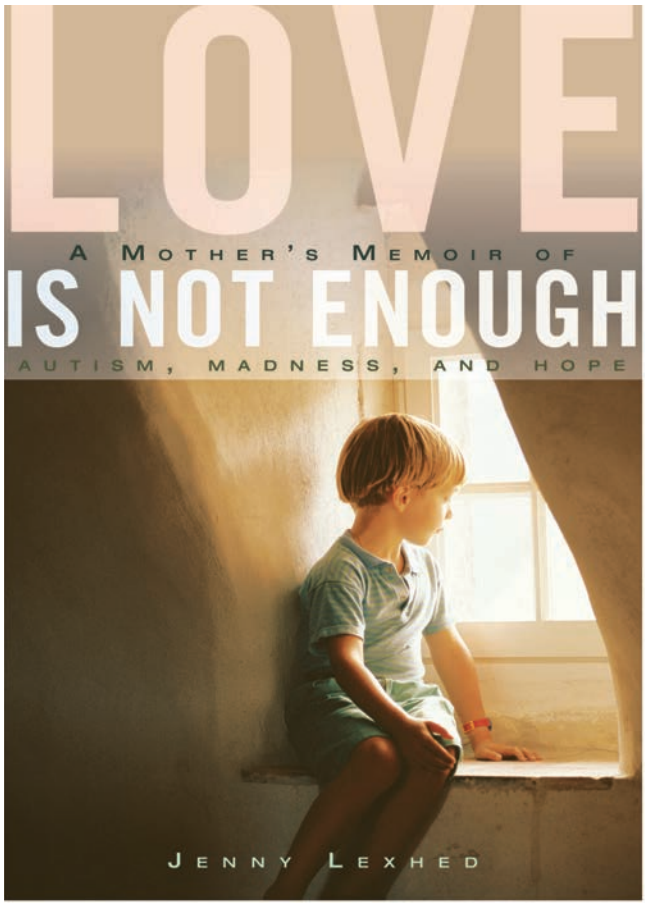
We need to make this world as good as we can for the next generation. It seems like for a lot of people, it's about power and destruction… But this event is about promoting happiness. Just because you're disabled, just because you have a disorder, just because you're labeled different or slower, doesn't prohibit you from living your dreams. I'm constantly dreaming, and I know so many people who are constantly dreaming. There's no reason why it can't happen, to go from being a small-town singer, to being on *American Idol*. It happened for Kelly Clarkson, Carrie Underwood, Chris Daughtry and Adam Lambert. The Rolling Stones just sold out the Fonda Theater. It's on the news. Will I get there? Who knows? I don't care. This is my path. This is my life. You play the cards you're dealt. The best players can win with any cards.

Hoskins: Where do you see yourself in five years?

Durbin: I don't. (*laughs*) I wonder what I'm doing tomorrow. My wife was asking me that, and I'd like to have bought a house and be paying a mortgage. Our son will be 11, and our daughter will be five and a half. I'll be 31, and my wife 40. I just want to be happy. I want to be playing music. I want to be able to go to all of my local stops in Santa Cruz, and see all my friends with disabilities living and working and thriving. ■ ABILITY

durbinrock.com
autismspeaks.org
americanidol.com





Help Me!

Can anyone help me? Get me out of here! I go to the light switch by the door again. I switch the overhead light on and off, my only way to communicate with the outside world. I let it shine for three short seconds, then three long, three short: SOS.

When I've doused the light, darkness sinks into my room on the seventh floor, my prison, Ward 22. I cross to the window and look out into the dusky summer night, moving toward dawn. I peer out over parking lots, buildings, houses and homes.

Is nobody there? Nobody listening, hearing, or seeing?

No one.

No one anywhere.

Just me.

Alone.

I rest my forehead against the cool windowpane and tears run slowly down my cheeks.

Happiness

Three years earlier, I'm sitting at my office desk, gazing over Johannes Park in Stockholm. It's early December, and the snowfall is light and flakey. It swirls slowly outside the window. A lone man walks by with his dog. A sudden pain inside my stomach, high up under my ribcage, is uncomfortable and I move to change position. It's my first contraction, but I only realize that later on. I am at the end of my first pregnancy. In little more than a week, my baby is due and I'm trying to finish up business and clean off my desk.

The office is lively. Telephones are ringing everywhere. People answer them, chatting and laughing. There are ten of us working here now. It's our company, our baby, in which we invest all our waking hours, from early morning to late at night. The company is thriving, and we're being written up in the press. When we started out, it was just the two of us, my husband Carl and me. In those days, we worked out of a basement in Vasastan.

That was back when people still faxed each other and the Internet hardly existed. We run a speakers' bureau and make our living on the spoken word. "Speech is golden" is our motto, in contrast to the adage, "Speech is silver and silence is golden." We help businesses and organizations find the right speakers for conferences and courses. We seek out speakers who have a burning devotion and desire to share their knowledge and experience, from politicians, CEOs, and experts to celebrities and performers.

I remember how Carl and I met just a couple of years ago: Moved in together, started a business together, got engaged, got married, bought a house and now, soon we'll have a baby. It's all happened so fast, and it's been great. Sometimes I wonder what we did to deserve it all. Life can't get much better.

The First Signs

It's midday, just past twelve. People crowd the main entrance to the Åhlén's City department store. Efficient businessmen and women take decisive strides through the doors, running errands on their lunch breaks. There are people everywhere, but they move smoothly and without bumping into each other to the escalator that takes them up into the upper floors. Others stroll around idly, trying out perfume and looking at makeup in the cosmetics department, here on the first floor. Two teenage girls giggle with joy when a sales clerk helps one of them apply some eye shadow.

Lucas and I are waiting for an elevator. All the moms know that the best changing room in town is on the fourth floor of Åhléns. It is large and well organized, with couches to sit on and nurse your infant, several tables for diaper changes, toilets for moms and dads, a play area for siblings, and a microwave for heating baby food. It's on the same floor as the children's clothing department. When you've finished caring for your little ones and they're fed and satisfied, there's always time to

look for some new garment they may need. The people at Åhlén's know how to get parents to shop.

The elevators take a while. I see that both of them are on the top floor. Next to me is another mother. In her arms, she's holding a little boy with curly, brown-hair.

"Hola, guapocito, mi cariño," she addresses him in Spanish.

She kisses, cuddles, and teases him.

She tickles his ribs. He wriggles, trying to avoid it, nearly choking with laughter. Then he sees me. Maybe I'm staring, I don't know. My gaze meets his. He turns serious, his lips pucker, and I wonder if he's going to cry. But then he breaks into a giant smile. I smile back at him and his brown eyes sparkle. He hands me his pacifier. It's blue and white, with a little brown bear printed on the middle.

"How nice," I say and hand it back to him.

It looks like he nods and quickly stuffs it back in his mouth. His eyes are still sparkling.

I turn to his mother and ask, "How old is he?"

"He'll be six months next week," she answers in broken Swedish and strokes his cheek.

"He's very sweet," I say, and she smiles.

I look at my own son. He has a tight grip on the edge of the carriage. He's just learned to sit up and still tumbles over easily. He seems entirely unaware of the little boy his own age, right next to him. Lucas sits with his face turned away.

What is he watching? I follow his gaze. Maybe it's the small white table fan spinning on the counter over there, maybe something else. I don't know.

Ding—my thoughts are interrupted, the elevator is here and the doors open. People exit and we enter. It's crowded. Two baby carriages, elderly ladies, young girls, and men. A lady in a green coat stands close to Lucas. She smiles at him and tries to catch his attention, but he ignores her and looks in another direction. She seems disappointed. I watch the little dark boy. He's smiling at anyone who looks at him, fully enjoying all the attention.

Faces don't seem to mean anything to Lucas. Strangers don't interest him at all. He's more fascinated with physical objects, like spinning fans or a fountain that sprays water, but also with shadows playing on the wall or bright lights. I think back to how, at his four-month checkup, I asked the doctor why Lucas didn't want to look at me or meet my gaze. She asked me to hold him close, turn him toward me, and say something to him. He took a quick look, and then turned away.

"There, you see?" She said. "He looks at you just fine!"

"But just quickly," I said.

"Don't worry. He's still little. He'll react more and more the older he gets."

She had no idea how wrong she was.

Different

Lucas is small, only two years old, when I begin to fathom and admit to myself that he's different. It's difficult to say what it is that sets him apart from other children. Initially, it was mostly a feeling, an uneasy omen of the great grief that was to strike us. He is our first-born, and we had no experience of how a child develops and behaves in different stages. Otherwise, we would probably have reacted sooner.

At the age of one, he could name some things and made an effort to say words when he wanted something, even if he sometimes used the same word when he meant different things, but now he seems to have lost what he once knew. He says almost nothing. It seems like he has regressed. If he wants something, he pulls me along and points to whatever it is. He points, but otherwise he uses no gestures to communicate what he wants to say. He neither shakes his head nor nods. He often gets frustrated and angry when I don't understand. He screams, kicks, and hits.

He often doesn't react to direct address and doesn't respond when we call his name. He cannot do what we ask him, unless he can read the situation and understand what's expected of him. If I ask him to pick up a ball that's in front of his feet, he can give me the ball, but he can't go into another room and fetch a ball. We start to wonder if he might have a hearing problem. Or does he? When I say, "Candy," he immediately comes running.

He has bad eye contact, except for a few occasions when he's highly motivated, like when he's playing chase. He can play that game endlessly. He's totally focused, and he screams with excitement when we chase him around the house. His eyes light up then, and his gaze is intense and follows our gazes.

Many other times he is entirely closed into his own world and is hard to reach. He goes off and only wants to watch cartoons and animated movies. Pingu, a clay animated film about a little penguin and his family, is a favorite that he watches repeatedly. Short, simple, and very clear brief stories, with sound effects but no words. Lucas becomes engrossed with the film and gets hysterical if we turn off the TV. He seldom sits still while watching TV but runs back and forth. He bounces and



Author Jenny Lexhed

jumps with both feet, up and down. Sometimes he drives around in his red pedal-car, a small plastic car that he maneuvers expertly. He gets up speed and drives straight over the parquet floor in the living room, then makes a sharp turn just in time to avoid the recliner in one corner, skids around, and drives back. He backs up and deftly handles his little car like no one else.

His motor development is very good. He began walking on his first birthday, and now, at the age of two, he has a good sense of balance. He climbs around and likes to balance along the back of the couch. However, he doesn't seek out physical contact in the same way other kids do. He doesn't like to hug and cuddle. If I'm sitting on the couch, he may climb up on my back, hug me from behind, and press his chin really hard against my head. If I'm standing somewhere, he may come over, take my hand, and press his chin into it, hard. He seldom sits still, and in his search for contact we become like two magnets that repel instead of attracting each other, for his advances are hard and often hurt. Sometimes, when he's very tired, he can sit still for a while in my lap. These are short periods, all too seldom, but I take advantage of every chance I get to hold him.

He has a different movement pattern. He walks on his toes. He flaps his hands, holds up his fingers in the air, and looks at them. He's fascinated by shadows and points of light. On a sunny day, he can stand for a long time, staring at the white kitchen wall, following the shadows of the branches blowing in the wind outside the window.

Otherwise, he has difficulty concentrating. Like a butterfly, he flutters around. Stops somewhere for a short while and then flits off to the next spot.

He doesn't like to play with toys but is more interested in examining things. He loves to spin things. If he finds a toy car, he doesn't drive it over the floor, he spins the wheels around and around. Rings, coins – he loves to spin anything that's round. He can also begin to spin himself around. At any time, without apparent reason. We try to stop him then. Otherwise, he'll continue until he's completely dizzy and falls over.

He twines strings. We have wooden blinds in the kitchen and living room. He runs from one window to the next and twines the strings on the blinds until they're one big mess, almost impossible to untangle. In the evening, when it's bedtime, he lies and twists my hair into tiny knots that I'm forced to cut off. It's hard to get him to stop.

He also likes to arrange things in rows. His movies, wooden train cars—he makes a long row on the living room floor. And he likes to throw things. He likes to stand at the top of the stairs and drop things. Ball, toy,

whatever, he watches it when it bounces down the stairs. Several times, he tips the TV from its table. He even throws things from the balcony down into the yard.

He loves water. He can stand for long periods in the kitchen on a stool at the sink and pour water back and forth between mugs and pots. Otherwise, he has a hard time concentrating for longer stretches of time. He tires quickly and runs away randomly, but it's different with water. We encourage his desire to experiment with food coloring, and he watches with excitement how the red drops dissolve in the water, or we may pour detergent that he can stir up into a pile of suds that glitter in all the colors of the rainbow.

He could stay in the bathtub forever. He likes to fill it with bubble bath and blow at the bubbles until they fly up in the air. He likes to pull out the plug and watch the water go around and around in a little whirlpool until it finally runs out. When the last of the water goes down with a slurping noise, he covers his ears.

At the age of two, he has discovered the toilet and it interests him. He knows how to flush, and he likes to put things in it and then flush. The flushing sound makes him cover his ears. I have to hide my earrings so they won't get flushed down. He often takes the toilet paper, puts it on the floor, and pulls on one end to see it roll away across the floor.

He has never slept much. He stopped napping at midday early on, before he was two. He still wakes up screaming several times nightly and has difficulty going back to sleep. He gets up at dawn, often around 4:30 a.m., and now the TV has become a lifesaver. A familiar movie will sometimes get him to calm down and even sit still on the sofa, while I lie and snooze next to him. I have to take night duty, since Calle has to work.

When we go to bed in the evening, we try to interest him in books, but he doesn't want to look at them and throws them aside. When we go to bed, I like to hold him, caress and hug him, but then he pushes me away. He wants to lie by himself, not next to me, close to my body. When we lie there quietly, trying to go to sleep, he sometimes laughs aloud for no apparent reason. He just bubbles with laughter, as if he's captivated by the sound of his own voice.

He's not interested in other children. If we're in the park, he doesn't notice them. Instead, he stands in the sandbox and splashes sand, or throws stones in puddles, totally unaware of others around him. He can treat his little sister, Sara, like an object or a piece of furniture. If she's lying on the floor, he can come over and sit on her. He often covers her with a blanket. If she's lying in his way, he'll pick her up, sometimes by the throat, move her out of the way and drop her onto the floor.

He neither cries nor shows in any way that he has hurt himself when he falls. He doesn't come to us to seek out comfort or solace.

Increasingly, I understand that Lucas is not like other children. He has always been different, a little more difficult and more demanding than other kids, but now the differences are beginning to be so big that they're noticeable. Somewhere in the back of my mind, the word autism is spinning. I don't know anyone who is autistic and have no experience with autism, but I know that it's a communicative disorder. I get onto the Internet and find the home page for the Autism Society, looking for information. I read there:

Persons with autism have great difficulties processing and understanding information so they can create wholeness and context in their experiences. They also lack the ability to understand and empathize with others' thoughts, feelings, and needs. The symptoms are usually divided into three main groups:

1. Serious impairment in the ability to create mutual contact

2. Serious impairment in the ability to communicate, and

3. Serious impairment of imagination, play, behaviors and interests.

Persons with autism and autism spectrum disorders often have a different, extremely uneven intelligence profile and specific learning impairments. Studies indicate that one of the basic impairments, when it comes to learning, results in persons with autism and autism spectrum disorders not being able to empathize with others, not being able to imagine other people's thinking and feeling, in other words, that other people's behavior and actions are steered by inner mental processes.

A lot seems to fit Lucas, but Calle and I don't want to believe that it's that serious, as terrible as autism. Of course, it's hard to establish contact with him, but he doesn't have a "serious" limitation in mutual contact. He shows interest in us and likes us. He learns things; if you show him how to perform correctly, he quickly learns new things.

We speak with Lucas' grandmother, Gunilla, about our suspicions. She lives nearby, sees Lucas several times a week, and they're really close. She babysits him and his little sister, Sara, often. She loves her grandchildren and is truly devoted to them. She immediately rejects our line of thinking. Lucas isn't autistic. He's so lively and happy. So full of life and joy. He loves to run around and be chased by all of us. He does have a hard time speaking, but he isn't very old yet. The arrival of his little sister is a big change, and it's common for children to regress a little, but they catch up again after a while. Gunilla has a lot of experience working with children, and we want so desperately to believe what she says. She suggests that we find a speech therapist if we're worried

about his language development, and we agree to do that.

The Swedish health care system gives everyone who lives or works in Sweden access to heavily subsidized health care. The system is tax-funded. The care is of the highest standard, but sometimes the wait to see a certain specialist can be long.

In our case, for each of the speech therapists we contact the waiting period is long, sometimes several years. In addition, it's mid-May, and many will soon be on vacation. But at last we find a therapist who has time for us in October. Maybe it's a good thing that we have to wait. Lucas may mature and catch up. We're going to take the summer off to have time for each other.

The summer passes and the fall arrives. Anxiety is constantly present, pressing away.

Things are not getting better.

The Boundary between Dream and Reality Disappears

I feel no hunger or fatigue. In the evenings, when the kids have gone to sleep, I sit up until three a.m. reading. Then I go to bed and wake up at five, ready to go. I often dream something about what I read the previous evening and awaken with new angles. I immediately arise, sit down, and write down my thoughts. My brain is never at rest. Thoughts have the speed of light. Wherever I am, I need to write down what I'm thinking because the thoughts are fleeting and I'm afraid they'll disappear. Even while I'm driving, I keep a notepad next to me, so I can jot down ideas. When I stop at a red light, I can write long sentences and I have the notepad on the steering wheel to set down the main points. Days pass and my thoughts are drowning my brain, and soon it can no longer take in outside stimuli.

One day, I'm on my way home from town. I'm driving alone in my car and approach the Danviktull drawbridge. Suddenly, I hear bells ringing. I look around and see that the drawbridge is opening and just barely make it, braking and stopping the car before a road barrier cuts my car in two. I've driven past the first red light and nearly passed the second. My car is alone, in front, closest to the bridge. The other drivers have stopped at the first red light. I see the bridge open before my eyes and understand that I can no longer drive.

I sleep even less. The boundary between dream and reality begins to disappear. One night I dream that my deceased father speaks to me and I wake up, believing he's still alive. A couple of months ago, it was ten years since he died in the car crash. I lie in bed and my thoughts are spinning. Maybe he DIDN'T die in the crash? Maybe it was all fake? Maybe he wanted to start a new life somewhere else and change his identity? If he had committed a crime, the statute of limitations would have expired by now, this year. How can I find him, if he's alive? Where is he? How can I reach him? I figure, if he is alive, he must have access to the Internet. Maybe I can find him that way, try and find his email address and contact him. I get out of bed and go up to our office in the attic and sit down in front of my computer. I write down a list of possible email addresses he might have and start sending emails into cyberspace, but to my disappointment they all bounce back with the answer "user unknown." He died near a place called Jenny. Was it a sign? Are there other places with that name? I search Google Maps. In Surinam, a country in between Guyana and French Guyana in northeastern South America, I find a spot on the coast called Jenny. He loved South America. Of course, that's where he is.

A window has opened that was previously closed. My senses are sharpened, and I take in everything in my surroundings. People turn to me in a different manner than before. At the open preschool, everyone gathers around me; I'm the focal point, and I lead the discussion. Perhaps it has something to do with my viewpoint? I see everything and everyone and cannot leave well enough alone. Energy emanates from me in an almost supernatural way. Is it something that affects others unconsciously, or is it just my own experience? The feeling is so strong and the energy surrounds all living things.

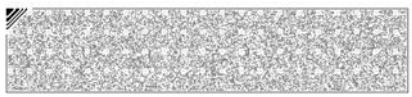
One day, I visit my friend, Camilla, who lives in the neighborhood. We're going for coffee, and Sara has a playdate with her daughter. I take the car and park in the driveway, lift Sara from her car seat, and put her on the ground. I take her small hand in mine and we walk up to the house. Suddenly, Rex, their giant, black German shepherd, comes bounding up. He's a little wild and usually runs around like crazy in the yard, but he's a good dog and all he wants to do is play. I bend down, meet him, and look into his large, dark brown eyes. Immediately, he sits and becomes completely calm. Our gazes meet for a moment that seems like an eternity. We have a connection that flows between us like an invisible force. When I get up, he follows us closely and rubs against my legs. We ascend the stairs to the front door. I ring the bell and Rex sits down, close by me.

Camilla opens. "Hi, nice to see you," she says. "Come on in. Wow, Rex is so calm! What have you done to him?" She laughs.

"Nothing," I answer and smile secretively. "We just said our hellos."

Strange things begin to occur, and it scares me. A ceiling light in the hall by the living room begins to act strangely. When I'm in the vicinity, it increases and decreases in luminosity, without my using the dimmer. At night, different toys begin going without my pressing any buttons to activate them. The telephone rings, but no one is there when I answer.

"Hello. Hello?"



All I hear are clicking sounds. No dial tone or voice.

When the children watch Cartoon Network or any other TV channel during the daytime, we have bad reception and can't watch. Suddenly, transmission is interrupted, and all we see is a snowstorm. It feels as if the air is charged with static electricity, and it's as if some supernatural force has taken over and is steering, or at least trying to, our lives. If I put on a DVD, everything is normal again.

One night, when Sara wakes up, I lay down beside her and she falls back to sleep. I remain with her, thinking of different rules and stances we should adopt in our family. I feel that candy on Saturdays only is a stupid rule, mainly constructed to make it easy for parents, instead of being for the benefit of kids. If kids are allowed to have candy only on Saturdays, a practice that is very common in Sweden, it's easier for parents to handle their kids' nagging by referring to the fact that they'll get it on Saturday. I don't eat candy only on Saturdays, so why should they have to? I hug my little girl sleeping peacefully beside me. She moves a little and talks in her sleep. I listen and hear her say, "Candy". Candy, I think. I was just lying there, thinking about Saturday candy. Can she read my thoughts in her unconscious? We are close, spend day and night together. Maybe small children, still developing a language, have a kind of sixth sense? Do they have telepathic abilities? Telepathy is a direct connection or contact between two sentient beings. It is the ability to read another person's thoughts or to transfer one's thoughts to another without the use of speech, signs, or other physical signals. I've read that there are researchers who believe that, several million years ago, before we developed a language, people communicated with thoughts. Maybe telepathy is something we all have when we're born, but the ability diminishes as we learn to speak?

Later the same day, I'm thinking. Lucas hasn't developed a spoken language. How are his telepathic abilities? What if he can read my thoughts? I worry about the terrible thoughts I've had and how it's affected him. I know that when we began to suspect autism, Calle and I wondered if Lucas would ever be able to live a normal life, with such a terrible handicap. It would be so limiting, so lonely. He would live in isolation, closed into his own world and be very dependent upon others. It went so far that we thought, independently of each other, that it would've been better for Lucas if he died, better than needing to live such a horrible life. Death would be liberating, in comparison with life. We wished the life out of him, our little child. When I think this, I hear how Lucas walks around and sniffles straight out into the air, one of his tics, like he usually does. He snorts, snorts, and sniffles.

I can't see him, but I call out to him, "Lucas, stop snorting!"

However, he doesn't stop and I go to find him. The little chubby three-year-old comes out of the bathroom, straight toward me. I see to my horror and despair that his nose is bleeding. Red blood is running from his nostrils down over his lips.

I start to cry, fall on my knees, and hug him. "Forgive me, Lucas, I'm sorry. We don't want any harm to come to you. We love you so much. We only want what's best for you. We want you to get well, to be able to talk with us. To be with us. Beloved child. You and Sara, you two mean the most to us. More than anything. You know that. You are everything to us."

After a while, I let go of him and get a Kleenex from my pocket. I carefully wipe his nose. My face is close to his and for once, our gazes meet. He looks at me with large, serious blue eyes, exactly as if he wants to say, "I know, Mom, I know."

I'm cold, in spite of all the warm sweaters I put on. At night, I can't sleep. When I close my eyes, I see pictures. Even in the day, when I close my eyes, I see symbols. It's as if my brain cannot relax. Impressions wash over me and leave me without peace. Everything must be interpreted, and I begin to read messages everywhere, in billboards, in ads from Pampers, in a TV show. A higher truth is touching my life and me.

One day, a black-and-white movie is on TV. It's A Giant Swede: Harry Victor. The main character is a kind of spy, and it suddenly occurs to me that my father was of course a spy. He worked for SÄPO (Swedish Secret Police) or something similar. That's why he's gone underground and disappeared. What a brilliant, logical explanation! That's it.

Up in the attic, there are two rooms, the office, which is the white room, and our cinema, with black walls and flooring. In the evening, I usually sit in the white room and Calle in the black. One evening, Calle is watching a movie and I go in to say something to him about the dream I had of my father, that I believe he is still alive. The air feels heavy and electric.

When I sit on the couch and tell him, my eyeglasses fall off. One of the arms has come off because the screw that keeps my glasses together has fallen out. I pick them up and put them on again. They sit a little crooked, since one arm is missing. I continue to talk and almost immediately, one of my diamond earrings falls off. Without any explicable reason.

It feels ominous. What's happening? Is it my dad trying to communicate with me? Is he sending me a sign?

My husband is now beginning to worry that all is not right with me. The next day, he calls my sister, Eva, and asks her to come and sleep over. I try to tell her about our father and that I believe he's still alive, but she won't take in any of what I'm saying and tries to prove the opposite. We get nowhere, and in the evening she makes sure we go to bed. I fall asleep, then wake up after a cou-

ple of hours, go upstairs, and sit in front of the computer again to search the world over for my missing father.

The next day, Calle wants to take me to lunch. He has arranged for his mother to come and babysit. We go to the Hotel Långholmen Restaurant. Long ago, the hotel was a prison, built in the early nineteenth century. Before Calle and I moved in together, we spent a night in one of their rooms, as they call the cells. Maybe he wanted everything to be as usual again and that was why he brought me there, but I feel anything but usual.

It's late April, and the spring sun is shining from a blue sky. The outdoor section is closed, but I succeed in charming the waiter into letting us eat lunch outdoors. I'm not particularly hungry and order a salad and a glass of white wine. Calle has a shrimp sandwich. We lean against the building, and the sun is warming us nicely. I'm glad we're alone, because I'm restless and have difficulty sitting still. I go and fetch more bread and dressing. Later, I go to the restroom in order to keep moving.

After lunch, we get in the car and Calle drives. He doesn't drive homeward. He takes another road, over the Västerbro Bridge and on to Kungsholmen. We turn into a parking lot, close to a large building. In spite of my mental state, I still have one foot in reality and I understand where we are headed. Calle parks. I open the car door, get out, and run away. Away from the parking lot, toward the green belt close by. I hide behind the trees. Calle runs after me. I feel hunted, like a wild animal, about to be captured. Calle can't catch me and calls my sister Eva, who comes. Together, they wheedle and reason with me and finally I follow them in, into the psychiatric emergency ward at St. Göran's hospital.

On entering, we pass a kiosk. I see the headlines, and it's as if everyone has something important to tell me. I sneak off from Calle and Eva and approach the woman in the kiosk, asking for one copy of each of the newspapers they sell. She starts putting together a bundle and they arrive and stop her just before I try to pay.

We see a doctor. Calle and Eva tell him about my background. He asks if I've had similar problems previously.

Eva says that I had hyperthyroidism many years ago. Hyperthyroidism is when the thyroid gland is overactive and produces excess thyroid hormones. This makes the body's functions speed up and leads to symptoms such as shaking, weight loss, and anxiety. It increases your metabolism, and your body goes into overdrive. I had heart palpitations, heightened pulse, sweats, shakes, and was irritated, restless and easily upset. I also lost a lot of weight. Eva thinks that my symptoms now remind her of those. After the doctor has observed and spoken with me, he concludes that this is not an overactive thyroid. He believes I'm suffering from a psychosis. Calle and Eva want to take me home with some sleeping pills, but the doctor thinks otherwise. Against my own and my family's will, I'm committed in accordance with Swedish law to compulsory psychiatric treatment. I receive Stesolid and Nitrazepam. I fall asleep and stay that way for fourteen hours.

Ward 22

Next day, I'm moved to the hospital a stone's throw from where we live. I'm admitted to Ward 22, which is on the top floor, maybe so it won't be easy to escape. The door is locked and can be opened only by the caretakers. The ward consists of a long corridor, with rooms on both sides. The women are separated from the men, but there are both in this ward. There are dormitories for multiple persons, but also private rooms. A few rooms are group therapy rooms and treatment rooms. The cafeteria functions as a dayroom too, and there's a couch and TV. There's lots of daylight in that room, and, from the tables by the windows, you have a view of the area for miles. I can almost see our home. At the end of the corridor, there's a smaller dayroom. You can listen to the radio there, and there's a TV that doesn't work. Halfway down the corridor, there's a smoking room, shared by patients and personnel alike.

I'm placed in a dormitory with three other women. Next to each bed, there's a small screen, so patients can have some privacy.

From the medical records:
At our meeting, the patient is very closed off. Quite correct behavior, formally. Describes the occurrences of the last few days and their son's illness initially in our conversation quite correctly and adequately, eventually beginning to slide into many associations about the possibility of treatment where she herself has found a way to teach the children to communicate. Quite emotionally unstable during most of our talk. Laughs inaptly and is close to tears alternately. Doesn't want to stay at the hospital, feels no need of care. Needs to go home and needs the support of her family.

My thoughts are spinning and I try to put them down on paper. I talk to everyone and try to explain what I mean. At night, when everyone has gone to bed, I talk to myself. The first night, I sleep for three or four hours, in spite of the sleeping pills. I receive stronger medication and then start having trouble speaking. It feels uncomfortable. I feel strange, like I'm amid strangers. I feel insecure. I want to go to my sister's place and rest up there, to be with someone who knows me and likes me. I don't want to stay in this place.

Calle comes to visit me every day. We have conversations with the doctor. I tell them that I want to leave here, that I don't want medicine. The doctor says I must stay until I'm better. He thinks I need the medication, and reluctantly I agree to it, in spite of the fact that it makes me feel very uneasy. ■ ABILITY

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INCLUDING PEOPLE WITH DISABILITIES IN THE Green Economy

The percentage of total employment associated with green goods and services has increased in the United States over the past several years, presenting employment opportunities in a number of related emerging fields. Green-economy jobs hold promise for people with disabilities, and inclusion practices would also improve the outlook in this growing sector. An increase in green occupations was spurred by the Great Recession in 2008, by increased climate change awareness, and by the trajectory to develop jobs in the anticipated low-carbon economy.

A focused effort to engage and train people with disabilities in green fields would bring this diverse, talented and largely untapped portion of the U.S. workforce into the emerging economy. The U.S. Bureau of Labor Statistics defines green jobs as positions in which workers' duties involve making production processes more environmentally friendly and less dependent on natural resources. According to a 2013 analysis by the bureau, there were 3.4 million green jobs in the United States in the fourth quarter of 2011. Twelve percent of Americans report one or more disabilities, and only one in about every three Americans with disabilities is employed. This condition presents a crucial opportunity to further employ people with disabilities in a growing labor market.

On the legislative front, the American Recovery and Reinvestment Act (ARRA) funded Pathways Out of Poverty grants and Energy Training Partnership grants. Both programs provide green job training for individuals with disabilities, and displaced workers among others.

However, misconceptions about the capabilities of people with disabilities are often cited as the reason why employers don't hire those with disabilities. Efforts to make green careers available and accessible to people with disabilities will ultimately benefit not only employees, but also employers. Employers would be expanding their pools of talent, skills and creative business solutions by taking the opportunity to fully employ those with disabilities in this sector. Furthermore, new markets become accessible when people with disabilities are employed, and research has proven customers prefer to patronize businesses that employ people with disabilities.

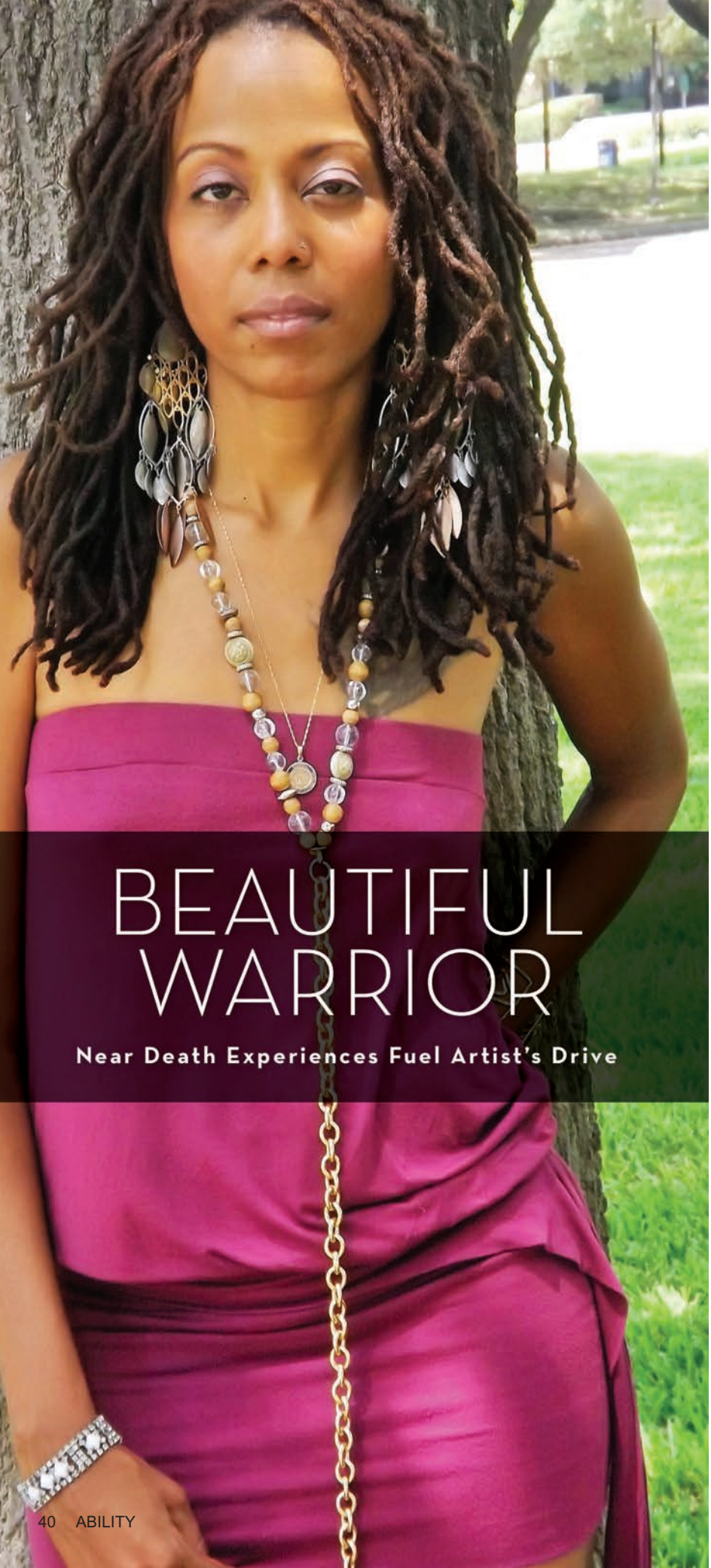
In order to include more people with disabilities in green occupations we recommend the following:

- The application of strict standards for funding green industry training providers
- Creating an inventory of current training programs to address potential gaps
- Development of a federal partnership with green industry employers that includes hiring agreements and career advancement options
- Tools and training manuals to provide funders, counselors and people with disabilities better information about the green industry job market.

As employment options arise to provide these green goods and services, people with disabilities ought to have equitable employment opportunities in this growth sector of the American economy. A focused strategy to train and engage people with disabilities in the green economy can provide a talented and largely untapped segment of the U.S. workforce, a greater opportunity to participate than previously realized. ■ ABILITY

by David Filiberto, PhD

David Filiberto, PhD, is an evaluator and social scientist with expertise in research methods, particularly the design and administration of survey instruments. David is developing for the Employment and Disability Institute in the School of Industrial and Labor Relations a research agenda focused on sustainability and the effects a changing climate has on vulnerable populations such as those with disabilities, the aging, and indigenous peoples. He has performed federally funded research on the effects a changing climate has on the aging population. He holds a PhD in Policy Analysis and Management, a MPA, and BS all from Cornell University.



BEAUTIFUL WARRIOR

Near Death Experiences Fuel Artist's Drive

Toni Alika Hickman has gotten good at telling death to take a hike. In 2004, she survived a brain aneurysm at 27, only to face a second one and a stroke just three years later.

"I'd never heard of a brain aneurysm," says Hickman, who headlined the YoungStroke 2015 in Jacksonville, FL, in June.

A prolific artist, she thought little of the headache she got one day more than a decade ago. But it was quickly followed by nausea and vomiting—a silent signal that the wall of an artery in her brain had weakened.

"My mother said that I looked like I had an attitude, and when she asked me questions, I answered her with one word." Alarmed, her mother called 911.

Hickman had some of the risks associated with brain aneurysms: She was a casual smoker, an African-American and a woman. Other risk factors include a family history, a previous aneurysm, and high blood pressure.

Surviving a host of calamities within a few years motivates Hickman to get done what she can today. She's released two albums, a book, a documentary, and has sung on albums with such chart-topping artists as Ciara and Jagged Edge.

"All of it has changed my life in a positive way," she reflects. "I love sharing my story. People need to hear that situations happen, and it's not the end of your life."

Always a risk-taker, Hickman left home at 15. Born in Queens, NY, and raised in New Orleans, she and a friend trekked to New York City as wannabe Hip Hop stars in the mid-to-late 90's. The duo stayed with the friend's aunt, as they door-knocked, determined to land a music deal. When it took longer than expected, and they'd worn out their welcome at the aunt's home, their other option was to stay in a shelter. The friend lasted two days, but Hickman, committed to the dream, stayed on for months.

"It was nerve racking: I got my clothes

stolen; there were prostitutes in one room...” Her mother begged her to come home, “but then my goal would not have been accomplished,” she says. “My whole attitude was that I didn’t come out here for nothing.”

She crossed paths with a compassionate social worker, who helped the homeless then-17 year old tap into a support network. That included moving into a halfway house. During a brief visit home to New Orleans, Hickman got a call from Suave House Records, for which she auditioned for a label executive by freestyling over the phone.

Finally, she was in! The company flew her to Houston to sign a recording contract, where she laid down tracks for 8Ball’s “Lost,” Mr. Mike’s “Wicked Wayz,” which went gold, and other projects, she recalls.

She had made it. Sort of. The publicity was phenomenal, but the paycheck didn’t match the hype. And then, three days before she was to sign a more significant deal with Interscope records, the first aneurysm lowered the boom, Hickman says.

“The energy shifted. Everyone I was working with in the industry backed up on me. They were afraid of my health. Everybody was so nervous for me, watching everything I did,” she remembers.

The second aneurysm—accompanied by a stroke—as the artery in her brain ruptured and leaked blood, changed the game altogether. She wound up in surgery. “They put me in a nursing home, and said that I wouldn’t speak or walk again.” It was horrible, and yet it could’ve been worse: She could have had brain damage or died.

During the recovery process, Hickman would attempt to get out of her wheelchair and walk. Instead she fell. And fell. And fell again. At some point, she was warned: “‘Toni, you cannot do this, you’re going to hurt yourself.’ And the next day, they’d leave me in a room, and I’d get up and fall.” But after a while, she got her legs under her. It was around this time that she started to favor her middle name, Alika, because she it seemed a better fit.

“My aunt used to call me by my middle name, but I never used it. I looked it up and found out that it’s Hawaiian.” Though it has several interpretations, Hickman embraces the one that means “beautiful warrior.” After everything she’s gone through, she says, “I like a name that, when people call me by it, or think of me, it defines my spirit.”

Surviving a series of calamites made Hickman health conscious. She gave up cigarettes, alcohol, sugar and began to eat more healthily. She also makes her own deodorant using aloe vera, essential oils and witch hazel (stored in the fridge because it’s preservative free).

“Preservatives that give products a long shelf life also go into our skin; 60 percent of what we put on our skin, goes into our blood stream,” she discovered through research.

In that same vein, she gave up straightening her hair, and now wears it in natural locks.

“My book, *Chemical Suicide*, was inspired by doctors telling me I could not perm my hair for one to two years… When I looked up why, it was because I had a big gash in my head after brain surgery, and they didn’t want chemicals seeping into the cut.”

Her unusual journey has connected her with others who’ve encountered unexpected twists and turns along the way. At her recent fashion show, in connection with her album release party for *Unbroken*, Hickman featured a number of people with disabilities, including a young woman and young man, both shot at an early age, and a young model with cerebral palsy. The three also appear in Hickman’s “People Pleaser” video from the same album.

“People do what is expected,” she finds. “The song says: Don’t be a people pleaser, follow your spirit before anything. And for people with disabilities, it doesn’t mean you’re not capable of accomplishing. We’re here, we’re beautiful, and there’s nothing wrong with accepting this.”

Six-feet tall and willowy, Hickman looks runway worthy. But she had to wrestle with her self-perception after the stroke weakened her on one side, and caused her to be partially paralyzed. She now walks with a limp. Her first album, *Crippled Pretty*, hints at her transformation.

“Spiritually, I really had to learn to love myself. I was upset with God. I was asking, ‘Why me?’ But the nurse said, ‘What are you crying for? What you really need to be asking is how come you’ve had two brain aneurysms and a stroke, and you’re still here?’”

Digging deeper into the meaning of life led to her two-hour documentary, *The 16th Strike*. The film is about “African-Americans and our struggles… and some of the things to do so we can heal ourselves,” she says.

Hickman’s healing process makes her a regular at the gym, where she heads for the elliptical machine. A former jogger, she still has hopes that she’ll once again lace up her sneakers, get out there, and run along the road less traveled.

“I’m going to be like Forrest Gump,” she says of the mythical film character, “you’re never going to be able to stop me.” ■ ABILITY

by Pamela K. Johnson

tonihickman.com



Nancy Villere - CrushPhotoStudios.com

ED ASNER AT 85

"IT'S ONLY THE BEGINNING"

Ed Asner has played the hard-nosed, but softhearted TV producer, Lou Grant, in four different series: *Mary Tyler Moore*, *Rhoda*, *Lou Grant*, and *Roseanne*. At seven Emmy's, he's won more than any other male entertainer, and is tied with his former co-star Moore. A two-term president of the Screen Actor's Guild, Asner fights for causes he believes in, including gun control, banning the death penalty, and making sure people with autism find meaningful work. *ABILITY*'s Lia Martirosyan and Chet Cooper spoke with him at his L.A. home.

Ed Asner: What do you do?

Lia Martirosyan: I show up, editing and journalism.

Asner: You saved my life.

Martirosyan: Have I?

Asner: Where would I be without a good editor?

Martirosyan: This is true.

(*Asner's eye begins to run.*)

Asner: Both in writing and in film. Would you hand me those Kleenex up there? Thank you. For a small fee you each can have one.

(*laughter*)



Nancy Villere - CrushPhotoStudios.com

Lia getting some laughs in with Ed Asner

Chet Cooper: Before or after?

Martirosyan: It's only valuable after.

(*laughter*)

Cooper: On eBay.

Martirosyan: Or Craigslist? eBay and Craigslist, here we come.

(*laughter*)

Asner: What prompted you all to come see me?

Cooper: Great question. We were going to ask you that.

Asner: What do you mean? I didn't invite you. What would I want you in my house for?

(*laughter*)

Cooper: We were gonna ask you, "Why are we here?"

Asner: I have no idea. Get out!

(*laughter*)

Do you like my bear up there?

Cooper: Is that from the Inuits?

Asner: Yeah.

Cooper: Is that from Charlie? Do you know Charlie? There was a famous Inuit artist who had lost an arm, had his arm cut off, but he did dancing bears.

Asner: Did he? I don't know where the documentation on that bear is. I've got it stuck away some place. But I love him.

Cooper: I was a partner in an art gallery, and we specifically sold Inuit carvings from the Northwest Territories of Canada. We would work with the different tribes and they would ship them down. It was in Newport Beach. I love that art.

Asner: I love it, too. I've got a lot of Northwest masks and everything we haven't hung yet which I bought in my first trip to Vancouver.

Where are you from?

Lia: Well, I was born in Armenia, but I live out here in LA.

Asner: It's a lot like Armenia.

Lia: Actually, Glendale…familiar with it?

Asner: Little Armenia. (*laughs*)

Cooper: Okay, the reason we're here is your connection with autism.

Asner: You know, Autism Works Now recently had a Temple Grandin & Friends: Musical Benefit for autism.

Martirosyan: You and your son, Matt, were honored there.

Cooper: I took a Kleenex.

Asner: Put it back!

(*laughter*)

[Asner's late co-star] Ted Knight talked about driving by a guy on the freeway who was picking his nose. Ted honked his horn, and when the guy looked at him, Ted yelled, "Put that back!"

(*laughter*)

Martirosyan: Where were you born?

Asner: In the Kansas City, MO, hospital, but I lived in Kansas City, KS.

Martirosyan: And you grew up in that area?

Asner: Oh, yeah.

Martirosyan: So how old were you when you came out to Hollywood?

Asner: I came to Hollywood in '61. I was 32, a man.

Martirosyan: What brought you out here?

Asner: I started acting in Chicago, carried on for six years in New York, and by then I'd had enough of New York. I did a *Naked City* [TV show] here in Los Angeles, and saw agents and producers and my appetite was whetted to move out here, and that's what we did. While shooting *Naked City*, which I worked on for about a week, I called my wife back in New York and said, "I think I want to check the place out more. And then I spent another week talking to agents and people and called her back and said, "I want to move out here." So we sublet our apartment in late February, early March. My mother and brother pooled their money to buy us a new Chevy Impala, and my wife hired some movers. We rented a 14-foot U-Haul and stuffed it to the gills. Everything was perfect. We had about 1,000 pounds left over, which we consigned to Mayflower to deliver. And every goddamn piece of furniture that we sent was damaged by them. A sofa, a beautiful cherrywood harvest table, gouged, gouged. Unbelievable, criminal.

Cooper: Mayflower's our main sponsor for the show.

(*laughter*)

Asner: Well, they can go to hell.

(*laughter*)

We stayed with a friend for about a week in Hollywood, and then went looking around and found an apartment above the garage on an estate in the Hollywood Hills. Rudy Vallee's estate was at the end of the street, and he had tried to get the city council to change the street name to Rue de Vallee, but they wouldn't do it. I don't know who owned the estate we were on. We had a little TV, and my wife would make dinner and we'd watch it. The second night we were there we heard a rustling outside. She went and peeked through the blinds of the window. There was a large avocado tree growing right next to the apartment, and she beckoned me over. Two raccoons were on their backs, chewing avocados. And I said, "This is for me." I've been chewin' on avocados ever since I got here.

Martirosyan: Are you doing much acting these days?

Asner: I tour with a one-man show, and I do movies, if you're making them. I'm quite viable, in every sense of the word.

Cooper: What's the one-man show?

Asner: It's called *FDR*. I've been doing it for about four years. It's done well. Now I'm in a rehearsal period with a writer-producer from the *Mary Tyler Moore Show*, Ed Weinberger. That's a one-man show and we're trying to work it up into viability. It's called *A Man and his Prostate*. We hope it'll attract flies.

Lia: Prostates always do.

(*laughs*)

Asner: Mine certainly has. In fact, it flies.

Cooper: Where is it playing?

Asner: We performed it in Missouri in June.

Cooper: Do you show President Roosevelt using a wheelchair?

Asner: Oh, yeah. I enter in a wheelchair. The rest of the time I'm walking around with two canes. It's from the point of his coming down with polio. It's the successor to *Sunrise at Campobello*. Dore Schary wrote the initial play, and we monkeyed with it and touched up on it, deleted some, added some. It's a nice piece.

Cooper: Will it play LA?

Asner: It did; you missed it.





Cooper: You didn't call me.

Asner: I know. And I won't be calling you.

(*laughter*)

Asner: Maybe in my next life you can catch it.

Cooper: Has anybody filmed it?

Asner: About two years ago. I don't know what happened to it. It's lying around some place. I'm better in it now than I was then, so I would prefer to reshoot it, rather than use the older version.

Cooper: How many more bookings do you have?

Asner: Just the one. Today I've got a rehearsal for my next one-man show, and I may get very busy with that. So I'll leave *FDR* in the dust, who knows? The Shadow knows.

Cooper: And the next one is about the prostate?

Asner: Yeah.

Cooper: Is that your personal story?

Asner: No. It's about "Ed." He wrote this charming one-man show about his troubles. I've heard one out of every two men will come down with that problem.

Cooper: I've actually heard that almost all men die with prostate problems. They don't die of it, but they have them.

Asner: That's right. There was a point there when they decided that rather than operate, to leave it alone, because you would probably die from other things before the prostate would kill you. I don't know if that's any longer the truth. Knock wood. I don't seem to have any of those problems.

Cooper: Coming back around to autism, would you talk about your family's connection to it?

Asner: Well, I have four children. The youngest, Charlie, is 27; he was deemed autistic when he was seven or eight, which is late. He's high functioning, and the lady I was going with at the time tended to regard him as her primary endeavor. We eventually married, and he became her main charge. We've had him all over the place. He went to school in Chicago, and he loved it there. I did, too; it's a great city. And he was at a health group here for about a year. We didn't care for that. He eventually came back and tried Evergreen, in the state of Washington. And that was low control, low guidance. But he needed something more enveloping.

After a year there, he spent a few months at Santa Monica City, and then we heard about Chapel Haven in New Haven, CT, which dealt in a wonderful fashion with autism and its associated disorders. They were excellent. I would also tell you that when he graduated public school we sent him to Cal Poly Middle School. They had never had an autistic kid and were hesitant in doing



so, but they finally consented, and he had a marvelous three years there. I certainly recommend that school. It's an excellent school.

Cooper: Where is that?

Asner: It's in Pasadena. Well, it's right across from Cal Poly U.

Cooper: So kind of the Pomona area?

Asner: Yeah. There's also a high school associated with it, too. It was deemed that he probably could not tackle the high school sufficiently enough. We then sent him to Chicago. And right now he is involved in the New Haven hospital. It's called volunteer service, where they sign up and they are then shifted from one department to another volunteering and assisting. He's worked well at some of the departments and not well at some of the others. But it's designed to prepare him for going into the outside world, to prepare him for work in the outside world.

Cooper: We have a program called ABILITY Corps. It's for volunteers with disabilities to work with other non-profits that have volunteer programs, just exactly what they're doing. It's a gateway, a mid-road, if you will, to see what they like, what they're comfortable with, and hopefully engaging them into moving into a career choice and getting hired somewhere. That's so important.

Asner: Yes. From seven or eight on, he's been monomaniac. He gets locked onto a subject, which most autistic kids do, and hates to leave it. Black holes were a favorite of his when he was seven and eight. But he's moved on since then.

Cooper: That's a deep subject, though.

(*laughter*)

Asner: He could stay on that subject forever. Thank God he's moved on. He's a very bright fellow, and I hope to God we find the area of life that will give him happiness and productivity.

Martirosyan: Were you aware of autism before your son—

Asner: Not at all, not at all. My lady at the time, who did such a great job with Charlie while we were bringing him up, often said that she doesn't think he had autism, she thinks he has Asnerism.

(*laughter*)

Lia: She's a smart lady.

Asner: She is, very clever, yeah. I don't know where she is now, but I hope she's happy.

Cooper: How long has your son been part of the hospital volunteer program?

Asner: Six months. His stint there is coming to an end, so I'll be going to Connecticut soon. They'll issue reports on him, grade him, judge him. At the same time, Chapel Haven's advisors, caretakers have been there to help him, advise him and better him. I just want to make him happier. I haven't gotten there yet.

Cooper: Do you know Joey Travolta's Inclusion Films?

Asner: I know of his wonderful work in trying to find work placement [for people with autism]. I think what Microsoft is doing is fantastic. They respect the autist's ability to retain information and think of a level of detail and depth or excel in math and code. And they try to place as many of these people as they can. I think it's a—because I've often said that the world would be a happier place if it was run by autistics. And it may well be. But I think Microsoft's got the right idea, and I hope other major corporations take the hint. I also know—what's the name of that other group? (*Calls "Liza."*)

Liza: Exceptional Minds?

Asner: Thank you. Exceptional Minds [Studio]. That's a nice name, isn't it? It's certainly accurate. I've seen their work. It's excellent, particularly in animation. It's a job trying to sell major studio producers on the idea of taking on people with autism en masse.

Cooper: Do you know if your son has tried anything in



Ed looking for his picture in our Mary Tyler Moore Issue

that realm yet?

Asner: No. I've never seen any of his—graphically, there's nothing breathtaking about what he does there. He pursues chess, working the mind all the time, mentally rather than graphically.

Cooper: Let me show you something, because you asked about the magazine.

Asner: An interview with Mary Tyler Moore? I've heard of her. What's she doing these days?

Cooper: This was a while ago; we talked to her about having diabetes. [Moore, 78, was diagnosed with Type 1 diabetes at age 33.]

Asner: (*flipping through the magazine*) You don't show me in here one little bit, do you?

Cooper: There might be a picture of you.

Asner: There's Ted Knight. He made it in, but not me… I'm so glad you made it to my house, now get out!

(*laughter*)

Cooper: I was lucky to find that at the last minute.

Asner: What other surprises do you have for me?

Cooper: "Mary, come on out!"

(*laughter*)

Have you talked to her?

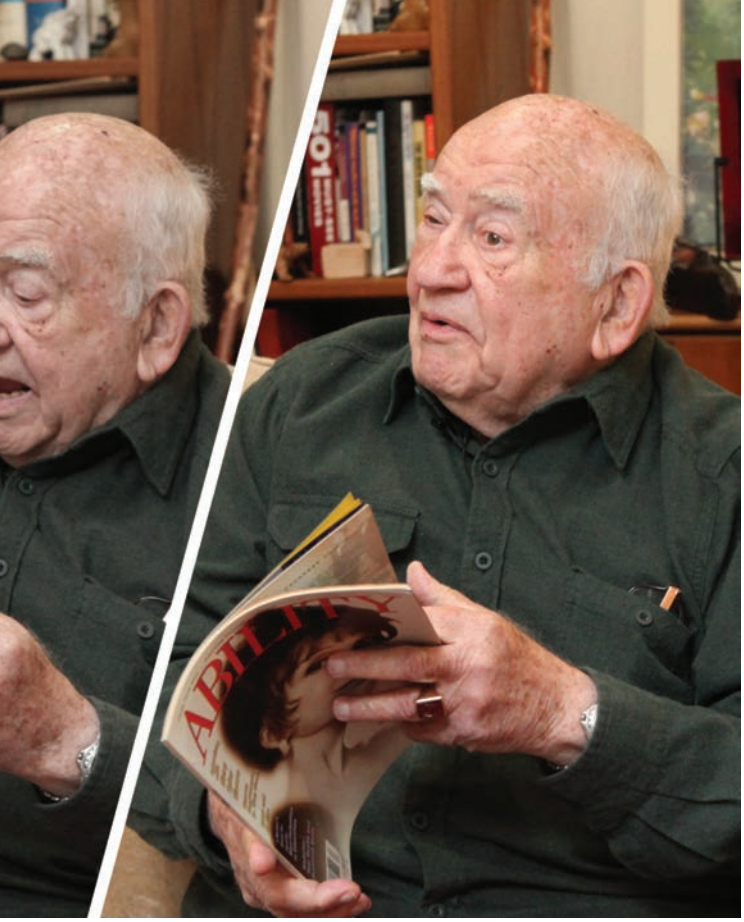
Asner: Not in a year or so.

Martirosyan: Have you met Temple Grandin?

Asner: No, but I'm a great admirer of hers. I think what she has done is—talk about bread on the waters... She earned her PhD. Her vocal ability is not extensive or clear, I would say, but I've seen the results of her work. She's improved the method by which animals in stockyards go to their death. That terrible fear generated in animals prior to their being slaughtered is horrible for them, and throws a lot of adrenalin into the bloodstream and probably is very harmful to us, as well. So she has provided, as best she can, the methods and means by which animals are not confronted so blatantly with the horror of their impending death. I think the results of her efforts and her research will be far reaching.

Martirosyan: Are you a vegetarian?

Asner: I'd love to be. I wouldn't be fat if I were. You ever see any fat vegetarians? As he got older, my father would complain when my mother put beef on the table. In Kansas, during the summers, the last thing you want to see is a big, thick piece of meat. He'd complain. In Kansas, you don't get that much fish, either. It's meat or swim. It has to be an admirable way to eat. My father avoids sugars, but he hasn't defeated the gluten monster yet. You have to defeat that if you're trying to



be a non-fatty.

*Martirosyan: Very insightful. (*laughs*)*

Asner: Did you hear the story of the gal who comes into the pharmacy and tells the pharmacist what she wants, and he says, "Cyanide? I can't give you cyanide. I could lose my license and be sent to jail if I did. What do you want cyanide for?" She says, "I want to kill my husband." "Why do you want to kill your husband?" "Because he's been sleeping with your wife." "My wife? How do you know that?" She pulls out a photo and shows the two of them together. He says, "How much cyanide did you want?"

(*laughter*)

Seriously, though, I went to a dinner recently where the focus was the death penalty, and I saw several people who had been exonerated. There was a trio, one had spent 40 years in jail, the other two, like 38 years. Men, of course. At least two of the three were very well spoken, very good-looking, all put there because a 12-year-old kid lied about them being the perpetrators.

Cooper: The same kid?

Asner: Named all three of them. And the kid later recanted his story, and the detectives wouldn't admit it. This goes on all the time.

Cooper: Was this a fundraiser?

Asner: Yes, for various justice projects... Everyday you read about a prosecutor who failed to disclose certain exculpating information. It's horrible. I met a guy there who was accused of killing his mother, and spent 20 years in the joint.

Martirosyan: What happened?

Asner: At the time, they took the kid who was 17, and surrounded him with jailhouse snitches. They created a story that eventually got him indicted and sentenced. I don't know if they sentenced him to death, because he was 17, but certainly for life. There was another kid staying in the house who actually killed the mother…] undoubtedly to get the money that she had on her.

Martirosyan: Wow.

Asner: Fortunately, that young man who'd been wrongly imprisoned was there with his wife; she was a South African, and they seemed very happy.

Martirosyan: How long have you been involved with death penalty issues?

Asner: Years.

Martirosyan: Do you remember what got you into it? What sparked your interest?

Asner: I tried to help the accused before. I remember going to Missouri and trying to meet with the governor to try to save a guy's life, but I wasn't successful.

Cooper: That's got to be heart wrenching: When you work to try to save somebody's life, and the system doesn't listen.

Asner: It is… Getting back to autism: One in 68 suffer from it. It's probably a bigger number now. It affects a high percentage of kids.

Martirosyan: How have you seen the awareness of autism change throughout your son's life?

Asner: The numbers themselves began to increase so much. One of the best things you can do about autism is to find jobs and careers for those affected by it, in part because they're very good at what they do.

Martirosyan: Yes.

Asner: There was this time when he was riding with me as a kid and I already had some fame and a cop pulled me over, I did a wrong turn or something. As the cop came up to the window to write the ticket, Charlie leaned over towards the window and said, "Do you know who you're talking to?" That's one of the main efforts we have with autistic children, autistic adults. Because of their inability to lie and because of their lack



Will and father, Matthew Asner



Ed and grandson Will

of immediacy or awareness, to get law enforcement to understand that there are these types of people that they cannot exercise ordinary tough-cop bullshit. They've got to assess the situation and respond accordingly, and hopefully, amicably treat sufferers from autism.

Cooper: There's a major correlation of the death penalty and imprisonment of people with different mental health issues.

Asner: Oh, God, yeah. A lot of 'em.

Martirosyan: Is that a picture of your son there?

Asner: No, that's my older son, Matt, who is a project director for Autism Speaks. He's done a fantastic job there. Matt also has a son who is autistic. Asnerism all over again. He did a great job with an Autism Speaks event last year. They had a great march at the Rose Bowl.

Cooper: Yes, we were there.

Asner: You were there? With 50,000-some people, right?

Cooper: And three.

Asner: Oh, yeah, we don't count you.

(*laughter*)

And then, shortly after that, he had their third concert at the Pantages Theater [in Hollywood] of Light Up the Blues. Steve Earle, Chris Stills, Shawn Colvin, and Neil Young were there. They played beautifully. There were a lot of good acts.

Cooper: Do you know Neil Young?

Asner: No, I never met him. Jack Black was the MC. Brad Pitt was there and contributed a very funny auction routine that he did with Jack Black.

Cooper: And your son helped put that on?

Asner: Mm-hmm. That's his third year of staging it.

Cooper: Is he working out of New York?

Asner: Here.

Cooper: We met with Autism Speaks out of New York since we created the first employment site for people with disabilities on the web, back in 1995.

Asner: What was that called?

Cooper: ABILITY Jobs. We focus a person's ability, ABILITY Magazine, *ABILITY Corps. Autism Speaks raises a lot of funds for research and advocacy.*

Asner: They have, really. I'd tip my hat if it had one.

Cooper: So you've had an incredible career.

Asner: It's only the beginning.

Cooper: That's an interesting comment. Is there anything you look at and say, "I would have liked to have gone this other direction"?

Asner: I do. I'm not heralded in every hallway in the world. I still have to be discovered by a lot of people. [points to a picture] That's my father right there, by the way.

Cooper: Which one?

Asner: The one on the right. His brother came over from Russia after him, spent a few years with him in the junkyard. That's the junkyard behind him. And then he went back to Russia, my uncle. He fathered seven kids, I think, almost all of them wiped out in the Holocaust. And the one remaining is in a senior citizens' home in Windsor, Canada. He's about 98, I guess.

When the Nazis came in, there were four healthy sons, the daughter, and a brother with a disability. The four healthy sons decided to take off to the woods, which is what the Jews did whenever they needed to escape. They decided that the sister would stay with the brother. The four brothers created a nucleus of a partisan band, and during the course of the war, three of them were killed, one by the Germans, one by the Polish fascists, and the third committed suicide before he was taken. Abram, the one who survived, married his wife in the camps and eventually came and settled in Canada.

Cooper: Interesting background.

Asner: How long have you been in business with this magazine?

Cooper: Twenty-some years.

Asner: You don't have a watch on?

Martirosyan: Twenty-five-ish years.

Cooper: I started when I was six and a half. And Lia, here, sings opera.

Asner: You're worth something. So you're not gonna juggle?

Martirosyan: I might.

Asner: I'm tryin' to work up an act where you can make some money.

Martirosyan: With fire or without?

(*laughter*)

Cooper: Have you ever done stand up?

Asner: No. I can't even do good sit down. That has to be the hardest job in the world. It certainly must be a suicidal pursuit to finally think that you can get out there and entertain people just shooting the s—. And people who do it with beautiful precision and order, I just marvel at them.

Cooper: You could do it. If you can do a one-person play—the good stand-ups are good actors. They made it look like it's spontaneous, but it's all—

Asner: I can be funny as stuff occurs to me, but to be able to sit down and order your material and create from beginning to end, with variations—naturally they vary it all the time. It's to be envied.

(*to Lia*) I'll let you have a box of Kleenex if you sing. (*to Chet*) Maybe along the way you'll find that picture of me from the Mary Tyler Moore article.

Martirosyan: Take it up with Mary.

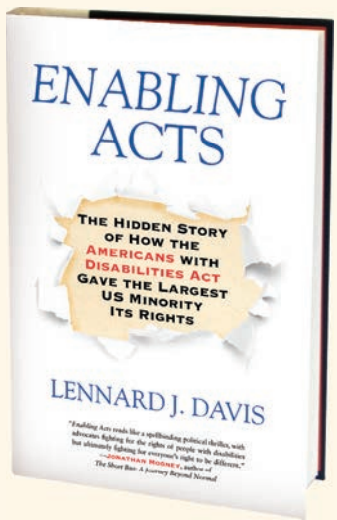
(*laughter*) ■ ABILITY

autismspeaks.org
autism-works.com
exceptionalmindsstudio.org



ADA 25
AMERICANS WITH DISABILITIES ACT
1990-2015

DISCOVER THE HIDDEN HISTORY OF THE ADA



"The essential account of the determined activists, seasoned politicians, and unheralded citizens whose efforts a quarter century ago launched a transformation in American law and culture that still resonates today."
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"*Enabling Acts* is a must-read."
—SENATOR BOB DOLE

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Dan Buckingham always knew he wanted a life outside of the ordinary, but he never imagined the route he would take to get there.

Dan is a 34-year-old digital producer of AttitudeLive, a Paralympian and a world traveller. He's played wheelchair rugby from Australia to Athens, and won a gold medal along the way. But it's his role as producer on AttitudeLive that gives him the greatest personal satisfaction.

This innovative web platform delivers high quality short-form and long-form documentaries, live-streaming of Paralympic sport, video and written blogs. All led by people with lived experience of disability. It's part of the Attitude Group, based out of Auckland, New Zealand. The company also creates television content with a focus on diversity and disability, as well as holding Notional Awards for people living with a disability.

How he got to this role is its own story. At 18 he was studying surveying at Otago University in Dunedin, New Zealand. Sport was his passion. He was playing club rugby for Otago when a scrum collapsed. Dan found himself on the ground, unable to feel his legs. "I didn't have any idea what spinal cord injury was, I just knew, something bad's happened."

Dan was instantly paralysed by the dislocation of vertebrae in his spine, resulting in tetraplegia.

It was devastating at the time, and for a while he couldn't see his future clearly. And it's one of the reasons he is a passionate advocate for AttitudeLive.

"How great it would have been when I had my injury to call up a story about another young guy who'd been through the same sort of injury I had, and come out the other side. That's something I could really have done with early on, because it shows you just how a new path is possible."

When Dan came out of the hospital rehabilitation unit, he had to reassess everything about his life, including finding a whole new career. A couple of years went by as he tried different options and then eventually started a journalism degree at Canterbury University in Christchurch, New Zealand.

Television producer and CEO of Attitude, Robyn Scott-Vincent, was on the lookout for a presenter for her then new TV programme about people living with disability.

When she gave a guest lecture at the journalism course Dan saw an opportunity, and so did she.

Recruited for Attitude Pictures as a presenter and researcher, Dan took a leap in the dark—one that fulfilled all the ambitions he had about a challenging and creative career.



Dan Buckingham & colleagues bringing projects to life at AttitudeLive

"With Attitude I have met some incredible people… people who have made me driven to want to get more out of my own life, but also many people who have given me a greater sense of wanting to be part of something greater than myself by helping to make change at a higher societal level."

Eighteen months ago Robyn came up with a concept of a web platform to host Attitude's considerable library of programmes—more than 400 episodes documenting the experiences of people living with disability.

Dan took on the producer's role and the concept grew into the goal of a creating a global online community—to deliver niche content to a world audience.

"We see it as a community hub for anyone living with disability, whether it's the person with the disability or a family member. There are over 400 stories on the site, each one personal and unique. We also feature content from all over the world, both opinion pieces and factual reports. For instance, you can find everything from one of our staffers editorial "The day I stopped caring about what others think of my disability" to a report on a new smartphone that responds to eye movements."

The design of the site has been taken to new levels. The brief was always to ensure the platform offered accessibility to all.

The platform has been designed with the highest accessible features, multi-lingual closed-captions, audio descriptions, and an option for dyslexia-friendly typography.

"It's been optimized for screen readers, there's captioning on every story, and we made sure it's easy to navigate."

For many people living with a disability, the internet has been a social revolution, allowing people to connect with others whether they're in a bedroom in rural New Zealand, or a tower block in Chicago.

"We've got an awesome engagement level with AttitudeLive, with people who arrive there spending a lot of time on the site. A big part of this is watching all the video content, but we also have a lot of really well-written opinion pieces and we deliver high level, distilled information. What we really want to do is connect the community.

An exciting development we have happening right now is the partnership we've developed with *ABILITY Magazine*. While we're proud of what we do here, New Zealand is a small community compared with the reach *ABILITY* has—we're looking forward to showing what we do over here, and seeing how Americans and the international community as a whole will react and engage". ■ ABILITY

AttitudeLive.com



MAKING science ACCESSIBLE

Consider two images: In one, three kittens look towards the camera, and in the other there's a diagram of the molecules in a single aspirin. The former shows three fluffy cuties with eyes and noses, the latter only black characters and lines on a white background.

Now imagine that you are blind and have to rely on a screen reader to tell you what's displayed on your computer monitor. If no other information is available, you'll need computer software to help you decipher the images.

Companies such as Google, Facebook and Microsoft have come up with ways to identify the cats in images, but they've not done as well with helping people who have low or no vision recognize diagram, such as the one of the aspirin molecule.

While at first glance the cats may seem to be more complex an image than that of the Aspirin diagram, once you've seen lots of cat pictures, your eye is trained to instantly recognize the shape of yet another cat, even if you've never seen the picture before. You can even identify the vague outline of a cat, because the details are not critically important. But with images of science content, details are everything.

When you want to describe diagrams to teach them to students, you need to be precise. It does not help a student to get a vague idea of a diagram. They need to know precisely what it depicts. If you have the picture of a square, it will not help only to know that it is a polygon. To understand a chemical molecule, you need to know all the atoms it contains, and how they are combined via bonds. So if you get a small part wrong, you might as well not depict the diagram at all.

Consequently, science subjects are the most difficult to teach to students with visual or print impairments. For sighted people, think back to your own math or chemistry classes in high school or college: Diagrams and images of geometric shapes or images of atoms and bonds were an integral part of your studies.

Ideally students who are blind are taught science diagrams with a mixture of tactile graphics, 3D models, and teacher assistance. Students with low vision use tools to magnify images both on paper and on the board. And students with other impairments, such as dyslexia, often need material presented in high contrast colors, such as yellow lines on a blue background, or white on a green one.

In reality, these tools are not always available. When visually impaired students are being taught in mainstream schools, there may be little understanding of their needs, or in environments where there's not enough money to fund special support, this population can be

clearly disadvantaged. In fact, in many countries, even in developed ones, visually impaired students may be actively discouraged from taking science classes, regardless of their ability level, simply because they can't get the material or support they need for their studies.

One would think that moving towards more computer-based teaching, replacing printed textbooks with their electronic version, would resolve this dilemma. But moving from printed material to electronic books only solves parts of the accessibility problem.

Although text is immediately accessible and can, for instance, be voiced by an eBook reader, without the need for audio recording of a human reader, graphical content is generally only transformed into electronic images. While visually this achieves the same result as in print, it does the opposite in terms of a graphic's accessibility.

Once you have an image, the information it contains is effectively lost; all you are left with is a rectangle of meaningless pixels. It is totally inaccessible by screen readers, and any text contained in the graphic is also now just a collection of pixels that can no longer be voiced.

If you are relying on magnification, an enlarged, fixed-resolution image will become grainy and illegible. For dyslexic readers, images do not allow them to change foreground and background colors for their reading preferences, or enable highlighting of text within the image.

While there might be accessible captions, they are generally not sufficient to explain the graphic. So to make it fully accessible, one needs to explicitly add the explanations in an alternative format. However, in the mass transition of printed material into electronic books, this problem is often inadequately addressed, or not addressed at all. As a consequence, science textbooks in electronic form are often less accessible than their audio-recording counterparts.

One can solve this problem by creating specialist software for drawing diagrams in an accessible format that allows a reader to listen to descriptions of the diagram and interact with it. But this raises two new barriers:

On the one hand authors actually have to be aware of the existence of the software and use it to draw diagrams. On the other hand, students need to use the same software to read the diagrams, meaning that they not only need to purchase the program, but also learn how to work with it, which imposes a learning curve above and beyond the actual subject they're studying.

The problem is further compounded by more and more material being produced on the fly. It's become easy and cheap for everyone to create their own custom handouts, including graphics prepared with drawing programs that they can put online for students to work through independently. But many teachers are unaware of the technology available to create accessible content, or may not have the means to do so. Therefore the knowledge gap between students who can work with graphics and those who can't continues to widen.

The main motivation for our work is to bridge this gap, and to lower the barrier for students with visual or print impairments to study the sciences, and also to support already working scientists who acquire such impairment now or in the future.

We are building a technology that does not erect new hurdles between student and content. Our software does not rely on authors to generate accessible diagrams, and can deal with images of from and an array of sources, regardless of how they were created.

Images are automatically analyzed and turned into a format that is open, standardized, and accessible. Students can use them on their desktops, laptops or tablets, along with their regular web browser and normal screen-reader or magnification tool, without investing additional time and money in a specialist-reading tool.

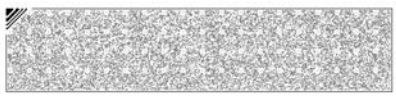
While this solution might sound obvious, it's technically a highly challenging task. Since we have no control over the type and format of the images that come in to be read by our software, the most challenging part is the initial image analysis.

Diagrams can be well-drawn, high-resolution images, but they can also be cropped from scanned books with dirty pages and fingerprints. These images are cleaned so they can be correctly interpreted.

Interpretation naturally depends on the type of diagrams we need to recognize. The current technology concentrates on chemical diagrams of molecules, which are crucial for studying chemistry and the biosciences. As there are many ways to express the same molecule as a diagram, depending on author preference or author emphasis, our software has to deal with these style differences and interpret different depictions of molecules in a uniform way.

Once the basic structure of the diagram, and thus of the chemical molecule is determined, the program further analyzes the molecule, and computes as much information as is needed to generate a detailed and full explanation of the diagram.

But even if sufficient explanatory text is provided, just listening to it generally is not enough for a student to fully grasp the nature of a diagram. In an ideal teaching situation, students are presented with tactile graphics or 3D models that they can explore to get a feel for the structure and shape of an object, and to be able to ask the teacher what the different parts are.





Dr. Volker Sorge evolving technology for the greater good.

If we want to simulate that on a computer, we have to provide a means for students to interact with a diagram, to explore its structure step by step, and to obtain meaningful information while doing so.

We consequently do not just provide a single explanation for the whole diagram, but also for its components, as well as summaries for sub-structures. Thus when a reader encounters a diagram in the text; they can first listen to its summary, and then dive into it, exploring it in depth using simple keyboard interaction.

During exploration, sub-structures are described, highlighted and magnified. Print impaired users are further supported by the possibility of changing contrast and color combinations. This interactive exploration provides students with an experience similar to tactile graphics or models. Moreover, the spoken explanations can substitute for teacher explanations providing the learner with additional independence.

We have evaluated our software in experiments with high school students, mainly at specialist education colleges. In particular the reaction of chemistry teachers was very positive, with one stating that it is "of benefit when students are accessing written documentation electronically, as the student would not need to divert to a tactile diagram (which may not be available), but can investigate the structure using the web browser."

Our vision for the future is that most, if not all diagrams in electronic books and on web pages, can be automatically identified and replaced by accessible formats to provide a seamless reading experience for visually and print impaired students, enabling them to thrive in the sciences. Currently our product realizes this vision for diagrams in chemistry. But we are also working on other subject areas, such as geometry, physics, and biology.

While providing visually and print impaired students equal access to teaching resources is an important issue to ensure equal opportunity for all learners, regardless of their ability, there is little industry involvement and limited funding available for these tasks. Nevertheless, Volker Sorge is currently taking time off from his academic position to concentrate on these efforts in a dedicated start-up company, Progressive Accessibity Solutions—seeking to raise awareness of the potential diagram access that technology can offer, and to help the technology evolve for the greater good of the next generation of students. ■ ABILITY

by Dr. Volker Sorge

Dr. Volker Sorge is an Associate Professor at the University of Birmingham, UK. He is working with his research group on the recognition and analysis of scientific documents. He was a visiting scientist at Google, working on accessible mathematics and has been working on accessible chemical diagrams with a team of colleagues in Birmingham: Dr. Mark Lee and Dr. Sandy Wilkinson.

progressiveaccess.com

RAISING OUR WEB STANDARDS

In today's world of technological advancements and digitization, nearly every resource uses the Web as a base platform, including education, research, entertainment, health and daily life. Staying connected is of pressing importance, so the Web needs to benefit and be accessible to everyone, including people with disabilities. Out of this need the term Web Accessibility has emerged, and led to the development of standards such as the Web Content Accessibility Guidelines (WCAG).

Upwards of 285 million people across the globe are estimated to be visually impaired, according to a report by the World Health Organization (WHO). Unfortunately, most websites still have accessibility barriers that make it difficult for this population to access many important resources. In an empirical study of the problems encountered by blind users on the Web, results indicate that only 50.4 percent of the difficulties experienced by users were covered by the success criteria in the WCAG.

One major barrier the visually impaired encounter is access to information-embedded pages. Graphs have always been used in many different forms and variations to provide pictorial representation of data and information. The growing trend and demand for data visualization, through graphs as opposed to text, has led to further expansion of their various forms. To date, graphs are widely used across the Web, but most commonly as simple images. Consequently, a major goal of web accessibility is the adequate representation of graphs by screen readers.

While screen readers are somewhat adequate tools for recognizing text on web pages, they are still limited in extracting information from visual content, such as graphs. When graphs are displayed as images, their designers rely heavily on the ALT tag for screen readers to recognize them. However, to be most effective, the Web pages must follow and respect the guidelines recommended by WCAG.

Several algorithms have been devised to recognize the graph images on a web page and translate them into text format that can be read by screen readers. Owing to the algorithms limitations and strict requirements, a widely acceptable practical solution has yet to be proposed. Furthermore, in case of an omitted ALT tag, or an ALT tag with an empty value, the screen reader skips over the image element, causing users with visual impairment to miss some content completely.

evoGraphs is a jQuery plugin that allows creation of dynamic and stylish graphs with the capability of being screen reader friendly. The plugin is fully customizable to the needs of the user, and it's comprised of HTML, CSS and jQuery components, which reduce page-load time significantly. Furthermore, the plugin's design is universal, in that it can easily read SVG graphs, which are widely used on the Web to render high-quality, two-dimensional graphics.

Extensive testing has shown that, compared to traditional image-based graphs, the plugin is nearly twice as fast in terms of page-load times. Various screen readers were tested for accessibility across multiple platforms by a control group of sighted and visually impaired users.

The concept behind evoGraphs is not just to present the elements of a graph to the user, but also to present the elements on the basis of their significance. For example, in a graph of 10,000 elements, visual users can identify the largest and smallest elements with little or no difficulty. However, for people with visual impairment, finding the largest and smallest elements entails going through the entire set of elements, which is not practical. The ability of customization allows the developers to present only the most significant elements, as per their perception, to the screen readers. Understanding that this does not necessarily reflect a user's definition of significant elements, we're working to create a browser extension to allow the users to select the information that they wish to extract from the graph.

The plugin presently supports only horizontal and vertical bar graphs, as well as pie charts. Conversion of image-based graphs to evoGraphs is not supported dynamically, but could be achieved by manually plugging in the values. In terms of future improvements, plans are under way to include more graph types, to import a CSV file, and to develop a conversion tool for image-based graphs. Extension of this plugin to incorporate D3 Visualizations and maps is also in the works. ■ ABILITY

by Ather Sharif

Ather Sharif is the founder of EvoXLabs and Spinal Cord Injury Video Blog. He's pursuing a graduate degree in computer science at Saint Joseph's University. A quadriplegic, software engineer, freelance web developer, researcher, and Google scholar, he has a passion for consulting on Web accessibility.

athersharif.com

NOW I CAN DO IT MYS3LF

Math Software Empowers Students of All Abilities

Our economy increasingly depends on technology. So many of the best-paying jobs in the coming years will be in that arena. In fact, there were 6.2 million scientists and engineers in the US in 2012, according to the Federation of American Scientists. Unfortunately, people who are blind are vastly underrepresented in technological fields.

A great many of today's schools also rely on technology to teach. In a math classroom, it's not unusual to see a student in front of a computer wearing a headset and progressing through a lesson plan.

A few years ago in some Kentucky classrooms, students with dyslexia got a chance to try technology to see if it would help them not only read the text in their books, but also to solve the math problems. The results were a success in more ways than one: Not only did kids' scores go up faster than even the students who didn't have dyslexia, but their sense of empowerment also increased. They no longer waited for a teacher's aide to come by and read with them; they could listen to parts of the book as many times as they needed to without embarrassment. "Now I can do it myself," they said.

When I started exploring math accessibility more than a decade ago, this is what I hoped would happen. At the time, I worked on Wolfram Research's Mathematica product. One day, John Gardner, a physicist who lost his sight late in life, contacted me and explained the obstacles he encountered trying to use sophisticated Mathematica software. It was an intriguing issue to tackle, and one that could potentially open the world of scientific computation to people with vision disabilities. So with Wolfram's consent, I developed a prototype that thrilled John. For various reasons, however, Wolfram decided not to turn the prototype into a product.

FIRST STEPS

Design Science in Long Beach, CA, expressed an interest in making accessible math software, and I joined their team to pursue my ideas. The company had already developed a free plug-in to Internet Explorer called MathPlayer that would display MathML. We received a grant from the National Science Foundation (NSF) to explore making MathPlayer accessible to everyone. We finished the prototype of MathPlayer 2 within the grant's six-month time line, and the version we released was well received.

To "speak" math, as in so much of human language, there are many special cases and exceptions. The initial version of MathPlayer had a few dozen special cases. The current version has over a thousand. Every new iteration of the software adds more rules, so that the speech gets closer and closer to what a teacher might say in the classroom. Educational Testing Service (ETS) received a Department of Education grant that helped us develop a more natural language for "speaking" math, and to expand MathPlayer so that it works with Microsoft Word.

With the release of MathPlayer 2, people who were blind or had other learning challenges could use the software to read a web page with math in it for the first time. This proved to be a big hit when I showed it off at conferences, and eventually I heard back from teachers and parents who said the product made a significant difference in their children's education.

During the ETS grant period that lead to the release of the beta version of MathPlayer 4 last March, I joined my

ETS colleagues Beth Brownstein and Lois Frankel at the Texas School for the Blind and Visually Impaired. There we met a student who was preparing to head off to college the following year. He tried out the precursor to MathPlayer 4, which included the ability to move around an expression, as well as to relisten to parts of a problem. The more I showed him, the more excited the student got. By the end of the demo, he told me that he had been worried about how well he would do in a calculus course, but with the new MathPlayer he felt confident he could succeed.

I'VE BEEN WAITING FOR THIS

Sina Bahram, a bright PhD student in computer science also encouraged me, and contributed some ideas for MathPlayer 4's design. After he gave it a try, Bahram, who is blind, sent me an email that read: "This is the first time in my life I can just open up a browser and begin interacting with mathematics. I'm not sure you can understand how profoundly wonderful that is to me, and how many years I've been waiting for such a thing."

What a great feeling it is to know that MathPlayer has taken an important step towards increasing the representation of people who are blind in the fields of science, math and engineering. In the last year, about 700 people used the software to make math accessible on the web and in Microsoft Word documents.

It's been a bumpy road getting to this point. There were barriers that couldn't be solved simply by writing software. MathPlayer makes use of a W3C standard called MathML. When MathPlayer 2 was released, only Internet Explorer with the MathPlayer plug-in and Firefox supported it. Limited support of MathML meant that most people used images for math instead of MathML, which allowed the "math" to render everywhere. Textbooks had similar problems.

To resolve these issues, I joined several committees to ensure support for accessible math in standards for various formats such as DAISY books, the new EPUB 3 eBook format, PDF documents, and National Instructional Materials Act Standard (NIMAS) for K-12 textbooks.

After showing these groups demos of what could be done to support math, they all agreed that MathML was the way to go. The big breakthrough was last year when HTML5 became a standard, and MathML was part of it. Now it's an official part of the language of the Web. The icing on the cake came this year when ISO and IEC groups adopted MathML, making it an international standard recognized by many governments.

+14 MORE LANGUAGES

Maybe you guessed this already, but I like math. Not the math taught in schools, which usually involves memorizing facts and formulas, but real math, which is about solving puzzles. I have been fortunate to meet people who've been willing to solve the puzzle of translating MathPlayer's speech into other languages. Because of them, the software currently supports Chinese, Czech, Danish, Dutch, German, Greek, Finnish, French, Icelandic, Italian, Japanese, Norwegian, Spanish and Swedish. Although three quarters of MathPlayer users are English speakers, about 25 percent use of one of the translations.

MathPlayer's first international languages were Spanish and Chinese, the latter of which is by far the most popular. For these translations, we were lucky enough to find Dana Li, a high school intern who knew lots of math, had taken many years of Spanish, and was a native Chinese speaker. What I came to learn that first summer is that speaking a language doesn't mean you have any idea how to speak math in that language. (For instance, can you say "the square root of 10" in that language?) When she joined Design Science for the summer, Dana came with a hidden advantage: Her mother had an engineering degree from a university in Beijing. As I told Dana's mother, "Thank you Ms. Li. You went far beyond the standard scope of motherly love!"

In the past, educators could rightfully say that math accessibility was costly and difficult. By one estimate, converting a math textbook to Braille in the US costs about $60,000, and requires roughly six months. MathML and the digital era are changing that, helping us to enter a golden age of accessibility.

Safari and VoiceOver on Apple devices will also read, navigate, and create Braille on refreshable displays for MathML-encoded math on webpages. ChromeVox will do it on Chromebooks. JAWS, the screen reader with the largest share of the market, jumped on the bandwagon and released a new version last year that also reads MathML.

There's more to this subject than reading and understanding equations. But here too, there's been great progress recently in creating accessible calculators and software that can make mathematical plots accessible via sound, and combinations of hardware and software for enriching tactile diagrams, so that someone can use touch and feel, as well as hear information that isn't easily represented in Braille.

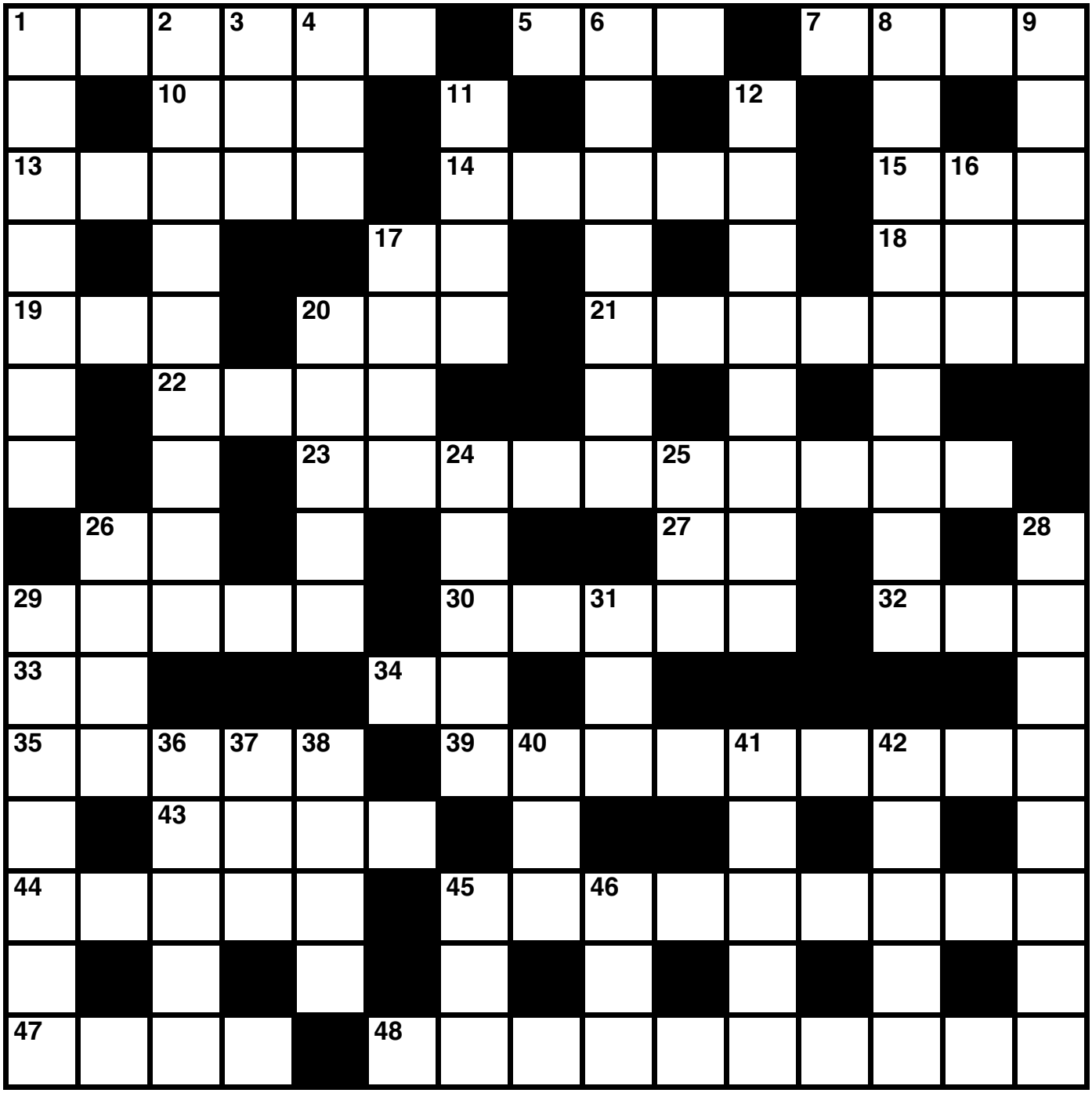
The next big step is making it easy for people to do math on a computer, which should offer great benefits over pen and paper, as is the case with writing. Maybe I'll be the one to develop that software, or perhaps someone will get there before me. But the most important thing is that it empowers people of all abilities to do the math. ■ ABILITY

by Neil Soiffer

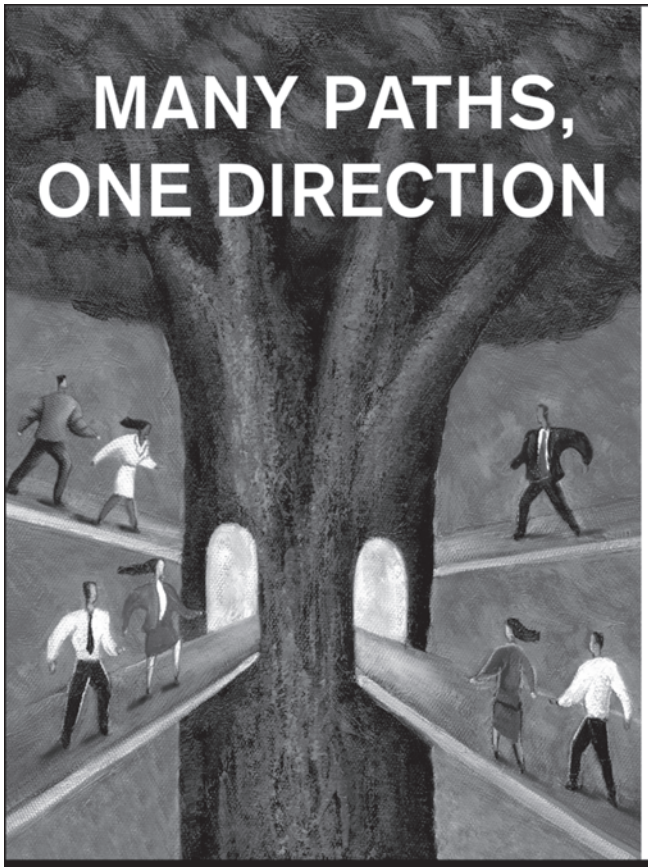
Neil Soiffer is a senior scientist at Design Science, where he's helped develop such standards as MathML, DAISY, EPUB3, NIMAS and PDF/UA.

dessci.com

ABILITY's



Crossword Puzzle



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DIVERSITY CREATES ENDLESS OPPORTUNITIES

ACROSS

1. China's incredible sports star and inspirational speaker, who lost his leg when 9 years old, 2 words
5. "A Change is Gonna Come" singer, ___ Cooke
7. Forthright
10. Where to find porters
13. 2014 movie showing the trials Martin Luther King went through to handle injustice and inequality
14. Question after a bad joke, 2 words
15. Beer keg feature
17. __ Capitan, majestic mountain
18. Delta scheduling word, abbr.
19. Switch position
20. Opinion
21. Enduring for ever
22. Connections
23. What to do after a fall or setback, 4 words
26. Titan's locale
27. Salt Lake city locale
29. Bach composition
30. Cry from "Pirates of the Caribbean"
32. SEC football team
33. NFL position, for short
34. Time period way back, for short
35. Bird that is a symbol of patriotism
39. He became a popular musician despite battling Cerble Palsy, Chris _____
43. It wasn't built in a day
44. If you have a ___, you have a future (message from 1 across)
45. Keep going, no matter what
47. ___-Me (Austin Powers character)
48. Be just perfect, 3 words

DOWN

1. "Don't know much about ____" song from Sam Cooke
2. Inspirational
3. Kind of rap
4. Hard core association that Long Haul Paul belongs to! abbr.
6. City in Belgium
8. Buddhist Master Cheng Yen: "Do not underestimate yourself: people have unlimited _____"
9. Majestic country where Mt Everest is
11. "____ Betty" show
12. "_____, Courage and Wisdom" India Arie song
16. "One Day ___ Time" 2 words
17. Make less difficult
20. Transition
24. Help someone else learn a skill
25. Summer month
26. Heavy marching band instrument
28. Most courageous
29. Fourth of July principle
31. Went fast
36. R & B singer who sang "I'm So tired of Being Alone," Al ____
37. Mauna ___ in Hawaii
38. Small-screen trophy
40. "__ of Destruction": 1965 protest song
41. He was a "Superman" in his work to help people with spinal cord injuries
42. Easy on the wallet
45. Baked taro dish
46. Scoundrel

Crossword Puzzle

answers on page 62

SEE BETTER AT ANY AGE

AUTHOR
- The Miracle of Pi in Eye
- LASIK in the 21st Century
- Cure for Keratoconus

VOTED BEST
- Newsweek Showcase Top Doctor
- LA Daily News Readers
- VC Star Readers
- Consumer Research Council

DOCTOR'S DOCTOR
- Surgeons & Physicians
- Chiropractors & Dentists

SURGEON TO STARS
- Actors & Celebrities
- Olympic Athletes

FOR PATIENTS 18-45
- Thin Flap Lasik
- ICL

FOR PATIENTS 45-65
- Superlasik
- Pi in Eye

FOR PATIENTS ABOVE 65
- Pi in Eye
- Laser Cataract Surgery

OTHER THAN LASIK
- Pterygium
- Intacs & Cross-linking (CXL) for Keratoconus

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Crossword Puzzle

The Makeathon, by TOM, will take place in San Francisco September 11-13



Tikkun Olam Makers

Bay Area Makeathon; an innovative event that will utilize design technologies and self-manufacturing capabilities to create solutions that assist and empower people living with disabilities

Google.org

UCP United Cerebral Palsy

tomglobal.org





DISABILITY UNITY FESTIVAL





Disability Unity Parade & Festival

SATURDAY, SEPTEMBER 26, 2015

UN Plaza & Civic Center Plaza • San Francisco, CA

11:00am - 3:00pm

Strengthening Our Communities
Celebrating 25 Years of the ADA

DisabilityUnityFestival.org

Festival Contact Info: (408) 673-7590 | DUF2015@svilc.org

Also Featuring:

California #ADA25 Conference
Friday & Saturday, September 25 & 26, 2015
UC Hastings • San Francisco, CA
DisabilityOrganizing.net

DO Disability Organizing network

Conference Contact Info: (877) 427-0387 / (800) 900-0706 TDD
conference@disabilityorganizing.net









ILRCSF support • information • advocacy

CRIL

Independent Living

MARIN CENTER FOR INDEPENDENT LIVING

SVILC www.svilc.org

CENTER FOR INDEPENDENCE of Individuals with Disabilities

Y.O. YOUTH ORGANIZING AND POWER

CFILC

2016

Multi – discipline Rehab Treatment Rehacare & Orthopedic Canton/6th

廣州國際康復設備展覽會 | 廣州國際福祉輔具展覽會

Concurrent Event

The 3rd International Rehabilitation Canton Forum

廣州國際康復論壇



Attention

25-27 March, 2016
(Friday, Saturday and Sunday)
2016年3月25-27日（周五，六，日）

Poly World Trade Centre, Guangzhou, China
(No.1000, Xingang Dong Road, Guangzhou)
中國・廣州・保利世貿博覽館（廣州市新港東路1000號）

en.cantonrehacare.com

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www.lifelabs.ucp.org

My Child Without Limits.org

A resource for families of children with a range of disabilities to connect, ask questions, and find valuable, reliable information.

www.mychildwithoutlimits.org

My LIFE WITHOUT LIMITS

A resource for adults with disabilities and their families tackling issues such as access to college, employment, transitions, relationships, and other topics.

www.mylifewithoutlimits.org



LIFE WITHOUT LIMITS

for people with disabilities and their families

visit: www.ucp.org

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ATiA Assistive Technology Industry Association

ASSISTIVE TECHNOLOGY PROFESSIONAL DEVELOPMENT OPPORTUNITIES

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ATIA's Online Professional Development Webinars Program provides the latest information on AT products, services and best practices from leading regional, national and international presenters – all year round! Register for online webinars to remain on the forefront of assistive technology.

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Save the Date

Pre-Conference: February 2-3, 2016
Conference: February 2-6, 2016

Caribe Royale All-Suites Hotel & Convention Center
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50 MILES
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TO END MS

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CONNECT AT CHALLENGE WALK MS:
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REGISTER NOW & START FUNDRAISING TODAY:
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October 21-23, 2015
The Westin Lake Las Vegas Resort & Spa
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www.accessibilityassociation.org/access2015

IAAP International Association *of* Accessibility Professionals

Register by September 18 and Save!

IAAP's inaugural educational conference will allow you to:

- Network with other professionals from around the world focusing on accessibility issues and implementation
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- Meet with leading product and service providers in the exhibit hall
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Arts & Services for Disabled, Inc. introduces

The Creative Health & Wellness Clinic

an outpatient treatment program for children and adolescents with various disabilities

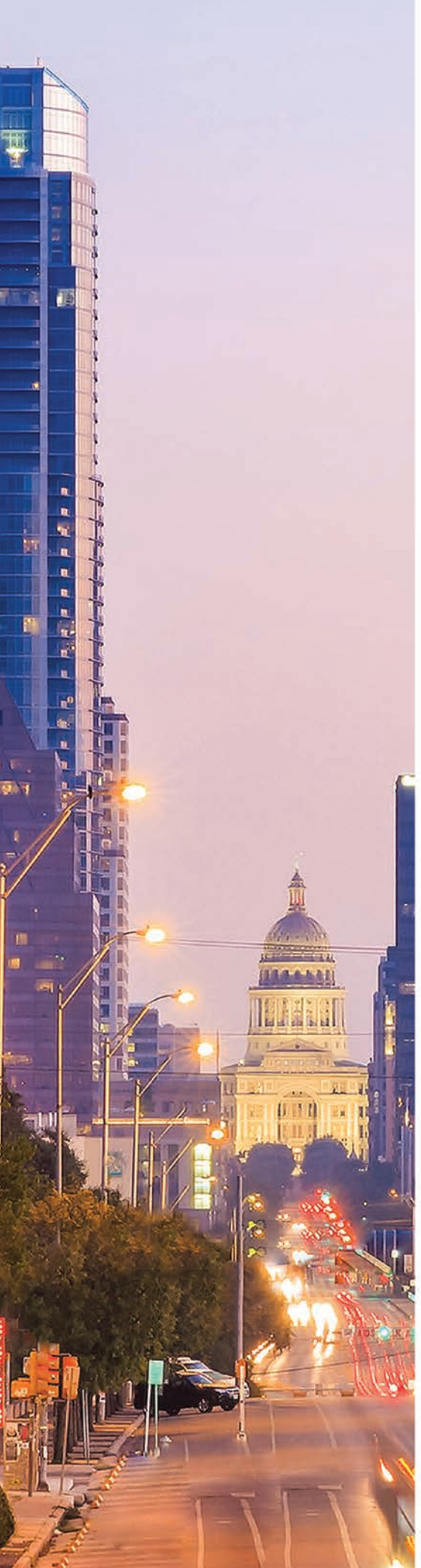


We believe each child has a unique and innate preference in how they access and achieve their own learning needs. The Creative Health & Wellness Clinic specifically addresses these needs through our distinctive approach, Creative Arts IN Therapy & Creative Arts AS Therapy, which employs creative arts therapies to reach and teach individuals with disabilites, working with them through play and music to achieve their non-musical goals.

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This is the preeminent national event that focuses on disability inclusion in the workplace, supply chain and marketplace. This conference brings corporate, government, disability-owned businesses and BLN affiliates together to create an environment where people with disabilities are fully included as employees, entrepreneurs and customers.

2015 PROGRAMMING INCLUDES:

- **Workplace** – Hear from companies on how they achieved success in recruiting and employing people with disabilities. Sessions focus on improving your bottom line. Understand the Return on Investment (ROI) for hiring, promoting and retaining employees with disabilities.
- **Marketplace** – Learn key trends and dynamic strategies on effective and accessible marketing practices that tap into a loyal consumer base with $220 billion in spendable, discretionary income.
- **Supply Chain** – Learn how to diversify your corporate or government agency supplier diversity programs by utilizing businesses owned by people with disabilities, including service-disabled veterans. Discover how USBLN certification and the Disability Supplier Diversity Program® (DSDP) can help accelerate business growth and contract opportunities for disability-owned businesses, including companies owned by service-disabled veterans that are important contributors to local community growth and development.
- **JAN's Accommodation Solutions for Business** – Discover cutting-edge job accommodation solutions from senior JAN Consultants.

JAN Job Accommodation Network
Practical Solutions • Workplace Success

What can YOU do?
The Campaign for Disability Employment
www.whatcanyoudocampaign.org

At work, it's what people can do that matters.
What Can YOU Do? Visit www.whatcanyoudocampaign.org

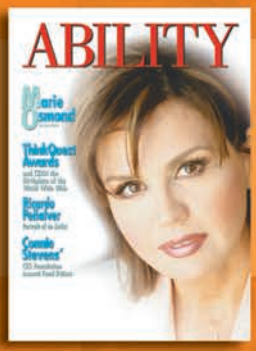
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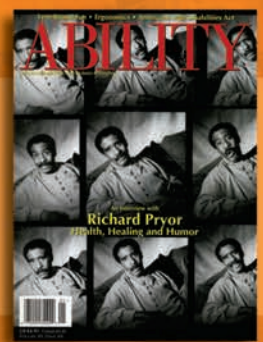
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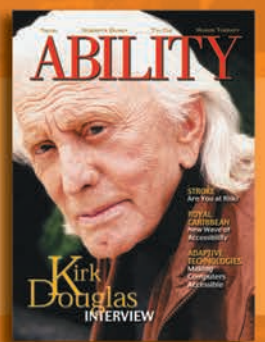
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For Denise, this is the start of a new chapter.

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