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ABILITY



GABBY GIFFORDS
Won't Back Down

Steven Verdile & the SQUEAKY WHEEL

JUSTICE BERNSTEIN
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It's been a crazy busy summer! I have already done two MX schools and I will soon be doing a 3 day ladies ride camp at Cycle Ranch in Texas. My most recent school was at Last Chance Raceway in Helena, Montana I had about 13 riders it was a lot of fun. My friend Shelli helped me interpret again and she is always fun to hang around with. We hit a few breweries and different restaurants on our drive up there and back. That is always a nice adventure to try out different spots.

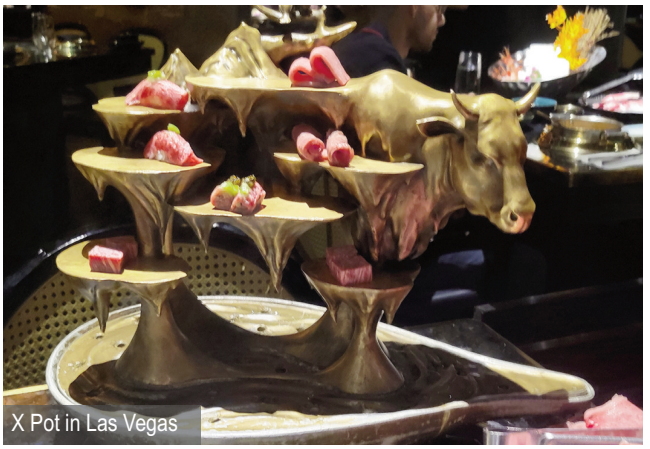

Ashley training corner turns in Montana

This August I will be going over to Sweden for the Ride Cake finale. That should be exciting, that is when I will get to ride on the electric bikes again. I am excited to see everyone and to have another chance to ride on those amazing bikes.

In September I will be going to Luxembourg as a guest. They will be having their first supercross ever and they have invited some of us racers to go over to watch and to promote their race! That should be a good time.

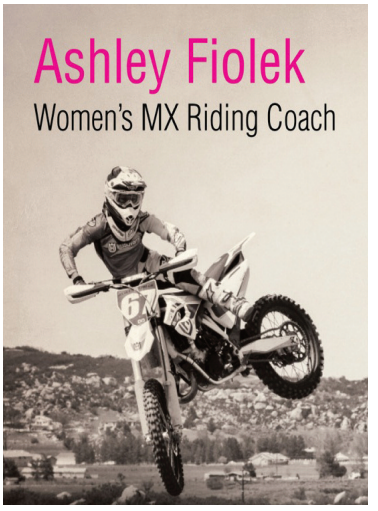

Electric motorcycle Cake

In addition to doing classes and attending different races I have been enjoying the summer weather and have gone on a couple of camping trips. It's so beautiful here in Utah to be able to do that. Even when its super hot if you are up in the mountains its cool we have also gone tubing and the water is super cold, but feels great! I sold my house in California and to celebrate Lindsey and I went to Las Vegas we had a lot of fun there. We enjoy gambling, but didn't win, oh well. I have always wanted to go to this restaurant in Vegas it's called X Pot. Whenever we have been our friends didn't want to go. This time it was just Lindsey and I so we had the chance to go its the most amazing Asian food. I highly recommend it if you have the chance to get to Vegas.


X Pot in Las Vegas

That's all for now I will update you all on how the classes and races went next time.

■ ABILITY



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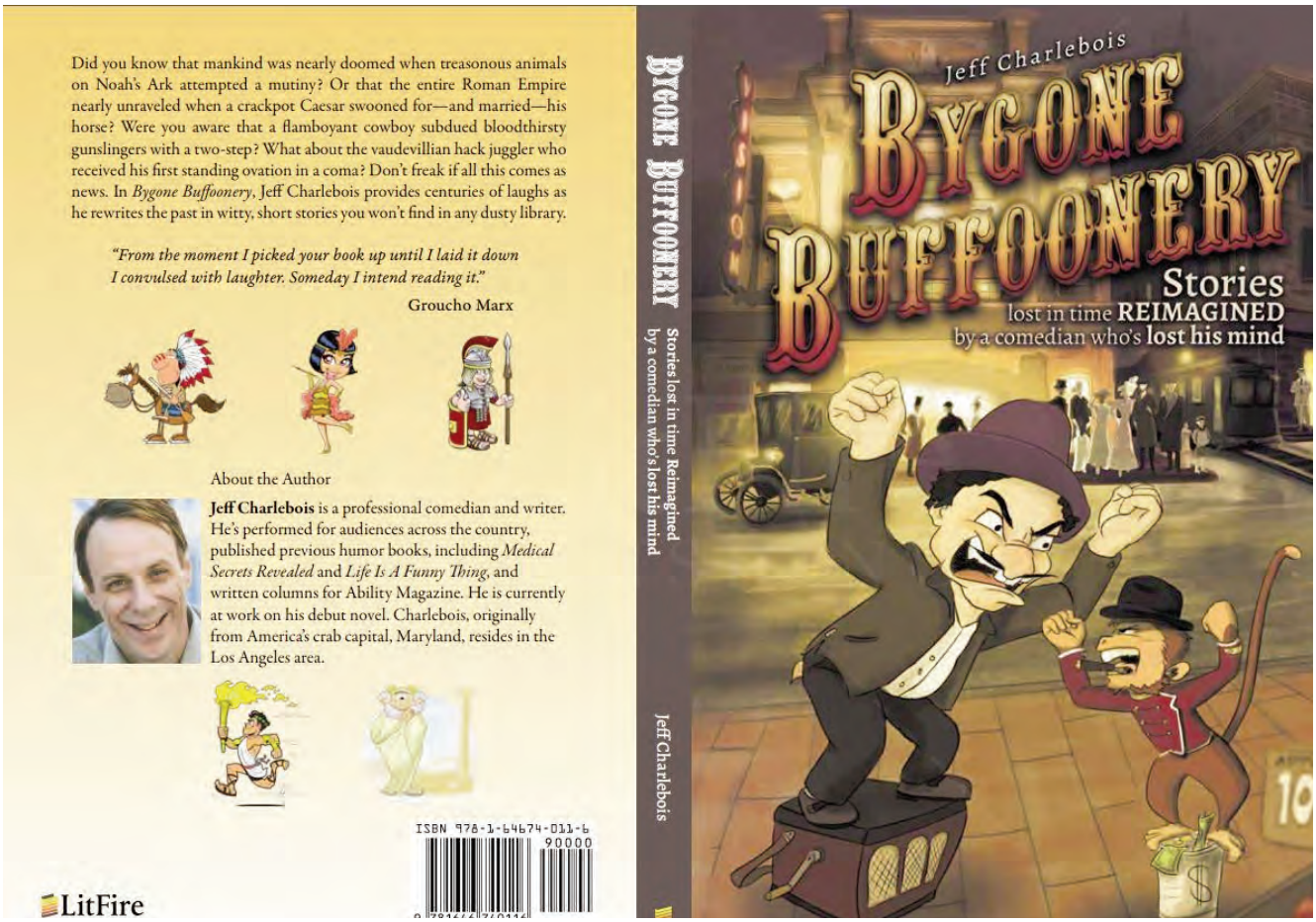




I'm Not a Fan

When I was younger I used to love sports. I played them all; football, baseball, basketball, tennis, miniature golf, etc. I was always outside horsing around with some ball and wouldn't come in until it was dark. When there was a window busted on our house there was no guessing game of who done did it. Maybe I just liked playing outside or maybe I just knew if I were inside my mom would have me cleaning the house that I had been kind enough to mess up. But, as much as I liked playing sports, I liked watching them just as much. But times have changed. My love for watching professional sports is about the same as watching *90 Day Fiancé*. Sadly, sports have been hijacked by politics, too many commericals and new rules.

Let's talk football. I used to really love watching football, now I'll just watch it without the love. The game used to be good back in the days when they let the players play. In those days a player could hit the quarterback, use the cleats to step on hands, decapitate a receiver. Is that good stuff or what? Now on almost every play, no exaggeration, there is a flag on the field.



A ticky-tack penalty that slows the game down and gives one team an advantage. And it's usually something minute like stepping on your opponent's toes or ripping off someone's helmet. I did muster the strength to stop watching football for a while. It wasn't easy, but I had to take a stand on something that disturbed me. The only thing that keeps me watching football is the gambling. I love betting on games, almost as much as I hate losing my money, which seems to happen a little too much.

I've heard gripping by some soccer and WNBA female athletes that they don't make the salary amounts the pro male athletes make. Well, true dat, but there's a reason. Sadly, you gals don't fill stadiums and arenas. No doubt you babes are great players, but you're just not pulling the crowds, which is where much of your salary comes from. But, it's not us nasty men's fault, for once. As the comedian Bill Burr has stated in one of his routines is quite frankly the women aren't coming out to support the women. You ladies are staying home watching *The Kardashians*, who, by the way, make millions. See how it works? You get paid by the viewers.

Then, if I look at golf, a sport that I loved playing and watching some players are shaking up the PGA by leaving the tour and competing over in Saudi Arabia, that big sand trap in the Middle East. Apparently, the pay is better. Why go for the million when you can go for the ten million? Maybe some of our golfers can hide some oil in their golf bags and bring it back here. Many of the golf scores are lower than our gas prices. It seems like it would be too hot to play golf over there. The good thing is if your hands get sweaty you can always dry them off when wearing you're ankle-long thawb. I'd be afraid to win a tournament over there. One of their princes had a news reporter assassinated over a story he didn't like. Could you imagine what they'd do if you beat one of their favorite golfers? Chop off your hand, maybe? Not good—you need that for putting.

I hate to say it, but I've become a little soured on sports. I never go out of my way to watch them anymore. I'd rather waste my precious time polluting my brain on Netflix. I even read books instead of a baseball game. Yes, some people still read. Today, it seems anything that was once good has now been dismantled. Sport's figures seem entitled. Many don't seem too grateful to make the lucrative amount of money they make. Kick me one of your checks. I don't want to hear anything more than my favorite player or team win. Just do what you were put on this earth to do, which is play ball and entertain us with your extraordinary God-given talents. Oh, and win me some money for a change. ■ ABILITY

Jeff Charlebois

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周妤宸 在音乐里舒展生命

Zhou Yuchen: Expanding Her Life in Music

Zhou Yuchen was born in Sichuan in 2002, an accident at the age of 5 leaving her blind in the right eye and reducing the already-poor vision in her other eye to somewhere between 20/200 and 20/100. She has been playing piano since early childhood and is skilled with traditional Chinese musical instruments, such as pipa, zhongruan, liuqin, and guzheng. She has won more than 50 music awards, including the "gold prize in the China Finals of the 3rd International Mozart Piano Competition". She was also selected for a warm-up show as a reserve instrumentalist at the Beijing Winter Paralympics Yanqing Awarding Ceremony in March 2022. Currently she is studying the International Preparatory Course at the School of Music and Recording Arts, at the Communication University of China.

One day in August 2003, as the sun poured in through the window, a little girl who had just turned one was playing with an electronic piano, her chubby little hands flying over the keyboard to produce a flow of sounds, her young face full of surprise and curiosity.

This moment, which was captured in a photograph, is often revisited 19 years later by the girl's mother, Zeng Zhaoyong, and the subject is Zhou Yuchen. Time has passed, and the babbling toddler has now grown into an adult who is profoundly connected to the world of music, as she was always destined to be.

"A trophy child of Mr. and Mrs. Jones"

A member of what is known as the "post-00" cohort in China, namely children born in the 2000s, Zhou Yuchen has much in common with other people her age. She sometimes flips through Tik Tok and Bilibili, and at other times falls for pretty earrings and dolls. Unlike many people, however, she lives with grade-I visual impairments in China's classification of disabilities. In her world, sound is more reliable than color.

Showing an interest in music from a young age, Yuchen began to learn piano when she was three and a half years old. In addition to the piano, she was also good with traditional Chinese stringed instruments like the pipa and zhongruan. In late January 2022, the Disabled Persons' Federation in Chongqing phoned her and invited her to attend the rehearsal of a traditional Chinese instrumental music performance at the Yanqing Awarding Ceremony for the Beijing Winter Paralympics. Zeng Zhaoyong was very proud that her daughter had an opportunity to showcase traditional Chinese music as well as herself on the world stage.

All these musical achievements didn't happen overnight. For more than ten years, Zhou Yuchen has been shuttling between competitions in Beijing, Shanghai, Guangzhou, Shenzhen, Hong Kong, Singapore, and Malaysia – to name just a few – and has won more than 50 music awards in China and abroad, including such noteworthy trophies as the "Gold Prize in the China Finals of the 3rd International Mozart Piano Competition".

"My friends often say that they want to swap kids with me," Zeng Zhaoyong said with a smile. Yuchen is apparently a "trophy child of Mr. and Mrs. Jones", as the Chinese catchphrase goes. She is sensible, diligent, and outstanding in school. But behind all these achievements, the mother and daughter mostly keep their struggles over the years to themselves.



One morning in 2007, when Yuchen was 5, a child next to her accidently whipped her in the right eye with a skipping rope in the kindergarten. She was too young to realize what had happened and the teacher did not pay attention. When she collected her daughter that day, Zeng Zhaoyong saw that one of her eyes was red and swollen, but it was already too late. The cornea of the girl's right eye had become detached. After examining the child, the doctor accused the mother of being negligent, but it didn't help: Yucheng had lost her right eye. After that, the vision in her left eye declined sharply, due to childhood glaucoma. From elementary school onwards, she started trying to adapt to the life of "someone who can't see."

Yuchen could read books only with the help of magnifiers and electronic visual aids; otherwise everything was a blur. "I can only see that it is probably not white," Yuchen said. In class, she tried to learn by listening to and memorizing all that the teacher was saying since she was unable to see the blackboard. If she wanted to "see" some leaves and flowers, she had to feel their shapes and textures with her hands.

It took Yuchen more time to learn things, be it music scores or schoolwork, but her intelligence, good memory, and outstanding grades secured her a place in a well-known key local middle school in Chongqing before she graduated from elementary school – with a waiver of the tuition fee.

In the school's traditional Chinese music group, Yuchen got her hands on a greater variety of traditional musical instruments. Thanks to her piano background, in which she had developed a good sense of tuning, she was often asked to help the other members, who would line up in front of her waiting for their instruments to be tuned before the practice started. Over time her sense of music became better and better, and such interactions with her teammates led to her learning more instruments. Pipa, zhongruan, liuqin, guzheng, guqin – Yuchen picked them all up very easily. "Musical instruments are interlinked." Familiar with one, she could learn another fast, being highly perceptive as she is.

Her academic workload increased as Yuchen moved on to junior high school, and she began to feel some difficulty in keeping pace. However, she and her family didn't opt for a special education school. Yuchen hoped that she could study and take the college entrance examination like everybody else. "She wanted to make it work through her own efforts," her mother said. "And she feels that she can do what others can." The daughter was mentally strong, and the mother envisaged a future where Yuchen learned to be independent and blend in. Zeng Zhaoyong hopes that her daughter can always learn and grow within the able-bodied community.

One of Yuchen's deep disappointments is that she had to forego college entrance examinations as no use of electronics, including electronic visual aids, was allowed on-site, but this did not prevent her from continuing her studies. In 2019, while studying at Chongqing Culture and Art Vocational College, Yuchen was offered a place in the Trinity Laban Conservatoire of Music and Dance. One of the four leading music schools in London, TLCMD is known globally for its creativity and forward thinking. Several times they expressed the earnest hope of having Yuchen bring Chinese musical tradition to the UK, but the high tuition



and living costs seemed daunting to her and her mother.

In 2020, when the first wave of Covid-19 swept the world, Yuchen opted to defer her offer. Just then, she was selected for a co-education program of the School of Music and Recording Arts, at the Communication University of China, to which she was later admitted.

Friends for life and study buddies

Freedom is in the air on campus, and youngsters in their late teens can't wait to cut the apron strings and live independently of their parents. Zeng Zhaoyong was also mentally prepared at this point. "I should have let her go long ago, and she should have her own life". But Yuchen is not that anxious to "run away" from her mother. She doesn't see her mother's love as restricting and confining, and she understands how much her mother has done and what she expects. She has even come to terms with her parents' divorce. This has a lot to do with the mutual dependence and trust between mother and daughter. Their relationship remains close and strong, like friends for life.

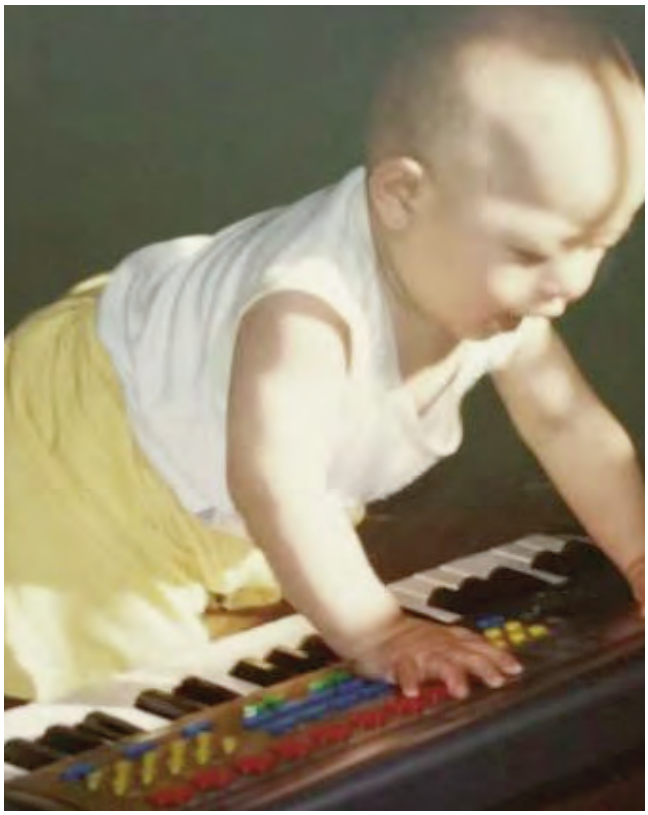
Zhaoyong is very keen on appearance. Like all young mothers, she loves dressing up her daughter and helping her to use eyebrow pencils and lipsticks. Yuchen in turn calls her mother by the nickname, "sister", with a grin.

During her college years, Yuchen often shuttled between Beijing and Chongqing on her own. Her mother often joked that she was being "shipped" like goods, referring to the special services airlines or railway departments provide for people with disabilities to travel alone safely. This is how she communicates with her daughter – open and direct, without circumlocution.

When it comes to academic pursuits, the women are more like study buddies. "We make plans every semester according to the school timetable and the learning schedules for various musical instruments, and our to-do-lists are broken down into minutes." Zhaoyong, a marathon runner, is optimistic and energetic, and she makes a rather strict and meticulous study plan for her daughter. Mondays, Wednesdays, and Fridays are scheduled for Yuchen to practise two of the musical instruments; Tuesdays, Thursdays, and Saturdays, the other three. Nothing can override these one-hour sessions. Yuchen is very self-disciplined and, therefore, able to work well with her mother, whether it's academic or musical study. In study hours, she stays focused and efficient; at other times she enjoys playtime to her heart's content.

Zhaoyong often says that she has experienced a "second growth" by working as her daughter's study buddy. Seeing her daughter's continued growth, she feels that all she has gone through is rewarding in itself. Her tasks include transcribing musical scores, both numbered or stave, in extra-large fonts – an accumulation of several sacks of them. To address the high cost of her daughter's music studies, she once juggled three jobs and still managed to pick Yuchen up from school on time. During this interview, a package was delivered to her door containing a copy of "Family Education Instructor Qualifications Certificate". With this Zhaoyong would like to move to a flexible work schedule so that she can take care of her daughter's needs more easily.

There are occasions when Zhaoyong finds herself down



in the dumps, and Yuchen can feel it. "But she doesn't want me to know. That's why I pretend not to." Yuchen is very sure of her mother's crucial role in her growth, but Zhaoyong seems inclined to give her daughter the credit. "She is very self-disciplined, and seeing her work so hard every day, I have nothing else to ask for as a mother."

Exploring the world through music

When asked if she has a gift for music, Yuchen always modestly answers that she simply spends more time practising it. Doing drills day after day have turned on a magical side of music, releasing Yuchen's brilliance and empowering her inner transformation as a person.

"In the last two years, I am happy to see that she has fully accepted her disability," said Yuchen's mother, with love written all over her face. Coming out of the shadows is by no means an easy thing. Compared to other people her age, Yuchen seems much more mature. "Now the importance of maintaining one's first family is being highlighted, but I think that's just one side of the story. How one sees oneself as a person is also important. What is done cannot be undone, but people can change themselves and foster growth for themselves." Blindness is an issue far more difficult to deal with than a broken family. For Yuchen, accepting herself and pursuing positive change is the only way to overcome the difficulties in her life since it is impossible for her to change what Fate has brought her. Fortunately, she has found solace in music and stepped into a wider world with notes flowing from her fingertips.

In his novella "The Musician", the writer Chen Chuncheng created a wonderful scene of synesthesia, in which a panel of examiners evaluates unidentified musical scores by playing each piece with their eyes closed and noting what their other senses tell them, including imagination, smell, taste and even touch. Each piece of work brings different imageries and emotions, like "wreaths turning around in the sun" and "waves of the Volga River", sometimes pleasant and at other times passionate. Music connects the senses and creates a richer experience.

Yuchen finds this description to her liking. "Everyone has a different imagination, visions, and feelings while listening to music. It is very complicated and inclusive, and you can see and feel more through continuous study and experience. Music has kept me good company on my path to growth. It brings me a lot of happiness and strength. By communicating with it, I know myself better, and I can see a more colorful world through its language. " For Yuchen, music is her window to the world as well as her companion.

In order to keep in practice while studying the university's preparatory course, Yuchen continued to learn piano with several faculty members working in the Central Conservatory of Music. One of them said about her: "Her inner world is pure and pristine, crystal clear like a pool of water, encompassing many things from outside, but not disturbed by the secularities that arise from such intrusion."

Sitting on stage, fingers on the keys, Yuchen instantly immerses herself in the music as the notes float in the air. The world of music is pure and boundless, and she is free of any physical defects, unleashing more from within herself and stretching the tentacles of her life to where she wants to go, unrestricted and unstoppable.

Now Yuchen, like everyone else, expects the COVID-19 pandemic to end soon. She aspires to be a music teacher or performer. "My thoughts about the future have been involving since childhood," Yuchen said with a smile. She still has a long way to go. Maybe she will just discover more possibilities to expand her life once she gets to experience a wider world. ■ ABILITY

by Wu Lijun
Pictures: courtesy of the interviewee

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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Speaking British Columbian Again

15,000 miles in three weeks

Last month, I was invited by Yamaha to attend the Touratech Rally in Plain Washington. Touratech is a company that makes and sells accessories for the on road/off road Adventure style of motorcycle. The rally was a great place to meet up with and increase supporters of my million mile journey for MS. It didn't take me long to to realize if I took an extra day riding from New Hampshire to Washington, I could retrace a portion of the greatest road trip I ever took. North from New Hampshire to Montreal and then west across all the Canadian Provinces would lead me to the incredible majestic awe of the Canadian Rockies.

Although I spent less than a day riding in the Rockies, I was flooded with the memories and emotions of that first trip. I snapped a few good photos before heading south to Washington, and vowed I would return to the magical mountains soon.

It is hard to believe it has been seven years since I last had a chance to ride across all of Canada. It was a business trip, I was heading to speak at seven west coast Multiple Sclerosis educational events where I would share my inspirational story to newly diagnosed patients. I started that ride in upstate New York and five days later I arrived at the first of 7 events - in Anchorage Alaska! I left early the next morning and made it all the way to the Arctic Circle before turning around and heading for my next stop a few days later, in Las Vegas!

Just following the GPS for the quickest route south, I accidentally found myself riding through the Canadian Rockies and in particular, on the Ice Fields Parkway. This stretch of road connects the famous Jasper and Banff National Parks. The mountains, the roads, the parks and the glaciers were all incredible sights for tourists who venture there on purpose, but imagine what it felt like finding them merely by accident!


90



I have travelled 400,000 miles on motorcycles since that June 2015 trip, but it still is the greatest place that I have ever discovered on two wheels. I had little time to stop and really enjoy the sights, but I still managed to get over 400 photos from that trip, mostly without even slowing down!

That trip was a turning point for me and my journey in many ways. It was the first time the pharmaceutical company had strung a series of talks together in a tour for me and did not argue with me riding my motorcycle to all of them. (That issue would rear it's ugly head three years later). Second, after a program in Los Angeles, I was introduced to the top executives at Yamaha Motor USA, which as we all know, led to my largest corporate supporter and current brand ambassador position.

A lot of planning went into that tour. Dozens of people were involved in the scheduling of events, locating venues, speakers, catering and event promotion. I had planned my routes and talks for weeks, prepared my bike and hoped I could make my side trip dream of riding to the Arctic Circle possible.

The most incredible road trip I ever took never would have happened had I listened to reasonable and sound advice from both family and friends who expressed concern about my safety. Not about my ability to ride 15,000 miles in three weeks alone across vast isolated areas of the continent without cell service and certainly



not worried about the bears and bison that did not work for Barnum and Bailey. Their concern was based on facts.

Ten days before leaving on my trip, I began to experience some health issues. I was out of breath and had pain shooting up my neck and over to my arm. Although I did not have a heart attack, doctors discovered I had an artery that was 99% blocked! Without a chance to go home for clean underwear, I was hurried into surgery where they put a couple of stents in my heart. I was released from the hospital 6 days before I was supposed to leave for Alaska on my motorcycle.

It might have been safer or smarter to listen to all the reasonable advice to cancel my tour, but instead, I listened to my heart. Life can create many opportunities that seem tough or out of reach, but giving in and giving up have never been part of my journey. I knew without a doubt the trip would bring me incredible value and riding has always been a part of my therapy for healing and dealing with many challenges I have faced.

I don't know if brushing up on a seven year-old Rosetta Stone "Learn British Columbian" CD helped at me all, but last month's ride through the Canadian Rockies proved to be just as important to my journey as that first time.

As I retraced some of that original ride, it was my finishing my million mile journey that weighed heavily on my mind, and this ride along the Ice Fields Parkway was just the dose of Motomedicine that I needed. It reminded me to buckle up and keep riding hard and I will eventually reach my journey's destination.

After all, If life were easy, everyone would get one. ■ ABILITY

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Nicole KOHR

Colie Creations

Nicole Kohr emanates positive energy, and speaks so eloquently even while casually chatting. Nicole had a myriad of symptoms since birth, but wasn't diagnosed with cystic fibrosis until the age of 5. Cystic fibrosis (CF) is an inherited life-threatening disorder that damages the lungs and digestive system. With years of no proper medication and lung damage, she was told she'd only live to 10 years old. During her uphill climb and years of being isolated in hospital rooms, storytelling became Nicole's lifeline. *ABILITY*'s Lia had the pleasure of catching up with the author and founder of the non-profit Colie Creations, where their mission is to advocate for patients through storytelling.

Lia Martirosyan: How are you doing?

Nicole Kohr: I'm good, how about yourself?

Martirosyan: Lovely! Where are you right now?

Kohr: I am in New Bern, North Carolina. We are very coastal, like, right on the water.

Martirosyan: Beautiful. Has the weather been kind?

Kohr: A little wonky, but I'm used to New Jersey weather, where it's just frighteningly unpleasant, so it's sunny out. I have no complaints.

(laughter)

Martirosyan: A little bit of sunshine usually helps with most everything.What brought you to this idea of Colie Creations?

Kohr: Just to give a little prologue, I am a 29-year-old cystic fibrosis patient. As of June 14th, 2019, I am a bilateral lung transplant recipient. I was born with cystic fibrosis. It's a chronic and technically terminal illness that primarily affects my lungs and digestive system. I was diagnosed at age five, which meant I have five years of scarring, and I also have two nonsense mutations, which is a very complicated way of me saying that there weren't many treatments available for patients like myself. So I spent most of my life doing two-week hospital stays called "tune-ups," in the hospital. I was absent from school a lot, and I think during those times of hospitalizations and sickness, I would write. I was a performing arts Broadway baby, so if I wasn't on the stage performing, I was in the hospital writing. I think that's where my love of writing and coping mechanism of writing got started.

Present-day, I am the founder and executive director of Colie Creations Inc. That allows me to do a few things. It's a nonprofit, and our mission is to advocate for patients of all ages through storytelling. The platforms we produced



stories through right now include children's books. I've produced three, and two are on the way. I am currently writing an original musical called "Fall Risk." We just onboarded a composer who has worked on Broadway shows such as "The Lion King," "Aida," very, very talented group. We are also about to do an accessible and inclusive fashion show in the streets of New Bern, North Carolina to bring more awareness to disability and pediatrics in the area. So altogether I'd say my background in performing arts and writing and my journey with cystic fibrosis led to my nonprofit career now.

Martirosyan: Thank you for that beautiful prologue.

Kohr: Thank you!

Martirosyan: Were your parents involved in theater?

Kohr: I was raised by a single Irish Catholic mother. Her name is Patty. She had no association with the theater whatsoever. (laughs) Neither did I, in the beginning, I was a very, very shy child. I was never diagnosed with neurodivergence, but I definitely had at a very minimum some kind of generalized anxiety. I think a lot of that chalked up to my lack of a diagnosis. I was always sick, always coughing, I didn't feel well, and so the only people I was comfortable around were my mom and, say, the handful of people in my life who knew that I had CF, because I was a gooky, yucky kid. I always had a respiratory infection or a problem with my bowels, things like that. So it was hard for me to socialize.

So my mom decided to put me in theater to help with the socialization aspect. And I came alive on the stage. It became the immediate love of my life and my go-to coping mechanism. Any performing arts thing. I was either performing in community theater or going to NYC for commercial work or doing ballet classes, tap classes, acting classes, you name it. That was pretty much my whole childhood.

Martirosyan: So you were able to navigate between all of the health issues you were experiencing, and your love of entertaining?

Kohr: Absolutely, yeah. In my youth, once I was diagnosed at five, there were only one or two treatments available for CF patients at that time. Unfortunately, I used and abused them somewhat quickly, but it did help. I had failure to thrive, and then suddenly those two medications alone really helped me excel, and I was a pretty health child up until about age ten. The ironic part about that was that my doctors, when I was diagnosed at five, said I wouldn't live to be ten, based on older statistics, which have increasingly been proved wrong, thank goodness.

So when I reached, like, middle school, high school age, my lung function started to decline and we started to run out of medications. I would run myself into the ground doing rehearsals and performances and those tune-ups would no longer be a proactive solution, they would be more of a reactive solution. I started to become someone who identifies as a patient. In my childhood I always identified as a performer first, or a survivor, and suddenly labeling myself as a patient was scary. The plan in my senior year was to look for a school that would accept me for a BFA (Bachelor of Fine Arts) in musical theater, but my mom and I had to have a very realistic heart-to-heart that said, "Your lung function is slowly declining



to 50%," and other things, such as diabetes and osteoporosis, started to come into play. I thought, "What will I do about insurance? What will I do if this performing arts career can't physically be up-kept by my future body?"

So I made the realistic decision to pursue a BA (Bachelor of Arts) in public relations, and that allowed me to work in the nonprofit field, have a 9-to-5, have insurance, and Colie Creations started around that time. I still needed that creative outlet. That's when I started to write children's books on the side and things like that, just to again balance out the reality, the coping mechanisms, my need for creative arts.

Martirosyan: When did you get your bilateral lung transplant?

Kohr: In June of 2019. If I had to pick the most impactful time of my life, it was then, because on June 1st of 2019, I was married. On June 14th of 2019, I received my bilateral lung transplant, only 13 days later, and by—

Martirosyan: So that was your honeymoon?

Kohr: (laughs) In a way! Just prior to that, I would have one call, all from my hospital bed. One would say, "What color napkins do you want for your wedding?" And the next call, five minutes later, would say, "Hey, do you have a living will?" And the next call would say, "Hey, you're moving up on the transplant list, you might want to cancel your wedding, because we don't know the timing of these things." It was a very vulnerable and confusing place to live.

Unfortunately, I think I had become so accustomed to an unhealthy work-life balance that that kind of became normal. It's become a priority of mind post-transplant to focus on balance and self-care and longevity.

Martirosyan: Quite the experience! After having received that, did you look at organ transplant donor's a little bit differently, in the sense of promoting that to the general population?

Kohr: Absolutely. In my youth, there were two things that sounded like threats to me. The first was a port-a-cath, and I think a lot of long-term chronically ill IV (intravenous) users and cancer patients, we usually all have a port-a-cath at some point in our lifetime, because our veins are so scarred from frequent IV use that the port kind of sounded like a scary last resort, like you've reached a certain level of sickness. But I had my port for 11 years. I cherished it. It was removed during my transplant for infection and immunosuppression purposes, but I loved my port. And the second one was a transplant. A transplant always sounded like a threat, or like, once you reach this stage, we are officially out of options. You are officially in end stage. But that's no longer the verbiage, and I'm so thankful for that.

A transplant is not a cure, it's just a treatment option. I highly recommend transplants, because in my experience the statistics are now outdated and there are so many impactful and healthy ways to go about it now. And even just having the conversation so that it doesn't seem like a threat, it's just yet another treatment option. I think it's beautiful.

I recently was doing the marketing for my original



musical "Fall Risk," and on Valentine's Day I wrote that "There's nothing more romantic than becoming an organ donor," because February 14th is organ donation day. It's my favorite!

(laughter)

Martirosyan: So romantic.

Kohr: Yup! (laughs)

Martirosyan: Tell us a bit about the musical. I heard that you got a grant to help produce it?

Kohr: Yeah, absolutely! "Fall Risk" is the name of my original musical comedy. It started out as just journal entries. If we were to flash back to my tune-ups in my elementary and middle school days, I would write lyrics and poems about how I was feeling, because I didn't tell people that I had cystic fibrosis, so those journal entries were my truth in what I was going through emotionally at my time. As I aged, I would look back at the lyrics and think, "Wow, it's cool to see where I was at different ages and how I felt about things, how I viewed things." Eventually I added to those lyrics. I added a book, I added music, and so those journal entries became an autobiographical musical of sorts of me being a perform having CF, doing tune-ups, pursuing a life on the stage, and then ending up having a transplant evaluation and transplant.

It's gone through so many variations as I've aged and as I've worked with more professional people. When the Cystic Fibrosis Foundation awarded us that first grant, it became more of a community project, which was wonderful. I had friends I met over Zoom during the global pandemic who were also transplant patients and CF patients had music degrees, and we put together this beautiful score of music. It's just developed since then, and now we're on a path toward off-Broadway, where hopefully we can start to send our book of music and script to producers and things like that and see if we can get a stage, get a CD produced and use that show as just another large visibility campaign for cystic fibrosis and Donate Life. I'm so excited that not only is it an opportunity to tell my story, but an opportunity to advocate and still have that creative outlet. it's been such a blessing.

Martirosyan: Have you produced it to the degree of knowing how many actors will be in the play?

Kohr: As of right now, 12 actors, but usually what hap-

pens in the workshop phase is, a producer will come in and say, "I can put this show on a stage for $80,000 or $250,000, which means you can keep your cast of 12 or we have to make some edits and limit it to a cast of eight." Something along those lines. So as of right now, it's a 12-person cast. We have done two shows live over Zoom, because we wanted an outlet for others during the pandemic, and those cast members are a range of advocates, people who were bedridden, but actors in their beds, and now we're recruiting a more professional, unionized cast. I consider all of them part of the "Fall Risk" family.

Martirosyan: Are you trying to cast individuals with either CF, or disabilities?

Kohr: That would be beautiful. I would love to do so. The only thing that makes the CF casting complicated is that I have CF, and CF patients are not allowed to be in the same room together. If they are, just for infection purposes, we have to stay six feet apart. So just for everyone's safety, we may purposely not cast a cystic fibrosis patients. But are we open to the discussion, to casting someone in the chronically ill community, absolutely. We would love to show inclusion and diversity in representation.

Martirosyan: Fascinating. Let's explore your books, can you talk about "My Pants"?

Kohr: Absolutely. "My Pants" is my award-winning book. It's my second children's book. I just recently saw "Hamilton" on Broadway with my family, it was Christmas, last birthday present. One line that really stuck out to my family and I was, "Why do you write like you're running out of time?" That line sticks with me because subconsciously, I think I've always written like I'm running out of time because of that initial expiration date that I was given, that I would pass away prior to turning ten years old. I think I always wanted to maybe for survivors' guilt leave a mark, you know? So many of my friends have passed from cystic fibrosis who were my age now or younger, and I feel this responsibility to tell stories.

The first book I wrote, "Two Cents," was kind of my coming out children's book. There's this piggy bank, and he has all these toys that keep giving him their two cents, and those two cents are weighing him down. I wrote it so that everyone could enjoy it and relate to the book, but there were bread crumbs about my journey through chronic illness. So by the time I made it to "My Pants," I wanted to put a little of—a few more bread crumbs about chronic illness. "My Pants" is about a neurodivergent girl. Her name is Celana, which is an Indonesian word for "pants," I figured that would be a cute tie-in. She is gradually being diagnosed with neurodivergence throughout the book, which could be autism, anxiety, SPD (sensory processing disorder), OCD (obsessive compulsive disorder), and because I identified as that as a child and I went through those experiences of anxieties. The book finds a way to show children different coping mechanisms if they're going through some of the same things. If you have anxiety about an upcoming baseball game, or noises that are too loud, or you're scared of the doctor. Having a scary doctor is a big theme in the book, and just having a support system with you. I wanted it to be a very awareness- and advocate- heavy book. That was my award-winning book.

And the event that we're doing soon, the "My Pants" Baby Fashion show, is based on that book. So things like that, where I like to take idioms and personification and a bread crumb of chronically ill journey advocacy and throw them into a children's book everyone can relate to.

Martirosyan: You did a third book, too?

Kohr: I did. That one is called "Water Your Human." That is about a little alien boy who wants to prove he is ready to take care of a dog. In order to prove it, he takes his school project, which is a human in a mason jar, think if you had to take the class goldfish home for a week, or the class hamster home for a week, or a plant and care for it, the same concept, except in this case the alien's taking care of a human. He has him in a little jar, and he's feeding him pizza and things that, say, a five- or six-year-old boy would take care of a pet that they don't know anything about. It's a funny story about empathy and caring for another. I thought that was a nice way to fill in maybe siblings or other members of the support system who maybe need to help take care of somebody else, and they need to be aware of what those needs are.

Martirosyan: That's very clever. "You've got to remember to water those humans!"

Kohr: Yeah, every day!

(laughter)

Martirosyan: They're so needy!

Kohr: So needy!

Martirosyan: We've covered quite a bit. Is there anything that you would like us to have asked you?

Kohr: Maybe the concept of transparency.

Martirosyan: Can you tell me the concept of transparency?

(laughter)

Kohr: I sure can! Like I've mentioned, when I was a child I didn't tell people that I had cystic fibrosis. This was for a few reasons. One, I didn't identify as a patient.



I wanted people to see me first and foremost as a performer or a writer, I didn't want the label of patient to affect the brand that I was going for. Two, it was a coping mechanism. If you ignore it, you don't feel it, right? And the third reason was because the performing arts community and everybody else was really ableist and discriminatory against the label of patient. They treated you differently. The handful of times I was transparent about my illness with, say, someone on the school bus or someone who was wondering why I was coughing or sweating so much, and I told them, they suddenly treated me like their mom's friend, very respectful to me. Or they treated me like I was made of glass, or like a billboard for inspiration, but not a friend or someone their age who was going to be invited to their party.

That was very hard for me to navigate as a child. It was hard for me to relate to people my own age or people who hadn't had a certain level of life experience related to healthcare or death. So when I was nearing transplant, around those last days at my work, transparency was needed. The masking had become a detriment. I needed a support system, I needed transparency so people would finally understand what I was going through and where I was at emotionally, where my energy level was.

I told my mom during my transplant surgery and thereafter to show social media everything. It was probably

one of the best decisions I've ever made in my life, because since then, I've had too many people reach out to me with their stories and send love and send me admiration, which I don't understand. I really only had two choices: I could do a transplant or I could die, those were my options. So people say, "How did you do it?" and I say, "I didn't have a choice, and you at some point in your life may not have a choice either. If I can do it, you can do it." That transparency is my new priority, just telling everyone my story and hoping that there's someone out there who has yet to dive roll out of their chronically ill closet and maybe this will be a coping mechanism for them, just hearing my story or having the bravery to tell their own. Transparency is so important.

Martirosyan: Not so easy for everyone.

Kohr: Right, it's true. It took me a long time, and I'm still dabbling with the pros and cons of it. But I think personally, that support system has helped me very, very much.

Martirosyan: I'm glad for you. We had mentioned a little bit earlier about the idea of casting, trying as much as possible to cast a really diverse and inclusive cast. And when I say that, it's not just the play, but have you seen much work related to the entertainment industry in casting individuals with disabilities?

Kohr: Absolutely. And the first example of that would be Deaf West's "Spring Awakening." If you're not familiar, I highly, highly recommend it. There is a female lead in the cast who uses a wheelchair and you would never know it. She is one of the most talented people I've ever seen in my life. She also starred in "Oklahoma." She recently released two children's books. Her name is Ali, and I love and adore her, and I'm so excited to see Broadway start to accept a more diverse cast of people even in very traditional and conservative shows. I'm excited to hop on that train. I want this to be inclusive from a disability aspect, a gender aspect, a race aspect, a cultural aspect. I think everyone needs to be included in the concept of "Fall Risk," because everyone is a fall risk, maybe not physically, but financially, emotionally, it touches everyone, and so should the casting aspect of the show.

Martirosyan: Real quick, when you said you would "never know it," what do you mean?

Kohr: If you were to listen to an album or a cast recording with her on the show, you would never know she was disabled.

I think in the '90s, when I was diagnosed, being labeled as a "disabled performer," instead of just a "performer" was very common. At this point in the present day and age, she's just a performer. Equal with everyone else.

In Deaf West's "Spring Awakening," she is onstage in a wheelchair, and she does all of the choreography just like everybody else. It's just somewhat adapted for her. She killed it.

Martirosyan: You're talking about Ali Stroker, right?

Kohr: I am, She's amazing.

Martirosyan: Yes. What's your next project?

Kohr: I'd say the biggest project is moving "Fall Risk" from script to stage, to the next professional milestone. And publishing my next children's book, which will probably come out Thanksgiving time, and then continuing to host in-person accessible inclusive events. Those are my next big things.

Martirosyan: Wonderful. And your next book is called?

Kohr: My next book is called "Last Straw."

Martirosyan: Lovely. You said "events." The events you're putting together are basically connected to something like a book that you're doing, or the play?

Kohr: I'd say it's all-inclusive under storytelling and patient advocacy. We're using the speaking platform to advertise other things we do as well.

Martirosyan: In this moment, where is Nicole?

Kohr: Right now it's just priority number one, self-care, all of my meds, all of my doctors' appointments, and number two is all of my writing. I write for two columns, I run my nonprofit, which includes general nonprofit administration and writing children's books and producing and writing "Fall Risk." Basically writing and health, that's what I do all day! ■ ABILITY

coliecreations.org



COLIE CREATIONS
Advocacy Through Storytelling



Jealchair

the SQUEAKY WHEEL

grease provided by Steven Verdile

The Squeaky Wheel slams on the brakes when it comes to "inspiration porn." The website is disability turned upside down and sideways to give readers a dose of laughter mixed with reality. Oof! It's satire (not the economy), stupid! Not to be missed are dramatic articles like "Americans with Disabilities Act Turns 32, Buys a Motorcycle and Gets a Cute Pixie Cut."

Out of idioms, *ABILITY*'s George Kaplan and Chet Cooper tapped out with Squeaky Wheel's brain-parent, Steven Verdile, to find out what's behind the curtain of this "The Onion"-like disability creation.

Chet Cooper: Can you tell us a little about yourself, where did you grow up, where did you go to school and who are you wearing?

Steven Verdile: Sure. I have SMA, spinal muscular atrophy. I grew up in Long Island. I went to St. John's University, which is in Queens, New York. I got my degree in graphic design. I started interning then, and I've been working for that company for the last five years. I'm wearing Squeaky Wheel.

Cooper: How did you come up with the Squeaky Wheel?

Verdile: Basically, Squeaky Wheel started because I graduated college a few years ago. I work as a graphic designer and I was interested in disability and comedy, and I was just trying to figure out sort of a project where I could bring all those different things together, something that I thought would really play to my strengths. I had a lot to say about disability at college. I had a lot of perspective that I wanted to share. It took me a couple years to figure out what the format would be. I was playing with a lot of other different projects that never saw the light.

But eventually I worked my way to the idea of, "Wait a sec! I think maybe a satirical newspaper is really the right angle for this," just because I feel like it plays into expectations and subverting expectations. Most non-disabled people's experience of disability is through news, through media, through television. It's not something that they're living, it's something they're being fed and that's being provided to them.

I thought, what a good way to counter that and to feed them the opposite story, to feed people the stories that aren't going on the news, but are actually happening. And the way to make that funny is to make it satire. That's how the project came to be.

Cooper: You wrote the articles?

Verdile: It started with me writing probably two or three design articles myself, just sharing them around the Internet in different places, and then eventually grew into the website, social media accounts. And then people started to reach out to write, and it's taken off for some time. One thing to note is that our team of writers is not local. We're all over the world. We have two writers from England, writers in California, in Florida, Ohio, Canada. It really is a diverse group geographically as well, which is pretty cool.



The Jealchair Has Arrived

by Steven Verdile

Let the ills of your genes match our wheels made of jeans with the timeless design of the first-ever Jealchair.

You asked for it, and you got it. The new all-denim motorized mobility device has hit the market, allowing trendy wheelchair users to ride in style and dazzle in a flappy contraption of tailored fabric.

Sitting at the intersection of fashion and mobility, the $32,000 device is a statement piece that says, "I may not be able to walk, but I am able to have a crush on Vanessa Hudgens in 'High School Musical.'" It's for the truckers, it's for the gays, and it's for the everyday wheelers who just want to roll the streets looking like a freshly pressed pair of Super Mario's overalls.

The new line of chairs also has models in leopard print, flannel and ugly Christmas sweater, allowing for every disabled individual to express their true identity — as long as their true identity is tacky and aligns with one of those four patterns.

Whether you're looking to cruise the runways of Paris or the narrow lanes of your grandpap's cornfield, the Jealchair allows you to feel confident while doing it.

Did your less cool disabled friend Tiffany steal your boyfriend? Imagine the look on her face when you pull up in a brand new Jealchair with a sparkly, bedazzled base and ripped-headrest premium add-ons.

Do people often mistake you for a senior or, even worse, a child? The Jealchair screams, "I grew up in the early 2000s," so you'll never have that problem again.

Disability is not just a medical diagnosis. It's a culture, it's a lifestyle, and now it's fashion, all because of the #Jealchair.

the SQUEAKY WHEEL

Cooper: Had you looked at The Onion and others like that as a model?

Verdile: Definitely. *The Onion* is the model, the goal, the perfect example of how to use satire well on the Internet. It's hard to do satire on the Internet, mostly because these memes and these short-form video content like TikTok are hard to beat. It's really engaging. So, to make comedy writing something that people are so interested in –and they have TikTok and all these other really stimulating forms of comedy– To make it work you have to be really clever and smart, and The Onion is a perfect example of that.

I also looked at a lot of other smaller satire magazines, *Reductress, Clickhole*, one that's about Broadway called The *Broadway Beat* that I've written some articles for myself. I definitely did look at a lot of other satire magazines.

George Kaplan: Did your time on the *Broadway Beat* inspire how you run *the Squeaky Wheel*?

Verdile: I wrote my first Squeaky Wheel article prior to getting involved with the *Broadway Beat*, although I was already a fan of theirs. And right when I started doing it, I was like, "You know what? I know that their stuff is really good." I was always really impressed with it. And then I reached out to them and said, "Listen, this is what I'm trying to do. I'm also a big Broadway fan. I'd love to write for you a little bit and see if I can learn from you guys, since you're such pros." I was sort of starting my own publication right as I was learning from them, and that overlap helped a lot. Their team is really great, very helpful. They taught me a lot.

Cooper: Did you look at *ABILITY Magazine*?

Verdile: I looked at tons and tons of disability press and

disability news. I've known *ABILITY Magazine* since I was a kid. I was familiar with the voice and the presence of *ABILITY Magazine*. I will say that largely the content that inspired Squeaky Wheel the most in terms of how disability is talked about is the really mass media, like the least common denominator, I would say, which is usually more like a *Buzzfeed* or a *Guardian* or something that's being read by so many people. So, it has to talk about disability at such a high generic level that it becomes easy to learn their language and their scripts, and then you can play with them once you understand the way they're using it for inspiration and things like that.

Kaplan: What did it feel like to have the Squeaky Wheel mentioned by *USA Today* in their crossword alongside *The Onion*?

Verdile: That was super-surprising, I guess is the right word. I didn't expect that. I had no heads up or anything like that. One of our writers had texted me and said, "Did you do this? Did you send this into them?" I said, "No, I don't even know what you're talking about." They sent me a photo of the crossword puzzle. I was like, "Oh, that's pretty cool!" And later I went through our followers, and I realized that one of our followers is the crossword maker for *USA Today*.

Cooper: It doesn't look like you're monetizing it yet. I was just thinking about the sustainability.

Verdile: I can tell you that within the writers' team, sustainability is something that has been brought up a lot in the last few months. As I mentioned, when Squeaky Wheel started, it was just me, and very quickly I realized that I didn't want it to be my voice. I wanted it to be a collective voice because I can't speak for other disabilities, other genders, other races. I wanted as much diversity within the voice as we could get, and that's when I started to seek volunteers who were interested in writing. As you mentioned, we are not monetized, so as of now, everything is volunteer, and that does make it sort of hard to keep people engaged with the writing on a regular basis.

One of our challenging principles and something that I don't plan on changing is that we don't really commit to any hard deadlines or schedules. That means that some weeks we don't have any stories to share. Some weeks we might have four or five. It really depends on how things are going. We do try to plan stuff out as best as we can, but especially dealing with a team where every single person has a disability, every single person has a full life outside of Squeaky Wheel that often implies some sort of job or school with major responsibilities. I don't want this to be a distraction for anyone. But fortunately, the people who write for us are doing an excellent job and they're excited. Our hope is that soon, hopefully, next year or so, we'll start experimenting with some different ways to monetize, and that way we can compensate everyone's contributions.

Cooper: Who's maintaining the site and the graphics? Are you doing that?

Verdile: Yes. With my background, my education is in graphic design, I do all the social media. I do the website; I occasionally write here and there. For the most part, we have enough talented writers that I'm not writing super-regularly myself anymore, unless I get an idea that I'm really passionate about. But I'm doing all the other stuff for now, the web stuff, the social media stuff, all the graphics. But again, as we're expanding, we're seeing people reach out who want to help out in different ways. Hopefully, at some point, we'll have other team members helping us with those things as well.

Cooper: What is your day job?

Verdile: I work as a graphic designer for a television company. I work largely in TV and media. Fortunately, I get to do a lot of disability advocacy work in the TV and film industry as well. That's a lot of how I learned so much about disability representation and how things are viewed in the media and how we can make it better.

Kaplan: What's your favorite part about doing satire?

Verdile: It lined up good with the skill set that I have and the way of creating that I was already comfortable with. It was just a matter of different projects starting, failing, getting confused, and then over time, probably after about two or three years of different venues I had been working on, I started on *the Squeaky Wheel*. And then it came very smoothly from day one. I think it's a good format for this sort of disability humor because part of what satire relies on is the surface value headline of, "This is what this means literally," and the secondary thing of, "This is the deeper meaning that it has to a very specific group of people, or to hopefully all readers." I think that, for the disability community as a whole, a lot of times we feel like we see the news and it means something different to us than it means to other people.

Cooper: Have you had any negative feedback from any of the stories so far?

Verdile: Very, very little, but it does happen. I would say it comes in two forms. The first is that you get people who just aren't really familiar either with disability culture or with satire, and the articles might feel a little bit mean or they might feel like they're mocking disabled people. And they'll comment about that. And the other things that we get a lot of times is that the disability community is one that wants to be super-inclusive, and that of course is what we want to do as well. So, we've gotten a lot of comments like, "This part of your website isn't as accessible as it could be," things like that, where they want our content to be the perfect example



for what inclusivity means. What's great is that we take that to heart, and when people make comments like, "This article is mean," "This article is offensive," there are usually people who are very quick to defend us who are supporters of Squeaky Wheel. I have made it a point that I don't reply to comments, ever.

Cooper: Whenever you're dealing with the public, it's amazing what happens when you're trying to do your best, and, of course, when you're doing something as subjective as humor, you get all kinds of stuff.

Verdile: And we're talking about some really sensitive things for people, things that can be dark, things that can be very vulnerable. It doesn't surprise me that some people are upset. We know we can't please a hundred percent of our audience, but we're confident in what we say. As a writing team, we run everything by each other before anything gets published to flag any jokes that might be a little bit over the line or things that we think might be sensitive for people. We do our best, and we hope that people who are reading understand that we're not perfect, we just doing our best to make them laugh.

Cooper: I know you're—relatively speaking, for me, anyway—relatively young. Do you remember *National Lampoon*?

Verdile: Yes. I love *National Lampoon*. I'm a comedy nerd. I watch a lot of stand-up and old comedy films. I grew up on a lot of that stuff.

Cooper: They offended everyone with their satire. It's amazing at your age that you would know about them. It's fallen off the radar for most people.

Verdile: There's a good *National Lampoon* documentary that came out, I'll say, a year ago. I forgot what it's called. It's on Netflix.

Cooper: Right. Just as the documentary ended I came into the picture. I took it over in the early '90s.

Verdile: *National Lampoon*?

Cooper: I published it for a few years.

Verdile: Oh, super-cool!

Cooper: That's one of the reasons I wanted to be part of this interview. I appreciate what you're doing. You've done a great job.

Verdile: If you don't mind my asking, is your background in publishing? Have you been with *ABILITY Magazine* for a long time?

Cooper: For a while. I started *ABILITY Magazine*.

Verdile: You started it! Oh, my gosh, that's very cool.

Cooper: Do you have any stories of things you never expected it to turn out the way it did?

Verdile: I didn't expect so quickly that people would understand what we were doing. I was very concerned from day one that I was like, "I'm going to launch this, and people are going to tell me, 'You're crazy, this is nonsense.'" And immediately I started seeing people sharing it and saying, "Oh, this is like The Disability Onion," things of that nature, where I was like, "Perfect. They get what I was going for right off the bat." So that was exciting.

And since then, it's just been a lot of really kind words and positive feedback from a lot of people in disability culture who I've looked up to and the other writers have looked up to for a long time. And to see that not only are we doing work that the community approves of, but that we're doing work that is a little innovative is exciting. I didn't really think of it as something innovative when I started it. I thought it was just something funny.

I thought it would be sort of a one-and-done, I'll write 20 or so stories and that would be it, and it would be over. I didn't realize that this is something that if you handle it correctly and make the right decisions and think about it carefully, maybe could be sustained and could become a voice within the community that might

have been missing.

Cooper: I love the idea. It takes a lot of energy to do it the way you did it.

Verdile: The next hurdles that we're working on are figuring out how to monetize and how to keep going. It is hard, like you said, but we're motivated and the reactions we've had have given us more motivation that it is something people want. We're going to do everything we can to keep giving it.

Cooper: Monetization typically is subscription and advertising. Are you thinking of both or something more?

Verdile: Our plan is to open up subscriptions on a very voluntary donation basis. I don't want the content ever to be behind a paywall. I know, even for myself, it takes a lot for me to spend money on magazine subscriptions. There are a couple I subscribe to because I really want to support them, but I know people have limited funds and I don't want us to be something that they can't access.

Kaplan: Is there any other project you see emerging under *the Squeaky Wheel* in the future, a different way to tackle content?

Verdile: Something in the immediate future that I'm hopeful about is merchandise and apparel. There's a lot of disability merch out there, and it's usually the inspiration-y type of "Disabled and Proud," things like that, which are cool, and they have their use. But we're trying to find something a little more unique and more our voice. I've designed some shirts and some hats and some fun things that hopefully will be coming out into the world my guess is probably around September. And also, all the profits, any money we make from selling merch can be used to pay our writers, which is the next goal for me.

Kaplan: It would be awesome to have merch.

Verdile: Yeah, I think people like it. I've shown some people the designs, and everyone wants their hands on it. Hopefully, it goes well.

Cooper: With your team and your creative capabilities, I think swag is definitely something to do. And you know how to do all that, creating a shopping cart? That's something you could build out yourself?

Verdile: It's something that I'm spending my weekends trying to learn. I've never run a business. I've never run anything of this scale. I'm learning as I'm going. I purposely set the website up in a way that is very easy to manage. I don't want to spend too much time trying to perfect it because I know we have some momentum, so I'm trying to keep it moving while our readers have energy, while our writers have momentum, and while I have the intention myself to keep pushing on it.

Cooper: Hopefully you find a silk screener or whatever products, clothing or whatever you're going to do that's connected to disability.

Verdile: I reached out to one company that I knew had an owner who is disabled who makes clothing, but I never heard back from them.

Cooper: Oh, that's too bad.

Verdile: So right now, I'm still looking.

Cooper: That would be great if you could do that.

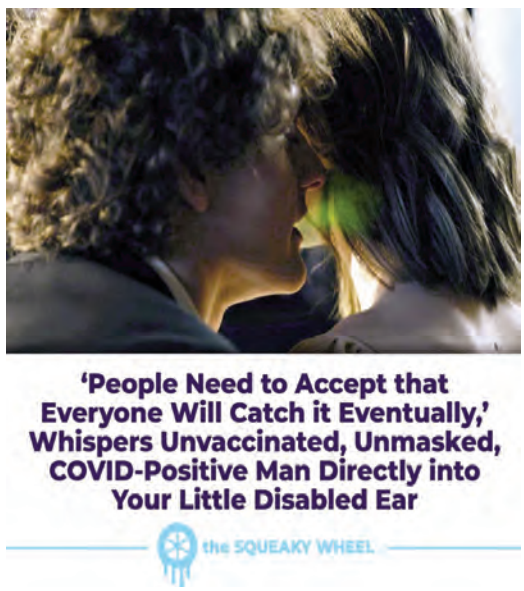
Verdile: So far, everyone who has helped with anything so far has been people with disabilities. I want to keep that as—that might not be true a hundred percent of the time for everything, but as much as we can, certainly we will.

Cooper: Yeah. We've done that as well for the past 30 years. It's very doable, but sometimes it takes a little bit more time to find the right talent.

Verdile: It's reflected in your content. When it comes from the authentic disability, it going to be authentic and interesting. I'm always amazed that our writers are so diverse and that we're able to be a consistent voice. I think we've had probably around 15 different people write articles for us so far, most of them writing probably three to five stories on average that we've published. It really is special and something I'm always impressed by, that everyone can capture our tone and that our team is able to be so diverse and to have such a consistent voice. It all feels like it was written by the same person.

■ ABILITY

the-squeaky-wheel.com



GABBY GIFFORDS WON'T BACK DOWN



Gabby Giffords, once a rising star in the U.S. House of Representatives, is the subject of a recently released documentary on her life and recovery from a gunshot wound to the head she sustained from the 2011 assassination attempt during an outdoor constituent meeting at an Arizona grocery story.

"Gabby Giffords Won't Back Down," directed by Betsy West and Julie Cohen of "RGB" fame, chronicles Giffords' rehabilitation journey as well as the continuation of her public work. Much of the documentary footage is interwoven with intimate video recordings by her husband, Senator Mark Kelly.

Giffords is one of the latest recipients of the Presidential Medal of Freedom, awarded by President Biden for her advocacy in gun violence prevention and aphasia awareness. Aphasia is a brain disorder where a person has trouble speaking or understanding other people speaking due to injury or disruption in part of the brain that controls spoken language.



Giffords last day in TIRR hospital

ABILITY: How did you feel receiving the Medal of Freedom?

Gabby Giffords: It was an unbelievable, amazing experience. From the phone call I received from President Biden to the ceremony itself, everything was a whirlwind. I am incredibly honored to receive the Medal of Freedom from President Biden, especially for something as close to my heart as public service.

ABILITY: What was it like being the subject of a documentary?

Giffords: Awesome! COVID was hard: masks, Zoom, no hugs…but the whole crew was fantastic. Visiting my mom, speech therapy, my Bat Mitzvah, riding my bike…and a whole lot of singing!

ABILITY: What do you hope people will take away from your life story?

Giffords: For me, it has been really important to move ahead, to not look back. I hope others are inspired to keep moving forward, no matter what.

ABILITY: Do you know of Carl McIntyre and "Aphasia: The Movie"?

Giffords: I haven't seen it but will absolutely put it on my list!

ABILITY: What's your advice to people looking around their own communities and wondering what they can do to help?

Giffords: Be a leader. Set an example. Be passionate. Be courageous. Be your best.

ABILITY: Tell us about the op-ed article you wrote for the Washington Post -- "Aphasia makes it hard for me to speak. But I have not lost my voice."



DC Memorial photo by Pete Marovich

Giffords: As someone who has been living with aphasia for over a decade and will continue to for the rest of my life, I wanted to use this opportunity to speak to the more than two million Americans who are in a similar position and to help inform those who are not. More than 85% of Americans have never heard the word! The new documentary about my life, "Gabby Giffords Won't Back Down," does a great job of showcasing what it's like to live with aphasia.

ABILITY: What do you tell yourself when things are difficult?

Giffords: Move ahead! There's no point in reliving the past; we can only control our futures.

ABILITY: How do you maintain your very positive outlook and optimism?

Giffords: I want to make the world a better place. Thanks to my wonderful support system and the resources I have to aid my continued recovery, it's hard not to be positive.

ABILITY: Is your recovery a process of discovering a new Gabby Giffords or a fight to reclaim the old Gabby Giffords?

Giffords: A new one: better, stronger, tougher.

ABILITY: You've made remarkable gains in your ability to speak. Are you optimistic about your continued recovery?

Giffords: I'm optimistic. It will be a long hard haul, but I'm optimistic.

ABILITY: We heard you are learning Spanish, had you ever thought of learning sign language?

Giffords: I'm partially paralyzed on my right side, which would make that challenging. But I am passionate about communicating with people with differing abilities, and "CODA" was one of my favorite films of the past year! I'm so glad it got the recognition it deserved.

ABILITY: Tell us about the memorial honoring gun violence victims on the National Mall.

Giffords: In 2021, we held our first Gun Violence Memorial on the National Mall to honor the 40,000 lives lost to gun violence annually in this country. Earlier this summer, we held our final Gun Violence Memorial on the Mall to honor the over 45,000 lives that are lost to gun violence every year—a massive, tragic increase from the year before. In between, we took our memorial on the road to cities across the country, demonstrating the far-reaching impact of this epidemic.

■ ABILITY

giffords.org

Meet Sweet Tooth Cherylee Houston +



Cherylee Houston is a British actress known for her roles as Izzy Armstrong in BBC's "Coronation Street" and as Maz, a character in Houston's BBC Radio 4 comedy series "Tinsel Girl". Both characters show the power of authentically cast disabled in the entertainment industry and bring awareness to their audiences, especially young actors with disabilities.

ABILITY Magazine's Chet Cooper and Karina Sturm spoke with Houston about life before her diagnosis with Ehlers-Danlos syndrome (EDS) as well as her career and drive to teach and support upcoming generations of performers and crew with disabilities.

Chet Cooper: How did you find yourself saying, "I want to go into acting"?

Cherylee Houston: As soon as I grew out of the idea that I wanted a sweet shop. At about age six, I saw the film, "Annie." It was the energy and a delight. It was exhilarating to see somebody sing and dance. I can't sing or dance. (laughs) I found it was such an exciting world. It was a world of make-believe, but there's so much in acting that gives you a lot of joy.

Cooper: You had an entrepreneurial mind back then?

Houston: (laughs) No, I think I liked sweets an awful lot. What I thought was "What better way to spend your day than to be surrounded by sweets?"

Cooper: (laughs) How did you move into a different direction after six?

Houston: Our school didn't do many school plays, but I was always asking. My teachers must have found me really irritating because I always wrote things, and I would stand up in front of the class and act these out! Which is mortifying if you look back at that now!

Cooper: You stood up in front of the class—you weren't using a wheelchair then?

Houston: My disability was there, but I didn't become a wheelchair user until I was 24, and I was still undiagnosed. So, I was in a lot of pain, but I didn't really understand the world of disability.

Karina Sturm: In previous issues, we spoke with actress, Jamila Jameel, and Meghan O'Rourke, journalist and author who wrote "The Invisible Kingdom," which not only talks about her EDS and chronic illness journey but dives deep into gender bias and why women especially get misdiagnosed so often.

Houston: Brilliant because EDS is so much more prevalent than people realize. So many people are undiagnosed and told they have other issues.

Sturm: When did you first notice symptoms, and when did you get diagnosed?

Houston: There was an enormous gap between EDS starting and being diagnosed. I noticed symptoms at about the


TRIPLE
CREATIVE CONFIDE TIVE
Disabled Artists Net
Fire exit
WRITERS INITIATIVE PROGRAMME
Hosted by:
DANC
ARTS COUNCIL ENGLAND



age of eleven. I was always known to be accident-prone and clumsy, with my joints constantly dislocating and my ankles rolling over when running. However, the pain really kicked in at that age and just got worse and worse from there. I couldn't run anymore; I couldn't stand for long; I couldn't hold pens; I had to type on a computer at school. By the time I got diagnosed, I was 24, and a year after, I became a wheelchair user.

Sturm: Are you using the wheelchair due to your pain or the dislocations from EDS?

Houston: Whenever I stand up for more than a couple of minutes, I can feel my calf splitting. So yeah, it is because of dislocations and severe pain. I'm a bit like that advert of the man who starts as a crawling ape and then slowly becomes a standing man, just that it is the other way around for me. I am standing, and within a few minutes, I'm crawling. [Laughs.]

Sturm: [Laughs.] I like that you can take your pain in a humorous way. Can you share your challenges along the path of getting a diagnosis?

Houston: In my early teens, I was told I had a growing disability, then arthritis and MS, and then they decided I was making it up. For ten years, they said it was a mental health issue. I got to the point where I stopped speaking about being in pain, even though I was in severe pain. This part was tricky and impacted my identity quite a lot because I'd struggle, but I couldn't tell people how much I was struggling.

Sturm: What types of struggles did you face getting into acting?

Houston: Let me go back a little bit. When I was in drama school, I was told as a wheelchair user, I had no right to higher education in the UK. Disabled people officially have not had the right to education until the year 2000. However, my drama school tried their best considering the times. They said that I had no right and they had no legal obligation to educate me anymore, but they would still let me stay.

It was at the time because of all those prejudices by the society–which to some part are still there today. I remember at the end of the third year of drama school, everybody got a mentor. I didn't because they said there were no disabled actors. It took me a while to realize how wrong they were because I was not yet part of the disabled acting community and the disabled creative community.

But early in my career, I'd have jobs taken off me when they realized I was disabled. I was auditioning in car parks because the set was inaccessible. I did my makeup outside in the rain because the green room was upstairs, and they just put a little tent up for me. People were trying to adapt, but they were acting like they were doing something nice for me rather than me being allowed in and seen as an equal. It's not been the journey you can expect as a non-disabled actor, but it's taught and educated me a lot. And I've been part of a community I would never want to miss. I like being disabled for what it's taught me. I don't like the pain side of it, but I would not ever want to lack those experiences. It's given me a different life and a life that I've appreciated.

Sturm: How did you then finally land your first acting job?

Houston: I was damn determined. I wrote to every single cast and director, every theater in the country, and then I got my first job in a disabled theater company in Liverpool. I continued to write to everybody until I got more jobs. Then I contacted agents. I had twelve TV credits before I got an agent because nobody would take me on. For instance, with "Corrie," we were given an eight-page script and had 36 hours to learn it. So, I lived those 36 hours. I knew that script backwards. You have to just put everything else aside and do it.

Sturm: Do you feel like that is partially due to always having to do better than our non-disabled colleagues because we have to prove ourselves all the time?

Houston: It's weird, isn't it? If you put in the same as your non-disabled peers, would they assume less of you? I've never dared try it. It's a lot of pressure we put on ourselves caused by the fact that people assume so

little of us all the time. I've run so many courses for disabled actors over the years and always told them, "You have to be far better than your non-disabled peers. You have to smash that ball out of the park. You have to be the most prepared person. You have to because they will overlook us otherwise." If I sat in a line of people doing the same work as me to the same standard, I'm not going to be picked. Maybe that's what it is: You have to stand out so much more that they can't ignore you because they'd be doing themselves a disservice by not employing you.

Sturm: In your career today, do the people on your set understand your EDS and what you need in terms of accessibility?

Houston: Oh my gosh, yes! They're phenomenal. But I've been there twelve years, so they just get it. I had a rubbish wheelchair for a bit where the front wheels wouldn't go over the wires. Every time I would come in, people just lifted it all without saying anything. If I'm having a bad pain day, they'll get it and distract me or do things in a light-hearted way, or people carry items naturally. But that's people becoming friends and being around you for a long time. When other disabled actors come and work with us, they say it's different than anywhere else because I think everybody on my set understands disability more now. We've got a new writer on the team who is a wheelchair user. And he was saying he was sitting in the canteen and got to the coffee machine. Somebody went, "Oh, that's a bit high for you, isn't it?" Next day, the coffee machine was lowered.

Sturm: During COVID, you filmed yourself at home for your TV show because of your high risk for complications if you got infected? How did that work out?

Houston: Again, they were phenomenal. When I was isolating, they wanted to replicate how disabled people were at home and unable to go back into the world, even though the world started to open back up again. So, they wrote that in the character. Then they auditioned my partner, who I live with, and he played the next-door neighbor. They sent us instruction videos, a TV camera, and all the sound equipment. My partner and I set it all up. We had a director on Zoom who taught us how to operate the lights and everything. They directed us, and we shot it and then sent them the footage.

Sturm: Awesome. That sounds like they really did their best to accommodate you.

Houston: Yeah, they said, "If you can't come to the set, we will send it to you. "

Sturm: That's so good to hear! It sounds like you've changed things with your acting as well as in the industry.

Houston: It's important to me that other people get opportunities to do their work and get their voices out



there. I just like helping people, but I think there's always a real sense of achievement in helping people to thrive. And then you see them throwing the ladder behind. That's what we as a community definitely need to do because we can elevate together and be much stronger.

Sturm: How did you start working with young disabled actors?

Houston: Straight after drama school–the summer–I went down to London and put on a show with friends. It was a profit-share. About six months, I later did another profit-share, and from then I met a director who was really curious about my disability. We were doing Pinter's "The Dumb Waiter," and she was the first director who went, "OK, you can't stand up for too long." –I was still walking then.– "That's interesting. How do we make that more applicable for you?" So, she made my character on the bed more, things like that.

We hit it off, and for five years we ran a company where we did stuff with disabled young people. We did casting training workshops because we realized that we had so few auditions with disabled actors, you needed to be really good at them. We did week-long training with loads of disabled actors in the theater. We put on several shows in that time.

But that stopped when I got "Corrie" because I couldn't



Danc acting workshop

do everything. I set up another company, and we worked a lot, so I'm managing both jobs now.

Sturm: That's such important work you do that truly creates change within the industry.

Houston: You know this anyway, but how our stories are told influences how disabled young people live their lives. They see that they can achieve their full potential. At the moment, the world doesn't allow them to see that, and I think that's really important to change.

Sturm: And it likely helps that Izzy Armstrong is one of a few disabled characters on TV that is actually played by a disabled person. Can you tell us why this is important?

Houston: True lived experience makes representation so much better. It tells the story in a much more interesting way. When a non-disabled person plays a disabled person, they play the society's opinion of that person. So it's never truthful; it's never realistic. Non-disabled actors play the disability, not the character. They also play the subtext wrong. I'm joyous in being disabled, so I'm not going to play this down sad subtext for everything I say. Society's opinion of disability and particularly specific disabilities is so far removed from the truth. That's where the difference is making significant shifts in having that lived experience. Because you have that lived experience on screen, people start to identify and connect with disabled people more. If you stay with non-disabled people playing disabled characters, they will play the pity, the charity, all the opinions that society has got wrong about us and keep them around.

Sturm: I understand that several episodes of *Tinsel Girl are* based on your own experience with EDS. How did you manage to produce this?

Houston: In 2006, I wanted to meet with a guy I got to know online. We said we would meet under the big wheel in town. So, I said, "Oh, talking of wheels, I've got some myself." He went, "I cannot do that; my sister is handicapped herself. I couldn't have that in that part of my life, too." And I thought I'm going to meet him and make damn sure he fancies me, and then I'm going to dump him. This was in my 20s when I thought whenever someone told me I wasn't attractive, I would make sure to show them what it feels like.

Then my friend asked me why I would not write a book about those experiences, which turned into an experiment because I realized I had really low self-esteem. I was fine with my mates, and I was fine with my work, but on the romantic side, I had no value because of my pain. It impacted so much of my personal life.

I was filming a BBC sitcom at the time, and the writer told the executive about my book. He liked the idea and tried to get it into TV, but then it was handed over to radio. I've now had seven series of it. We always look at what the big thing is that's happening in my life and then turn it into like a light-hearted comedy. It is a romantic comedy, but with a lot of EDS stuff thrown in there.

Cooper: So, now you have two jobs, you said?

Houston: I am part of the TripleC Collective (Creative Confidence Collective). I was one of the founding members. We're the TripleC, and we run DANC, the Disabled Artists Networking Community. We also run workshops for young people in education using drama, in disabled schools. We do a lot of outreach work, pre-COVID, and we also do attitudes and access training.

Cooper: The attitudes and access training, that's corporate-based?

Houston: Yeah. We spoke to the arts organizations. Because a lot of disability training is about facts and figures, we do it about approaches and attitudes. You can look at a blueprint of what your organization is trying to achieve and how to then work that through to get more disabled people involved in your company and how to make it accessible for them.

Cooper: Great! You do that in person?

Houston: We do it all over, really. We've been doing some for a theater this week, we did some for BFI last week on Zoom. Our main thing at the moment is DANC, where we have four master classes a week, which is skill sharing. It's been going four years, and pre-COVID we had 450 members. We now have over a thousand disabled artists who regularly engage and participate. It's about opening up conversations with the industry and the artists, (removing) the blocks to employment and then getting disabled people employed. That's going extremely well for people. We've got so much disabled talent out there. What's really exciting is they're starting to get employed more and more.

We've been doing stuff with actors for a long time, so we have actors, writers, musicians, dancers, we have all sorts of people. We've just started a dance strand. We've just started a visual arts strand.

What's great about it is that we've built this reputation and now production companies are coming to us and going like, "We want to start crewing up, getting more disabled cast in." And we help them facilitate that. We've set up a database, a talent-finder database, which means people can register–a bit like a LinkedIn–where you can register, upload your CV, links to your agent, links to whoever, and then whoever in the industry wants to employ disabled creatives, they can find them. Whether they're looking for a choreographer, a makeup artist, a dancer, a writer. They can just go into there and find it. It stops the disabled feeling like they're the only one, and it also stops the industry saying that they don't know where to find them. And that approach has really worked.

As it happens, and you know this anyway, as our stories are told, that influences how are disabled young people live their lives. They see that they can achieve their full potential. At the moment, the world doesn't allow them to see that, and I think that's really important to change.

Cooper: We are of the same mindset, we've been working toward the same things here in the US through storytelling and more currently abilityEntertainment. I applaud all the work you're been doing.

Houston: It's a personal mission that you don't want the next generation to live through the shit that you've had to, you know what I mean. You go, "This is really unjust! This is unfair! There's so much quality to people that they have to offer that's not seen." It's a labor of love for a lot of years. We're only finally now just getting a tiny bit of financial independence as a company, but all of us worked a lot of hours for free just to get it off the ground. I think that passion for change is you don't want to world to stay in this terrible state where people are perceived as different or as less capable.

Cooper: Yes. The biggest challenge is changing the mindset. And that mindset, as you've also pointed out, is often from people who are being denied access because they haven't seen role models. They haven't seen that there's an opportunity out there

Houston: That's exactly it. I've worked in schools for 20-odd years now. We've done a lot in disabled schools with TripleC. We did a year-long residency in a disabled school. We brought psychologists in to see why it works. So even if you were doing it in drama, somebody's giving you your choice, your opinion, your time to have that experience. In psychology, once you've had that, it doesn't go away. Nobody can take it off you again. It's just that the non-disabled world quite often doesn't allow the disabled child to have those experiences because they over-care

Cooper: I know you get a lot out of what you're doing on a personal level—your advocacy and all the work you do with young actors with disabilities— but there's also that other personal level of you being an actor. Where are you with that? Where do you want to be?

Houston: I think putting my toes in the water of theater this year is a nice step. Because I'm a chronic pain sufferer, I never look at big pictures because they're either too overwhelming or too scary in the disability sense, or I have to live in the moment to stay alive with pain. I don't make future plans much.

Sturm: One last question, would you mind sharing if there is someone who inspired you to be this incredible advocate for the community?

Houston: My mum and my godmother. When she passed away, I found so many petitions about things, and I really learned from her. If you're not happy about a part of your life, you can do something about it by having conversations with everybody around you in that same community. And you can make a change by pulling people together. And my godmother inspired me creatively, got me outdoors, and made me love the outdoors. Just two powerful women in generations where they weren't seen as equals. They taught me to never take no for an answer, to stand up, but to do it in a fun way and creatively and just bring everybody together to make a change.

triplec.org.uk

From Exclusion to Inclusion:

My Chevening Journey with Cerebral Palsy

Part I Chevening and University Applications
Jenny, Chinese Chevening Scholar 2022-2023, MSc Language and Intercultural Communication, University of Edinburgh

Background
I would like to begin my Chevening story by revisiting a wintery night in 1992, just a few days after my 8th birthday.

It was a small living/double-bed room with a four-pane window that looked out over a small courtyard covered in dirty snow – part of an old China Railway community tucked at a remote corner of north-western China. A dim fluorescent light bulb shone inches above our heads, weakly sending its power to the farthest corner of our old one-bedroom flat, a train whistling in the distance. We had had dinner; Father was sitting at a desk fiddling with his favourite tools, and I was sitting on Mother's lap, ready for her to make an announcement. I looked up. Something on her face told me that whatever she was going to say would change the course of my life.

"Tomorrow you will not go to school. You can no longer go to school. School is not for you."

Exactly what followed, I can't remember, except that I threw myself against Mother's chest and howled. Thus came the end of my brief and happy time in a local primary school, where I was only allowed to attend core classes as an "auditor". As a child, I could care less about any unfair treatment from the faculty or any flu virus that would put me down for days. I just wanted to be like everyone else.

I was diagnosed with a severe case of cerebral palsy when I was three months old. The neural damage in my brain turned me into "a stack of dry tree branches that were precariously bundled up together", according to my father. Fortunately, the lesions occurred in the motor cortex and spared the intellectual faculty. By the time I reached "statutory school age", I had already gained a basic level of linguistic and arithmetic literacy just by listening to the cassettes my parents bought for me.

For the following three decades, "sorry, there are no exceptions" was always the answer to us whenever we, with little information available from both government and civil agencies, sought hard for possibilities for me to access formal education and national examination services. Although my physical conditions had significantly improved thanks to the long-term application of traditional Chinese medicine and home-based physical therapy, the permanent lack of voluntary mobility in my arms and hands, complicated by the lack of overall bodily coordination, rendered me physically unfit in normal class and test settings, but intellectually I could not be accommodated in special education, either, which was slowly emerging as some special needs in China's disabled community finally began to be heard and addressed. Naturally, this exclusion resulted in a sad belief, as it did – and still does – among children like me, that I was the problem.

I had to leave school, but I never stopped learning. In six years I completed primary and secondary core courses from home based on a self-directed mode of study. At the age of 16, I started to narrow my focus onto the English language, and about three years later I embraced my career as a freelance translator working from home. To meet occupational needs and expectations, my areas of study expanded more broadly to include economics, business management, psychology, and linguistics. My curriculum vitae as a Chinese and English language service provider now includes one children's novel, six semi-technical publications, two films, two awards, and countless work assignments from national and international NGOs in the area of conservation. The advent of computers and the internet


F4
F5
Q W E R T Y
Ctrl



have created a pseudo-identity for me to get access with just a click of my mouse.

Jenny uses the computer with her feet.

Deep inside, however, I still felt a longing, a piece missing from the jigsaw puzzle I had been trying to solve all these years. Until I found Chevening in September of 2021, I had not really thought about why.

Chevening application

I heard about the FCDO's full scholarship programme in an international conference I was invited to attend by its organiser, the China Disabled Persons' Federation. As a speaking delegate representing the UK embassy to China, Mr. Chris Boobier, the then-head of Chevening's team in my country, introduced the programme to the audience in fluent Chinese.

Mr Boobier's outreach effort among Chinese people with physical disabilities coincided with my burning desire for change. It is a two-pronged aspiration. Professionally, in recent years, I feel that I have been banging my toes against an invisible wall as a freelancer working from home. To overcome the barriers, I need a meaningful upgrade of my linguistic expertise that entails total immersion in a target culture for an extended period of time. Starting from there, I aspire to be part of the research community and to guide intercultural practices between China and the rest of the world based on my wealth of practical experience over the years. This would require engagement with the academic world in my home country, which sadly I find inaccessible even today.

On a deeper level, having spent much of every day in front of a computer for nearly twenty years, I increasingly wonder about the true purpose of my life with cerebral palsy. The glaring divide between the "virtual-world me", a well-connected, resourceful and articulate intellectual, and the "real-world me", a stammering, shy introvert who looks mentally handicapped because she moves and speaks differently, is bothering me as I approach middle age. It may be true that I have been contributing to my family and community – even to my country in a sense – through my linguistic services online, but I hope to reach a profoundness by unifying my separate identities. By experiencing (and exposing) the gaps between "here" and "there" in access to education for all, I wanted to bring the two "me"s together into a positive force for change that would help build a new path of empowerment for China's less advantaged groups, providing an easy access to the kind of opportunities I wish I had had when I was young,

Obviously, I would be able to accomplish none of these ambitions from home. I would need a bigger platform of leadership, a place where I could reel in more resources and learn how to use them to edge towards my goals, before it is too late. This is why I decided to apply for Chevening right after Mr. Boobier's introduction.

It took me a while to figure out the complex web of Chevening's online registration forms, but the application process was plain sailing with the instructions of the local Chevening team and the details on Chevening's website and registration portal. I spent a week writing the four question essays and submitted them a week before the deadline. I did worry about my lack of formal undergraduate education. Thankfully, the portal offered a variety of options that would not have been considered "undergraduate" in China, and the team let me pass with a professional Diploma in Translation issued by the UK's Institute of Linguists and an old certificate of graduation from a little-known Chinese vocational college I completed by correspondence nearly 20 years ago.

When my application was progressed to the interview stage, I had another worry. Speaking in English impromptu for more than half an hour would be a challenge for most Chinese students, and more so for me as I, having lived in a social climate where everyone is expected to act the same as everyone else, feared that my non-conforming way of speaking as a result of oral hypertonia and poor coordination with breathing would be frowned upon, particularly in such a formal context of discourse. I even emailed a Chevening officer

explaining this. She responded by reassuring me that Chevening "operates a fair and open competitive process to select award recipients" and that the interview panel would be informed beforehand to accommodate any needs that I might reasonably have. On March 16, my interview took place online, as in the previous two years, due to Covid-19 impacts. To my relief, all three panellists huddling together before a webcam seemed very friendly, and I was given sufficient time to answer their questions. Then I spent the next few weeks commending myself for the few places I thought I did well and lamenting on the much more that I seriously wished I could do again.

University application

Another moment of discovery came as I went through the next step: university application. I had only had a vague idea of the general requirements for postgraduate programmes in the UK thanks to an earlier experience of helping a friend's daughter to apply. Without any academic background, would I be qualified, I wondered. To my delight, I soon learned that many universities would consider applications based on related work experience, as explicitly stated on the respective course pages. Better still, almost all the university websites I browsed had webpages dedicated to accessibility and the disability services offered on campus.

I knocked on the doors of seven of the oldest and most prestigious institutions, explaining why I had been excluded from formal education in China and what I had accomplished as a freelance translator and language instructor. In one of my winning personal statements, I started with the following:

"If every human being is a lone world concealed in and confined to his or her own perceptions, language is the only way for us to congregate, conciliate, and connect beyond the boundaries."

I even summoned up the courage to contact the admissions team of Oxford University. Unfortunately, they were one of the few "exceptions" that only accept students with a first-class honours degree – with no departures from the rule.

At the end of the day I narrowed my choices down to three: Edinburgh, Glasgow, and Manchester. I made Edinburgh my first option because, firstly, the programme I chose is more related to what I am currently doing and would like to build on, led by Dr. Ashley Simpson, an interculturalist who has established academic relations with my country. Secondly, it is a top university in Scotland, the part of the U.K. I'd like to explore for its cultural and linguistic diversity. Thirdly, the syllabus spans across a wide spectrum of social sciences and, in the second and final semester, allows students to select one optional course from other schools of the university. I believed it would provide me with the skillset to help (re-)establish connections between the



East and the West, the disabled and the able-bodied, the "self" and the "other", through language education and intercultural communication.

In late January I set out to meet the only condition on all the three conditional offers I had collected – English language requirements. Over the past few weeks I had been looking for the test option most viable for my situation, and none seemed doable until my special needs were brought to the attention of the British Council through the FCDO's team in China. On March 26, 2022, I sat for what was to be the second home-based examination in my life, following the DipTrans exam I took back in 2016. A customised IELTS test was arranged for me under the invigilation of two lovely ladies working at a local test centre. To make it technically possible and to conform to the test protocol, a huge suitcase of testing apparatus was shipped beforehand from the British Council China Office in Beijing, including two laptops, a camera, a fingerprint scanner, a headset, and some disinfecting spray and tissue. A few weeks before that an IELTS coordinator in Chongqing initiated communication to keep me informed. The level of professionalism and attention I encountered throughout the process, from registration to pre-test coordination to follow-up support, was both eye-opening and heart-warming. Two weeks after the test, I had my score - band 8 – which was high enough to secure a place in any of my chosen universities, yet a tad lower than I had expected from a professional translator. Oh well.



Jenny is taking an IELTS test from home

Conclusion: New Beginnings

After months of preparation, anticipation, and trepidation, the greatest jubilation shook my whole being around midnight on July 4, the day my Conditional Award Letter arrived.

A member of several Facebook groups organised by Chevening alumni, I have been made aware of what the award must have meant to over 50,000 successful candidates around the world over the last 37 years. For me, it is a joy that caught me off guard, a euphoria more profound than I could ever have imagined. For the first time in my life I feel a sense of wholeness of being. It comes with a realization, crystal clear, that I was not responsible for what was taken away from me.

I am not certain if I am all for the universal claim that everyone is born equal on all terms – I know I wasn't born equal, physically at least. But the first chapter of my experience with Chevening demonstrates that equality is not (and should not) to be treated as an outcome, but rather as a process of persistent efforts in all aspects of the society into which one is born, from legislation to policy to the "final extra mile" reaching specific groups and individuals. It may be manifested as a chain of statues written into national law, policies made at a roundtable of high-ranking decision makers, teams dedicated to making things happen, and communications one can access containing all the details they should know to keep such actions effective at grassroots levels. One part missing, and the system will not work the way it is intended. This is important in multiple spheres of social, economic, and political institutions, and particularly so in education, the first chapter of one's life, as declared in UNESCO's report on the "Measures Supporting the Right to Education for Persons with Disabilities":

"The right to education has been internationally recognized as an overarching right: it is a human right in itself and is indispensable for the exercise of other human rights."

On a personal level, life is a road full of obstacles, whether the traveller is categorized as disabled or not. Sometimes it takes sheer will to wipe away the tears, get back on your feet, and keep going, hurdle after hurdle, until you get there. Focusing on the result is important, but what matters more is tell yourself this is not the end. There must be a way, and take delight in every moment of finding it and making progress in the process, no matter how insurmountable the next barrier seems.



Jenny and her parents

When you do that, you soon will be leading the way not only for yourself, but your family, your community, and your country.

For future Chevening aspirants, I would suggest searching both in and out of yourself before you apply. Going through all that which I have described above is rewarding in itself, regardless of the outcome. It offers a brilliant opportunity to probe the depths of one's soul and ask important questions in life: Who am I as a person? Where do I want to go and why? How can I get there? How would my goals impact my home community and bridge it with the world, especially the UK? How does Chevening go in line with my worldviews and ambitions? What do I expect to get from and put into it? Make connections, collect as much information as possible, and string all the pieces into a powerful and convincing narrative that reflects answers to these questions. And stay resilient.

When I was invited to share these thoughts, I felt hesitant, reasoning that my case is so special that it may lose representability. What ultimately changed my mind was a WeChat message from one of my Chinese friends with cerebral palsy, who has taught herself to a point where she now earns a good income just with the tip of her left foot, and who cried the whole afternoon of the first day her younger brother went off to school. It was part question, part musing after I informed her about my Chevening and UK university application processes. "Sister, I think I would also have been able to attend college had we had the kind of education systems that exist in foreign countries." It's good to know that I've already made an impact, even though on a molecularly low level. This is exactly what I am meant to do.

In conclusion, please allow me to quote my favourite line from one of Chevening's less humorous posters:

"What is success? [...] To leave the world a bit better, whether by a healthy child, a garden patch, or a redeemed social condition."

A new chapter of my life has begun, and I hope it will lead to many new beginnings that might leave the world a bit better.

"I love you, mum and dad! But I know you love me more." ■ ABILITY

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Pete Buttigieg

BUILDING A BETTER & MORE ACCESSIBLE AMERICA

The U.S. Department of Transportation (DOT) is addressing both the climate crisis and need for accessible transportation, which both disproportionately affect people with disabilities. DOT is creating avenues for cleaner and more accessible transportation through legislative funding and providing grands for improvements and grants to fund innovative technologies.

With 32 years since the passing of the ADA, barriers to accessible rail transportation remain widespread in the US. An estimated 900 rail stations that serve millions of passengers were built before 1990. These legacy stations do not meet required standards of ADA accessibility.

A prime example of the need for accessible rail stations can be found in a previous article in *ABILITY Magazine*, "All Riders", which outlined not only the great human need, but the expanse





President Biden and Transportation Pete

of the problem of inaccessible public transport in New York City's Metropolitan Transit Authority (MTA). Less than 25% of MTA public rail stations are accessible. Further, a portion of those accessible stations have elevators that are closed for repair. This presents an even greater need and risk of injury for passengers.

President Biden and the DOT hope to remedy this severe shortfall with the All Stations Accessibility Program (ASAP). As part of the bipartisan Infrastructure Investment and Jobs Act of 2021, ASAP aims to help eliminate barriers to public rail stations and assist legacy stations in meeting or exceeding ADA standards.

Legacy stations will apply for funding geared toward transforming or upgrading these stations to meet or exceed ADA standards for serving individuals with mobility disabilities, including wheel chair users. The goal is to increase the number of accessible public rail systems across the country that were built prior to the enactment of the ADA.

In addition to ASAP, the US DOT recently awarded $2 million in innovation grants to organizations who won the Inclusive Design Challenge. First place was Perdue University who was awarded $1 million for developing an automated vehicle that incorporates universal design features to accommodate people with physical and sensory disabilities. Second place went to AbleLink Smart Living Technologies' WayFinder ADS that enables independent use of autonomous vehicles by individuals with cognitive and other disabilities. The University of Maine took third place for its Autonomous Vehicle Assistant (AVA) that assists passengers with visual impairments and older adults with ride-hailing and trip planning.

ABILITY's Chet Cooper met with Transportation Secretary Pete Buttigieg to discuss the DOT's continued commitment to accessibility as well as plans for climate friendly changes we can expect from DOT's work.

Cooper: You made a comment recently, which was kind of a fun comment, about the capability of President Biden riding a bike. Maybe we can start with electric bikes and sustainable energy?

Pete Buttigieg: One thing we're trying to support is active transportation. We need to make sure that people are able to walk or bike or roll to wherever they need to be. I think that's something that has been maybe more familiar for people living in city centers or dense urban areas, but it can bring benefit everywhere in the country. When we adopted a Fleet Streets approach in my hometown of South Bend, for example, that really opened up what had been a road pattern that was almost hostile to any traffic besides vehicles. It opened that up to people, and through that to small business, too because it



became a more inviting place to have a cup of coffee or browse a store.

All of these things add up to a more vibrant local economy, and they add up to more ease for people getting to where they need to go, especially when you start from the principle of safety. That's really what's on our minds as we work to make active transportation available to more Americans, and many of our grant programs do just that.

E-bikes hold the promise of making it more natural for a lot of people to commute to work by bike. I think that they present an opportunity in terms of people who maybe don't think of themselves as athletes or aren't able to bike longer distances on a traditional bike to now have a new means to get around. Again, safety has to be our guiding principle, so local communities, I think, are dealing with the necessity of managing the shared spaces and just the rule of the road in a way that is safe because these e-bikes can go obviously faster, not just farther, than traditional bicycles. But we see a lot of potential there, and we want to support local community visions for how they want to put these technologies to use.

Cooper: Are you looking to build a national charging network with universal standards?

Buttigieg: Our electric vehicle infrastructure program, where we're distributing $5 billion to states to establish a car-charging network along our highways, as well as a companion program called community charging, which is another $2.5 billion, they do carry standards. We don't want to dictate, of course, all of the particulars of charging stations that will typically be owned and operated by the private sector, but we do need to make sure certain things are true about them. We need to make sure that you are not, for example, confined to an individual network in order to be able to purchase power from a given charging station. Right now, that's often the case. So, it's as if you could only fill up at a Speedway gas station if you were a Speedway member, but not if you were a BP member. We need to make these interoperable. And accessibility is one of the considerations that's going into this as well. As we work with our counterparts in the Department of Energy to lay out the requirements and expectations for the states in their investments, we'll be, within reason, laying out some standards and expectations for how those chargers ought to work.

Cooper: You've been traveling around the country talking about and showcasing electric trucks and maybe trains and ships running on sustainable energy?

Buttigieg: Yeah, the great thing about this role and the daunting thing about this moment is that we need to be



Buttigieg Building a Beter America with Mayor Van Johnson at GA Port

delivering improvements to every mode of transportation in the country. We have provisions in this new infrastructure law that touch everything from commercial aviation to pipeline safety. We're administering a pipeline safety improvement program that's not getting as much attention as the other things, but it just gives you a sense of the range of what we do. We work on commercial space travel, port improvements–Anything related to how people or goods move around, we tend to have some role in it. What we're very proud of in this infrastructure deal is the opportunity to make more improvements than we have in certainly my lifetime, everything from the ASAP program that we're rolling out next week, to improvements to stations across the country for train station accessibility to the airport terminal program, which also, by the way, did a lot for accessibility. A lot of ADA improvements are coming to airports around America now through this funding, and we're proud to be able to bring that to communities of different sizes.

Cooper: I saw that at LAX, it will finally an airport worthy of what our country. I'm sure you've traveled around the world, many intertnational airports are way ahead of us.

Buttigieg: Right. By many measures, the U.S. doesn't have a single airport in the world's top 25. We want to change that. The President definitely wants to change it. Before we even get to the finer points of the aesthetics of it, we just need to make sure they work well, and that they work well for everybody. So, this round of terminal grants alone, in those 84 different airports, we were able to make a difference. There are big, recognizable ones like LAX all the way down to Chamberlain, South Dakota, where their general aviation terminal right now is a mobile home. In places in between, like Huntsville, Alabama, which will get new, better restrooms and finally be able to get ADA compliance in areas where they haven't before.

Cooper: Have you looked at anything to give a discount, let's say, to people who are low-income who would like to get electric, maybe a power discount or grant for junkers to remove these cars from the streets? There was Cash for Clunkers once.

Buttigieg: Yeah, there was a Cash for Clunkers program I think during the Obama administration. The approach that we've pursued had to do with reducing the upfront sticker price of EVs through tax credits. Unfortunately, there's been a lot of congressional mostly Republican opposition to that. But we are seeing that the scale effects are starting to pull down the cost of EVs, too. The cost of charging is a little different because it's in the hands of utilities, and there are 3,000 different utilities across the country. But we're certainly interested to see what kinds of approaches will be taken locally.



For example, you know, I used to run a utility as mayor. I oversaw the water works, and one of the uses that my successor put rescue plan dollars to was to reduce or forgive utility bills for low-income residents on their water charges. So, there are ways this can be done. It varies from state to state, and it gets a little difficult for us from a federal level on the transportation side of the house to have all the visibility into that. But we're certainly interested in approaches that will make the charging as well as purchasing electric vehicles more affordable for more Americans.

Cooper: What about charging vehicles at home or at an apartment?

Buttigieg: I think that a lot of folks don't realize that you can often charge a vehicle with a regular wall plug. Frankly, that's what Chasten and I do in Michigan with our plug-in hybrid, although it's quicker and more efficient if you can get a level 2 charger. But that only helps you if you live in a single-family home, where you have a garage.

A lot of people in multi-family dwellings are also living in areas where it's not yet profitable for a company to install a charger, for example, in the parking lot of your apartment building. That's where we think the community charging funding that we'll be distributing can make a difference. We'd buy down the difference, where it doesn't pencil out just yet for the private sector, but when we get that charger up in helps drive adoption and it helps, of course, people get in on the fuel savings that come with owning a vehicle.

Cooper: Is that part of your budget now?

Buttigieg: Yes, that's budgeted for this fiscal year, the first of five years, which across five years it'll be $2.5 billion. That'll go alongside the $5 billion. So, about $1 billion a year that's going to the states for their own plans. Those are more for building out the network of chargers across the U.S. highway system.

Cooper: That's good to know. I hope landlords and apartment complexes know about this. You've got to get that message out that that's available.

Buttigieg: Well, you can help us. We're working with communities to make sure they know that they can apply for this funding as soon as we get the notice out.

Cooper: Is there anything that you could share that is so different than what you expected when you accepted this position?

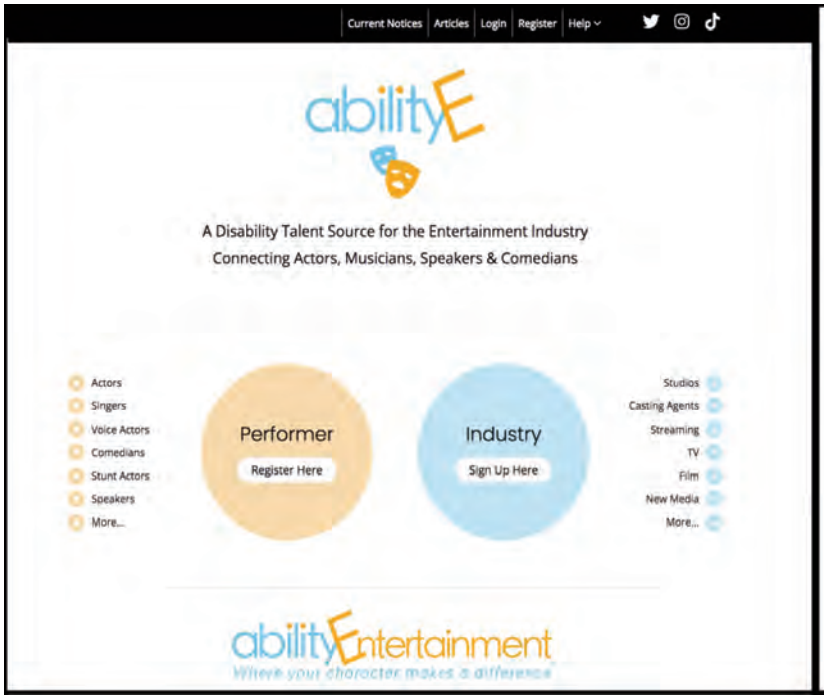
Buttigieg: You know, we do everything from overseeing the Academy for Merchant Mariners in Kings Point,

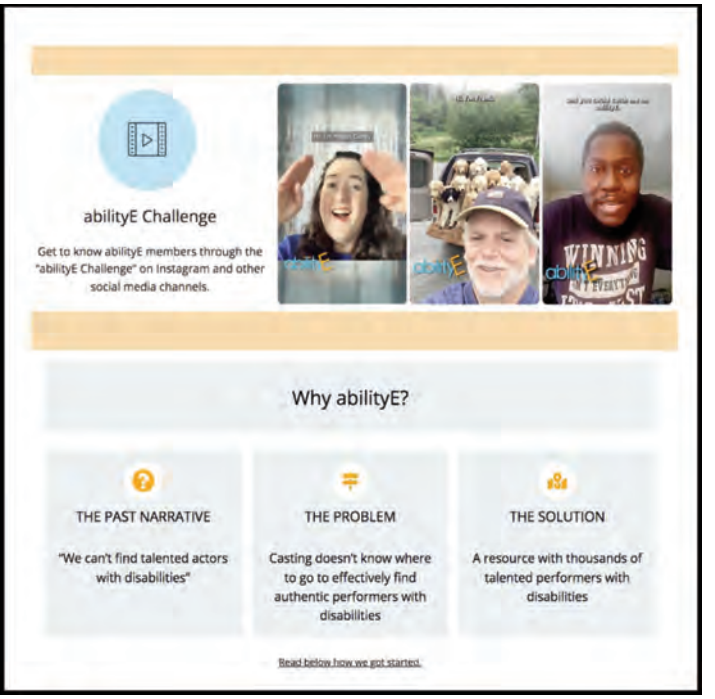


New York, to licensing commercial space launches. I think everybody knows we're the department of trains, planes, and automobiles, but even I am repeatedly struck by the sheer range of things we get to work on. They're all important. They're all exciting. There's never been a better time to do this work.

Cooper: I noticed you're traveling a lot. I know time is of the essence when you're traveling and you've got a tight schedule, but how are you managing that and also thinking about your travel as another form of pollution?

Buttigieg: We're trying to strike an appropriate balance in terms of our own travel and just how I get around the city. One idea that I–to be honest stole from Secretary Granholm–is to convert one of my security details to an electric car so that I can get around D.C. on a zero-emissions basis. But of course, part of my job is to travel and





to be in lots of different places at once. We want to see and feel and experience what's happening on the ground so that we make the best possible decisions as we guide what will ultimately be half of the $1.2 trillion of the President's infrastructure plan.

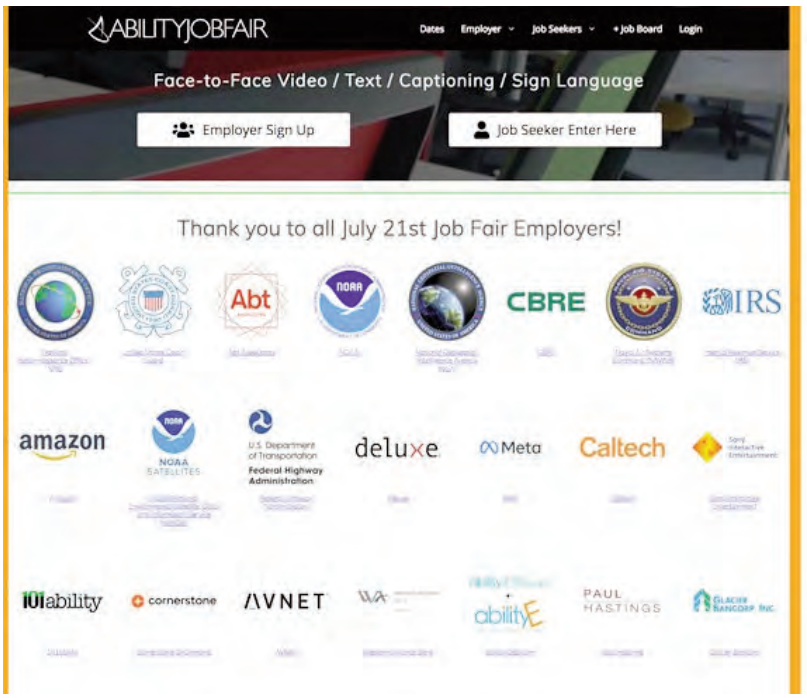
Cooper: I know your time is short. Let me quickly share my screen. We do several things. If you ever need actors, let's say you're producing a PSA, I hope that someone in your organization can access abilityE.com. This is the first major talent resource for actors and performers with disabilities for the entertainment industry.

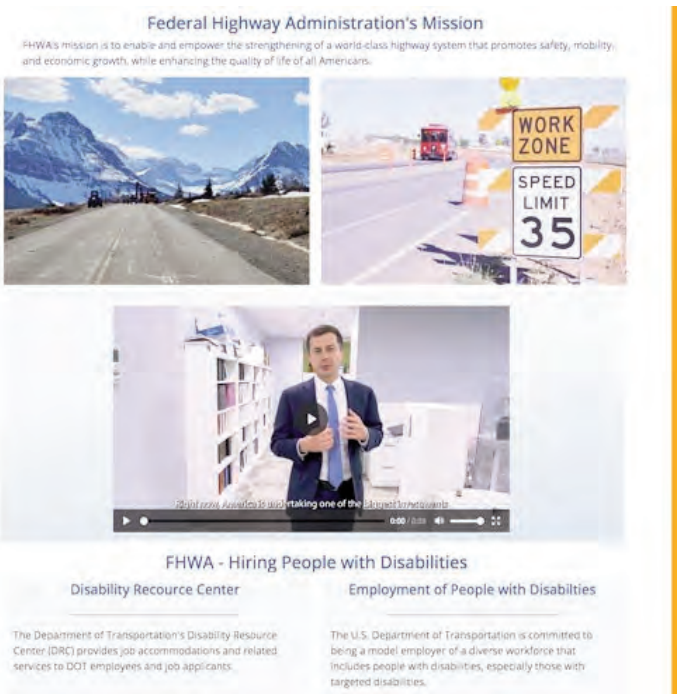
Buttigieg: Oh, perfect!

Cooper: And we're excited that your team at DOT joined us for our last ABILITY Job Fair. This is the most accessible online career fair, which includes face-to-face between recruiters and job seekers but also opens to sign language interpreters whenever needed. So, DOT is doing the right thing and looking to hire talent with disabilities for all the growth that you're involved in right now.

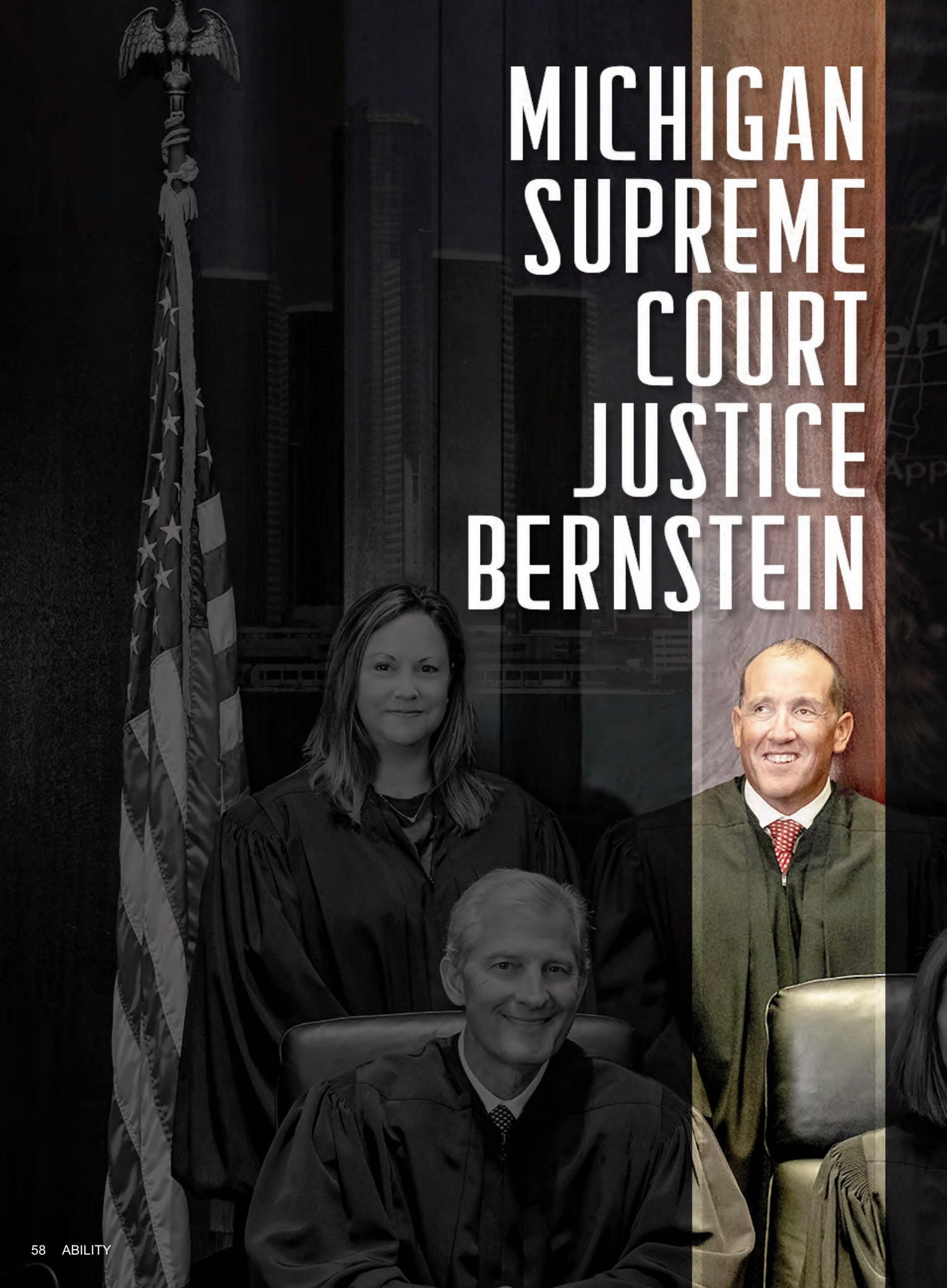
Buttigieg: Great! We definitely need that talent on board. I'm glad we're partnering with you to get the word out. ■ ABILITY

dot.gov





MICHIGAN SUPREME COURT JUSTICE BERNSTEIN



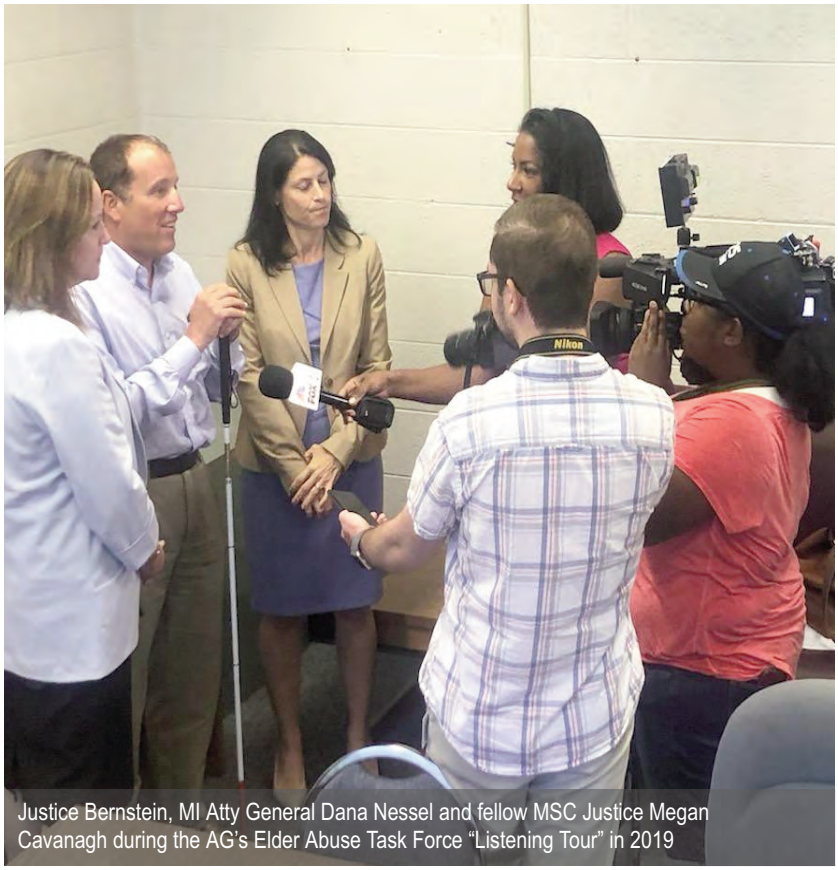
Fighting for Injustice and Greater Opportunities

Promises made, promises kept sounds like a campaign slogan. For Justice Richard Bernstein, the first blind justice elected to the Michigan Supreme Court, this is his life's mission. The promise? If Justice Bernstein made it through law school and passed the bar, he would dedicate his professional life to service, specifically service to other people with disabilities. He made good on that promise by representing plaintiffs in some of the most impactful court cases surrounding the ADA and by travelling the world promoting education and inclusion of people with disabilities. Justice Bernstein took a brief break from dealing with weight of recent cases and his current race for re-election to speak with ABILITY's Chet Cooper and share his history of honoring his promise of fighting for the rights of people with disabilities.

Justice Richard Bernstein: Hi! Thank you for calling, Chet, how are you today?

Chet Cooper: I'm good, how are you?





Justice Bernstein, MI Atty General Dana Nessel and fellow MSC Justice Megan Cavanagh during the AG's Elder Abuse Task Force "Listening Tour" in 2019

Bernstein: You know, it's been a long week. This'll be a nice respite.

Cooper: (laughs) OK, we'll both put our heads down and take a nap.

Bernstein: I'm up for that. But see, the problem is, when I wake up, all the stress and anxiety is still there.

Cooper: (laughs) It's still in the desk, or in your head?

Bernstein: Right. It doesn't go away, basically. It's pretty much right there. No change! This is not an easy time to be a judge!

Cooper: Maybe we could go backwards with that concept of being a judge. What do you remember prompting you to want to become an attorney?

Bernstein: You know what it was? We need more people with disabilities in more positions. It's that simple. It's just at the end of the day, the only way that things will change is if you have people with disabilities who will be in positions where they can have the opportunity to make an impact that will make life better for folks. Because at the end of the day—You know, what's so funny? I'm so excited to do this interview because, honestly, it's such an important thing. You know what always happens?—I'm sure you probably find this in the work that we both do.— This is what always happens. People always get it opposite. They always say, "Oh, you know, disabled people."

We know exactly what we can accomplish. We know exactly what we can achieve, and we know exactly what we are capable of doing. The challenge that exists is for able-bodied people to simply give us an opportunity and to give us a shot. Everyone always gets it opposite. They always say, "Oh, you know, it's great to give one disabled (a chance)—You can show what disabled people can do." No, it's wrong. The whole idea is all disabled people have tremendous potential. The real issue is we need people who are not disabled to simply give us an opportunity or give us a chance to succeed. That's really what it is. The able-bodied people have to change their perspective about what our potential is and see our capabilities.

Cooper: Yeah. It's always tough for me to interview people when I find that we're preaching to the choir ourselves; we know these things. But I wanted to get back to the original question. When you were in elementary school, junior high, high school, where do you think it triggered that you thought, "Law is where I want to go?"

Bernstein: I think my experience is probably similar to a lot of other people's experience because I think it comes down to the notion that you see that there can be some change. When you're in school, basically, it's that ability to stand up to people. It's one of those situations that when you have a disability, you're subject to the whim of other people. I think that, for me, my perspective was: There are so many things that happen to us every single day, and we have to advocate for everything. I felt that the law is the one area where you could really make a difference. I don't know if I can answer the question by saying what triggered it from that early an age. But what I can say is that when I did go to law school, when I was in school, it was a brutal experience. I remember because everything takes me four times longer. If it takes you an hour to do something, it takes me four. So, you have a one-to-four ratio.

But I remember when I was in law school, it was a struggle. I remember just getting through it, the intensity of trying to get through law school. I remember—I am a spiritual person, and it was a cold January night in Chicago. I'd just gone to Northwestern, I just remember, when I was in school, the fact that all of my friends did exceptionally well in law school. And I didn't do so well. But I worked so much harder. It was like I would work so much harder, give everything I had. My friends would do really well, but they didn't have to put in that same degree of intense effort, that raw tenacity, that intensity that I would put in every day. It was such a

difficult time.

I remember being spiritual. I prayed to the creator, and I said to God, "Look, I really want this. If you let me become a lawyer,—I want this like you can't imagine.— If you let me become a lawyer, I will dedicate my entire professional career to representing folks with disabilities who otherwise can't afford representation. But God, please, you have to let me get through law school, to pass the bar. You have to grant me this opportunity. If you give me this chance to become a lawyer, I promise I'll use it to help those with disabilities and special needs and I will provide representation that no one else is doing." And ultimately, miraculously, I graduated from law school, even more miraculously passed the bar.

Cooper: (laughs)

Bernstein: Which is a miracle.

Cooper: Were you able to have study groups with your friends?

Bernstein: No. Because I was too slow, my presence there wouldn't have benefited the group.

Cooper: I think most people don't understand that in law school so many study groups form, and if you're doing it on your own is more difficult.

Bernstein: Yeah. And I didn't mind it. I don't think it's hurtful, it was one of those things where when people come to study groups, they want to have the people they think will be more beneficial. I don't think I would be able to add to that. No, I just did it on my own. But my goal was different. My goal was I just get through and graduate. I would see that as a remarkable achievement.

Cooper: And if you passed the bar, even more so?

Bernstein: Exactly. It all kind of worked out. After graduating I went back to family practice. I was very lucky that I had a family law firm, and I went back and said, "I want to start a public services division. "We're not going to make any money. We're going to lose a fortune."

Cooper: (laughs)

Bernstein: I said, "a promise is a promise." I was really selling it. "I made a promise that if I would pass the bar that I would dedicate my professional career to helping people with disabilities. When you make a promise, you have to honor your promise." And my family was incredibly supportive, which was amazing. And that's why I did what I did. We started our public services division. We never charged for legal representation. We took on cases that nobody else was interested in and nobody else would take because they were too costly. They were way too expensive. We took them pro bono. I wanted people to understand that disability right is a civil right. I wanted people to not see this as anything other than basic civil rights, and that's what I did. I would take on these cases and fight.

Cooper: How many family members are in the practice?

Bernstein: My dad, my older brother, and my younger sister.

Cooper: Oh, great!

Bernstein: Yes. And I've been out of the practice now for eight years. But when I started, that was our family practice. They were kind enough to let me do the public service division.

Cooper: Nice. Do you want to share a couple of the bigger cases you were able to do? I have some of the background, but it's maybe best for you to share it.

Bernstein: Sure. A lot of this comes from kind of a religious perspective, having a certain spiritual guidance that I like to use. My first major case I remember was against the city of Detroit. That was an intense case, as intense as it gets. The city was operating its buses and about 60% of their fleet of the wheelchair lifts were inoperable. I represented paralyzed veterans. If you have only 40% of the fleet that's operable with wheelchair lifts, that means that it makes it near to impossible to get around and do basic things. You would have vets who would try to go to doctors' appointments and do the kinds of things that they would do, and they would get stuck in transfers. They'd board one bus that maybe had a lift that worked, and then they'd get to a transfer point and that lift didn't work, and they would have to sit there and wait.

This would go on for hours and hours. This is why I became a lawyer. It's ridiculous how they were treated. These were veterans. They'd plead with DDOT (Detroit Department of Tranportation), they would say, "Look, we really need help. We need to have operational bus lifts so we can commute. We need help." And they would get literally these little snarky orange cards that would come back from DDOT, and it would literally say, "Thank you so much for your interested in the Detroit Department of Transportation. We so appreciate your feedback, and we look forward to serving you." It was unbelievable. These people were struggling. We sued them. I had a huge fight with the then Mayor, Kwame Kilpatrick. This turned into a battle like you would never imagine. He went after me. This was vicious. It could not have been more vicious.

It was unbelievable how intense this guy was. He was telling people who worked for DDOT that they would lose their jobs because of me, and if they're upset about that, they should go out to Birmingham, where I lived,



Justice Bernstein with guests at 2016 Court Community Connections program at River Rouge HS (near Detroit)

and take it out on me. It was just really intense. And this turned into an absolutely battle. It was unbelievable how much we were fighting. This went on for seven years. We were fighting literally every week. I kid you not. This was on the front page of the paper. The mayor was saying, "We're not going to let Mr. Bernstein tell us how to run our city. We don't need outsiders coming in to tell us—"

Ultimately the Department of Justice intervened and came in and joined us as the plaintiff.

Cooper: How did it end?

Bernstein: It ended very well, though. The city had a monitor. It ended well because this set the standards and guidelines for all commercial fixed-route public transportation. Now, when you go to different cities and you see those kneeling buses, the ones that lean over, that came out of the DDOT bus case. This set the standard for all public transit providers across the country.

These cases tend to work out because you do it for the right reason. The other case I had that was challenging. I used to be a professor at the University of Michigan. I taught political sciences. I was an adjunct professor. I taught one class a week for a number of years, but then I sued them.

Cooper: (laughs)

Bernstein: So, I don't teach there any more!

Cooper: Oops! (laughs)

Bernstein: (laughs) I wonder why that happened! I make friends all over. But that was a really interesting one. The University of Michigan—I love talking to you, because my job is so intense right now that this allows me to remember why we do it. —It was wrong, and they knew it was wrong, and that's what infuriated me.

I represented the Paralyzed Veterans of America. The issue was that the PVA came to me, and they said, "Look, we need your help because we have a lot of folks who are not following through with their rehab because, when they come back from combat, from service, they get back and here they are going back to the university in ROTC or what have you.

The challenge is that when everybody else goes to a football game on a Saturday morning, they just sit in

their dorm room. They don't go. They don't participate. And these were guys and girls who used to do that. They're no longer feeling like they're a part of the community. When they left, they were able-bodied; and when they came back, they're wheelchair users. It's having a huge impact because they feel left out and isolated. They don't feel like they're a part of the community. They just feel a sense of isolation. This is enhancing that feeling of isolation that they're ultimately having.

We sued the university. They were spending $350 million on this facility to renovate it. And as you know, according to the ADA, if you alter a facility, you've got to bring it into ADA compliance. If you repair an existing facility, you don't. What the university was doing was just wrong, and they knowingly were doing this. They were basically approving different projects as individual projects. They would say, "We're putting in new benches." The next week they'd say, "We're putting in a new bathroom. We're putting in new cement. We're putting in a new scoreboard." Their entire argument was that "We aren't altering the structure. We're just making a series of repairs. Therefore, we don't have to bring it into ADA (compliance)."

The problem with that is every commercial facility will wind up doing exactly that. If you own a mall or a hotel, if you make a series of repairs, you're not altering it, under that argument, and therefore you don't have to make it compliant. It was sinister. So we sued them, and that went on for that many years.

Ultimately, that was another case where the Department of Justice had to intervene (laughs) because that was going to affect literally commercial facilities all across the U.S. Think about it. Let's say you're a hotel owner. You'll simply say, "I'm not altering. I'm just repairing. This is not an alteration. It's just a simple repair." That case resulted setting all the guidelines and parameters for what is an alteration versus what is a repair when you're dealing with a commercial facility.

And I'll just share one more. The third case I was very passionate over was a fight with Delta Airlines. That was really interesting, and I don't want to get too overly ethical, but the issue was does the ADA extend to U.S. aviation? Are people with disabilities covered by the ADA when they fly? This case ultimately set forth—it was a great thing—the guidelines and parameters for U.S. aviation, how you build an airport, how you modify an airport to the procedures and protocols that U.S. aviators have to follow in order to allow for those with disabilities to travel in a safe, accessible fashion. People have to realize that the airlines really didn't want people with disabilities to travel. (Compliance) costs a lot of money. Their attitude was "Fine. If you don't want to fly, that's kind of what we want. We would love it if you didn't fly. That would work great."

I had a plaintiff on that one, an amazing woman, national tax expert. And this affected her job applications and her employment. She was a nationally known tax expert and she was known in her field. Every time she flew—They didn't intentionally do this, but they broke her wheelchair. They didn't intend for that to happen. They didn't train their people or focus on how to transport it safely. And she had MS. When they drug her wheelchair out of the plane into the cargo, it would break it. And you can't use an airport chair. It's a custom-built chair. So, people would get to their destinations with no way to get around. They just stopped traveling.

We really worked on it. That was a big fight. What I really liked about that case and all of these cases—I like to be uplifting about this. After you go through so much, you're like, there should be something uplifting that comes out of it. — The thing that was really cool about that case, and I think all these cases, whether it was Detroit, University of Michigan, Delta, and others, what would always happen, especially in Delta, the people who worked there who were working on these issues would say, "This is incredibly reasonable. This will make life better for my kids." So many people have disabled children. Or they would say, "My parents are struggling when they fly, and this will make things a lot better for them." This is doable. And everything we're working on together will enhance the experience. And more importantly, it will result in making it easier and better. We can do this. We can make this happen.

What I loved about Delta was, as long as you're reasonable, once they see, in all of these cases, that you'll fight the distance, then you're not just making noise, you'll really fight as long and hard as you need to. And no matter what, you will not back down. In all these cases you'll have their summary disposition motion, their motions to dismiss, and you survive those motions and you get through them. Once you get through that initial fight, they know that you will fight this until the end because you've got a lot of fight in you.
And it doesn't matter that they outnumber you and you sit there by yourself. Literally, I would go to court and sit at a table by myself with no papers. I can't read them. I would sit by myself at my table with nothing, and the other side would have, like, ten people at their table. So, you would look at the visual. It was me at my table sitting by myself with nobody, blind, memorizing all this stuff. And then you'd look at the other table, and they'd have boxes of stuff, crates, and I have nothing. That's how it was.

Once they realized that you were going to be a fighter and you were not going to back down, — It happened in every case. —that people really get along with each other. They start to like each other. They get to know you. Most importantly, you really affect each other. You spend so much time with each other, you start to become fond of the other side, and they become fond of you. You start working together. And in Delta, they



Addressing a visiting school group at the Michigan Hall of Justice (Supreme Court courtroom) in Lansing

were like, "We'll go beyond what the consent decree says. We're going to do this, and we'll do it well. We're really into this. We really believe in this. We think it'll make a better experience not just for people with disabilities, but for all of our passengers." And they did.

Cooper: Nice!

Bernstein: They went further than what the court asked them to do. They're a wonderful airline. Are they perfect? No. No airline is. But have they made a wonderful effort? Did they make it a priority? It is something they care about? Are they sensitive to the issue? Absolutely. Perfect? No. But did they really want to do a good job? Yes.

Cooper: What is the difference between the Air Carrier Access Act and what you were doing?

Bernstein: That's a really great question. I'm so glad you asked that question. You're awesome. I've got to tell you something. This is a great interview because you really know. I love it when you do an interview with someone who really digs in.

Cooper: (laughs)

Bernstein: And in all the years I've done interviews on these cases, no one's ever asked me that question. And I'm ecstatic that you did. That's great. So here is the reason, the distinction—the problem with the Air Carrier Access Act is that it doesn't allow for private right of action. That is a huge problem. The reason it's so flawed and why you had such horrific service and why you had airlines denying service to people was that the only entity that could access the Air Carrier Access Act was the federal government. This made it impossible to enforce.

For example, let's say in transfer, they don't do it correctly, and you get thrown on the ground. Your only recourse was to go to the Department of Transportation. That was it. The airlines loved it because the DOT is not always the greatest in terms of enforcement.

And you run into the issue individuals can't enforce it, only the government can take action. Let me put it this way; it wasn't the government's priority at the time I was doing this litigation for them to do enforcement. They were really excited about it. There was horrible stuff happening to people who were flying, inexcusable things happening to all types of disabled travelers, to the point that a lot of people with disabilities would travel only if it was a requirement because things were so problematic.

Like with the DDOT case, you'd have a horrible experience, and all you can do is write a letter to the FAA, which is part of the DOT. You say, "Look at this horrible thing that happened to me." When I got involved in this, the reason our case developed and the reason we got involved is because the government wasn't. That's the issue. The ADA allows for a private right of action. This allows for individual people with disabilities to take action against the airlines.

Cooper: Everyone should be aware you took action, thanks. Have you heard of Dr. Hazeltine?

Bernstein: No, tell me.

Cooper: I forget how she got involved in this, but she was seeing so many wheelchairs, especially power chairs, being destroyed during travel, that she created carriers that fit perfectly within the cargo area of planes. She pitched them to all the airlines. She spent years and lots of her own money to build this out. It just never—pun intended—took off.

Bernstein: (laughs) I got that!

Cooper: Those are some big cases you worked on. They changed lots of lives from the work that you've done for many years to come.

Bernstein: It was not an easy case. I had some wonderful associates I worked with.

Cooper: I'm sure you've worked with some great people.

Bernstein: Yeah, we had some good people who believed in the cause.

Cooper: And it's great that the Justice Department stepped in on a couple of those cases.

Bernstein: That was helpful. At a certain point, you're fighting with a city and a university that have endless resources. The issue is that the cases were going to have national implications, so it's good that they came in. At a certain point, you've got to have a balance.

Cooper: I think Pete Buttigieg would have changed how the DOT handled cases. He's really in tune with trying to get more accessibility within all the things that DOT is doing today. There was an announcement made on the 26th (Anniversary of the ADA) about funds making train and metro stations accessible in older cities.

Bernstein: Great!

Cooper: Within a few years the level of access will be completely different.

Bernstein: That's fabulous! Oh, I love to hear that! I was unaware of that. With the court cases so crazy and intense, I've been in my own world. That's wonderful news. You sharing that, sometimes you have to look back and say, "It's not easy, but things are getting better."

Cooper: You mentioned the buses. Years ago, those buses weren't around. Now they can lean and be green. DOT has a lot of intersectionality whether it's accessible transportation, environmental concerns, health issues, employability, all of the aspects that come into play.

What are your views on ride share and autonomous vehicles?

Bernstein: I think they're fantastic. For someone like myself, Uber has been transformative, it's changed my life, it's amazing. I still use public transit, but Uber is amazing. The idea is it'll become a higher form of Uber.

Cooper: That's what I'm picturing. You just use your phone and a car comes to you and you get in and it takes you somewhere—no driver.

Bernstein: It's really incredible. Thinking about how it used to be before Uber, I still take the bus, but Uber has enhanced my life and made it much better. And now, if you take it one step further, they'll make it even better than that.

Cooper: Did you see the litigation against Uber for people of disabilities and charging extra time?

Bernstein: Yeah, I'm not allowed to comment.

Cooper: So, knock once for yes, knock two times for no.

Bernstein: (laughs) I like that.

Cooper: The Department of Justice sent us a press release about their settlement for charging extra time to passengers with disabilities. Uber has now changed their policy and provided a monetary settlement.

You're going to run for another term, correct?

Bernstein: I am. I'm finishing my first eight-year term and running for re-election to hopeful go on to my second term.

Cooper: The people vote, right?

Bernstein: There's always this ongoing discussion about is it better to be appointed or to be elected? There are issues with both. I am a huge fan of elections. I think that as difficult as elections are, I am one hundred percent supportive of the electoral process for judges. Here in Michigan, to be a Supreme Court justice, you are elected by the entire state. It's analogous to running for Senate. It's a state-wide office. If you want to be a Supreme Court justice in the state of Michigan, there are 11 million people who live in this state, and you have to be elected by the state.

Our Supreme Court races are brutal. You have the negatives ads, the literature, the push-polling, the push calls, the robocalls, the mailers, the television ads, billboards. It's the same as what you'd experience, like I said, as a Senate race. People ask, "Is that the best way to choose judges?" I say yes, but it's no fun when people do negative ads about you. It's not a fun experience, not something you look forward to especially for people with disabilities. When I did this eight years ago, we found this is what happens.



Justice Berstein 3rd from left…along with Justice David Viviano, 1st from left) With students and guests at 2019 Court Community Connections program at Traverse City Central HS

If this wasn't an election, but an appointment process and you had to go in front of a merit selection board, let's say Michigan had an appointment and you had to go in front of a board.

If you have a disability, you go in front of the board and people would say, "Oh, wow, that's so interesting! That's so great!" Or they use the i-word, "Oh, my God, that's so inspiring!" And as soon as you walk out of the interview and the door is closed, they'll say, "What a fabulous story, but I don't think that'll work. Let's go with someone who looks and sounds like us, whom we don't have to take a chance on. There's too much of a risk here. What if it doesn't work out? Let's just go with a safe bet, with someone we know won't require all these accommodations."

The great thing about elections is you take this choice to the people. What was fascinating was they found in the polling I won by 10 points, and the newspapers were trying to figure out what was going on. I got outspent 10 to 1. Why is it that this blind guy is doing so well in the polling, even though he's being outspent by so much? This was eight years ago. They found that people, when they were asked, said, "I really want this blind person. I want a person with a disability." And people were surprised at that. They weren't sure. It had never been done before. "Is this a risk, putting a disabled person on the ballot?"

It's one thing to have disabled people work with you, but now, you're asking for people to allow for a disabled person to be in a position where they make decisions that affect able-bodied people. People said, "We love it. This is what we prefer." And the reason was overwhelming, and the polling and the election showed it. People said, "My kid is getting bullied at school. I'm having trouble at work. My parents have to go into assisted living. I'm struggling constantly. I want someone who's able to understand what it means to really struggle. I don't need a fancy blue-chip lawyer. I want someone who has life experience and who understands what it means to really struggle, to be different." They found that people really respected disability because it allowed for them to reconcile and realize that you could understand their struggles and their challenges and their difficulties. That notion that people are sick and tired of people in government, people who make decisions at these high levels, who don't have a basic understanding or appreciation for what it means to have to face struggle or adversity or difficulty.

Cooper: Let's hope that view continues. I'll switch subjects. Can you talk about your advocacy work around the world?

Bernstein: I do these things that will make a difference and have an impact, but I've always thought that really the best thing I can do, especially as a blind person who's a judge, that my focus is to be a good judge. When people see you doing your work, doing your job as a judge, that's what allows for them to see the potential in having other disabled people serve as judges. My goal is to get people with disabilities to serve more in the judiciary.

Cooper: Whenever you travel around the world you're behind-the-scenes bringing awareness as a judge and blindness—

Bernstein: I've been working internationally for well over 10 years. I'll give you an example. I was working in Austria, and there it used to be very difficult for people to become judges. There's a publication there called "Profil," kind of like their "New York Times." They did a huge story about this issue. In Austria, if you want to become a judge, you have to go to a separate school for it. It's not an election. You have to go to school. If you were blind, you weren't allowed to go into school, to move forward to do it. The belief was that if you were blind, you couldn't serve as a judge. I did a speaking tour through Austria and did a lot of work. They've now changed it. If you have a disability and you want to be a judge, you can do it. This is the kind of stuff I do.

If you look up the Sydney Morning Herald, I helped Australia push through their disabilities act. You can find that in the Australian press. A lot of it started in Israel. Quick back story, I really wanted to be in the U.S. military and be a JAG officer. When I was coming out of law school, I interviewed, but they said, "Look, because you're blind, you can't serve in uniform." I said, "Even as a lawyer?" The issue was, you still have to handle a firearm, you have to carry a weapon. Obviously, you can't do that because you have no vision and you're blind. I said, "I don't know how many lawyers are running along tanks. I could still be a JAG officer." And they said, "No, it's a service restriction. We can't do it.

So, in Israel it's compulsory military. We developed a whole program that allowed disabled people to serve in different units as volunteers. I worked on this for years. Regardless of whether it was physical or cognitive, if they wanted to serve as a volunteer, they could do it. If you don't serve in the military, you're kind of left out of the culture. The person I was working on this initiative with was a top gun Israeli pilot, a JDF fighter pilot. That became so successful that it spread to militaries all across the world.

This became so successful that we developed programs within Israel to allow for disabled people to work within the Israeli government. And then Israeli businesses started joining on to become a part of this. It got to the point where Israel asked if I would be willing to represent them at the UN and speak about these issues and what was going on. So, I spoke at the UN, in Austria, because we combined it with the Austria work. There are a lot of parties involved different governments, a lot of people.

When you travel the world and go to different countries, there's one commonality that people have in other countries, including people in power. It's that many of them have children with severe disabilities. Because there is such a stigma to it, there needs to be change of attitude. I don't do policy or anything of that sort. But it's your existence.

I'll give you another example in India. I was working on the untouchables because, as you know, these are children with severe disabilities. I was working with the Indian press. I went into the worst slums to meet children that were the untouchables. My goal was spend time with these children, whom nobody else would even acknowledge. By being photographed with them, to be embraced builds awareness.

At the heart of COVID, no one was permitted to go in the court building. During the closure, I was asked to do this work in the Middle East. They were asking if it was possible to go and spend some time over there.

A prominent person in the Middle East told me, "I never realized the potential my son has. I never realized his potential. I never realized what he could accomplish or achieve. What should we do about it? How can we work together? What can I do to make life better for him or other people?" That's what I would do in Israel. Israel has a wonderful technical ability to come and help on this, devise programs and services. So that's what we did. We started developing—you can't just build a school. You have to have programming, modeling, know how to teach. To create these opportunities, create special ed programs, allow for the technical. You'd have to want from a lot of these countries being transformative in this area and Israel provided technical knowhow on how do you create special ed services? How do you have special ed programming?

Assistive technology. How do you use technology to be helpful and to be assistive? We would do things like have athletic programs and transit and all these aspects. I was basically helping to—The goal was to work with folks who have special needs kids and allow for them to be brought into contact with people who had tremendous technical ability, technical support, to create programs and services as a partnership and best practices with various countries that otherwise didn't communicate or work well with each other. This was the common thing that allowed people to work on, these parents with special needs kids designing schools, special ed opportunities, assistive technology, athletic opportunities, all that kind of stuff. I've been doing this for years.

Cooper: When you were in the UAE were you able to meet with Sheikha Jameela bint Mohammed Al Qasimi — she runs Sharjah City for Humanitarian Services?

Bernstein: I know who you're speaking of, I met with her, but I spent most of my time with others.

Cooper: I was fortunate to visit with her and tour the center and her work with families with disabilities—it's impressive. And more recently I was invited by NYU



Justice Elizabeth Clement; retired Justice Stephen Markman; and Justice Richard Bernstein at April 2022 Court Community Connections program at Hillsdale College

Abu Dhabi to give several talks to the international press about reporting on disability prior to the Special Olympics International Games. At the end, someone came up to me from the UAE, and said, "By the way, we've changed our language about disability…."

Bernstein: (laughs) I know. It's "people of determination." That's so good.

Cooper: I'm so glad you knew that. They are really trying to make changes. Switching gears. Are you able to give your view on term limits on the U.S. Supreme Court?

Bernstein: As a judge, I can't really get into it. I'll just answer the question by taking it back to my own situation. Here in Michigan, I like the way we do it. Every eight years people can choose. Hopefully, the people are happy with the work that you're doing.

Cooper: When I saw the eight-year term in Michigan, I thought the Supreme Court could have with a term of 20 maybe 30 years—not lifetime.

Bernstein: Here it's interesting. You're not allowed to run past the age of 70.

Cooper: In that aspect, I think age is a wrong limitation.

Bernstein: I can comment on this. I think that should be changed. I think that in Michigan, as long as you're standing for election, why is that not something that the people can decide. You're running for election, let the people make that choice.

Cooper: Yeah, 70 is the new 55.

Bernstein: (laughs) As long as you're able to do your job, if people aren't happy with you, they'll vote you out.

Cooper: Ever think about going back to your private practice?

Bernstein: My focus in this place, we've got so much going on. I've never had a court term that's been as difficult as this. We've never had cases like this.

Cooper: Can you give example of the cases?

Bernstein: I can't comment on the disposition, but I can comment on what's ahead of us. In this Court, the seven justices will have to decide reproductive rights for Michigan. We have to decide all electoral issues. The Court will decide all the rules, all the constitutional questions that arise out of an election—it has to do with redistricting, with the census. We're dealing with guns in our schools. There's an old saying, "The road to the White House goes through the Michigan Supreme Court." That's why it's so intense right now. I wrote an opinion on Flint water—We just released an opinion today about juvenile lifers, is it cruel and unusual to send a child to life in prison. That came out just today. I've never seen in my tenure on this court, such intensity as it is now.

Cooper: Such important and long-lasting decisions.

Bernstein: Yes. This court will make the final determination on several critical issues. ■ ABILITY

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Uncovering My Invisible Self

SPD and Other Neurodivergences

"She's always covering her little ears around loud sounds."

"It's just a baby crying. You seem rude plugging your ears. It can't help it."

"Are you three years old? Uncover your ears, and maybe you'll actually like the music."

"You're so picky with your food that it's embarrassing."

"I said to try it, not to pretend to gag and immediately spit it out."

"Those lights cannot be giving you a headache. They're not even that bright!"

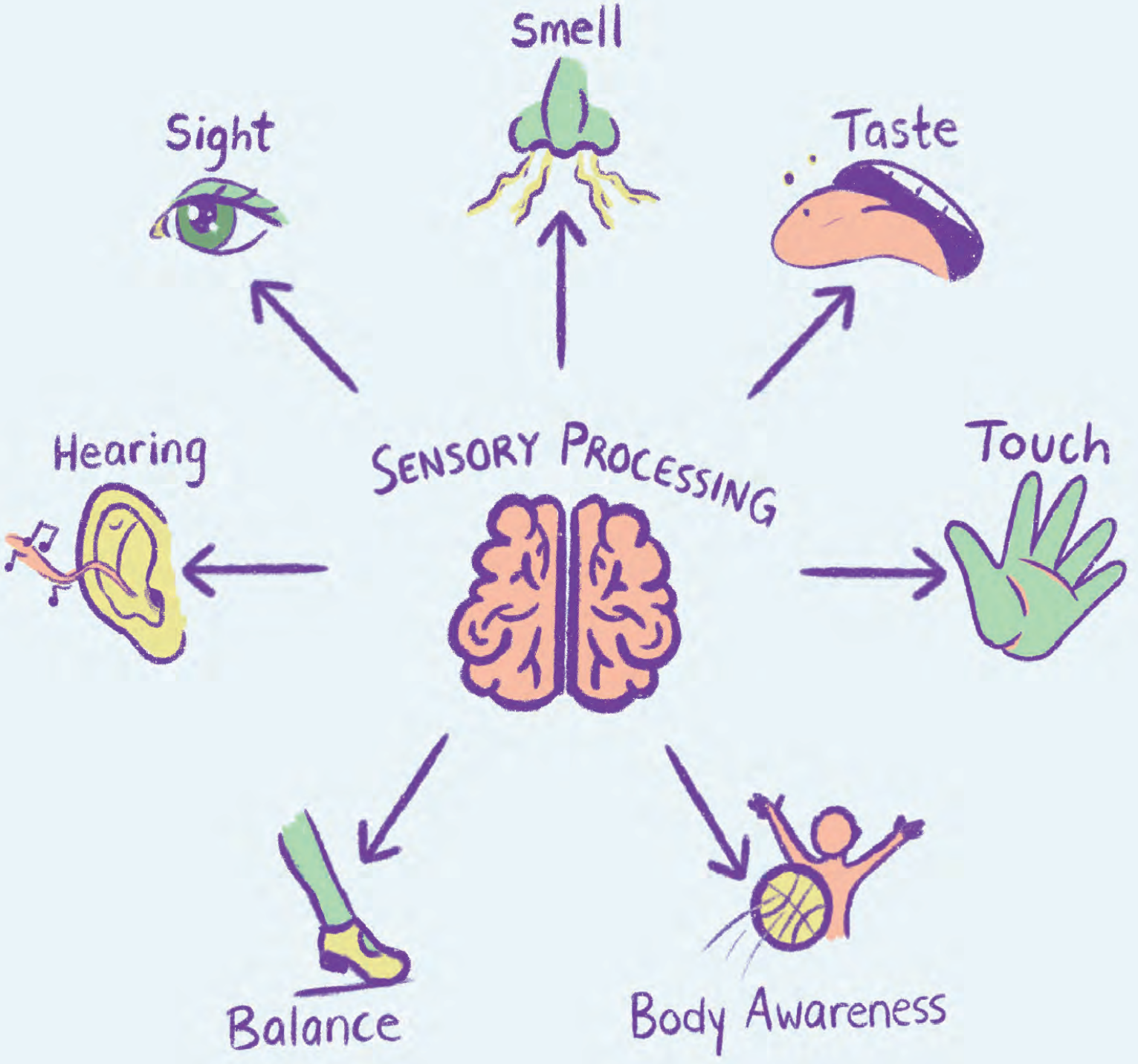
And most recently: "Are you seriously going to wear earplugs into this restaurant?"

These are just a few of the things I've heard throughout my life whenever I let it be known that a sound, taste, or light source was causing me extreme discomfort, and on some occasions, complete dysfunction. Little did I know that this is a majorly overlooked symptom of my own neurodivergence: Attention Deficit/Hyperactivity Disorder (ADHD) paired with Sensory Processing Differences/Disorder (SPD). I'm still on my journey of self-discovery, but I've found validation in my diagnoses and the communities I've found within the spectrum, and this has made all the difference for my well-being.

SPD, in my experience, is generally not as widely known as my other neurodivergences, such as ADHD and dyslexia. Although misconceptions and falsehoods surround my other diagnoses, too, it seems that I get more questions about SPD than anything else. SPD is a neurological condition in which the brain struggles to process, organize, and utilize sensory information (Butler, 2021). It involves seven primary senses: taste, touch, sight, hearing, smell, vestibular and proprioceptive (Dunn, 1997). It is thought to occur in somewhere between five and 16% of the population (STAR Institute, 2020). SPD has typically been associated with Autism Spectrum Conditions (ASC or ASD), but can exist independently, and can also commonly present alongside the following conditions: Attention Deficit/Hyperactivity Disorder (ADHD), Learning Disabilities, Fragile X Syndrome and Generalized Anxiety Disorder (Hethmon & Conrad, 2020). In short, SPD can manifest in many ways, and there's no one-size-fits-all approach (Butler, 2021).

Navigating life before I understood there wasn't simply something "wrong with me" was tough at times. Many people like to claim that they would never bully or tease neurodivergent people with Autism, ADHD, SPD, etc., but I've witnessed some of those same people making fun of how people spell online, how picky others' eating habits are, how "weird" their special interests are, how rude their facial expressions or lack thereof make them seem, or how they "overreact" when someone or something is too loud. I could go on for hours.

My life completely changed in 2020, and not just because of the pandemic. This was the year I was awarded a Fulbright scholarship to study for an MA in design in Newcastle, England--something I wouldn't have been able to do without the Fulbright Program. As soon as I arrived in Newcastle, however, I realized that I was completely alone, separated from my support system. I remember telling my dad on the phone that I had no structure, no family or friends, no way of managing things. This was also the first time I'd ever lived on my own, let alone in an entirely different country. This sudden change left me completely vulnerable, unable to function. In an instant, everything had changed. My routine collapsed. I stayed in bed most days and slept


Smell
Sight
Taste
Hearing
SENSORY PROCESSING
Touch
Balance
Body Awareness



whenever I could to avoid thinking of how to form a new routine because it seemed impossible.

Around this time, I met one of my best friends, Jess.

Though I knew some people through my flat's social media group chat, Jess was the first I met in-person. Within 24 hours, she let me know that she's autistic. Later, she told me that she disclosed this on the first day we met because she knew real friends would stay. Also, I'd already told her that I thought I might have ADHD, which made her more comfortable talking about herself. Her disclosing her diagnoses made room for so much learning, growing, and discussion of neurodiversity, through which I came to understand much more about myself.

Early on, I noticed that we had similar sensory-related experiences. Finally finding someone who understood me on that level was cathartic and enabled our friendship to grow faster and deeper.

I'm also grateful to the Fulbright Program for helping me seek therapy, find a psychiatrist and secure an official ADHD diagnosis. Without them, I probably wouldn't have been able to get one due to waiting lists and financial barriers. As a member of the global Fulbright family, I've made it my mission to give back to the community that's helped me so much. Starting in 2022, I've stepped into the role of president of Fulbrighters with Disabilities, a global, virtual chapter of the Fulbright Association. In this role, I hope to carry out the chapter's mission of supporting scholars with disabilities around the world and give others the opportunities that I struggled to find.

My university, meanwhile, helped me get my dyslexia diagnosis, which opened doors to me by making accommodations available. My therapist turned out to be a perfect match and helped me navigate many parts of my life that I'd never before understood. At long last, I felt validated, accepted, and cared for, free to be myself. After six months of therapy, I'd already learned many new coping mechanisms that enabled me to better manage executive dysfunction and be my most authentic self. I embraced wearing ear plugs in loud environments. I felt more empowered to speak up for myself if something was making me uncomfortable. I dropped many of the social masks I'd gotten used to wearing. I became more productive than I already was, more organized, and more confident about setting boundaries, something I'd never done before. Sometimes, I still struggle, but I no longer fear I might drown. I'm privileged to say that my family's also been extremely supportive. Inspired by my transformation, some of them even started doing research and seeking diagnoses as well.

Before heading to England, I'd already developed a plan for my research, which would focus on rural Appalachia and the lack of access to affordable internet services. By the end of my grant, however, I'd added another research project to my plate in the form of a thesis: How society could improve public spaces for those with SPD utilizing improved UX design frameworks. The basis of my thesis was to demonstrate that society must be more accommodating to individuals with SPD in a way that's easily accessible, supportive, and conducive to direct and concrete change. In my research, I focused mainly on approaches tried in the West thus far to better support people with SPD. I also investigated ableism in current UX/UI design practices and how to overcome it with newer accessibility models.

Cynthia Bennett, a leading advocate in UX disability and accessibility practices, says that often, when designers think about design, they tend to approach it with the assumption that "I am the designer" and "you are the user." This way of thinking locks in the premise that the designer is forever separated from the user and therefore



can only ever design "for" them, not "with" them. Aparna Pasi, the accessibility lead at Deque, has said that she hopes that one day, accessible design will become a more prominent practice within the design community. Pasi concludes that we shouldn't see accessibility as a project, but rather as a process (Pasi, 2020). I hope to utilize the research I accomplished to help others like myself and beyond.

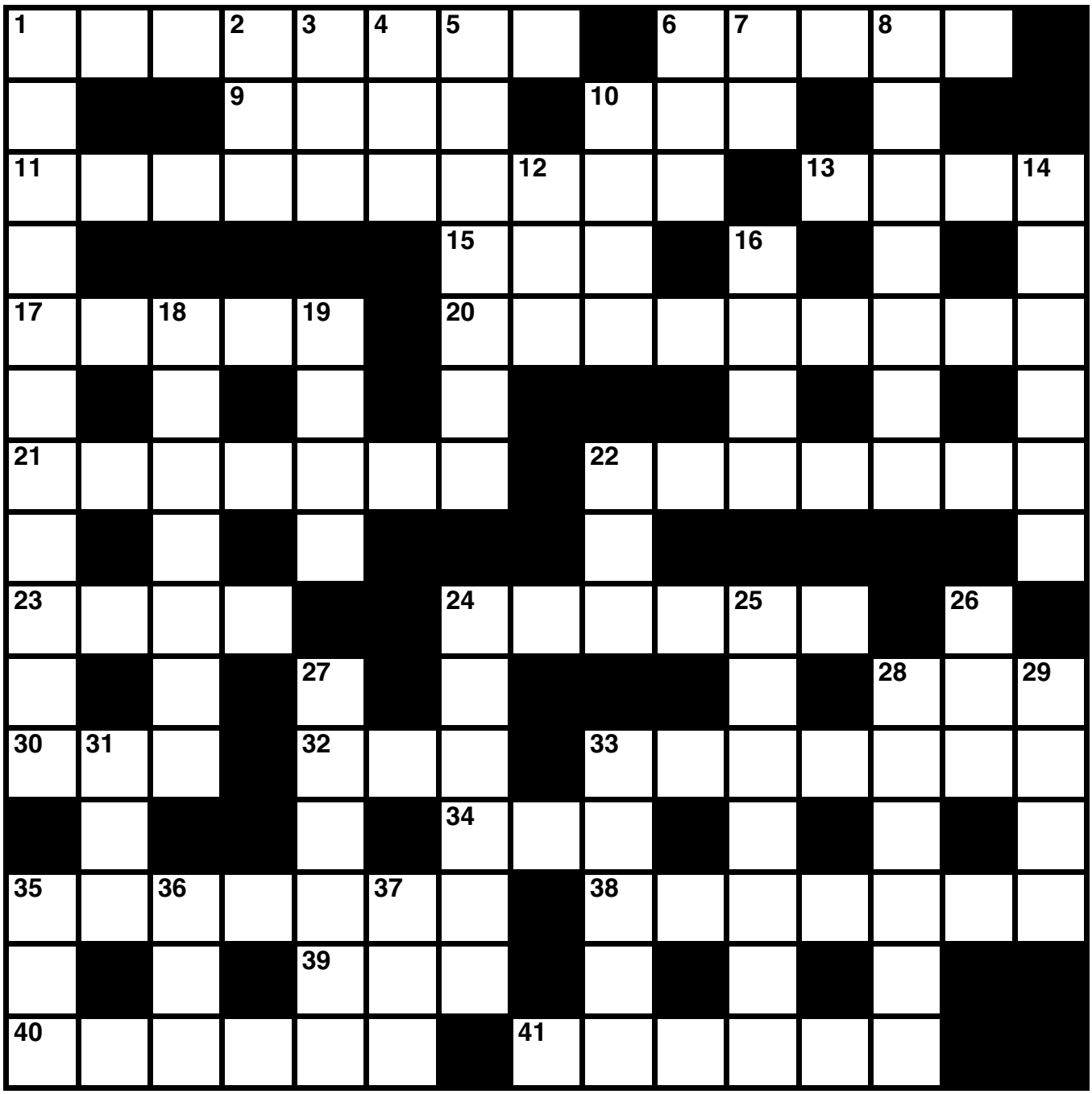
These days, when I hear ableist comments about my sensory problems or other diagnoses, I take it as an opportunity to teach and learn. The people whom you love the most can unknowingly be ableist. When this happens to me, I've learned never to charge in with anger because I get it: before I learned what I know today about neurodivergence, I was in their shoes with my own internalized ableist thoughts, which plagued me throughout childhood. Growing up, several adults around me fed me stereotypical and overly generalized comments about autism, ADHD, and dyslexia. As an adult, I reflected on those comments with more clarity, and this, as well as talking and working with other neurodivergent people and educating myself, was how I managed to grow. Little by little, I hope that our conversations will make people who're in the habit of making those unwittingly harmful comments more aware so that they, too, can learn and grow.

I'll end with one of my favorite quotes, which comes from Harvey Blume: "Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment?" ■ ABILITY

by Geghie Alayna Davis

news.utk.edu/2020/05/06/design-grads-road-home
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ABILITY's



Crossword Puzzle

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ACROSS

1. Very talented Florida artist who partners with Foot Locker to raise awareness of Autism, 2 words
6. Scientist who specializes in adaptive technology design. Joshua _____
9. Black in roulette
10. Sombrero, e.g.
11. First actress who used a wheelchair to appear on the Broadway stage, 2 words
13. Transparent
15. "Cool" amount
17. R.J. Mitte, for one
20. Making better
21. Writer of "The Invisible Kingdom" , Meghan _____
22. Get close to
23. Nightfall
24. Word before canal or hat
28. Swimsuit top
30. Whoopi Goldberg plays one in "Sister Act"
32. Lord's Prayer starter
33. Chinese urban planning and big data expert,_____ Mao
34. "Rocks"
35. He trains service dogs for people with autism, Frank ____
38. Jonathan Pangborn and Gabriel Reyes, for example (both disabled actors)
39. Plaything
40. She created her own TV series, "My Gimpy Life"- Teal _____
41. "Push Girls" star, _____ Rockwood

DOWN

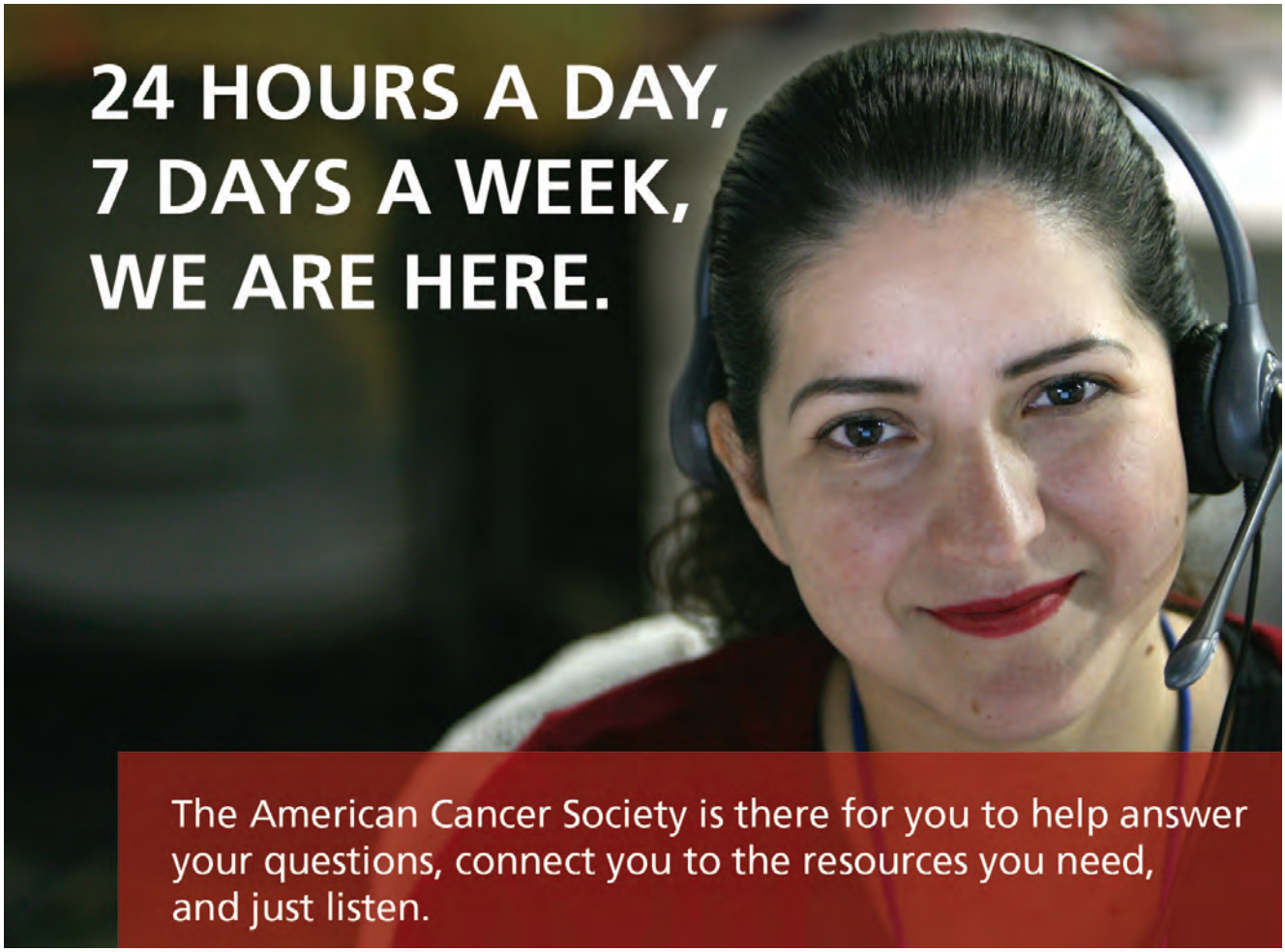
1. Actor, solo artist, filmmaker and disability activist
2. U.S.N. officer, abbr.
3. Camp bed
4. Balloon filler
5. Pledge
6. Spoil
7. Tech department, abbr.
8. Hitting the shore
10. Assistance
12. Actress Cattrall of "Sex and the City"
14. Piece of gold or chicken
16. Sukiyaki ingredient
18. Actress and activist for women's rights and for the environment, Celeste _____
19. Lightly cooked
22. Solar energy source
24. Equality
25. Gulf coast sea creature
26. It produces high quality wine
27. Give to charity
28. First Paralympian in a Sports Illustrated swimsuit, _____ Huckabee
29. Goals
31. Land of the brave and free
33. Cantaloupe
35. Negative prefix
36. "Brokeback Mountain" director Ang
37. Craggy crest

Crossword Puzzle

answers on page 76

Crossword Puzzle

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