

ABILITY

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WarnerBros. Spotlight

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Moto fans! Is everyone as excited as I am for the outdoor motocross races to be starting? My Saturdays are filled with watching races again....yay!

I have been a little busy I went out to San Diego and participated in the Ride Cake International race at the Del Mar Arena. They make super cool electric bikes! Definitely different than riding on a motocross bike. I was a little worried because most of the other girls that were racing have mountain biking background. I have ridden some mountain bike trails, but I was thinking I wouldn't have the right experience. The racing is a little different too, you don't really ride like a girls class or anything you ride by divisions and everyone is timed. At the end of the "motos" they just add up the times and see who had the fastest over all. I wound up winning the woman's class and now there will be a championship race in September—I look forward to seeing everyone again. Those Ride Cake bikes are pretty sick!



I also recently did a moto class in Oregon. I was at a track called Moto 541 it's a wonderful place and the people that own it are great! I had a really good time and my mom couldn't make it to interpret, but my friend came with me. We got to enjoy a few breweries and wineries while we were there so that made the trip extra fun for both of us! As usual I had a great time with the students and a lot of fun.

Now I am headed back down to Florida to watch my little brother graduate! Wow time flies.... I remember I

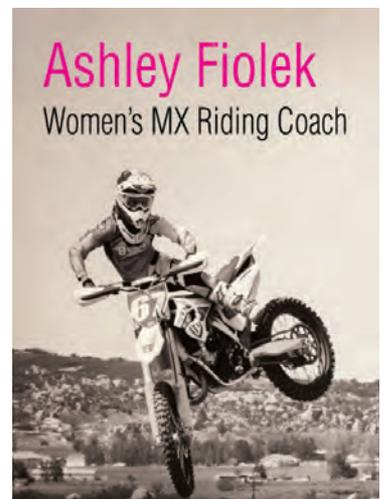
was 13 when my mom told me that she was pregnant with him. I was just starting to get really involved in racing. At first I didn't want a brother because I thought I would have to stop racing :-) haha...luckily that was



not the case! My mom told me and my dad we could pick his name because we wanted something related to motocross. We went with Kicker! My mom was like ok, but his middle name is James so when he becomes a doctor he can use James instead haha.

This will just be a short trip because we have to get back home. The last time I was in Florida I didn't get to go to Saint Augustine so this will be nice. I'm very proud of him he actually got some awards for his ASL accomplishments and received a Seal of Biliteracy! Wow and this is the man that would never sign to me when he was growing up haha.....

I have a couple more events coming up soon so make sure to keep checking my Instagram! ■ ABILITY



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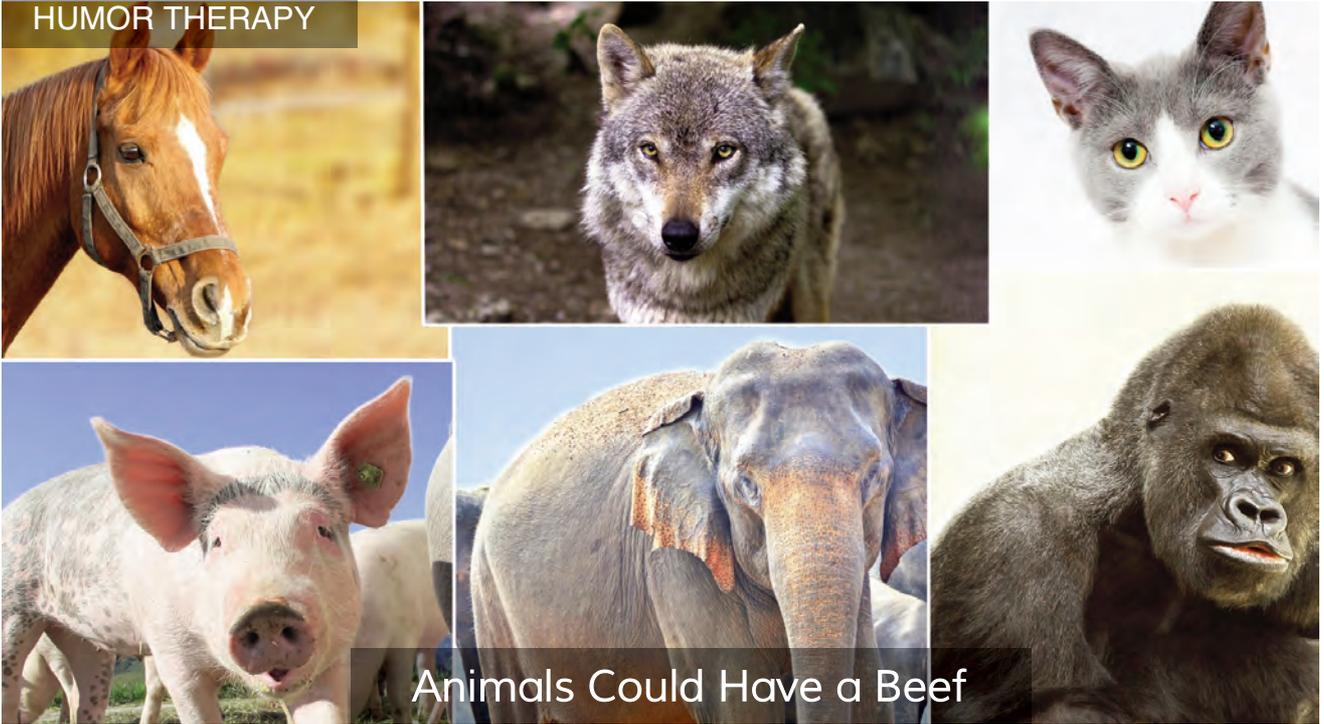


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Animals Could Have a Beef

Animals are a big part of human life. We love our pets. We go to zoos to observe them. We ride horses. We get milk and cheese from cows. And, of course, we make yummy dishes out of them. They are interwoven into our society. They have even become part of our everyday conversation as we use idioms to make a point or provide a description. I often wonder what the animals would be thinking if they could understand what we were saying. They may not be too happy.

I'm so hungry I could eat a horse. Suddenly, the horse's ears perk up. "Excuse me. You did not just say horse? I know you didn't say horse. Everyone knows we do not eat the horse. The pig, the lamb, the steer that's all-fair game, but the horse, no, no, no, the horse is off limits. You can ride us, race us, have us pull a wagon, we're not some one-trick pony, but I draw the line at eating. That's not in my wheelhouse. So, let's just leave the horse out of any dinner conversation. Can we do that? And another thing, we don't approve of you associating us with people who goof off. No more 'horsing around' stuff. The correct term is 'monkeying around.' That makes a lot more sense. We work our asses off. Also, this deranged 'beating a dead horse' reference. Not good. If we're dead, leave us be. We made your life easier while we lived, which is probably what killed us. So how 'bout you just hold your horses on that little ditty. And I'll end with this. If I'm thirsty and you lead me to water, I will drink it. Sorry to burst your bubble."

A wolf in sheep's clothing. "Look, I'm a ferocious wolf. I kill things for a living. I'm very mean and very intimidating. You will never, and I mean never catch me dressing up as a sheep. First of all, I don't look good in wool. Secondly, I'm a pack animal which means there's always other wolves around me. The last thing I'm

gonna do is dress up as a sheep. They would laugh at me. Shun me. I'd be the black sheep of the pack or, even worse, mistake me for a real sheep and eat me. So, keep wolves out of your conversation. There's no validity to a wolf in sheep's clothing. It just doesn't happen."

It's a dog-eat-dog world. "How in God's name did we get pulled into this? One day we're man's best friend then the next we're chowing each other. You're making canines out to be bi-polar. Sure, we'll bark at each other, play with each other, a little humping, some butt sniffing. Yeah, okay, we're not saying everything we do is socially acceptable but it's a far cry from us eating each other. That some sick stuff. You're the ones who have Jeffrey Dahmer in your human gene pool. Don't project your weird fetishes on us dogs. We're good with the dry food, cans and bones. We don't feel a need to eat each other.

Kill two birds with one stone. Upon hearing this a bird must be thinking, "I do not like the sound of that. Birds and killing in the same sentence. Now why on earth would you wanna kill a bird, two for that matter. We sing. We pollenate plants. We don't want any trouble. Leave us birds out of your homicidal proclivities. You've already killed the goose with golden egg. Isn't that enough? If I even see you pick up a rock, I will not be a sitting duck. I will fly the coup and drop a little present on you. Got that, chief. What's good for goose is good for the gander."

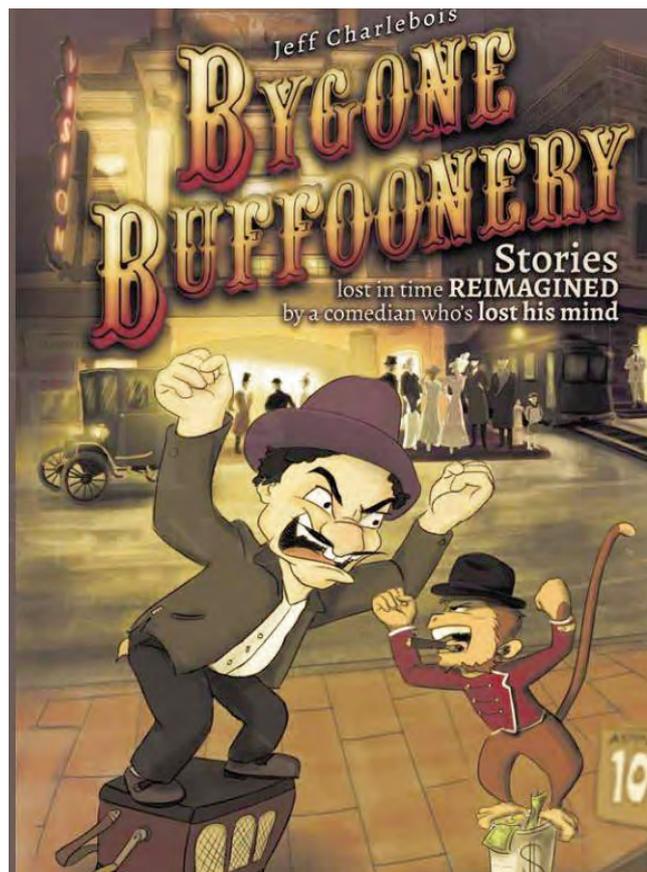
Putting lipstick on a pig. I can guarantee that the pig does not like this saying. "You did not just go there. I know exactly what you're implying here. You're saying we're ugly, and not just ugly, but so ugly that even lipstick won't do anything to change that. That's very rude.

I guess you were never taught if you don't have anything nice to say then don't say it. I guess the pig is low man on the totem pole. We're the ugly ducklings. Every human flaw is associated with us. You look like a pig. You eat like a pig. You smell like a pig. Clean up that pigsty. Get off our backs. We're like the black sheeps of the animal kingdom. You sure as hell don't have a problem with us when you're frying up that bacon or stuffing a pork sandwich into your mouth. And, while I'm on a roll, cast pearl before a swine? What's this all about? Pearls too good for the pigs? We can wear the lipstick but not the pearls? Wow, you all have some nerve. Do I think you'll ever stop these unflattering, distasteful comments associated to us? Sure. When pigs fly."

The elephant in the room. "What are you saying here? Are you alluding to my size? My weight, by chance? That I'm... fat. Say it. It just so happens that I happen to be big-boned. That's the way large mammals are. And, by the way, I'm comfortable with who I am. I like when I'm in a room and people notice me. I have nothing to hide. It's a helluva lot better than being the mouse in the room where no one knows you're even there. I'm a hit at parties. You know why? 'Cause people notice me. So don't say 'the elephant in the room' like it's a bad thing. Everybody likes to be noticed. I'm an attractive beast with a cute, wavy trunk. It's not like I'm the 800-pound gorilla in the room."

I smell a rat. "So, what if you do? You say that like it's a bad thing, like we smell like a pig. I'm sure every rat has a different smell to them. Some have a dumpster odor. Some have a sewer fragrance. Others might have a garbage scent. What's it to you? You shouldn't generalize. And, for the record, that cologne you're wearing is no day at the beach for me either. And why do you use the term 'ratting someone out?' We always keep our mouth shut. You never see us squeal like a pig. We ain't stupid. Snitches get stitches. You rat-face bastard. You know it's not easy on us. It's a frickin' rat race out there."

The cat is out of the bag. "It better be the hell out of the bag. Who puts a cat in a bag? Are you demented? Those are signs of a future serial killer. We like a little cat nip, a squeaky toy, a few treats but this bag thing, no, that's not our bag. Get it? Please, I would appreciate it if you would stop using this saying. People get ideas and, before you know it, there's bags of cats everywhere. And what if people forget to let the cat of the bag? Answer me. Cat got your tongue? And, let me throw this one in that tends to be bantered around quite a bit. There's more than one way to skin a cat. Are you kidding me? Cat skinning? Once again, we're treading in serial killer territory. Maybe you're just planning on making a Maine Coon hat in hopes of being the talk of the town? You people are sick. Just so you know, that thing about cats having nine lives, it's an old wife's tale. Just like you, we got one. So go skin a potato instead. And I'm sick and tired of the 'look what the cat dragged in line.' We bring you something nice like a mouse or



lizard and somehow it becomes a bad thing. Wow, talk about looking a gift horse in the mouth. Sorry if I sound like I'm the cat's meow."

A leopard can't change its spots. "Yeah, so what? We never said we could. And why would we? It just so happens we like are spots. The more spots the better. It beats stripes. Nobody looks good in stripes. That's why we eat the zebras. Zebras don't eat us, do they? Besides, stripes make you look fat. You stick out like the elephant in the room or an 800-pound gorilla.

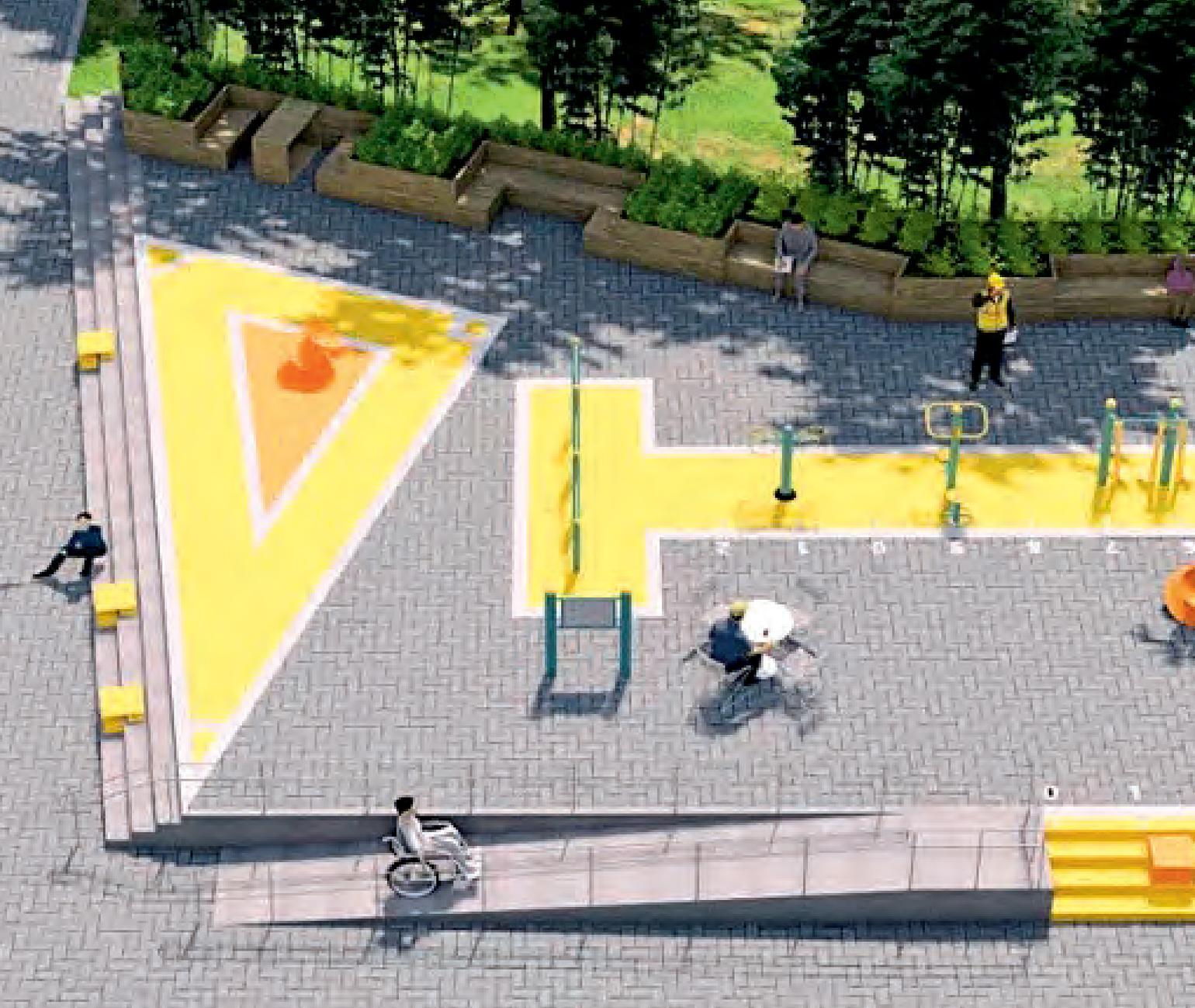
Blind as a bat. The bats huddle together and begin murmuring in squeaky voices amongst themselves. Finally, they all look up and say, "Yeah, we got nothing."

Maybe it's best that the animals can't understand us. They might not be too happy with us injecting them into our everyday vernacular. An irritated hamster may not be a big deal but the last thing you want is a pissed off lion or wolf. That's how people get hurt. I was actually hoping to weasel out of doing this article but I'm not a sly fox. That's what a snake would do. Plus, I know I'd be in the doghouse with my readers. Besides, this is one of my cash cows and I just can't stop writing cold turkey. Well, that's my swan song. I hope you enjoyed it. ■ ABILITY

Jeff Charlebois

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茅明睿 透视数据背后的城市

Mao Mingrui: Looking into the City through Data

Mao Mingrui

He chaired Cloud Innovation Hub at the Information Center, Beijing Municipal Institute of City Planning & Design, before moving on to head the Beijing Community Research Center and take on the role of CEO at Beijing City Quadrant Technology Co., Ltd (Urbanxyz.com), a data science start-up he founded in Beijing, China.

Mao Mingrui is not so much a city planner as a social observer. In his career he has spent more than 20 years traversing city streets and neighbourhoods and doing the things some might call “performance art”—like counting how many electricity meters there are in a hutong, “camping out” in a neighbourhood just to see how residents go about their day, feigning blindness to experience how well tactile pavement works for blind people... and even going out to count the amount of dog droppings on the street. For Mao, these strange actions or commonly-seen objects often bring pleasant surprises when translated into data.

For this, he relies heavily on observation and data analysis in order to carry out city planning, a process of understanding the massive and complex intricacies related to a city by collecting the attributes of things, people and behav-



ours. As Mao put it, “City planning is not a high-level thing. Only by paying attention to other people’s actual needs and adopting a people-oriented approach can cities become more liveable.”

A city observer off the beaten track

Mao is nicknamed “online celebrity planner” thanks to the dozens of public appearances he has made since he started his business in 2014. On Yixi and Dedao, the Chinese MOOC platforms, for instance, he gave fascinating speeches about the aspects of urban planning that might appear to be dull and boring for many. This is partly attributable to his down-to-earth way of talking, and partly to his long years of observation of city data.

Why do electricity meters and dog droppings have to be counted? When asked a question like this about something which would never have occurred to most people outside his profession, Mao explained: “It’s a detail closely related to neighbourhood lives. Take pet droppings for example. More droppings mean that more pets are walked along this street, and they also reflect where people tend to go, which in a sense represents the extent to which the street feels welcome. Of course, this can also demonstrate local public hygiene issues.”

Compared to conventional city planners, the approach of Mao and his team seems a little “off the beaten track”, but to many people’s surprises, he is definitely not an “ignorant outsider.”

After his graduation from Wuhan University, majoring in city planning, Mao Mingrui joined the Beijing Municipal



Institute of Urban Planning & Design. In 2013, he and his colleagues set up “Beijing City Lab”, a youth community composed of planners, architects, geographers, economists and other researchers in many fields. Together they worked during the day and shared their findings at night, driven by nothing—no task-based bonus or client contract—except their passions.

In 2014, Shi Weiliang, the then president of BMIUPD, realised that city planning sounded an urgent call for change. In the tradition of research-driven practice at BMIUPD, Mao helped establish a Cloud Innovation Hub.

“Big data provides more data sources for us to learn about the city. With the help of big data, we can understand the individual’s spatio-temporal behaviour and needs with respect to planning, and these will profoundly change how we approach planning.”

Later the state issued a call for “innovative and entrepreneurial talent” and released a detailed directive for incentivizing researchers to leave their government-assigned posts and start businesses. This was an impetus for Mao’s entrepreneurship. In 2016, Beijing City Quadrant Technology Co. Ltd was founded with commitments to improving city governance through data science, and this was a change of direction for Mao’s career.

The needs for better tactile paving revealed by thousands of data entries

Mao Mingrui said that he had lost his sense of smell for many years due to nasal allergies. “One thing that hit me the hardest is the ‘social death’ I’ve experienced in my life.” On the morning of a weekday, Mao recalled, he pushed his way into the crowded subway train and steadied himself by the door before he discovered that the others were moving away. Without giving it too much thought, Mao began to look down at his mobile phone. It wasn’t until several stops later that he found a large pool of vomit next to the door. “I believe the entire carriage smelled terrible, and I also believe that other passengers must have thought I was an ‘oddball’.”

The experience of “social death” due to an olfactory disorder made Mao realise that he was overlooking problems around him. After this incident, he began to draw his attention back to city life, at times surprised by new discoveries around him: there were eight hand-made individual shelters for cats in his neighbourhood and 22 waiting seats just outside of his favourite hot pot restaurant. He was building a subtle connection with such details which he noticed. His own olfactory impairment also led him to think that an individual’s perception of the urban environment may impact how they relate to the city, and may even affect their happiness. No longer satisfied to be merely an observer, Mao began to consider how to engage and make a change.

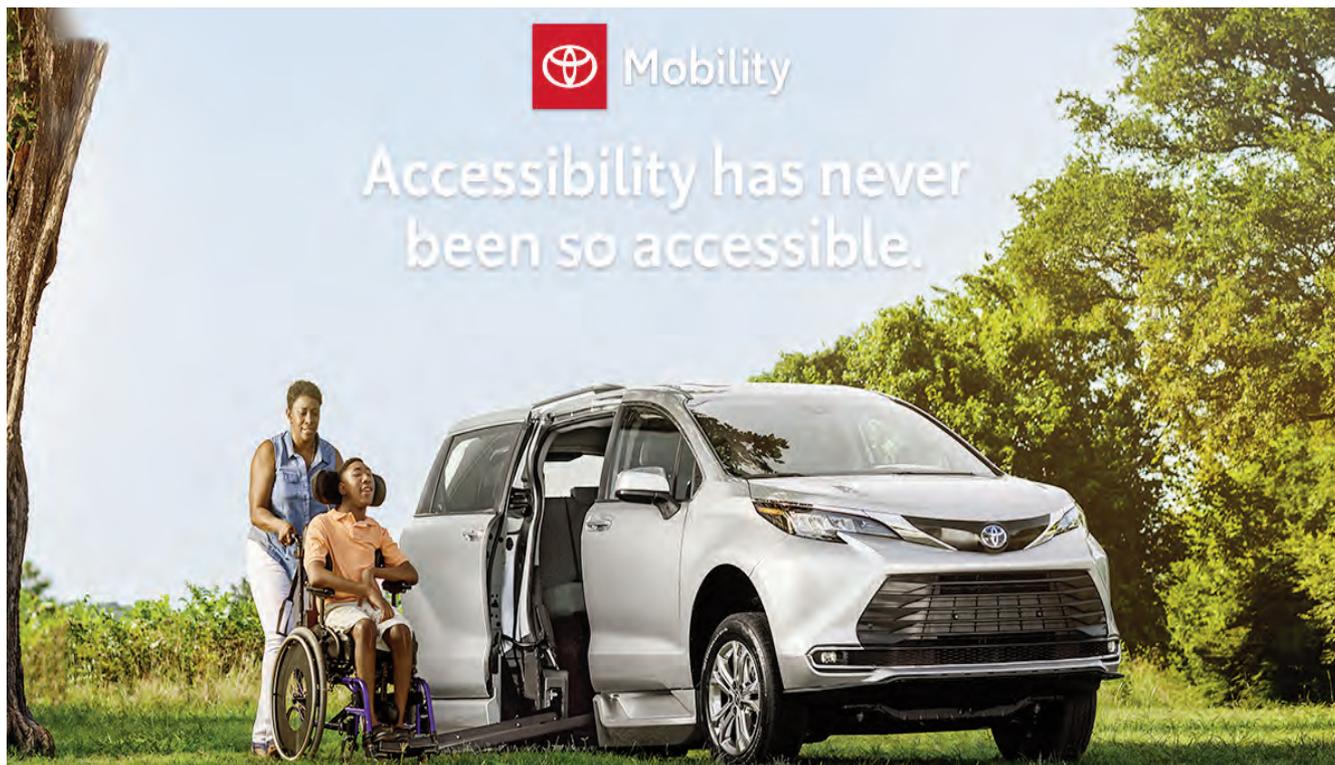
One weekend in 2018, Mao came across a blind man at a bus stop, and was quite surprised to learn that he was going to “watch” a movie at Mind’s Eye Cinema. This was the first time he knew that blind people could “watch” movies. During their conversation, Mao learned about the difficulties the man and other members of the blind community had when traveling, and reached a better understanding of how blind people lived. “It seems that I tend to feel empathetic towards this group maybe because I have an olfactory disorder. I want to experience the world of blind people and wonder if tactile pavements really are friendly to them.”

On the International Day for the Blind in 2019, Mao’s company, in collaboration with a local aid group for the blind, organized a “Walking Blind” event to evaluate how accessible the streets were by observing and recording the behaviour of young blind volunteers.

Six blind children were videotaped while they walked a 1.6 kilometre section of Shuangjing Street in Beijing. “On this street, seeing people only need to take 7 turns while blind people need to take 73 turns, which is 10 times more.” Prior to spatio-temporal arrangement, the team attached more than 9,000 tags to specific factors identified in the 10-hour video, including obstacles on the tactile pavement, surrounding barriers, facial expressions, arm movements, blind cane taps, etc.

Mao found that the same part of the street meant a 1,600 metre walk for seeing people and more than 2,600 metres for blind people when using the tactile pavement, which could not offer precise guidance for the whole journey, even though it was there for most of it. “We divided the pavement into 16 sections, and calculated the turn index, disconnection index, deviation index, etc. according to their on-site status and the video data. Then we took out six sections with ‘wave crest’ deviations for analysis. Finally, we concluded that too many turns and disconnections are the main reasons for blind people to deviate from the tactile pavement.”

This was a little surprising for Mao. Too many turns make it difficult for blind people. The causes of this problem include the C-shaped turns around ground



obstacles such as manhole covers, the Z-shaped turns used to connect disjointed strips, and the L-shaped turns that lead to zebra crossings at intersections.

“Some blind children lose their sense of direction when they deviate from the pavement, and it is difficult for them to get back onto it by themselves. The surrounding trees and vehicles may pose dangers to them.” According to the video-based statistics, each child hit an average of 76 obstacles with their blind cane, including 13 bollards, 12 telephone poles or lampposts, 49 walls and 2 bicycles.

“The most important thing is the emotional changes that blind people show while walking.” The team tagged the volunteers’ facial expressions and movements in the video, and selected 11 typical movements or facial expressions, such as hand-flinging, frowning, and head-scratching, that showed annoyance. During the walk, a total of 543 “upset points” were recognised, and most of them occurred when the travellers came across uneven surfaces, obstacles, tactile interruptions and other unexpected hurdles along the way. “They showed an extremely high frequency of negative emotions when they walked under the overpass, because they couldn’t hear the traffic light buzzer.”

Would tactile pavement be user-friendly if it conformed to all the accessibility standards and specifications currently available? Having been a city planner for many years, Mao insisted that friendly urban facilities are always people-oriented. “Even by accessibility standards, we may only find 20% of the problems, and the rest are not made explicit on paper. For example, the distance between a flower bed and tactile pavement

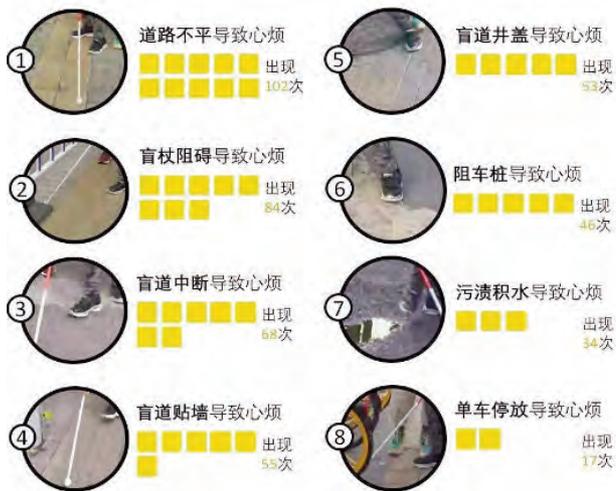
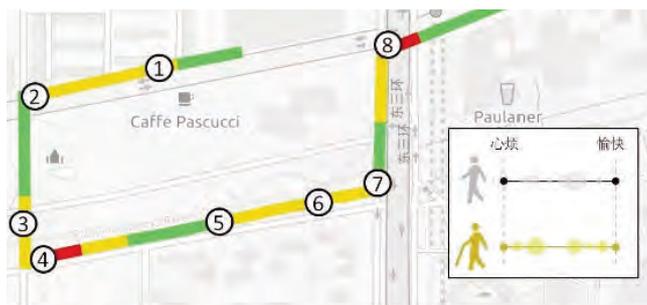
seemed up to par at the time of construction, but as time goes by, some trees grow out of the flower bed, and blind people will keep hitting the branches when walking along the pavement. That’s why we must employ all our human senses for city planning. What we need to do is make everyone’s lives better, with timely updates to relevant standards and regulations, and spatial planning in alignment of how a city actually works, through behavioural observation and data research.”

For Mao, this research project was a success. By using the analysed data, they pinpointed the difficulties and needs of blind people walking, and evaluated the shortcomings of tactile paving. When the government released a “Beijing Action Plan for Further Promoting Accessibility in 2019-2021”, Mao’s company was commissioned to carry out a large-scale general survey of accessibility facilities.

“The previous effort was not cost-effective, and the lengthy follow-up analysis lasted for more than two weeks. It would not be feasible to conduct a large-scale urban accessibility survey this way.” Mao began to think about whether any technology was available in data science that could be used to survey the streets for blind people.

He found his inspiration in automobile reversing radar: “Equipped with radar, the blind cane could detect the distance of obstacles by reflecting radar waves, and warn the user with a buzzer. After collecting the data of radar waves and GPS, we could then understand the problems faced by blind people and the surrounding environment they are in while walking.”

Based on this idea, Mao and his team spent two months



making a “radar” blind cane. In 2020, the new device was used to scan all buildings, public facilities and road sections within a radius of 5 square kilometres along Shuangjing Street. In this way they created the first urban street neighbourhood accessibility report in Beijing. With this achievement they took the lead in piloting an accessibility construction project across the capital.

“In fact, the streets may be unfriendly not just to blind people, but also to everyone moving about in the city. The space and other features of a street reflect the real status of local social life and the spirit of a city. We can’t ignore these ‘dangers’ and ‘pains’. Tactile paving probably won’t be needed anymore when all roads are made ‘easy’ one day.”

Spaces optimised for human use

Mao and his team are always looking for continuous improvement through practice in the context of data science. What they advocate is not a planning method, but rather a perspective of design in terms of good technology. In addition to the “radar” blind cane, they have developed a series of smart planning tools, such as the Cat’s Eye Quadrant and Bat Ultrasound Quadrant, and integrated them to collect data from the nooks and corners of the city.

Apart from tactile pavement, gathering places like community squares and parks, in Mao Mingrui’s view, are all urban public spaces activated by the people. All groups in a space should be considered in the planning and design processes, and their presence will inspire the

planner in a positive way: is the planner able to address the daily needs of residents, provide basic amenities, and reduce disturbances to the lives of community members, in community planning? Is the planner able to make full use of the space, route activities to a specific venue, and create a community friendly to all?

Whether it’s the elderly, the young, the able-bodied or the disabled, urban development means different things to different groups. “An urban public space that is truly friendly is not a product of the planner, but a creation arising from public engagement.” Mao believes.

In a design contest sponsored by the Chaoyang Branch of the Beijing Municipal Planning and Natural Resources Commission and Zhongshe Social Work Development Foundation, Mao’s team was shortlisted with their micro-renewal programme for an extremely inefficient community space, where they had asked local residents, regardless of their ages and backgrounds, to join in and envisage how the space was going to change for the better.

“Before, you could say it was an abandoned space, and the people passing by barely paused. After the renewal, there are trampolines and swings for children, fitness equipment for the young and the elderly, flower beds with seats and accessibility ramps. We have also done some data analysis. The number of daily visits has increased by 50%. Residents come here for exercise, rest and socializing, and there are twice as many stays. The venue now has more viscosity. In fact, this is an example of what can happen with citizen engagement.”

Mao’s perspective was greatly influenced by American urbanist Jane Jacobs. In her book, the *Death and Life of Great American Cities*, she introduced a planning concept quite uncommon in the 1960s, along the lines of: “Pedestrian streets can be safe and healthy for socialising only if they are continuous with all kinds of grocery stores alongside. Green spaces and urban open spaces are not dynamic in themselves, and isolated parks and squares are dangerous places. Local areas should be integrated with other functional facilities to be significant as a public place.”

For Mao, cities are organic, and city planning is also a process full of life, supported by a beating heart and soul that pays attention and respect to everyone who lives in the city. ■ ABILITY

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*



60+

地球一小时



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Road Block

Multiple Sclerosis is a condition plagued with physical symptoms that seem to come and go. As the disease progresses, the level of disability typically increases. Many symptoms like numbness, fatigue and cognitive difficulties are all but invisible to others. One thing for certain is, nothing for certain. Yesterday I climbed a ladder to fix the antenna struck by lightning, yet last week my leg was numb. Today I can walk the dog around the block, tomorrow it may be impossible. When I have a good day, I will push myself to get stuff done, because tomorrow might be that day I can't seem to get off the couch. Unpredictable, unknown, unimaginable. Daily life with chronic illness can teach us a lot about perseverance and how to deal with life's rollercoaster of uncertainty, including road blocks.

When I started my journey to help others with MS, I did not really know where it would take me, but I soon found an angle to help me start making a difference. Within a year, I had become a patient advocate for one of the therapies and began speaking at events around New England, earning some money and getting to talk to other patients. I worked hard to develop a good story that would be acceptable by the FDA and the regulatory departments of the pharmaceutical companies while still inspiring others to find something they love to do in life and to make it more important than their disease.

By year three I was sharing my story at two or three events a month and being asked to speak at even more events, some I could not even get to. I was traveling all across the country, strictly by motorcycle.

Four years into my quest I was forced to make a decision to keep my day job or go on the road speaking full time. The difference in compensation was about half, but I knew my ability to grow my audience and I had faith that I could market myself to speak at more events and make up the difference.

A month after quoting my real job, one of the companies stopped providing educational events for patients and my income from speaking was cut in half. I worked harder and was able to secure more events from the second company, becoming the most requested speaker in the country. I was also becoming a public figure in the motorcycle industry and many fellow riders and companies offered their support in my million mile quest. I started doing



seminars at rallies and although there was no income, I was growing my follower base and gaining the support of major corporations like Yamaha, Bridgestone and Aerostich. I was getting most of my travel expenses and gear covered and I was able to squeak by with speaking income from the pharmaceutical company.

After 18 months of riding across the country full time, everything changed and my journey hit another giant roadblock. The drug company I had worked so hard to become the top requested speaker for had decided to change their travel policy. The legal department believed a patient riding a motorcycle to their events across the country was a liability for them and decided I could no longer ride my motorcycle to share my story about how I am riding my motorcycle for MS! After attending over 200 events for them without any issues, I was told I had to arrive by airplane and limos like everybody else. I fought the new travel rule as it only affected me and was discriminatory because of my choice of transportation. It was not a battle I would win, so I had no choice but to quit speaking for them. Not only did I lose my only paying speaking gig, I lost the 70,000 miles I was accumulating for MS each year riding to these events! No money and no miles certainly seemed like a dead end.

I did not give up.

I began looking for bigger motorcycle events and an MS

charity that I could work with and perhaps inspire patients again by speaking at their educational events. MS Views and News began booking me for some events and offered to help with my expenses when I was fundraising on my bike. Yamaha also stepped up and started reimbursing me for expenses when I made appearances at national motorcycle events with them. By getting all my travel covered and getting paid to speak at a just a few live events, I could just about squeak by financially.

The International Motorcycle Show is the largest motor-sports trade show provider in the United States. Each year, hundreds of thousands of attendees enjoy spending a day or a weekend exploring the latest and greatest models, buying accessories and checking out the latest gear from leaders in the motorcycle industry. By 2019, I had convinced the management of the International Motorcycle Shows to give me a shot providing a few travel seminars at their events where I was already attending as a guest of Yamaha.

My seminars worked out well, and the show paid me a decent income for an event I was already attending. I was humbly excited, realizing I was not only being recognized as an industry expert, but that I was getting paid real money for my advice and a chance to share my MS story to other motorcycle enthusiasts at the largest possible national venue. I felt like I had found a new source of income to replace what was lost from the pharmaceutical



industry. One thing was certain, they would not tell me I couldn't ride my motorcycle to the events!

When Covid hit, all the live MS patient events across the board were cancelled and I believe will be changed forever. People living with damaged immune systems are not willing to risk gathering; no matter how good the free chicken dinner is! For me to continue making enough money to stay riding would mean finding a new revenue stream or growing my trade show and rally presentations.

Last year, I received income by speaking at three of the International Motorcycle Shows and a few other small events. My seminars received a lot of positive feedback and so I offered to do more this year. My 2022 contract was going to include speaking at all eight shows across the entire country. I blocked off my calendar and began planning the cross country routes I would take to the events, traveling over 30,000 miles from from June through October. The income from the 8 shows would provide me just enough money to stay on the road the rest of the year and the paid travel would count towards my million mile goal. Win, win. win!

Two weeks ago, I got punched with the biggest road block yet.

After 40 years, the International Motorcycle Show has

pulled the plug on all trade show events; FOREVER.

While this news surprised everyone involved, it slapped me rather hard because it leaves me struggling for the first time with the possibility that my journey may have indeed reached the end of the road.

■ ABILITY

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DANE CAPO

Dane Capo has long dreamed of data entry and loves to travel. His life took an unexpected turn when his grandmother passed away, leaving him all of her art equipment. Dane and his family discovered his hidden creative talent. He became a painter.

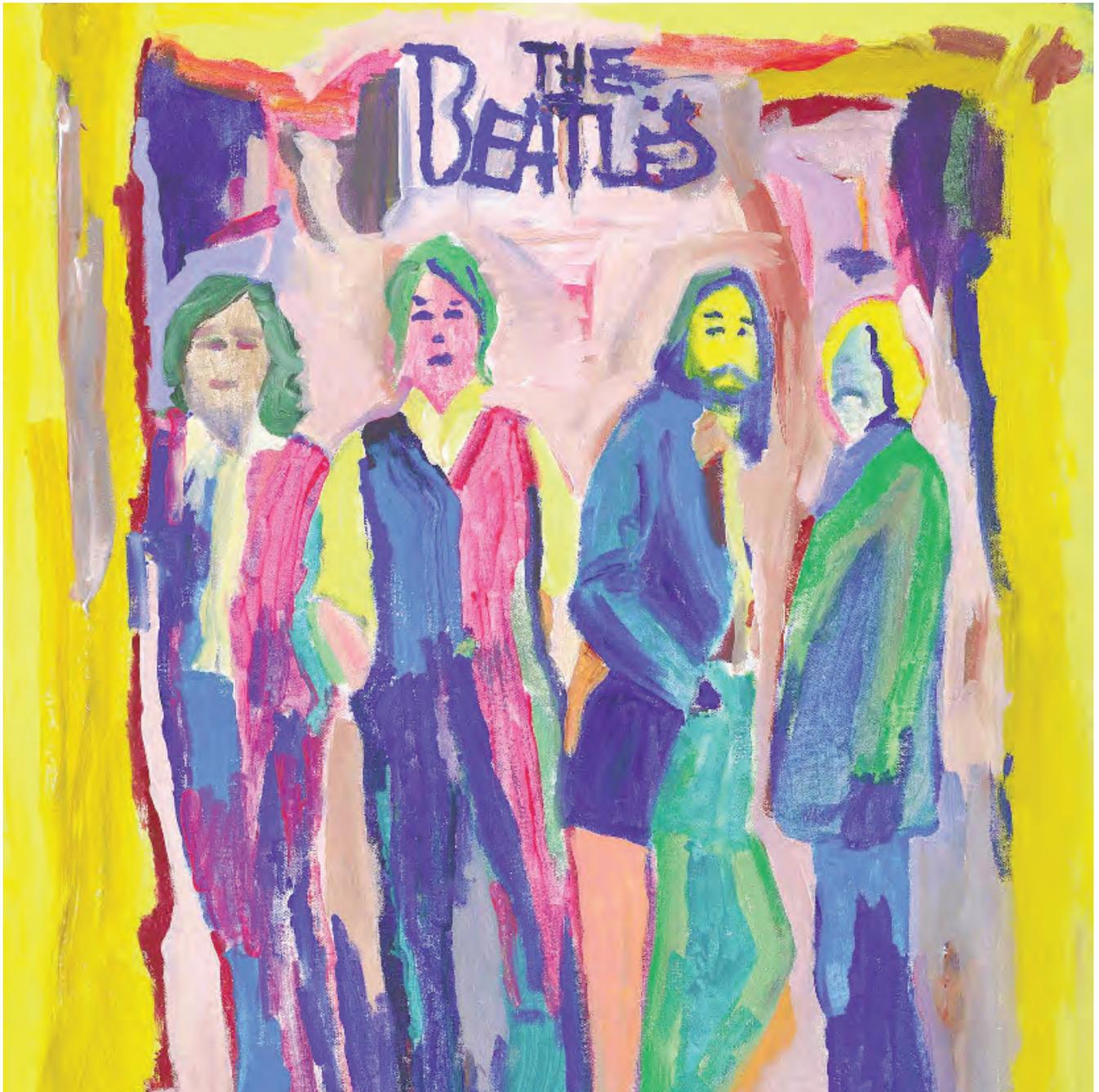
Dane likes an array of trailblazers of art, Picasso, Van Gogh, Matisse, Frida Kahlo, “and I even like Andy Warhol” he mentions. Dane’s journey has led him through a fantastic world of art, accompanied by any challenges that came with his many seizures and an autism diagnosis at age 5. On a lovely afternoon, *ABILITY*’s Chet Cooper, and talented service dog trainer Frank Mallatt, who also happens to be on the spectrum, chatted with Dane and his mother, Krista Capo.

Dane was home-schooled and took a liking to studying art history. After his grandmother died, all of her paint supplies went to Dane. This is when he felt inspired to paint his interpretation of Matisse’s self-portrait. “It turned out absolutely amazing” Krista exclaimed. And so, he continued painting and studying art history. About three years later, Dane had his first show, and was hooked. “When he got so much recognition and finally felt like he had a purpose in his life because of the way people responded to his art, he decided that he would continue painting.” Krista shares.

Dane is not shy from the limelight. As a matter of fact, he is inching closer to a big goal. He says, “I always figured that the only time I would paint more was if there were a million people coming.” Before painting, Dane struggled with employment.

After getting a job coach and interviewing several different places but not getting hired,





Krista felt their biggest issue was that Dane wanted mainstream employment. “Those things aren’t available to him because he has a diagnosis of autism,” she explained. Due to lack of employability, they decided to take things into their own hands and started an art business. In California, after going through many job search agencies and too many interviews, they moved to Florida, just outside of Tampa. “There was no ability for him to move out of our house. Our house was small. He wasn’t having a life of independence in any way, shape, or form. He’s got 14 cousins here and some of them have kids. So he’s got, like, 9 second cousins. It’s cheaper long-term. We could afford to open the gallery space and have a place to operate this business properly.” says Krista.

Dane’s parents secured him a house where he lives independently minutes from them with a roommate who’s neurotypical. He likes living on his own and without his parents. Next on Dane’s agenda? “I’m trying to find a girlfriend now,” he went on to exclaim, “If I ever get into working at an airline data entry position, then that can help me find a girlfriend.”

Frank had wise advice for Dane: “From my experience, or lack of experience, going online to find love in the neurotypical puddles has never been very comfortable. I would be happy as we evolve and get awareness out there to find places for people like us to maybe—or at least people who are OK with us to meet and greet. You might find with your artwork, you’ll be very surprised that you’re going to get a lot of attention. You’ll find



Ringo Starr with Dane's Beatles painting

people coming to you as opposed to you trying to get out there and get to them. You're doing very good for yourself. You may not like what you're doing, but you're doing very well for yourself. And that unto itself is how love can be found unto itself."

Although Dane would much rather move to Italy than spend 10 or 20 years in Florida, Krista feels a great amount of growth in leaving California where everything was stagnant for them.

Dane has a hunger for travel, but also keeps his options open for the film and banking industries. He mused, "I would think that if it was like a traveling-related job that had me go for six months somewhere, then I would figure the film industry. But when non-traveling like that, I

would figure airlines or banks or government or insurance offices... or government office or any office, airlines."

Krista chimes in that he particularly wants jobs in those fields because they come with travel perks or free tickets to Disney. From free tickets to Disney or Universal, to film industry unions, he's really thought all of this through.

Born and raised in Southern California, Dane's parents fueled his love for travel, "We went to Australia twice, New Zealand once, South Africa once, Toronto and Vancouver, Canada, more than once, and Mexico and even went to Boston and New Orleans, Shreveport, Baton Rouge."



The family has recently opened a gallery by appointment only in Florida, where they currently reside. Since Dane taught a sold-out art class and was asked to teach a few more, Krista hopes to transition the classes into the art gallery. Krista feels if they can make that successful, she said, “We’ll be able to generate a sustainable income for him through teaching, which gives him a sense of purpose and pride in his life—which is something that’s hugely lacking for this population.”

Frank had a few motivating words to add: “If I could encourage you to follow your dream as far as the data entry, if that’s what you want to do. Do it until you decide that that’s not what you want to do or enjoy it while you’re doing it. I actually wrote software myself for a while, and I really did enjoy it. It’s not something I would want to keep doing for the rest of my life, but I did enjoy it while I was doing it. I wrote software for one of the first distribution companies here in California for the cannabis industry. I wrote their software for their

intake and outtake because nobody else wanted to do it at that point. And that’s data entry unto itself, and then they had me doing the data entry. It’s something to do, and there are niches there. Play around with it, find out what really draws your interest, and then run with it because they’re going to come at you very, very strongly. Our skill sets, especially when we have a high point, and if yours is data, you’re going to be just streaming good at it, and fast. And that’s what they cannot find with neurotypicals, to be honest.”

The art world has swung open a door of communication and a way for Dane to connect. And his fearless uninhibited approach as an artist sparks curiosity and motivates others to come back for more. Dane still dreams of data entry, travel and being a landlord. But for now, Dane shares his talent with the world. ■ **ABILITY**

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JOSEPH



A photograph of a garden path. In the foreground, there are several succulent plants with thick, rounded leaves. The path leads into a lush garden with various green plants and trees. The background is slightly blurred, showing more foliage and a stone wall on the left side. The overall scene is bright and natural.

Building Technology & Awareness for Better Accessibility

Dr. Joshua A. Miele was awarded the MacArthur Fellowship for his accessibility technology that assists blind and low-sighted people to navigate the physical and digital world. According to the MacArthur Fellowship, the award goes to “individuals who show exceptional creativity in their work and the prospect for still more in the future.” Dr. Miele currently is Amazon’s principle accessibility researcher, helping to develop things like tablets, TVs, and Echo devices accessible for people with disabilities. Dr. Miele was blinded and burned at the age of four when a mentally ill neighbor threw acid at him. For Dr. Miele, that was something that happened over forty years ago, and he has moved on in a big way. He has had a distinguished career as a scientist at Smith-Kettlewell Eye Research Institute along with a twenty-year career in academia. He plays bass in a band, is famous in Berkeley for his pasta salad, and is married with two children. *ABILITY*’s Chet Cooper met with Dr. Miele to talk about his drive for accessibility, “meta-makers” and much more.

Chet Cooper: I’ll jump right in with the MacArthur Fellowship award. Tell me about how that happened and what it means to you.

Dr. Miele: It is an extraordinary honor, and I’m still figuring out what it means for me. Anyone who works in academia or in creative fields knows about the MacArthur Fellowship. It’s an extremely high honor and very rare.

It was completely unexpected. In fact, I thought that when I switched from working in the nonprofit government-funded academic arena, and went to work at Amazon as accessibility researcher, that I was closing the door on the dream of being a recipient of this award. I thought, “Oh, well, I guess that’s not going to happen to me now.”

Winners don’t even know about their nomination until a few days before the award



Miele using braille keyboard

announcement when they receive a phone call. When I received that call, it was much more extraordinary than I ever could have imagined. First, because I thought that that possibility was gone, and second, because it was so totally unexpected!

Cooper: Do you know how the fellowships are given?

Dr. Miele: The fellowships are given on the basis of being recommended by your peers, by the people who know your work. The MacArthur Foundation has a large network of external, but anonymous, nominators within the academic and creative communities.

I've been a nominator. Nobody recommends somebody for anything other than the fact that they deserve it. The idea is that you don't tell the people that you're nominating them. It definitely adds to the excitement of getting that phone call!

Cooper: What does the fellowship provide?

Dr. Miele: The grant money is provided over five years. It opens doors for incredible opportunities. The money is both an invitation and an opportunity to do whatever you want to do. I've spent a lot of time in the world of grant-getting, and this is not a grant you can apply for. You can't go to the MacArthur Foundation and say, "Please, sir, let me have one of these."

(laughter)

The fellowship has two amazing angles. The money that

comes with the MacArthur Fellowship is unlike other grants. With most grants, you ask for the money and submit proposals with hundreds of pages. The review process determines the eligibility and success of your proposal against other people's proposals. When the money is awarded, you're expected to do what you said you would do, plus, completing all the reporting requirements.

The MacArthur Fellowship has no such expectations. The money they give you is money to be used in any way that you see fit that will further your work. Depending on who you are and what stage of life you're in, sometimes that means setting aside money for your kids' college, because that's something that you are worried about, and it is preventing you from being creative and doing your work. For some people it might mean setting up a lab or outfitting a studio. There's no expectation of reporting back to the foundation what you did with the money.

It is no strings attached. When they say no strings, they mean no strings. I'm talking to you because the MacArthur Foundation said, "Hey, would you mind talking to this guy?" I don't have to talk to anybody. I don't have to write any reports. I don't have to go to any MacArthur meetings. I don't have to do anything, which is unlike any other award like this. It is truly no strings attached, which is an unbelievable gift. No strings attached is liberating in this aspect. That's one angle of it.

The other angle of the grant is visibility. The MacArthur

Fellowship is a very high-profile award. It offers the opportunity to talk about what I do with folks like you, and with other people who are interested in what I do. These are invitations to talk about my work. Invitations that maybe I might have never received. This gives me a phenomenal platform, and the time to let people know about accessibility. It makes the creative work that I do in accessibility highly visible. I'd be happy to talk about that if you want.

(laughter)

Cooper: That's a great segue into the work you've been doing, which I think is very impressive, a history of your work. For people who do not know all of the things you've been doing, let's back up in your career. You chose Berkeley as you entered into academia. Why?

Dr. Miele: I was born and raised in Brooklyn until I was about nine. We moved to the suburbs at that time. Brooklyn isn't a very easy place for a blind kid to get around by themselves.

I went to a small high school of about 1,200 kids in Nyack, New York. I had been going to school with the same kids since I was in third grade. Everybody thought they knew who I was. Everybody had formed their opinions about me in third or fourth grade. It was very constricting.

I applied to Berkeley as an undergraduate. It was my first choice, where I wanted to go. I wanted to go to Berkeley because in tenth grade I realized that Berkeley had an element named after them. That is advertising that you simply can't buy. You've got an element on the periodic table, man; every nerd who wants to go into the sciences is like, "Wow! Berkelium? Stanfurdium? Those are obviously some places that are worth knowing about!" I came to Berkeley. I absolutely loved it.

I wanted to strike out on my own. I wanted to go to a large urban university where nobody knew my name and was as far as possible away from everything I knew and was part of. I wanted to build an identity that wasn't constructed for me in fourth grade. I wanted to be my own person. I wanted to get around independently and I wanted to go to a badass school that had an element named after it—

(laughter)

—because I wanted to be a physicist. Berkeley is central to the mid-century narrative of American physics. It had everything I wanted. It was 3,000 miles away from my family.

(laughter)

It was in a beautiful, large urban area where I could get around independently, and it was a huge school where I

could be pretty sure nobody would know who the hell I was.

Cooper: I'm assuming, tell me if I'm wrong, that part of losing your sight in that particular trauma, that stayed with you in that school, I would guess, and your friends.

Dr. Miele: No, not really. I was burned when I was little in Brooklyn, not in the context of the school where I grew up. That happened in Brooklyn. It was not an effort to get away from that trauma. It was an effort to get away from the assumptions that everybody had about what a blind kid could do and be. I formed some amazing friendships in my going to high school at Nyack, some of my closest friends are still the people I was friends with in seventh grade.

Cooper: That's great.

Dr. Miele: But I did want to get away from most of those kids, because they sucked.

(laughter)

Cooper: We want names!

Dr. Miele: (laughs) I wouldn't want to give them the honor. Nyack, New York, is a provincial little place. I think that it is a common experience for kids to want to get away from where they grew up so that they can build an identity as an adult. That's what I wanted to do.

Cooper: Sometimes those small towns don't have opportunities if you're a big thinker and want to do something that's beyond the scope of a small community.

Dr. Miele: It's much more the small community. That was just one aspect of it. The no sidewalks and no public transportation was a bigger factor. If I wanted to do that, I could have gone to New York City. But I wanted to get away from where I grew up. I wanted to push myself. I wanted to be in a new place where I didn't have a support network so that I could grow, be my own person. I didn't want to be near my family. I love my family dearly. I miss them. I'm the only one out here in California. They're all still back in New York, and I visit a lot. But I wanted to be able to grow, and I didn't think I could do the growing I wanted to do if I stayed close to my family. So I went 3,000 miles away, to a place that did have sidewalks and that did have public transportation. And accidentally, I knew nothing about Berkeley's disability rights history.

Cooper: I was curious if you knew of its robust history for disability rights.

Dr. Miele: I knew nothing about the disability rights movement, about the free speech movement. I really didn't know anything about the history of the place I

was going to. All I knew was that it was a cool urban place that was huge.

I also did not embrace my identity as a blind person until I came to Berkeley. I was blind. I knew I was blind. I wasn't trying to pretend I wasn't blind. But I sure as hell didn't put that first in my identity. I was a smart rebel who hated school; I had a lot of things ahead of blindness in my self-identity. Before I came to Berkeley, I didn't have a lot of blind people around me. I went to a blind camp as a kid. But I didn't meet cool blind people until I came to Berkeley, and then I met a bunch of them. Little did I know that Berkeley was a great place for people with disabilities! The disability rights movement was still ringing in the air in the late '80s when I came here. Many of the figures who were part of the disability rights movement were still in the community, still here, still doing things.

The aesthetic of the disability rights movement was everywhere. When I came to Berkeley, I found my people. I found blind people. I found people with disabilities at Berkeley, and I had never wanted that to be part of my identity. I had always tried to set that aside and say, "Yes, of course I'm blind, but I do all this other stuff!" Then I realized, "Oh, my God, not only am I blind, not only is it cool to be blind, not only are there all of these cool blind people I want to be friends with. Also, these cool blind people can be my mentors, teachers, friends, and guides in this world." It made me think and feel that blindness is part of my identity that I don't need to be ashamed of. I can be proud of it. I can embrace it and have it be part of the upfront element of my identity and who how I project myself to the world.

I'm so thrilled that I was able to make that transition so young. Some people spend a lifetime feeling shame about their disability and trying to say, "Hey, don't think of me as a disabled person, think of me as a father, as an engineer, as a software developer who just happens to be blind." But in fact, I'm not somebody who just happens to be blind. Blindness is a central part of who I am and what I do, and it affects absolutely everything that I engage with. I am thrilled that I was able to come to that understanding as a college student, and start to understand my place, my ability in the world to be a disabled person and to be proud of that. Not just to be comfortable with it, but to be proud of it. Does that make sense?

Cooper: Yeah. We've been following and seeing that there's absolutely a shift going on with language, where there was person-first language after the ADA, and there are shifts going on right now of disability pride, as you're saying, even in the comments in the video I saw. You definitely say blind people. "Blind" is a lead rather than "person" first.

What was your first breakthrough technology?

Dr. Miele: The work that I do, I do it because I have to.

I got into designing accessible technology because I need the technology that I want to use. I consider myself part of the Maker culture. I think people with disabilities are meta-Makers. Not only do we have to be inventive, but we have to be inventive in order to do the things we want to do. A lot of the time before we can participate in any particular activity, we have to apply creativity to figure out the way we can participate. You have to come up with solutions, and maybe your community has some solutions that are already out there, but a lot of the time, you're the one who has to figure it out. For me, especially when I was young, I had to come up with my own solutions for things.

Many of my earliest things that I would design or make were just for my own purposes. The first public-facing thing I was involved with, that I think of as an innovation, was OutSpoken, the screen reader for the Macintosh. I didn't have any part in creating, but I did have a hand in helping shape its evolution. I came along after it was already released. Berkeley Systems was a small software company that was the first company to figure out how to do a screen reader for a graphical environment. I joined Berkeley Systems while I was an undergraduate as a college job. I was doing tech support. Soon I was doing technical writing, and before long I was doing basic design work on how features should behave.

It's because I needed that tool. A screen reader is a thing that I need in order to do the things I want to do. I was highly motivated to make it something that worked well for me. And because it was a product that was being used by hundreds if not thousands of people, it needed to work for everyone. It was a great training ground on not only designing stuff for myself, but designing for a larger community of customers, of blind people, of users who needed this tool. OutSpoken was a great—one of the earliest things I got to work on. I'm very proud of that.

There are many subsequent tools I created again in order to meet my needs. When I went to grad school, we were using a program called MATLAB, which is sort of like Excel on steroids. It's for data manipulation, management, and visualization. Everybody in my lab was using MATLAB. It had a command line environment, so it was easy to program MATLAB, but all of the graphing and visualization tools were completely inaccessible. I spent my first six months of grad school writing a set of accessibility tools for MATLAB. That was a real achievement. Basically, once I had those in hand, I could use the same tools that my fellow students and scientists were using to manipulate, manage, and display my data using sound, touch.

That trend continues. TMAP, the Tactile Maps project, is another moment of realization: "Wow, this mapping thing is really going to work! This is a tool that people never had before. I thought, "not only will it change the



way blind people navigate, it will change the way everybody thinks about maps.” Because most people think of maps as being highly visual, but they are not. They’re spatial, and spatial information is completely adaptable to non-visual modes of presentation, but most people don’t think of it that way.

My favorite technologies are the ones that serve a purpose, that enable blind people to do things that they couldn’t do before or which were more difficult to do before. These technologies cause people to rethink their assumptions about the tool or the context of that tool’s use.

Cooper: The mapping, where is that today?

Dr. Miele: TMAP, the Tactile Maps Automated Production project, is now with to the San Francisco Lighthouse—I gave it to them. They use it to produce maps for their clients all over the world. They run a website where any registered person can request, download, and print out a tactile map on their own Braille embosser for free. Google it, you’ll find lots of resources about it.

Cooper: Are you familiar with Web for All?

Dr. Miele: Yes. One of the reasons why the MacArthur Fellowship is so important to me is that it basically is a signal to the world that accessibility is not just web accessibility. Web for All is a great organization. I have huge respect for all of the people out there doing web accessibility. I don’t find web accessibility to be a compelling and fun problem to work on. It is a relatively solved problem, and it’s just now a matter of implemen-

tation. I find it most exciting to work on creative problems where there are no guidelines and standards, where there are still wide-open questions about, what does accessibility mean in the context of this new project?

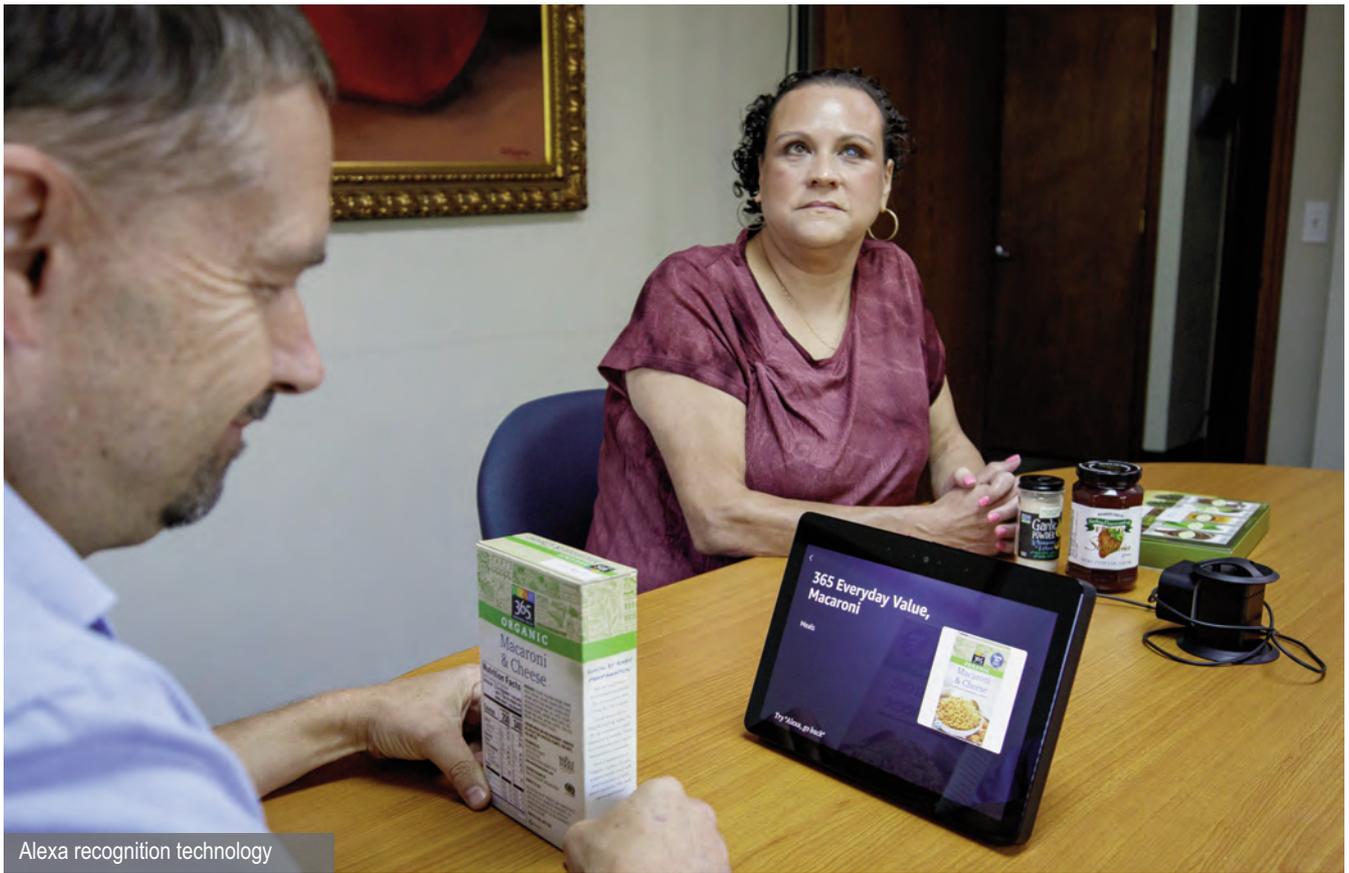
I have lots and lots of friends who are in web accessibility, but I myself am not a web accessibility evangelist. I’m not a web accessibility developer. I’m professionally adjacent to but not of the web accessibility community.

(laughter)

I think it’s great; it’s wonderful that they do that. It helps me personally, because I need good web accessibility. But I don’t find it exciting. The MacArthur Foundation says, “Hey, look at this, everybody! It’s not just about web accessibility. Accessibility is way beyond 508. It’s way more than just making your website or your app accessible. It’s about design. It’s about thinking deeply about disability and its intersection with usability.”

Cooper: What are your thoughts about OrCam?

Dr. Miele: The world is full of tools that can be used to help blind people do what they want to do and do it better. I am a huge fan of tools that let us do more things than we were able to do before. Some of the technology out there in the world are technologies that try to make people feel less blind, to act more like a sighted person in the world. I’m a cane user. I use a cane to get around. In my younger days, I was a dog user for a few years. I know both of those worlds. I’ve been approached by lots and lots of sighted folks who want to develop a tool



Alexa recognition technology

that will help us get rid of the cane. And I think that is a misplaced view.

People say to me “The cane is so old and so clunky. It’s so embarrassing, because you look blind when you’re using a cane, and people don’t want to look blind.” My response to that is the cane is an incredible piece of technology. It is one of the most remarkable, reliable, and nuanced pieces of blindness technology in existence. The idea of a technology that can replace the cane—a smart cane or such—with something that can tell you what’s in front of you is misplaced. This sort of thinking comes from the misunderstanding that looking blind is a problem. I recognize that not everybody lives the blind-first existence that I do. Not everybody is as comfortable as I am in looking blind.

But really, I am. The amount of independence that people can gain by being more comfortable with being blind and gaining the skills of blindness, is enormous. A lot of the time, technologies are offered as a replacement for developing these “blindness skills.” A twentieth century blind person would develop such skill and comfortably. But now that we’re in the twenty-first century, a people are thinking, “Well, maybe those skills don’t matter any more.” But they do.

A technological replacement for building skills is not going to serve us well as blind people in the long term. I would rather people developed skills and got comfortable with being blind rather than leaning into technolo-

gy that enables them to be less blind and develop fewer skills. I also am not a huge fan of expensive technologies. When a piece of technology costs thousands of dollars, that’s a time to say, “Wait a second, most blind people are actually, literally, living in poverty.” The majority of blind people are unemployed and don’t have the kind of money to spend on these expensive technologies. They do have the wherewithal and the resources to get training, build skills, and confidence as blind people. So again, the expensive technologies are sexy, they’re cool, but more often than not, they are designed by sighted people for blind people. Yes, I know there are blind people involved in OrCam. OrCam is not a technology that comes from the blind community. Neither are these smart canes or other cane replacements.

Most blind people who are independent realize that expensive, complex technologies will be less good than what they already have.

Cooper: Yeah, pricing is always difficult, lots of different areas within health and disability, it’s definitely a challenge in that respect as well as what you’ve been saying. I was thinking about the technology that scans and describes certain items, isn’t that the work you’re doing with Amazon?

Dr. Miele: Yes. There are a lot of different tools these days for using cameras to read text or identify products or do things like that. You can get apps on your iPhone

or Android. But again, not all blind people can afford iPhones. If you are blind, in order to use a mobile device effectively, you need a certain degree of skill with a screen reader. One of the things that we've done at Amazon is to create a product identifier; we call it Show and Tell. It uses the camera on Echo devices, such as Echo Show.

Amazon has many different Echo devices. Some of them have cameras and screens and some of them don't. The ones with cameras are able to do the Show and Tell feature. Before I tell you how it works, the whole purpose of it is to identify an unopened bag, can, jar or a box of something that you don't know what it is. If you've got five unopened cans on your shelf, you can't just open them all up find out what it is. This is a problem that blind people have faced for many years. Some people use special organization schemes. I always put the clam chowder on the left and the chicken noodle soup on the right. That's one way of doing it. You can also put Braille labels on your cans.

But now we have camera technology that's fairly available to everyone, it's possible to use cameras to identify what something is. We built this experience so that people who have Echo devices can have not only an affordable way of accessing this kind of functionality, but one that is relatively hands-free. If you're using a smartphone, you've got to hold the phone in one hand while you're trying to identify the product pointing the camera. With the Echo Show experience, you can just hold it up in front of the camera and say, "What am I holding?"

Show and Tell is really convenient for people because a lot of people have Echo devices in their kitchens already. So using it as a way to identify groceries as you're putting them away or if you're looking for a particular product on your shelf—beans or olives—that's exactly how it is used by people with different levels of sophistication, so it's really convenient. Even if you're a computer genius, it's really easy to use, but if you are someone who doesn't feel comfortable with computers or you're new to the blindness world, or don't know how to use an iPhone, everyone can use this. It comes at a very affordable price, the price of an Echo device.

Cooper: What was your role in that development of that technology?

Dr. Miele: I basically helped the team understand who would be using it and why they would be using it. The team initially had the idea that if they didn't get a hundred percent match, that it was a failure. I helped them understand that what the blind person needs is not an exact match, but even a little bit of information can go a long way. So I had them incorporate not just image recognition and matching with their catalog, but brand recognition and also OCR (Optical Character Recognition). So if you don't get an exact match, even if you don't get any brand matching, you at least get a little bit

of OCR that will read some of the stuff on the label. I helped them understand what the success looks like, not from your standpoint as a computer vision scientist, but from the standpoint of a blind customer. And success is anything that helps me figure out what this can or box is. It doesn't need to be an exact match; it just needs to be some information about what I'm holding. Very often that is enough to let me know it's clam chowder, not noodle soup.

I helped them understand what a blind person needs in order to hold a product in front of the camera and get real-time feedback. I also helped design the instruction, onboarding information, tutorials, and instructions that help people learn how to use the Show and Tell.

I helped design the usability research to put it front of customers. Doing research with blind and visually impaired people is not something that most researchers know how to do. It has some unique requirements. Some of my primary roles at Amazon is to help researchers understand what disability-inclusive research looks like, what accessibility research looks like and how to do meaningful customer experience research with customers with disabilities. That was part of the Show and Tell work I did, as well as work I do in many different areas of product development at Amazon.

Cooper: Great. Some of the other things you've done beyond that, can you describe, no pun intended here, YouDescribe?

Dr. Miele: (laughs) YouDescribe, sure! Audio description is a tool that blind people use to get access to video. Video accessibility for blind people is based on an additional audio track that describes what's happening on the screen. It's a human reading a script that is designed to be concise, to stay out of the way of the existing dialogue, and other parts of the sound track. It is to impact the original composition as little as possible, but to give a blind viewer the information they need about the visuals in order to be able to benefit from, enjoy, or otherwise use the video programming. Audio description is the converse of captions. Captions make the audio part of the program accessible to people who can't hear. Audio description makes the visual part of the program accessible to people who can't see.

But it requires a lot of creativity and editorial decision-making. My original thinking about YouDescribe was that audio description was entirely in the hands of professional describers. In adding audio description to a piece of video, you have to work closely with the video creator in order to not violate copyright. You can't just go and add a voiceover track to somebody's video and then redistribute it to make it accessible. That's illegal. All of the audio description that was available prior to YouDescribe was created by people who were professionals working within the video—the film and TV



industry and cooperating with the copyright holders.

I looked at that and said, “We’re never going to get it done like that.” There’s too much video out there. That’s a great model for film and TV, but with all of the video that’s being created and posted, we’re never going to get audio description for that, because it’s an expensive process to do it in the professional way. It requires professional engineers, professional scriptwriters, professional voiceover artists, and the redistribution of additional assets. It’s prohibitively expensive, which is why there’s so little of it or was so little of it at the time.

Again, my favorite technologies are the ones that not only perform a function for people but that make us question our assumptions. What have we been doing so far? How we should be thinking about that technology and that experience in the future? YouDescribe is a web-based platform. It’s free. It lets anybody anywhere add audio description to any YouTube video and share that with the world, all without violating the terms of use for YouTube. Because all we’re doing is allowing anybody to create voiceover content for an existing video. We’re not adding audio description—we’re not modifying or redistributing the original video.

We store the added voiceover content separately along with the time stamps and the information about the associated video. When you go to YouDescribe to play any audio description of a YouTube video, it is synchronizing additional audio content with that video so that a blind person can know what’s going on.

One of the things I love about YouDescribe is that it can be used by professional audio describers to add content to YouTube videos, which streamlines the process for the describers. They can do it as paid work. If somebody says, “Hey, I’ve got this YouTube video. It needs description, can you do it for me?” that’s a job that somebody can do for pay. But it’s also available to a world full of volunteers, people who want to make it accessible for their blind friend, their colleague, their student. YouDescribe is used by teachers of the visually impaired all over the world to make content accessible for their blind students. It’s used by colleges to make their online courses accessible to their blind students. It’s used by people who just love a particular genre and want their friends to be able to appreciate it. It’s used by teenagers who want to do some cool volunteer work. It’s an easy, fun way to contribute to make the world a slightly better place.

YouDescribe has a request list, so if I have a video that I need description for and there’s no description for it, I can add it to the YouTube request list. A volunteer can come along and describe it for me, and I can have that description in hours or less, sometimes. YouDescribe also offers a rating system so that you can rate the quality of audio description, not just the quality of the video, whether you like the video, but you can rate the description, which is really important for describers, in the same way that if you take a Lyft and you give them less than four stars, they pop up a bunch of questions and say, “What could we have done better?” The same thing happens on YouDescribe. If you give a video less than five stars, there’s a bunch of options that you can click

to say what could have been better. It's feedback for the describers on how to improve. I'm extraordinarily proud of YouDescribe.

Cooper: You should be!

Dr. Miele: Thank you. YouDescribe is a demonstration. It's not intended to be an endpoint. It's intended to say, "Look what we can do if we allow anybody to add audio description! Not only can different people describe the same movie or piece in different ways, but you can have a professional do it, you can have a teenager do it." We have not always had black voices or Latino voices in audio description. That's one of the reasons why I want different voices to be speaking, and when I say "voices," I don't just mean the physical voice; I mean the intentionality behind those voices, the perspective and the experience of the people doing the description.

Description is an extremely subjective process. It's not like captions. Captions can be done right or wrong. In audio description, there are lots of ways to do it right. Depending on who you are and what your perspective is, you will describe something differently than someone else. I want everybody to be able to describe stuff. I want us to experiment with what description means, who are the describers, and what should we be looking for in different types of video?

Different types of material require different types of descriptions. You don't expect the same kind of description for Saving Private Ryan as you would for a video of your five-year-old's birthday party. There are different requirements, and this is an opportunity to play with and evaluate what those different things are.

I honestly would be so thrilled if we could apply this same technology to any video that we watch and bring in other voices and commentaries. By the way, another use case for YouDescribe is professors who are not using it for accessibility, but as a way of adding educational commentary. That's I think a great use case, right? The same technology can be applied.

Cooper: It should be used everywhere in describing what's on the screen.

Dr. Miele: Even if it's a blank screen, even if it's just an audio recording with a blank screen, it's worth telling the blind audience, "Hey, there's nothing on the screen."

That's information. We have to be aware that there are different levels of description. There are some things that can be described really well by people who are masters of the art—because it is an art—and then there are some things that are not described as well, but can still be enjoyed. Many films dialogue-driven—like My Dinner with André—which doesn't require a lot of description. It's so much better with a little bit of

description, even when it's incredibly dialogue-driven.

Cooper: Yes! So you're on a STEM trading card.

(laughter)

I love that concept of STEM trading cards. How did it come about?

Dr. Miele: They asked me if I would be willing to be part of the project, and as with so many things, you have to make sure that people aren't jokers, that people are going to represent disability respectfully and appropriately. I made sure that they were able to do that. I was very impressed by their understanding of disability and their sensitivity to the issues that I was concerned about. I worked with them to do the STEM card. In the same way that I'm incredibly proud to be a MacArthur fellow, one of the things that is overwhelming to me is the brilliance and impressiveness of the other people I'm now associated with, the other fellows.

Cooper: Your peers.

Dr. Miele: My peers from this year and from years past, extraordinary people. The same thing is true of the STEM card. These are cool people. These are people doing important work. I've never met Temple Grandin, but I sure am proud to be connected with her through the STEM trading card deck. These are people I'm proud to be associated with. STEM education is really important to me, not just for blind and visually impaired kids and kids with disabilities, but for other kids. Kids who are ostensibly non-disabled can learn and realize that their disabled classmates are just as capable as they



are and can achieve if they are given the right opportunities.

I don't think that the idea of the STEM trading cards is so much for disabled kids to have them, to hold them, and to realize that they're well represented, although I think that's part of the idea. But the main, the bigger picture is to say to the kids without disabilities, "Hey, look at these people! These were kids your age once, and look what they're able to do. Look what they've achieved. Take a look at your classmates who have disabilities and realize that they are capable of this kind of achievement, just as you are, with and without a disability." That's why I was happy to participate in that. I always try to emphasize this. The technology stuff that I work on, I do that because it's fun, because I love doing it, and because the accessibility of the tools we use makes a huge difference in our ability to do the things we want to do.

But the bigger problem is the social dynamics and fighting ableism and assumptions about people with disabilities. The STEM trading cards, the Blind Arduino project, and other connected concepts are part of the bigger and, I would argue, more important picture. Again, going back to the language stuff, it's important, but the thought process and the assumptions that underlie the language are more important. Similarly, accessibility is important, but thought process and the assumptions that underlie the creation of inaccessible technologies is the bigger problem. Fighting that problem from the elementary school level on up is the way we're going to get a handle on it.

Cooper: Anything else we might have missed that you'd like to share?

Dr. Miele: I want to tell you about the Blind Arduino project.

Cooper: Yes, absolutely.

Dr. Miele: The Blind Arduino project is basically a grassroots effort that I have been spearheading that encourages blind people to get involved to build devices themselves. Robotics and hobby robotics is really big in STEM education these days. Most schools have a robotics club that might build stuff and compete in national or international robotics competitions. Those teams are really intended to be hands-on learning opportunities for kids who are interested in going into STEM fields. Blind kids are more often than not not included in those opportunities because there's the perception that, "How could you do that? You're blind." The Blind Arduino project grew out of this need to understand barriers faced by blind people wanting to participate in the DIY hardware prototyping.

Arduino is an inexpensive, open-source microprocessor platform used by everyone from young hobbyists to high-tech developers to build computerized devices, sensors, motors, wireless communications, and a lot of other tools. It's very simple, very easy to work with. I've been encouraging opportunities that invite young blind people to build the skills necessary—because just like everything else, blind people can do it, but they're not going to do it exactly the same way the sighted kids



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do it. There are different tools and techniques that they need to know about in order to participate as equals. But once they know about those things, they can participate. The Blind Arduino project is disseminating information about those tools and techniques. It promotes the fact that it can be done and encourages young blind people to self-advocate for their participation in mainstream hobby robotics.

I see this as hitting on many of the same things I just mentioned about STEM. It's not just an opportunity for the blind kids. I want those sighted kids who are on the hobby robotics teams to say, "Oh, I didn't realize that my blind friend Tania could participate in the hobby robotics." But now of course it's obvious that she can, and I want kids to be thinking about and solving the accessibility problems of STEM learning together. Once you get the blind kid in the hobby robotics team, it's just a short hop to start thinking about, "What kinds of tools does Tania need? How can we collaborate with her to build cool tools to help her do other things she wants to do? How can she design her own tools to do the things she wants to do?"

Maybe, Tania is now more likely to go into a STEM field. Maybe to go into engineering accessibility tools and designing more cool stuff, by encouraging blind and sighted kids to work together on accessibility problems will drive the world out of its inaccessibility.

The other thing that the Blind Arduino project is doing is publishing designs for accessibility tools that might not be available for sale. You can't go to Amazon or to

eBay to buy an accessible oscilloscope. You just can't buy one. But you can build one. I want the designs for accessible oscilloscopes, accessible multimeters, and accessible tools that you would need as a high-performing electronics enthusiast to be available. Building them yourself will be the best way to do that. The whole idea of this kind of DIY blindness stuff goes way back to the early twentieth century; the ham radio movement was disproportionately populated by blind people. They could build the stuff themselves, and they could talk about it using just voice over the air.

That's why so many blind people were ham radio operators. It also reconnects with what I was saying earlier about blind people and people with disabilities being meta-Makers. We aren't just Makers. We are makers of the tools we need in order to do the making we want to do in the first place. Before you can make the thing you need, you need to build the tools you need to make the thing.

Cooper: Exactly!

Dr. Miele: It has so many lessons about self-reliance, self-advocacy and teaching, learning, and community-building. It's an amazing—again, my favorite things aren't just things that do something—they're things that encourage us to shift the way we think about disability and accessibility. ■ **ABILITY**

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youdescribe.org
stemtradingcards.org/dr-joshua-miele



Diana Elizabeth JORDAN

Actor and self-described “artist” Diana Elizabeth Jordan is having quite the moment. Her one-woman show, “Happily Ever After”, debuted at the Hollywood Fringe Festival last year. This year, she was selected out of thousands to take part in the WarnerMedia Access Talent Spotlight Program. Jordan, diagnosed with cerebral palsy at age 2, which mildly affects her speech and gait, is breaking down barriers. *ABILITY*’s George Kaplan spoke with the artist about her craft, the three p’s and intersectionality in the entertainment industry.

Kaplan: You were recently selected out of thousands to participate in the Warner Bros. Discovery Access Talent Spotlight Program. Can you tell us more about that?

Jordan: Yes. Oh, it was probably one of the most incredible professional experiences of my life so far. Warner Bros. Discovery has a talent development-type program, and in January they put out an open call for actors with disabilities, many actors, indigenous, transgender, a lot of communities that are historically marginalized in life and by the entertainment industry.

So, I submitted a monologue. Then I got a call to submit a scene. I didn’t hear for a long time, so I thought, “Oh, well, you know.” And then I got an email, “We’re

still deciding. You’re in the final 80.” And I thought, “Well, that’s cool! Out of thousands, I made it to the final 80. Yay!” And then one night my manager called and said, “Are you available for an interview by Warner Bros. Discovery tomorrow? They want to ask you a few more questions.”

And I’m like, “OK,” and I rehearsed my interview all night long with myself. And then when I got out of the interview, they said, “Congratulations!” It was amazing!

It was a week of not only working with 19 other incredibly intersectionally diverse artists. We’ve all become a family. We’re still texting each other almost every day. But I got to work on a scene; I got to work with a great director. I was a team partner with Ashton Grooms. I got work on the scene, I got to do a monologue. Everyone gets a recorded scene and a monologue that are going to be edited and do a virtual showcase which will go to casting directors that cast for Warner Bros. Discovery. It was awesome! It was a lot of work, but it was just such a beautiful experience with really beautiful people.



Kaplan: What were the major takeaways from that experience?

Jordan: Never give up. It's the thing to never give up. And the interesting thing is you never know until you try. I almost didn't submit because it said "emerging," and I thought, "I'm too old. There's no way they're going to take me. I'm too old." So, I almost didn't submit. I think it reminded me that you always have to give it a try because you never know. If I hadn't tried, I never would have gotten it. And also, that the journey is worth it. For me, there have been so many ups and downs and so many setbacks and whatever that I've had, but there are also rewards, and the rewards make all the tough steps really, really worth it. I just felt really valued as an artist. That I was appreciated and valued for what I bring and brought to the table, and that I appreciate and value what everyone brought to the table. It just reminded me, don't give up. You've got to keep going because you never know.

Kaplan: Absolutely, I love that. Last year you also performed your one-woman show "Happily Ever After" at the Hollywood Fringe Festival. How did that project materialize for you?

Jordan: That was a several-year project. It started out as a 10-minute piece. I worked with an artist named Tanya Taylor Rubenstein out in New Mexico with the storytelling workshop she did. I think it was 2014 or 2015. So, I did that 10-minute piece, and over the years, it kind of grew and shaped. And then right before the pandemic started, I performed a version of that where I work, at Performing Arts Studio West. I thought it was

in nice shape, and I was looking to do it and submit it at the 2020 festival. And then the world changed! (laughs)

Kaplan: (laughs)

Jordan: That year off gave me the time to really develop it. I added more. Then I got a diversity scholarship for the 2021 Hollywood Fringe Festival. Again, I just did it. It was a lot of work. I had an incredible support team.

Nothing I've done in my life has been by myself. And my mom made my costume. But it was just working and finding a venue, and the venue I found, because of the pandemic, wasn't going to allow a live audience, so I did it all virtual. I did it live every day, every time it was virtual. It was an incredible experience where I wore the producer hat and then the actor hat because I had to wear both. So sometimes I had to think, "How am I marketing this as a producer?" and then when I got to the theater, I gave it to my support team, our collaborator, so I could be the actor.

Kaplan: Do you have plans to do any more shows like that?

Jordan: You know I really would love to tour "Happily Ever After" at some colleges. I think it has a really good message about patience and learning to love yourself. Now that things are opening up a little bit more, I would love to do the show again. It's definitely one that—I haven't put it to bed. It's just resting right now, but I definitely would love to do it again for a show or a conference for sure. So yeah. I hope it's not done. I don't want it to be done yet.

Kaplan: Yeah, you only got to do it during the pandemic, during a quarantine kind of moment.

Jordan: I really would love to get this newest version, the latest version, up in front of a live audience because, even though I know people are laughing and stuff, when you're virtual you don't really get to feed off the audience. There's an energy when you're doing something live that I love. There's the energy from the audience that I missed. I would love to have that.

Kaplan: How did you start acting?

Jordan: You know, I always knew, since I was a little girl, that that's what I wanted to be. I don't think I ever wanted to be anything else. My dad's older sister, my aunt Rhoda, was an actress, who died. She died a year before I was born. Growing up I heard stories about her. I think I was one of those kids who was born knowing that I wanted to be an actor. I often joke that I entered the world in highly dramatic fashion because I didn't breathe on my own for 45 minutes, which causes cerebral palsy, so I've always been a bit of a drama queen in a good way.

I've just always loved performing, telling other people's stories, creating, it's almost just like it was innate. And I have artists in my family. I don't know; it was just always an interest. I wanted to do it. It was almost like second nature to me, creating.

Kaplan: What goes into selecting a role for you? What do you look for?

Jordan: I really look with heart. If I'm selecting, no matter whether I'm selecting or if I'm giving an audition, I always try to find to heart of the character. Whether that heart is cold, what is the character's Why? Why—I'm making it very personal—it becomes me, living in that imaged circumstance. For example, why am I really angry and bitter toward people? Why do I just need to be loved? Why do I need to get the story out? It's more about the why. It's really for me. I love variety, too. I love playing survivors, vulnerable characters, but it's also fun to play a busybody and have some of that. To me, it's always finding the heart of the busybody. Why am I a busybody? [She becomes a busybody.] Maybe I really do care about people and I'm a busybody because I know so much, and therefore it's my duty to share all the information I have because I'm very inspired! That's the heart of my Why. Does that make sense?

Kaplan: Totally does. Would you say you're more attracted to comedy than you are to drama? What really makes your heart sing when it comes to acting?

Jordan: It's both! I think I find them both equally. It's like when someone asks who's my favorite nephew. I have two nephews. I love them equally. They're both very special in their own way. So, I think that I don't



Diana performing *Happily Ever After*

know if I have a favorite genre. It more depends on the character I get to play. It's fun to do comedy. Comedy's a blast. I love doing comedy. And also, it's up to who I'm working with, given I'm often inspired and motivated by my team partners. I'm doing some sketch comedy in a couple weeks, and I'm having fun because I'm so motivated with them and I'm so motivated by the actors I work with. It's the community and the team that I love about it, too, and that comes whether it's comedically or dramatically. My scene partners are touching me and pushing the buttons to make me laugh or whatever. So, I love that, too.

Kaplan: You teach acting at the Performing Arts Studio West. Can you tell me more about how you got into teaching?

Jordan: Yeah! (laughs) I taught a bit when I was in Chicago. When I was getting my master's degree—I moved out to Chicago in '98 to get my master's degree.—And in '99 I needed to find a job. So, I went to apply for a job at a Carl's Jr. And the guy says, "When I come back, you're going to tell me why you want to work here." And I started crying because I didn't want to work at Carl's Jr. (laughs) I met my boss and he was talking about the studio he had was looking for an acting teacher. So, I started working there in the summers, in between graduate school. And after I graduated, I worked there full-time. We're going into our 23rd year, I think it is.

I think it opened in '98. We offer programs to artists with disabilities. I'm one of the acting teachers. They have been featured in more than 2,000 roles in film and television. And one thing about that is, to me, every major actor has a day job. I think teaching what I do is the extension of who I am as an actor. I love the idea of supporting other people in the development of their dreams. Watching the clients, we refer to them as clients, not students, watching them shine is a really awesome feeling. And seeing them grow, seeing actors grow as they've been coming to the studio, it's a great group of artists I work with. I love my coworkers. They're all amazing. It's like a family.



Diana on stage "SomeDay" at the Cornerstone Theater

Kaplan: That's great! I know you're aware that *ABILITY Magazine* sponsors abilityE.com—connecting casting with authentic disabled actors. Many members are new to the industry. Do you have any advice for anyone starting out? Any auditioning tips?

Jordan: I do. Honestly, I'd love to talk to you more about it because I'm thinking about how I can get more involved with that, too.

Kaplan: That'd be fantastic!

Jordan: I'd say patience, persistence, and passion—the three Ps. Patience, because you have to be really, really patient. Things may or may not happen overnight. Persistence. You have to have a drive and know that there will be rejection. There will be difficult times, and to be able to persist in doing that and taking daily actions. And then you have to do it because you love it: passion. It's not about whether you think you'll become famous or whether you think that you'll make a lot of money. Not that those things aren't nice. They are, believe me. But there has to be a passion for being an artist. I mean there are lots of things, but the things that come to mind right now are to be patient, have persistence and be passionate. When you pursue your dream and what you love, to me that's like, you're so lucky. That's a bless-

ing. Not everyone has the courage to pursue their dreams. I've met people who go, "Oh, I always wanted to be an actor, but I never tried." There may be a reason.

But, if you can, have that passion to be and you can be patient and persistent and not worry. And also, there are things that are not under your control. You can do a great audition and still not get selected. I know with the showcase that there were tons of amazingly talented people who auditioned. I happened to get this one. I don't get everything that happens. I did get this one, and that's because of patience, persistence, and passion.

Kaplan: How do those three Ps guide you when there's so much discrimination and barriers in Hollywood still?

Jordan: The same way, I think. You know, I think there were times—and I'm not going to lie— It can get really frustrating. Sometimes I feel like we, as a community, and I, as an individual, have been saying the same things for years and years and years and years. "The barriers are starting to come down." But it's like two steps forward, one step back, and then two steps forward, three steps back. There's always this. But the passion is that when I hear that we're not ready yet, I wonder when are we going to be ready? The persistence. You just have to keep going because, if you don't, it's

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not going to change. If everyone gives in to the frustration, if as a collective we give into the frustration, we won't break down the barriers, because we're frustrated.

Kaplan: What do you think still needs to happen in terms of those barriers coming down? What would you like to see?

Jordan: There's been so much growth in the past two years. I would like to see the diversity and the intersectionality within the large disabled community be more visible. I think when it comes to disability on TV, we still see predominantly images of Caucasian men. That's changing. There are more people of color, more people from other multi-marginalized communities who have disabilities on TV. Definitely when telling disability-specific stories, but also, I'm an aunt in real life, so why can't I play an aunt in TV? I didn't become a mom, but not every actor on TV who plays a mom has been a mom. I just want to be able to tell the stories of other actors with disabilities, for us to be able to tell stories that celebrate the diversity and intersectionality of the human spirit, whether they'll show — and some will be funny, and some will be not real serious. And we have this image of the physical barriers. I think breaking down the attitudinal barriers and the physical barriers that would allow access for actors. We're doing more home auditions, but we need to break those barriers, too, so that we have more equity.

And again, I tend to be a positive person. I am so grateful for every opportunity I have had. I've had a lot, and I'm truly, truly grateful for that. But that doesn't mean that after years of pursuing my dream, I don't still have dreams. I would love to book a series. Or maybe one day go to the Oscars. Those are the dreams I have. It



won't be the end of the world if it doesn't happen, but I still dream and I still work hard toward manifesting those dreams.

Kaplan: That's great. I was actually going to go there next, on what your goals are for the future or if you have any future projects you have coming.

Jordan: I would love to book a series, a supporting role in a really fun drama, maybe a period drama. I'd love to work a supporting role in a period drama so I could wear all the fun costumes. Also, theatrically because I love stage. I would love to work at the Mark Taper Forum in LA or with Michael Douglas or the Geffen Theater. They're all here in LA. I would love to do more stage work, do a great, wonderful play. And then also find opportunities to direct. Those are my future goals. Those are some.

Kaplan: That sounds great. You've called yourself a disability inclusion "activist." What does that mean to you?

Jordan: It means I use my art to talk about disability inclusion and equity. I do that through artistic means. There're not titles for what we do. We kind of have to create our own path and then say, "You know what? You need me!" I conduct workshops through my company, the Rainbow Butterfly Café on disability inclusion and equity in the arts. I use my workshops to teach about disability history, disability distance. I use the word "activist" because it's a combination of art and activism. To me, my art and my activism are very much intertwined. ■ ABILITY

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WARNER BROS. DISCOVERY

Access

Discovering the Talent of Tomorrow

Warner Bros. Discovery Access boasts several programs designed to mentor and develop diverse talent within entertainment. After the recent merger between Warner Media and Discovery, the team and its mission remain, “creating inclusive pathways into the industry”. *ABILITY*'s George Kaplan spoke to a passionate Grace Moss, VP of Equity + Inclusion Programs at WBD Access, about these programs and her investment in seeing participants succeed.

George Kaplan: We spoke to one of the participants in the Warner Media Talent Spotlight Program, and they had a lot of amazing things to say.

Grace Moss: That's so nice to hear, thank you!

Kaplan: What was the motivation for the program?

Moss: We're ultimately the talent development arm of the Equity Inclusion Division for what is now Warner Bros. Discovery. Our team is dedicated to finding emerging talent. We're on the ground at festivals, in conferences. We are facilitating our own programs and bringing in talent that way. Our goal is to identify this talent from historically excluded groups and put them on the radar of our executives. Whether it be for staffing or for career opportunities, our job is to find that talent and also make sure that they are well prepared for the opportunities that we hope to place them in. That goes hand in hand with the variety of workshops that we have within many of our programs. It's not just finding the talent but giving them the tools so that they can succeed once they find that opportunity. So that they can not just survive but really thrive, whether it be in the writers' room, on set, on stage to perform. That really is the goal for the Access team.

Kaplan: How was the recent Talent Spotlight Program?

Moss: I have to say, I may be biased because I drove the whole thing, but it was one of the most meaningful and powerful initiatives that I've worked on in my career. And I've been doing DE&I [Diversity Equity & Inclusion] pipeline programs for over a decade here at [Warner Bros. Discovery], including my time at NBC. I think it was a unique opportunity for me, personally, to get to work with talent that's outside of the writer and directors and behind-the-camera folks. This was specifically

for actors. I had done a little bit of that at the scene showcase, but I really got a chance to get connected with the participants. I think the most fulfilling thing for me was to witness that community grow in that week that we had together, really bond and embrace each other's work and celebrate each other, support each other.

On day two, when we did our table reads, everybody read the scene. And we all were able to share initial impressions. I broke down in tears because I was so moved at the collection of talent that we had brought, both by their skills and also to see the way that they supported each other and were cheering each other on. That was just day one or two. And then, of course, at the end of the whole week in LA, everybody was emotionally connected and we built a family through this workshop. I think most importantly, we're going to get these folks as many opportunities as we can within the Warner Bros. Discovery portfolio. We're in the process of building that distribution list of folks within the company who we can start to share the showcase with. That's ever-growing. I just can't wait to see it.

Kaplan: That's exciting! So, you have the showcase to show and deliver to people?

Moss: Yes. I know many of the showcases for the industry are in person or historically have been. This one was done in a way where we recorded everything on set first. It's now in post, and we'll distribute that final showcase link.

Kaplan: Why are talent pipeline programs so important?

Moss: Oh, gosh, for so many reasons! Oftentimes historically and institutionally, it has been very difficult for folks from these marginalized communities to get their foot in the door. So, to have a team to act as advocates internally and be able to dedicate themselves to finding that talent, and again making sure that they are equipped with all the tools they need to succeed, I think that's why it's really important. I think before departments like ours were born, programming teams oftentimes have so much on their plate. It's really cool to have a team specifically focused on finding the talent and presenting them to the network and the studios for those opportunities. And with that focus, we're able to really

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Andrea Ramos



Christa Rapaglia



Gugun Deep Singh



Benny Wayne Sully



Suzen Baraka



Daisy Washington



Murad Yunus

curate the experience, to make sure that it's also a holistic experience. It's not just, "Here's a workshop on auditions." It's, "Let's talk about how you should navigate the industry as, let's say, a BIPOC (Black, Indigenous and people of color) talent. Let's talk about how we can make sure that you are presenting yourselves in interviews or on your résumé in a way that will get you seen and get you through those doors." We take a comprehensive approach to making sure that they have all the tools that they need.

Kaplan: For the Talent Spotlight Program, did you whittle 7,000 applicants down to 20?

Moss: Yes! And I will give credit to our casting directors. We worked with ABL Casting. They got through the bulk of it. They had multiple rounds to narrow down—I think our team, when we got our eyes on it, it was down to 80. So, we saw 80 and then narrowed it down to 20, but I do want to give credit to ABL to narrow down that 6,900. It was a really, really tough job that took months, and we're so happy with not just the talent themselves, but the wide assortment of talent.

One unique thing about this particular program is that we amplified our effort for communities from the disabled actors, Native American and Indigenous, Middle Eastern, and North African, and trans talent as well.

And I know oftentimes showcases tend to just be Black, Asian, Latino—which is totally fine, and we also did that as well. —But we wanted to make sure that we specifically targeted those four other communities because they often get even less access than those other groups. I think that’s another reason why our initiative was really important.

Kaplan: There’s intersectionality now among those groups, too, which makes it even more of a reason.

Moss: Absolutely! And that’s something that we’re always thinking of, even in our other programs. We are working with the Black Theater Coalition as an example. We wanted to make sure, “Let’s find some Black talent, but also let’s check with talent who may have disabilities who are also Black.” We’re very much conscious of that for all our programs, and it just happened to really align here. We got so much intersectionality in this program, which is nice.

Kaplan: What stands out to you in an application when you’re going through so many applications all the time, not just for the Talent Spotlight Program, but for your other programs under Access?

Moss: Generally speaking, first and foremost, it will always be the technical skill, whether it’s a TV script or a performance. That’s what they need to have to even move on to the next stage and to really succeed. That’s first and foremost. Second to that, in many if not all of our programs, we do have an interview phase, or at the very least an essay portion where we talk about why they want to be doing this program or what type of diverse perspective they’re bringing into that particular craft, again, writing and directing. We look at them as a whole. We look at their personal story, and also see how they are in a room. You could have somebody with a wonderful script, a great essay question as far as why they are deserving of this opportunity, but we also want to make sure that they can handle themselves if we do put them forth for a staffing opportunity; that they’re comfortable, that they’re likable, that they can pivot and handle themselves in the room really well because, ultimately, our goal is to get them to our shows for various opportunities. And we just want them to shine in the room as well. Those are a couple of things that stand out for us.

Kaplan: You talk about following up with these participants and making sure they succeed. In what ways does WarnerMedia Access do that?

Moss: Even though, let’s say using our Access writers’ program, that program officially wrapped in March. Now, even though we’re not meeting with them weekly like we had been for the past seven months, we’re creating a look book that we are then going to circulate to all our programming teams across the portfolio. Same thing for Talent Spotlight. We have a look book with bios,

IMDB, making sure that all the executives have easy access to the talent and that they have their information readily available, whether it’s a link to their script, a link to the showcase. We make the time and make it really easy for them to check out the talent. So, getting that out.

And then also, making sure that we maintain the relationships. The writers’ program, using that as an example, I’m continuing to meet up with them for lunches, checking in on what they’re working on, waiting to hear what shows they might be interested in staffing on in the next few months. Once they’re in the program, that’s the beginning of our relationship. After that it will just continue on for the years to come.

Kaplan: Fantastic! Since you’ve been involved in diversity, equity and inclusion have you seen the industry evolve over time?

Moss: Sure! When I started—I think my first formal role in DE&I was around 2012 — At the time, we were still making a business case. We were doing presentations on the buying power of this community. I think we have thankfully evolved to where that’s not even a question anymore. Everyone understands that this is important for the business. Now it’s just a matter of converting that understanding into actual opportunities. That’s why, again to your previous question about the importance of these pipeline programs, we’re there to make that conversion. We have the interest of the company. They’re open to meeting new talent now, and we’re here to say, “Here’s great talent that we’ve vetted, that we’ve worked with and interviewed, that we think would be great for this opportunity, this writers’ room. Let’s us help you.” I think now it’s a matter of making those connections. Well, I guess another thing that has changed is that, back in the day, about 10 years ago, there was a little bit of a dearth of writers of color in general, especially at the lower levels, like the staff writer level.

Now, because there are so many amazing programs out there, there is a lot of great talent at the staff writer level, the story editor level. So now, I think the changes that we’re now trying to—We’re now seeing these gaps in the mid- to upper levels. So, I think it’s important to now focus our efforts and examine how we can fix that bottleneck or try to address those shortages of talent in those mid- to upper-level producers, as an example.

Kaplan: So that’s what you see as what needs to be done in the future, more of that bottleneck?

Moss: Yes, reevaluating. —The changes or the problems or the issues in the industry are always evolving. Ten years ago, it might have been, “We don’t have a lot of great staff writers of color that we can put out.” Now it’s definitely showrunners, of course. That’s something where we saw that need. We have a

showrunner program to have a pipeline of great talent to put forth to lead these shows.

So, I think it depends on what part of the industry. For us, because we have such a broad scope of work, we're looking into doing some work on the accounting team. We're able to expand our efforts below-the-line as well. I think it's ever-changing, but we try to pinpoint what those real needs are at this point and not just do a writers' program just for the same of doing a writers' program. How can we curate it to be very specific to that need?

Kaplan: What's next in the pipeline?

Moss: Gosh! One thing, last year we launched our inaugural Early Career Boot Camp. That was special because it wasn't for production. This was specifically to build our talent pipeline of folks who want to get into the corporate world, future executives. We are launching the second cycle of that program. What's exciting for this go-around is that we've expanded our partnerships to include even more organizations. For context, last year we partnered with RespectAbility, which is an advocacy group for—well, I'm sure you know—people with disabilities. We also partnered with the Trans Film Center, MPAC (Muslim Public Affairs Council), and IllumiNative, an advocacy group for Native American and Indigenous talent. Again, so successful that we've expanded it to include three additional orgs, which is Urban League, Center for Asian American Media, and NALIP, the National Association of Latino Independent Producers. That's a great example of how we're evolving, trying to be as inclusive as possible and expand our efforts. So, we've got that.

We also have—it hasn't been assured yet, but we are internally developing some writers' programs specifically in the comedic space, so more to come on that. And we're continuing to support—on the unscripted side, we have a great partnership with HBO Max, where last year we were able to place three producers from underrepresented groups onto three series.

Kaplan: Wow!

Moss: Yeah, yeah! And they were sort of elevated, it wasn't just a lateral move from associate producer to producer. They were all promotions. We were able to get that going and have that wonderful partnership. We've placed two more people on series in 2022, so that's exciting. And then, I'm not sure what else we can share. We are doing some work in the LATAM space. We're doing some work with news, journalism programs, basically taking journalists into scripted writing. But I don't want to speak out of turn because I did at South by Southwest.

Kaplan: Is there anything else you would like to talk about regarding Warner Bros. Discovery?

Moss: As far as the accessibility piece, I wanted to share that we did consult with RespectAbility from the casting phase as far as making sure that our sites were accessible. We also did work with a production accessibility coordinator, both at the location scout, to make sure that we had the right bathrooms and everything was placed properly to installing lights for our actors who are deaf so that they can have alarms accessible, to working with the hotels to make—We had an actor who was a little person and making sure that she had several stools in her room and in our rehearsal spaces. We also had a production accessibility coordinator onsite for the entire week, and we also made sure, given the advice from that group, we also had a quiet room for those who had neurodisabilities who might need a space to get away from all the sensory experience.

That's something I'm really, really proud of. We wanted to make sure that all of our actors felt safe and seen and had everything they needed to deliver the best performance, and also have a safe and welcoming experience. And then we also made sure that we had four ASL interpreters every single day in LA, two per deaf actors. I hear that that is oftentimes not the case, so I wanted to make sure that we not just met those guidelines, but exceeded them. I'm really proud of that.

Kaplan: Great. I wanted to know if you're aware of what we're doing with ABILITY Corps' abilityEntertainment for disabled actors? *ABILITY Magazine* is a founding sponsor of abilityE.

Moss: I think when I was at NBC, I remember hearing the pitch. I'm glad to see that it moved forward. That's amazing.

Kaplan: That must have been pre-launch, it's up and running now.

Moss: That's great! Congratulations! That's much needed, obviously. I'm so glad to see that this is up and running. Whenever you're ready, I'd love to have a demo maybe for our team, just so we know how to navigate this and make sure to share it with others. ■ **ABILITY**

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Celeste THORSON

Celeste Thorson is a writer, producer, actor and advocate. Her advocacy spans women's rights, diversity, environment and disability awareness. She is the ultimate expression of diversity herself. Celeste's mother is of Lebanese, Spanish, French Huguenot and Apache Mescalero Native American descent. Her father was born in South Korea and was adopted as a young child by the Thorson family in Colorado. On her father's side she is of South Korean and Scottish Irish descent.

- Cooper: Can you share your involvement with Shane's Inspiration now called Inclusion Matters?

Thorson: Inclusion Matters, yeah.

Cooper: Is that the first time you experienced that event, have you been to a playground?

Thorson: Yes. I discovered Inclusion Matters when it was Shane's Inspiration about five-ish years ago. I was inspired by their mission and seeing these tangible contributions to our community. I had been to the playground without knowing it at Griffith Park, then once I went to their event, it educated me on what that enables people to experience and how it





brings a community together. Over the years I've been following their mission, trying to be supportive towards them, their advocacy and educational programs. Having a child of my own really made things even more profound for me, because I wanted my child to be able to play with people of all different backgrounds and to grow up appreciating the beauty in everyone's diversity. Bringing him to the park where everyone of all abilities can come together, and that is just a natural part of his experience and the evaluation of his friendships, I think is a really beautiful thing. I'm now able to reap the rewards of having my child be able to play with people of all different backgrounds. That's really exciting.

Cooper: How old is your child?

Thorson: He'll be three! He's two right now, he just attended one of the play clubs, did T-ball and hockey for the first time, surrounded by so many children and adults of all different backgrounds and abilities. Whether it was differences in mobility, whether or not they're neurotypical, it was really beautiful to see everyone come together and share this experience. He just loves it. It warmed my heart to think that, again, he's growing up in an environment and a community where everyone's celebrated.

Cooper: What were you doing there two years prior to having your son?

Thorson: Well, I've been a human and environmental rights advocate for many moons. It turns out that part of human rights is equal rights, and part of equal rights is disability rights. It's a very all-encompassing umbrella when you simplify everything down to basic human rights, sustainable inclusion and making sure that people have the abilities to meet their most basic needs with an equitable approach to what's provided by our community.

Cooper: Not everyone connects the dots as easily as you just did. I also saw you did a short piece with Easterseals.

Thorson: Yes, I really appreciate them. A photographer friend of mine, his son is a part of Easterseals and benefits from all of their advocacy, support and programs. He brought me into a couple of their events. It was again wonderful to participate in that and be part of the community that brings together so many different folks and makes sure that they feel supported.

Cooper: The one I saw, was it Disneyland?

Thorson: No, it's a walk that they do.

Cooper: Oh, the walk, right.

Thorson: One of their fundraising events. It's really fun to see everybody come together, I also really love supporting Special Olympics and all of their programs. Seeing all of these different athletes come together and do their best work, celebrate the wins, cope with the losses, you know? It's wonderful to be there to cheer people on through their experiences and support their athletic endeavors.

Cooper: After the 2019 Special Olympics World Games in Abu Dhabi that included thousands of athletes representing 170 countries the UAE changed their country's language. They don't use the word "disability". Now they say "people of determination."

Thorson: It's so beautiful seeing that representation, and how powerful it is. You can literally change the way that government frames the conversation and the rights of entire groups and populations of people, what that would mean for their quality of life and their, again, human rights. Sometimes it's these more inspiring events and stories, seeing people living their dreams, their best lives, that makes people see the truth. Which is that it's beautiful, something to be celebrated, to be included in our everyday conversations online. All of our experiences are valid and deserve to have a place where they can be celebrated.

Cooper: You also do a traveling show. Is that an active part of your life?

Thorson: Certainly since COVID, not so much! But I finished that program quite a while before COVID, I had worked on a couple of different travel shows. I also have a kind of a lifestyle program that I work on myself. I do a bit with on-camera, whether it's acting for different television programs or some behind-the-scenes work as a writer, producer and director. Right now I'm working on an Ed Tech (Education Technology) edutainment-type project that creates content for educational purposes. It's exciting to make accredited courses more accessible to people of all backgrounds in high school. That's a lot of fun.

Cooper: Is that part of the curriculum in the schools? Or is it an add-on to a program that schools can buy?

Thorson: Really both. There are so many ways that schools can utilize this resource, whether it's through course expansion, course recovery, or through independent study. As we know, during the pandemic, so many teachers were thrown into the fire of, "Hey, not only do you have to be a professional educator, but now you have to be a webmaster!"

(laughter)

Thorson: "And an online teacher, a troubleshooter on the help desk, technical support, all of these different things, learn how to connect with students and engage

them in that modality." This company called Subject does a great job of trying to bridge those opportunity and achievement gaps. They support teachers, learners, administrators in being able to access those resources with a world-class, rigorous curriculum, amazing teachers and educators who are instructing to connect with the Gen Z audience and leveraging that communication style, which is a very unique and specific style.

Cooper: Interesting! Years ago I was working with at-risk youth in school systems dealing with different learning modalities using temperament theory, do you know Myers-Briggs?

Thorson: Yes.

Cooper: Trying to reach those students who were what the schools would consider "problem children" and how to reach them. You're looking at millennials as a broad base. Are you looking at any divide in how to reach certain mindsets?

Thorson: Absolutely. I grew up with, Bill Nye, the Science Guy, and Reading Rainbow, all of these wonderful things, which was a form of distance education, if you think about it. Or online learning, all of the things that weren't in person. I bring a lot of information from those education programs. Bringing it full circle to utilize my talents trying to reach this Gen Z generation. Their attention spans are different. They're the TikTok generation. They're the Instagram generation. They respond to very succinct sound bites rather than the longer forms, storytelling, oral history, that I responded to when my high school teachers were lecturing in front of the class and telling us a story. Now they kind of want to catch the quick and, "Give me the need-to-know Cliff Notes, and make it funny!"

(laughter)

You know? It's definitely a different language in communicating with them. And also understanding that they're digital natives. They process information and they prefer to type something out rather than write it in cursive. All of these different things that help them achieve their academic goals by meeting them where they are.

Cooper: Did they come to you, or was this your project?

Thorson: They came to me. I'd worked with one of the media directors there, on many different projects. We'd collaborated on music videos, travel shows, all types of different things—with my background in edutainment, he thought of me to bring me on as a writer and executive producer. I've been really enjoying that project, especially during COVID seeing how Ed Tech can transform the lives of youth. Seeing that there were a lot of gaps created, a lot of children who unfortunately fell behind and need the opportunity for credit recovery now



more than ever. It's wonderful to see the schools be able to use this as a resource that's accredited, and can help them achieve their goals.

Cooper: I heard you use the term "neurodiverse." Are you doing anything in that realm?

Thorson: I'm hoping that there will be more—obviously, one thing about this particular program is, it can be accessible on your computer, so that already can help folks who really need a quiet space to focus. But I wouldn't say there's the type of accessibility yet. It's such a new company. I know that's something that is in the pipeline, takes a lot of mindfulness and making sure the curriculum is orchestrated that way. I know that right now they're focus on pacing guides, which makes it accessible in certain ways. Sometimes you have to still follow the semester, but the timing of how you roll out the courses can be a little bit different based on people's learning styles and where they need more support.

Cooper: Can you talk about other causes that you support or advocacy work that you do?

Thorson: Absolutely. I believe firmly in human rights. The baseline. It encompasses so many different aspects of the human experience, acknowledging that as the foundation across—all the different countries really benefit from having that basic declaration of human rights abided by and enforced by as many countries as possible. That's something I'm very passionate about. And of course included in that are women's rights, LGBTQ+, people with disabilities, people of color. All of those experiences are validated by a lot of human rights, a lot of respect for human rights. We still have so far to go, and in some cases there are certain rights that are being rolled back. Sometimes it feels like two steps forward and three steps back. As long as we're trying to move forward in the right direction, I'm passionate about moving that cause forward. But I think there are

far too many adversaries these days.

Cooper: Did you say “rolled back” or “Roe’d back”?

Thorson: “Rolled.” (laughs)

Cooper: You gave a talk at the UN (United Nations) on women’s rights, could you talk about that?

Thorson: Yeah, the UN Women SoCal invited me to do a keynote for International Women’s Day, which was a lot of fun. I was able to share some of my perspective on women’s rights.

That was a really incredible experience, being surrounded by so many women from all different backgrounds, generations, sharing our collective experiences, American women and immigrant women. Looking at women’s rights as a whole from what we’re experiencing here to what women in India are experiencing, what women in Yemen and Iran are experiencing. Talking about all of those different things and being able to reflect on the privileges that we have here as well as how far we still have to go, that was a wonderful conversation. One of the best parts was hearing women from so many different backgrounds and their personal experiences. When they were sharing those things with me, sharing the pieces of advice that they would have given their younger selves, or that they would give to other women, was an inspiring experience. I had them write postcards to share with other women, and I put them up online in some cases. I still go back and look at those. They’re incredibly inspiring.

Cooper: How did they choose you for the keynote?

Thorson: In Laguna there was a lady who was a big advocate, and she reached out to me, having seen the work that I had done over many years and invited me to be a part of it.

Cooper: Have you heard of the Convention on the Rights of Persons with Disabilities (CRPD)?

Thorson: Is that the Ability convention that you do here in LA?

Cooper: No that’s the Abilities Expo. Sorry, I’m still in the UN frame of mind. It’s the United Nations’ CRPD. It’s similar to the ADA in concept, each year, usually around June, the UN has this event, and the state parties, which are the countries, come together along with NGOs. Oftentimes panels during the CRPD invite speakers from around the world to share and discussion disability centric issues.

Thorson: It sounds incredible. I love what you’re talking about. It’s true, when you travel to all these different countries, even just basic accessibility can be really challenging. I remember traveling to Italy and going

through public transportation, the train stations, the beautiful architecture, beautiful stone buildings that have been there for ages, and nary an elevator in sight, you know? I kept thinking, how do people in wheelchairs, people with mobility restrictions and limitations travel here? I asked some of the gentlemen who were working there, I guess they were like police officers at the train station, and they just kind of laughed, actually. They thought it was laughable that I would ask that question.

It was kind of a bit of a culture shock for me, because in that moment, it made me so grateful for what the ADA has done in America. Even countries with a far richer history than us, who have had a little bit more of a head start in the formation of their countries, are still needing to support their communities and haven’t quite gotten around to that yet. I would love to see how the UN is implementing some of these equal rights policies and how that would impact people with the most basic needs of transportation and getting where you need to go, for example.

Cooper: A lot of countries rushed to sign and to ratify, but then came the implementation. That’s the difficult part. For some countries it can be costly when you have an infrastructure like Italy with steps everywhere.

Thorson: Mm-hmm, yeah. And I understand if it’s in some places where you have historic buildings and things that maybe are protected in that way. But in train stations, or when it comes to public transportation and accessibility, post offices, public services, that’s where it really caught my eye, even just cobblestone streets are not particularly welcoming. The lack of support was palpable.

Cooper: We haven’t done much, but there’s a group we’ve communicated with several times based in Italy that is leading the charge, and one of their offshoots did a really interesting program in Venice where they created these ramps. You know how they have all these old bridges going over all these small channels, and sometimes there are steps on the bridges, and they’re too steep. They created platforms that would navigate in such a way, I think it was called Access Venice.

Thorson: Wonderful!

Cooper: When we were there, they had scaffolding type ramps going over all of the small connecting bridges. I don’t know if they stayed, or we were just there at the right time.

Thorson: It’s wonderful that you bring that up. The architecture and the way that these cities are built is not conducive to access, but the one thing about Venice is, they have so many floods, that even if they did want to put something up permanently, it would end up being under water at some point. So it makes sense that there’s

a scaffolding that they can move around. I remember that they were using the same type of platforms during the floods, when the water would be rising and you wouldn't even have access to the stairs if you wanted to. They used those ramps and walkways, and they're able to move them around or raise them up or lower them.

Cooper: Several of the water taxis were accessible for a wheelchair to get on. So there is movement. It just may take a while.

Thorson: Yes! And that's ironic, because that's probably the city you would imagine being the least accessible.

(laughter)

Yet they're one of the more progressive in making changes and putting the time and implementation in.

Cooper: Another place that's accessible is South Korea. Have you been there?

Thorson: I have, I got to visit family, my grandmother's sisters and my grand-aunt and her family. I was invited for Asia Model Festival award. They brought me out and they had all of these different performers and actors and models from around the world. It was really interesting.

Cooper: Did you ever take the subway?

Thorson: I never took the subway when I was in Korea, but I did in Japan.

Cooper: Yes, Japan's really accessible.

Thorson: And I do remember how well thought-out so many things were in Japan.

Cooper: Something that we found that we don't see in the States, they monitor everything, Japan, in the subway system. Even though the gaps are really narrow and they're really not an issue, they know when somebody's using a chair, and what cabin of the train they're in. They run with this little hand held ramp and lay that down covering the small gap between the train and platform.

Thorson: Just a fold-out, just a small ramp?

Cooper: Right it only folds out flat. This covers the gap. Dubai is another place that's completely accessible. You can't even tell the difference between the train and the platform. It's seamless.

Thorson: Wow, that's wonderful. That level of consideration is so important. They're going to spend the money anyway, so might as well do it right the first time if you can.

Put a little bit of planning and a little bit of consideration into it. That's what I'm hoping with all of these new infrastructure bills and things that are happening. It would be wonderful if they could put the time and consideration into building an infrastructure that is accessible to everyone in our community.

Cooper: Can you talk about these projects you're working on?

Thorson: Today I was pitching three shows to a production company and planning pre-production on two filming shoots, two separate shoots that we're filming next week that I'll be directing. Both are for Ed Tech, educational accessibility. One of them is interviewing superintendents about the future of education. The second one I can't talk too much about, but it's also in the educational genre. Those are the things that have been keeping me very busy. I feel like I'll be able to take a nice long bath and exhale next Friday leading into the weekend. There's a lot of logistics and a lot of planning going into that.

Cooper: So right now most of your time is spent in that room?

Thorson: Yes. During COVID, and honestly, after having my son, I was reprioritizing my energy. I wanted to focus on ways that I could utilize and channel my talents into something that would be fulfilling and would give me the ability to spend more time with my son. In the on-camera world, you need to be where you need to be when you need to be there, and there's very little control that you have over that. Coming at it from a producer-director role, I'm able to create a little bit more flexibility and organize things so I can address my priorities in the best way. Whenever I get on-camera opportunities, I've been able to be a little bit more discriminating about them and determine if they're the best fit for me, whether it's the location or the travel time, if it's on the other side of the country or in a different country. If it just doesn't feel right at the moment, I've taken a step back in that way to make sure that I'm building independence in my son. And now I'm seeing the benefits of that. I'm seeing his independence and I'm feeling like, okay, now is the time when I might be able to start pursuing more of those interests and going more into that realm again, but believe it or not, I'm still nursing. That's something that's been important to me. I know I won't be able to do it for a very long period of time. Not forever! We're right towards the tail end here, but it was one of those things where I've had the luxury and the privilege to not have to interrupt that, and I know that so many mothers haven't had that opportunity.

Cooper: When you write do think about disability inclusion?

Thorson: That is such a great point, and something that I remember being asked about at the Inclusion Matters



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event. They were asking about representation. I think one of the biggest things as a writer is that not every character needs to be explicitly spelled out what their life story is. They can just be who they are, they can be human, and so many different roles can be played by people with different backgrounds. You don't have to make it about that, about what abilities they have. It can just be that they can tell that story, and it might have nothing to do with the overarching story line, it can just be that they're doing their job in the script, and they happen to have different abilities than we do.

Having a disability and seeing it on camera is one of the most powerful things, because you really don't have to have a lot of back story or explanation. There's so much depth in that story just looking at that person and understand what they may have been through to get to where they are. Seeing CODA, that was such a powerful story, and to know that the actors were fluent in sign language, clearly their proficiency did not happen overnight. It was part of their lifestyle, their human experience. That's what I want to see more of on camera. That's why I think starting with the writers is such a powerful thing. If you can make the story about that, that's wonderful. But you could just be a lawyer like any other lawyer and they just happen to be in a wheelchair or hard of hearing or have a different life scenario and a different background. It's really important to have the Writers Guild of America, the Producers Guild, the Directors Guild get involved.

Cooper: Let me ask you about your acting these days?

Thorson: During the pandemic, obviously, I tried to focus more on writing and producing, because that was something I could do from a distance, remotely. The acting roles I was being offered were not conducive to maintaining the safety of my family, to be honest. It was a big risk to fly to Mexico and film for three weeks in the middle of a pandemic. Didn't seem like the right thing to this new mom! (laughs) So, yes, I've been channeling my energy into this project right now. There are some acting opportunities that have come up that I've passed on because they haven't been the best fit. I am looking forward to later this year getting more involved. I'm auditioning occasionally as well, but being able to be present with my child is important. I know that at this age—in a couple years he'll be in school, and I won't be able to spend as much time with him. It'll be a whole new ball game. I still love doing on-camera work, so I know that when the right opportunity comes along, that's what I'll be focusing on.

I was recently a recurring guest star in "The Haves and Have-Nots," which was a Tyler Perry show. That was a lot of fun. I'm sure once the stars align, it's always that way, when things are the right fit and you're the strongest choice, that's when opportunity comes to fruition. ■ **ABILITY**

photos by Nancy Villere

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The Invisible Kingdom

Living with complex chronic health conditions is like living in the invisible kingdom, according to Meghan O'Rourke's new bestseller with the same title. O'Rourke is a journalist, poet, author and the recipient of numerous awards, including a Guggenheim Fellowship, a Radcliffe Fellowship, a Whiting Nonfiction Award, and the May Sarton Poetry Prize, among others. On top of being an outstanding writer, O'Rourke raises awareness for conditions such as Lyme disease, Ehlers-Danlos syndrome, autoimmune conditions, and many more, which she all has herself. With *ABILITY Magazine's* Karina Sturm, O'Rourke talks about her book and what it truly feels like to be residing in *The Invisible Kingdom*.

Karina Sturm: Good morning, Meghan! It's still morning on your end of the world, isn't it? So as someone who lives with Ehlers-Danlos syndrome myself, I must ask: Aren't you tired this early in the morning?

Meghan O'Rourke: I put my son to bed last night, lay down with him and fell asleep at 8 PM. So I'm feeling amazing. (Laughs).

Sturm: Oh, that sounds so lovely. Maybe we should start by telling our readers a bit about Ehlers-Danlos syndrome since





it's such an unknown illness. And that's not the only diagnosis you have, right?

O'Rourke: I got mysteriously ill in my 20s, and no doctor that I saw at the time recognized that I was sick. I began having a more severe version of the issues I've had all my life, for instance, joint and muscle pain and different injuries. I had brain fog, fatigue and a variety of pain for more than a decade, but in my 30s, all these symptoms grew much worse. So I started to piece together a puzzle. It turned out that I had an autoimmune disease: autoimmune thyroiditis. Additionally, I also had Lyme disease that had never been diagnosed. After I got treated for it, I felt much better. However, those were not all. Eventually, I was diagnosed with postural orthostatic tachycardia syndrome (POTS) and with hypermobile Ehlers-Danlos syndrome (hEDS), which was actually the very last diagnosis I received, but it is the one that helped me make sense of symptoms that went way back to my childhood. It was like getting the last piece of a puzzle and suddenly seeing the world more clearly.

Sturm: I'm almost through with your book, and obviously, I can relate to all of what you said about being gaslighted by medical professionals, experiencing gender bias in medicine, and so much more. As you are well aware, these experiences are not uncommon for people, particularly women, with complex conditions; they happen to almost all of us at some point in our diagnostic journey. It took me four years until I found out I had EDS, and along the way were so many traumatic experiences with health care providers. They wouldn't believe me and instead told me it was all in my head. That's all part of your story and your book, *The Invisible Kingdom*, as well. From your perspective: Why is it so hard to get diagnosed with conditions like Ehlers-Danlos syndrome, Lyme disease, ME/CFS, and so many other complex chronic illnesses?

O'Rourke: The book uses my story to launch a larger investigation into precisely this question. Why is it so hard for those of us who live with these poorly understood medical conditions to get a diagnosis? And why are we so often stigmatized? Why do we constantly hear this disease is all in your head or caused purely by stress? The book is a quest to answer that question. And the answer is complicated. But some of the reasons I talk about in my book are that modern medicine likes to measure and see, and it struggles to treat anything that it finds hard to measure or hard to see. It's also best at acute care and pretty bad at chronic illness care of any kind. Second, medicine has what I call a woman problem. It has a history of gaslighting women and dismissing women's testimony. And not only does it dismiss women, but it also didn't study women's bodies for a long time.

Karina Sturm: Right.

O'Rourke: So a lot of the research we have is based on biologically male animals, and it turns out that many drugs work differently for women than for men. Take all this, together with a medical system that's incredibly siloed and fragmented, and you have a disaster. Another fact I talk about in the book is that you can trace a history of medicine stigmatizing diseases it doesn't understand. Tuberculosis was believed to be a disease of sensitive souls, cancer as a disease of repressed emotions, and even multiple sclerosis was called hysterical paralysis. When medicine can't measure and treat something, it tends to psychologize it. And as we both know, these conditions are still poorly understood and desperately need funding. And I think in order to get there, we need to start a discourse that points out medicine's conceptual shortcomings.

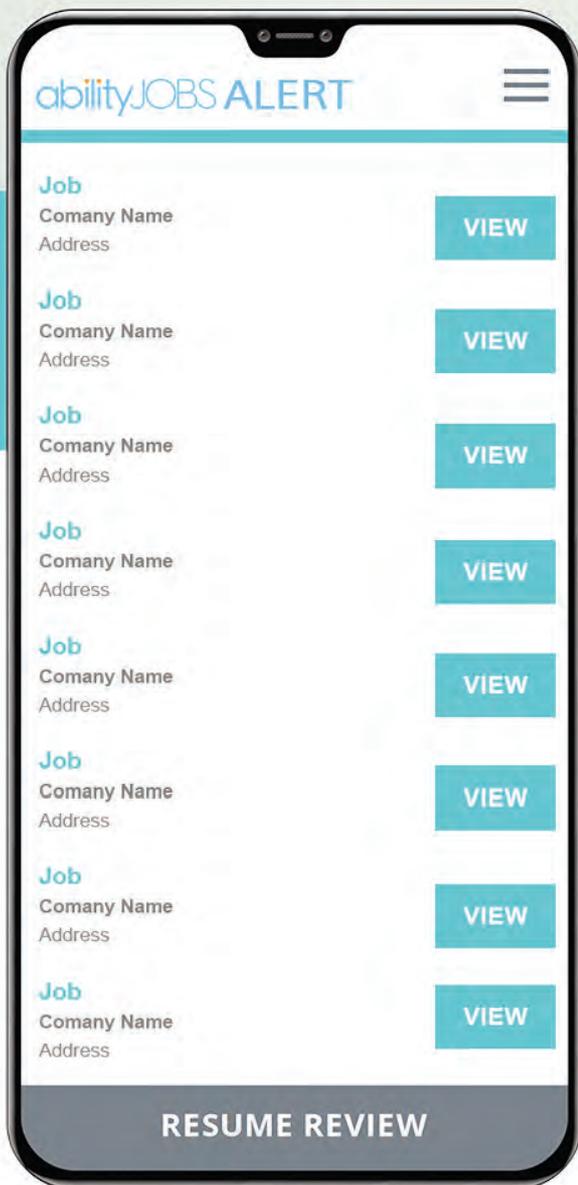
Sturm: I wholeheartedly agree. You are pointing out all those issues with the American healthcare system by using your own personal journey as an example. Now, you are sharing a lot of deeply personal details about your life. For example, you are talking about how your husband had a hard time understanding your symptoms. Can you tell me why you decided to share all these intimate parts of your life publicly?

O'Rourke: This was a decision I made early on because I felt that if I wrote the book only as a work of research, some of the urgent realities of being chronically ill would not be clear to readers. My primary goal for the book was to make those of us who live with chronic illnesses feel less alone and feel seen. I had realized that while my story was one in which I felt really lonely, there were actually millions of people out there like me - all of us dealing with different realities. But I knew that we all have one common thread: most of us feel invisible and unheard. So I thought that as a writer, my job was to share the messy realities of living with chronic illness and presenting the full picture in a way that hopefully would come across as a form of active companionship. I wanted to create a book that would be your friend. Your friend would tell you these things.

Sturm: I think you managed this quite well. At least most of the comments I read about your book were very positive. However, there is always this one person that does not like what you have to say, right? As a fellow journalist, I know that you cannot please everyone. Up to this day, I am unsure how to deal with negative feedback that's, let's say, not very constructive. I saw that one of your readers criticized the mentioning of systemic racism in your book and offered you a fainting couch. Do you feel comments like this are rooted in a lack of experience regarding chronic illness and disability? And how do you react to people like that?

O'Rourke: I mean, I think it is important to talk about systemic racism. I would be more concerned about a critique that felt valid to me. Of course, certain aspects of the book are stronger than others. You do your best as a

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writer, especially as a writer with a chronic illness. One thing I have noticed being on Twitter and getting responses to my writing - and this also reinforces what I already knew to be true as a journalist - is that a lot of people just don't care about chronically ill people. They are happy to write them off and would be fine if we all suffered in the pandemic and more and more of us died. I think you come up against that reality, and it's a reminder of the challenges that we face every day.

Sturm: Very true. We have unfortunately all seen what society thinks of us during the pandemic, haven't we? It was quite heartbreaking and eye-opening to me, and I am still not sure how to deal with the frustration the last two years brought up. However, do you feel there is a way to reach exactly those people and change their minds? As a journalist with a disability who also focuses on the representation of people with disabilities, I have been wondering about this for a while now. Sometimes, it feels like no matter what you say, some people will never hear us. Tell me how you approach this challenge?

O'Rourke: Look, there's probably 5 to 10 percent of people you can never reach. But there is a huge number of people who just haven't yet thought that deeply about chronic illness because they haven't had to or because it's abstract and hard to understand. I was one of those people before I got sick. One of my friend's mothers had ME/CFS, and I was like, "Why can't she just not be so tired?" I think people need a framework to understand chronic illness. So your work with *ABILITY Magazine* is very important because it is offering a framework that helps people understand. And the reason we have frameworks and language is to put names and shapes to things so that we're not constantly explaining every aspect of existence to one another.

I think that the work to do right now, in the middle of what I call a silent epidemic of chronic illness, is to offer that framework, popularize it, and talk about it on TV and in the news. And will there be haters? Yes, there will always be haters, but who knows if they're even real? And also, you don't need to persuade every single person in order to create societal change. You just need to get the middle. And so I focus on that.

Sturm: Sadly, I think you are very right, and our community will be much larger very soon. So all we can do is to offer support to those who will join us due to COVID and help them figure out life as a chronically ill person.

O'Rourke: Exactly.

Sturm: I know you wrote a big part of the book during the pandemic since you are talking about it in *The Invisible Kingdom* as well. But when did you start the whole process from the initial idea until you actually finished it? How long did it take, and what challenges did you have to overcome?

O'Rourke: I began writing in 2013. At the time, all I knew was that I had an autoimmune disease. I began writing the book thinking it was really about autoimmune diseases. But as I was on this quest for answers, it became clear to me that something else was going on. My autoimmune markers would come and go, and yet, I was really sick, even after being treated for autoimmune thyroiditis. In 2014, I was diagnosed with and treated for Lyme disease. I got much better after some period of time taking antibiotics. Basically, the book reflects my own quest to getting answers in real-time.

I didn't finish writing the book until 2021. So I was very close when the pandemic happened. As the wave of COVID-19 hit America, I remember thinking, "This is alarming because so many people are going to die, but also because it's likely that there will be some kind of chronic aftereffect of this virus."

And there's going to be a battle to get that recognized to get treatment for those people. So in the spring of 2020, I began researching whether people were getting COVID and afterward would not get better. While this was the summer when not much had been written about long COVID, I was talking to people, listening to their stories. I decided to write a long piece for *The Atlantic* about it and delayed finishing my book until I had wrapped my head around the scope of long COVID, what it really looks like, and how it might or might not change medicine and research. These are all questions I'm still reporting on as a journalist. It was clear that I couldn't finish the book without talking about long COVID because the book is specifically about chronic conditions that are exacerbated by or triggered by infection. Some autoimmune diseases, ME/CFS, post-treatment Lyme disease syndrome, or chronic conditions that we suspect may be shaped by infection in ways we don't understand; they are what some researchers call infection-associated conditions. So the short answer is: There was no way to not talk about long COVID. And that delayed the book for a year. During this whole time, I was living as a sick person with bouts of wellness and unwellness. So it took a long time, and I needed to be very patient.

Sturm: Wow! So it took you eight years?! That's real determination.

O'Rourke: Yes, I wrote the book between 2013 and 2021. But there were times I had to take off because I had kids and my dad died, or because I was sick.

Sturm: How much time did you spend on the research part, for instance, talking to experts?

O'Rourke: Yeah, I spent a tremendous amount of time. The book began in earnest during the year that I was at the Radcliffe Institute at Harvard. I had a Guggenheim fellowship to do research. So I spent the entire year full-time researching, meeting with people and going to dif-

ferent labs, reading a huge amount about medical history and the history of healthcare in America, and talking to historians at Harvard and MIT. And then, I kept doing that research over the years that followed while I was writing at the same time. The reason I spent a whole year on research was that I needed to have a sense of why these diseases were so hard to diagnose and treat. Of course, I have my own intuitive thoughts about that. However, I really wanted to figure out if what I was seeing was replicable for others. I also spent about a year talking to nearly 100 different people living with illnesses, such as autoimmune diseases and ME/CFS.

I also had a wonderful research assistant at Harvard who helped tremendously.

Sturm: Now that you did all this hard work and published *The Invisible Kingdom*, what do you hope to accomplish with it?

O'Rourke: I hope that the book brings some company and context. We both are talking from our perspective as two people who are invisibly ill, but hopefully, we can make the millions who are sick feel seen and heard, too, even in a small way. I also hope that relatives of people who are sick, doctors, and healthcare workers, might read the book, and, by virtue of animating one person's lived experience, it helps them have a little more access to this experience. When I say brain fog, for example, that term just slides past the person who has never experienced it. It's very hard to convey the lived reality that someone hasn't experienced themselves, so the book is asking them to slow down and live alongside these illnesses. I've heard from sisters, mothers and daughters. One daughter wrote me a beautiful letter about how she now understands her mother's life completely differently.

Sturm: That's amazing. I am glad your book inspires people to walk in our shoes. That's not an easy task. Are there any people that inspire you - personally as someone with a chronic condition, but also professionally as a journalist?

O'Rourke: Who inspires me? A fellow journalist who inspires me is Ed Yong. I think the work that he has done to bring clarity and context to long COVID is so important. And he didn't have to do that work. His insistence on this reality and his deep interest in the scientific causes for it and also the cultural reasons for ignoring it feel like a wonderful model for any journalist, whether they have a chronic illness or not. I was lucky enough to become acquaintances with Jennifer Brea, who made a wonderful film called *Unrest* about her experience with ME/CFS. And she was able to finish that film far before I was able to finish my book. She and Julie Rehmeyer, who wrote a beautiful book called *Through the Shadowlands*, reminded me that it was possible to do this even when we're also living with illness.

Sturm: Yeah, Jennifer Brea and Julie Rehmeyer are role models for me as well. It is quite impressive what we can achieve not despite but because of our chronic illnesses. But I know from my own experience that it is not easy to be a journalist/writer/filmmaker with a complex chronic condition and invisible disability. What are the biggest challenges for you?

O'Rourke: For all of us, self-compassion is really hard, and managing the flares and the reality of illness, alongside the desire to live a life and, in my case, work. I'm lucky that in 2022, now, I'm well enough to work a significant amount of the time. When I was at my sickest, I couldn't write. The cognitive problems I was having, the brain fog, was so severe that I lost years of my working life. I was able to do little chunks here and there but was very limited. So I will never take for granted the blessing of being able to work. But I still have flares; I still am sick; I still have a lot of medical appointments and lots of medications. I constantly have to try to manage and maintain my cardiovascular system so that the POTS doesn't get worse. So it's hard and frustrating, too. In the past few months, I had several wonderful opportunities I couldn't commit to because I had to spend a fair amount of time taking care of my body in a way that I think an able-bodied person doesn't have to. My husband doesn't have to spend any time taking care of his body, for example.

Karina Sturm: (Chuckles). Yes, I know exactly what you mean.

O'Rourke: To this day, I think it's hard for him to understand. I spend several hours a day just maintaining my health. I have to do a certain workout. I have to stretch. There is a whole set of things I have to do.

Sturm: I hear you. Preparing for medical appointments, physical therapy and rest in between: basically, half the day is spent managing my illnesses for me.

O'Rourke: Absolutely right. Traveling to doctors who aren't right nearby because you have to find those medical professionals who really know how to treat what we have... One of my doctors is three hours away. It's not like I can just go down the block to any physician.

Sturm: And again, I feel you. For some of my conditions, I have to travel to other countries to see specialists, which means investing a lot of time and money.

O'Rourke: Exactly. I totally get it.

Sturm: I know you do. What advice would you give to other media professionals who may not "get it" (yet)? You know, those professionals who want to write about disability but have no personal connection to the subject?

O'Rourke: Center the voices of those who are disabled.



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Center the voices of chronically ill people. Listen really closely. I think a lot can be done when we pause and listen and think about how we might feel if these were our experiences. Also, think about the small things, like the details we were just talking about: the amount of time that is spent on the phone with insurances or traveling to the doctor or researching the right treatment options, or the challenges when flying with a wheelchair and how airlines treat you. I mean, just all of that. The textures of everyday life are really important to understanding; what it is really like to live with a disability. And do not patronize us.

Sturm: How do you feel about the current representation of people with disabilities in the media? What needs to change, if anything?

O'Rourke: (Laughs). Everything. We need to start by talking differently to children from a very young age about bodies and illnesses and disabilities. I was on a TV show recently, and they were shocked that I talked to my sons about my illness. They were like, "Well, of course, you don't talk to them." And I said, "No, I talk to them about it." I do. I don't give them more information than they can handle at any given time, but they know about my conditions. Chloé Cooper Jones' new book, *Easy Beauty*, is a wonderful memoir about ideas of beauty and bodies that is shaped by her having grown up with a disability. She recounts the ways in which

people assume she needs more help than she does, in some cases, and in others, ignore when she needs support. Most of all, she captures the way that people tend to see everything about her life through the lens of her disability in reductive and damaging ways. So I think we have to get away from this othering that happens and towards a more nuanced and sophisticated discourse that allows for the variety of human experiences.

Sturm: Can you give us some spoilers? What's next for you?

O'Rourke: I'm writing another piece about long COVID and how it might help people who live with other conditions. But I am also starting to think about a new book; I don't really know yet exactly what it is, but I think it's somehow about time.

Sturm: About time? Okay, you need to give me more details. (Laughs).

O'Rourke: It's a book about this period in one's life where one may have kids or one's parents are no longer alive: this moment in life where you start to live in the past along with the present. I'm hoping to write a little bit about Ehlers-Danlos syndrome more specifically, too. ■ **ABILITY**

meganorourke.com



frank MALLATT

Critters 4 Service

Frank Mallat is a multifaceted service dog trainer extraordinaire! “I’ve always had a gift with animals, with my autism, it’s always kind of led me that way.” expressed Frank. Autism wasn’t mentioned to him or even entered his realm of daily thoughts until later on in life. He had quite a unique story and connection with his mother. COVID-19 and the passing of his mother caused Frank to pivot the course of his life, pushing him to focus professionally on service dog training. *ABILITY*’s Chet Cooper connected with Frank and they shared a fascinating conversation.

Chet Cooper: What got you involved in the training of these service dogs?

Frank Mallatt: I started off taking care of my mom. At 35 I got my diagnosis for the autism. Years later my mom came along, she was discovered. We were separated for my whole life until 21 years ago. She’s been with me for 20. She has a 90-second memory, and I within a year realized nobody else wanted to participate with her, basically, and were going to leave her in the care home that she was in at that point. So I went down and got her out of there, and she was with me for the next 20 years until she passed of old age.

Chet: You said a 90-second memory?

Frank: Oh, yeah, I’m sorry, I kind of glazed over that. I can send you the article as well. Yeah, she had a TBI (Traumatic Brain Injury) when I was about a year old and ended up from a four-month coma to years and years later when she was discovered. She had improved to the point of having a 90-second memory. She had no TBI training or anything like that, 30 years of just basically survival.





Frank's mother Mary with service dog Bunny

Chet: Caused by the TBI?

Frank: Yeah, wiley as heck, though. Oh, my God, that lady could run me in circles with the 90 seconds that she had to work with.

Chet: You keep looking at your watch, "I have another 30 seconds!"

(laughter)

Frank: Yeah, sometimes almost on the dot. But as her health—we ate better, more nutritious, that's how it also helped me to learn my journey working with autism, that a lot of it has to do with how you take care of yourself, in the best-case scenarios. In her case, it wasn't a mistake, I was really happy I had done it, but I got her in such excellent health condition that she could dance at a three-band festival and be really pissed off if the band was done.

And that's why she needed a dog, because in between those songs, she wouldn't remember who she came with or anything like that. So I created a whole world around her with the dogs so that the dogs would go to her in between songs. She would be comforted and know that she was—where she was supposed to go, the dog would bring her to me.

Chet: Did you find that she had an immediate connection with the dogs no matter where she was in the 90 seconds?

Frank: Yeah. I think like me, she had an animal connec-

tion, because the more animals I surrounded her with, the more she would stay with that environment. The calmer she was in the long run. I started off with just one dog to keep an eye on her. The dog would even walk her across the street. It looked like she had a leash on the dog, but the dog was actually leashed to her, she was leashed to the dog. That was just a behind-the-scenes type thing. That's why I'm now making service dogs for children with autism. I know that I can make an ethical—the type of dog that when you do have to tether a child to the dog, they don't get hurt, that's the kind of dogs I can produce. Gentle, loving, they will be very caring. But those are very rare, few and far between, luckily.

Chet: How do you choose the type of dog?

Frank: I waited two and a half years for my male dog, I guess it would technically be the stud. I went with poodles because I did my research on dogs. I've always worked with dogs out of the dog pound, rescue dogs. They were more in my financial realm, I guess would be the proper way to say it.

(laughter)

I did my research. I decided to make my mom a service dog, and I did a lot of research, and poodles came up as the most Swiss army knife-type dog. They could do anything. They have done anything. And the final caper for me was when I found all the—what little information there was way, way back in the circus days, when circuses were the biggest entertainment you could find, and the poodles were one of the best-taught shows you could see at the circus.

Chet: Yeah, now that you're saying that, I think I do remember poodles doing tricks in a circus environment.

Frank: Yeah. They think outside the box, and that's what I created with them, working with the poodles. I'm not only going to stay with poodles, but my gene pool at this point is all poodle. (laughs)

Chet: You're breeding them as well, then?

Frank: I've allowed three litters to be made very carefully. I'm very careful about that. I don't get them fixed until they're at least two years old, either. They're perfectly well behaved. COVID forced us to keep them as a pack, if I could jump the rail here a little bit.

Chet: Mm-hmm.

Frank: The only reason I started working with so many dogs at once was because of COVID. Originally, I was just going to copy any other dog-making company and do it exactly like they were doing it, especially once Mom passed. I figured the easiest way would be to copy somebody else.



Chet: You were going to model after others and it wasn't working for you.

Frank: I was just going to copy other service dog company, where they do one dog at a time, farming them out to different families to train them and such. From COVID, I was forced to keep the first litter, which has turned into my therapy pack, which also trains the dogs underneath them. My personal dog that I waited two and a half years for, I've got video of him teaching the first litter the fenceless boundaries of our yard while keeping the puppies inside the yard the entire time. I barely had enough time to run and grab my camera to get a video of him making the last turn of the yard with the puppies.

Chet: That's wonderful!

Frank: And that's the litter of puppies that turned into my therapy dogs. They are these rocks that teach all the other dogs. It's a whole new way of training service dogs as well as allowing a person who has a disability to—who might be on a higher spectrum or whatever you want to call it, to be able to make service dogs and give back to people as opposed to back in the day when I worked 9 to 5 cooking or waiting tables, pretty laborious work.

Chet: You were able to create a model with the dogs that you have now that they might be able to train the trainer.

Frank: Exactly. To a certain point, yeah, that's the way it kind of works. And the other thing about pack-training

the dogs—if they're going to an autistic person, they have most of the tasks they would need to get to be a legal service dog. They are at the two-year age, so they can go out and learn other tasks, including scent training, specific stuff, life-saving techniques and such. That's where they would be at. The amazing part of it is one guy—although it needs to be more people, but one autistic person is able to make this many service dogs. This year the dogs that are turning two will be—I think we have six, so we're looking for six homes at this point.

Chet: Is there a specific type of person you're looking for to get the dog? You mentioned that you want to have a high-level spectrum, but the autism spectrum is so diverse, do you try to work with the whole spectrum?

Frank: I try to work with the whole spectrum, because dogs are so—I liken them to people. I mean, I understand them better than people, to be honest. They have so many personalities, so many different things that drive them, that I try to introduce the dogs to their clients as a pack, and I let the dog—I watch and I let the dog pick out the client. Does that make sense?

Chet: Nice.

Frank: Okay. That's something I've only been able to do twice, and I'm starting to see the flaw in it as we grow, like having too many dogs in the pack.

(laughter)



Frank and his mother

Frank: The flaw is that as we grow, we won't have that group gathering as much as before, and at some point we will have to pre-pick the dog for the person. I'm not looking forward to that, but as we grow, I know it's part of the transition. What I am doing, though, is, I'm talking to a person out of Florida and another person out of the Mississippi area who is also autistic and loves animals and understands animals more than people, but they're stuck in dead-in jobs, like Jack in the Box or something like that, which is a high goal for their parents to at least have them stabilized and be able to take care of themselves, but if I can take what we're doing here and give them an opportunity to start it there, we could really make a huge difference on the service dog industry.

Chet: I always liked that idea of multiplying the efforts and then allowing people—as you know, there's more than the service dog. There's the entrepreneurial nature of any business. That becomes a bit of a challenge, but if you can also help them with figuring out how to make it sustainable for them to pay the bills and pay themselves for the work they're doing, that's a great model.

Frank: Yeah, that's what I'm looking forward to, bringing in people who can put that together. My gift is speaking to animals, and I know that. It would take a lot away from me. That's why we're still fundraising the way we are, until we get grant writers. Although we do have some help coming. I'm very excited about that. We have a graduating student from Humboldt, that's now Humboldt Cal Poly, or Cal Poly Humboldt, I don't

know how they word it yet.

Chet: There are only two Cal Polys. You're saying there will be a third now?

Frank: Humboldt State University is now a Cal Poly.

Chet: I went to Cal Poly Pomona.

Frank: When it was Humboldt State, I went there to a veterans' Upward Bound program, and that's where I got labeled, whatever you call it, tested for my autism, which was kind of late.

Chet: Did you happen to hear anything about a princess from the UAE?

Frank: Not to my knowledge.

Chet: Sheikha Jameela bint Mohammed Al Qasimi from UAE went to Humboldt. I think she had many university choices, and she chose Humboldt. I know it's a beautiful area up there, maybe that was part of it.

Frank: Yeah. I lived next to the campus, and there was not a lot, but there were a few really noticeable well-to-do students. They were driving fancier cars than I've ever had.

(laughter)

Frank: I got a used one that was in the same realm, and I

was like, “Oh, my gosh, I can’t believe that!” One year out of high school driving a limited edition BMW.

Chet: I don’t think that was her. She played down any wealth. She’s a very down-to-earth person. She works around disability issues. She created a center that helps children with disabilities, SCHS (Sharjah City for Humanitarian Services). That’s how we met her, at a conference in San Diego called CSUN, I don’t know if you’ve heard of it, an assistive technology conference at Cal State out of Northridge?

Frank: No. I’ve pretty much lived in a shell with my mom for the past 20 years. I took us off mainstream television and such—I keep saying “such” (laughs)—mainstream television and things for, like, the first year I had Mom. Back then, she would parrot commercials. So if she heard a commercial enough times, she would just—she’d be able to parrot it right back to you.

(laughter)

Frank: Which is amusing, but it got real annoying quickly, so I just turned it into—back then you could get Netflix and there was just you and Netflix and nothing else. The hardest thing was to keep the movies going for her.

Chet: Are you the only child?

Frank: No, there’s another sister and another family member was discovered. She had an illicit child in high school age, then my sister and myself. I was the only one who wanted to pretty much having anything other than to know that she was alive. It was that important to me. It was like a light bulb came on. I have a weird connection with the other side. One time when I was all messed up on life and too young to figure out that there was much of a future going on, I was having a tantrum with myself, and just out of the blue, I said, “I just want my mother!” and I heard, “We could do that,” it appeared in my brain and I heard a bell and a ding and a tickle in my chest where I get the connection nowadays, when there is a connection. I knew immediately that there was something going on, but I didn’t know what. The frame of mind I was in, I was like, “Okay.” I never hallucinated, so I didn’t think it was anything like that.

Now here we are 40 years later and I’ve pretty much got it down. It was a really big, obvious, “Hey, here you go!”

Chet: It was a win for the both of you.

Frank: Yeah, it definitely was. We both blossomed from the time that she was with me. I like to say we nailed the landing. She was tenacious. She got me to be a good guy.

Chet: That’s really good. The overflow of what you’re

doing now with the service dogs, hopefully will continue to spread helping others have a better quality of life.

Frank: My goal is to get me replaced by other people like me who are younger and I don’t want to say money-hungry, hopefully not, because I’m not. That’s one of my biggest problems, that I don’t like money. I’d rather barter my way through life than worry about cash.

(laughter)

But that’s not a functional thing! (laughs) And that’s where we’re at with this, trying to figure out funding and such. I don’t like money, but we definitely need money.

Chet: Einstein said, “Barter is smarter.”

Frank: I didn’t know that.

Chet: And I add to that, “But it’s harder.”

Frank: Yeah, it is, and you’ve got to be creative! (laughs)

Chet: Well, that’s the fun part, being creative around it. But not everyone can figure out creativity and be sustainable with just barter, even though that’s the way society originated. Currency was something we had to come up with because barter was difficult for a lot of people.

Frank: And hard to keep control of—to process, excuse me.

Chet: I’ve seen a lot of your videos. Did you have a little icon, an avatar, that looks like a Bigfoot?

Frank: Yeah. I grabbed it and I recreated it a couple times over, yeah. That was my old computer business. That was a Bigfoot guy working on a computer.

I was trying to come up with a video company back then, and that was one of the things I was using. And there’s another one that’s one sitting in front of a computer, and then I modified it to a laptop, and the newest one I was playing with is a Bigfoot that I believe is hanging on a drone.

(laughter)

I pretty much let all those websites go. Now I’m down to just Critters4Service and Frank Mallatt.

Chet: Are you shooting video with drones, too?

Frank: Yes, yes! I’ve been shooting some of the video—I’m good at content, but I haven’t been real good at editing. I’ve got a few really, really good shots that I haven’t edited out yet, like four-camera-angle shots with



the dogs bursting out of the car, doing what they're supposed to do for me, and then coming back, showing the dogs coming out of the door in control, like, they'll come out for me one at a time and sit down around me, waiting for the next dog to come out, until I give them a release command. Just a lot of different video stuff. Them interacting with animals. YouTube has some on there. Facebook has a whole bunch.

The one I think you saw was Bigfoot Data. It was a confusing time for me. It was right after I closed the computer business. I was just started to play with drones. If you were in the YouTube stuff, you might have seen the videos of the—I was doing videos for the nonprofit food bank.

That was my first beginning with drones. Now I have a couple of 6k drones, and we've got some really, really good shots.

Chet: Those 6ks are high enough def that you can take an image and it's still high-quality.

Frank: Yeah. At 6k I can take a single slice off of the reel and it's perfect.

Chet: That's really cool. I've never flown one.

Frank: Luckily, they almost fly themselves.

Chet: That's kind of what I'm picking up. That's why Amazon and others might be using them for delivery,

because they could just program in the coordinates.

Frank: Yeah. The ones I'm using, I could use the same exact software that's one them and preprogram them like, if you're doing an agricultural field and want to inspect it, I could fly pre-patterns, specific stuff. It's very universal. Mine was a competitor, an actual competitor for DJI. Originally the company that built them, they make the car recognition stuff, like when a car gets close to another one and the lights come on and tell you that you have another car close to you. That kind of technology. My drone has top, bottom, front, left right sensors, so if I'm flying at something, it'll literally not let me run into something.

I felt I kind of rambled on there, for the most part.

Chet: Not at all, I think it's a nice touch with your mother and how you got involved in service dogs.

Frank: Yeah, I'm really excited about it growing and moving forward. I'm not—the reality of where we are financially is scary as you know, but the bigger picture, knowing that I'm still in that leap of faith, and if nothing else, I keep getting little tickles from the other side, that little tingle I told you about in the chest. Every once in a while I'll get a little cheater tingle to let me know that we're not (laughs)—into imminent demise. I think we're fine. I'm sure I'll probably think of a hundred things I didn't say. ■ ABILITY

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Brenna Huckaby

Three-time gold-winning Paralympian Brenna Huckaby went from surviving bone cancer to becoming a world class snowboarder. Huckaby, classified as SB-LL1 snowboarder, found her category phased out from the 2022 Winter Paralympics and took action. In January, she won a court ruling against the International Paralympic Committee, allowing her to compete in SB-LL2 events where she took home gold in banked-slalom and bronze in snowboard cross. Huckaby met with ABILITY's George Kaplan and gave glimpse into the mind and motivation of a champion Paralympian. Huckaby also shared the secret to her success.

George Kaplan: Just over 10 years ago you overcame something I have personal experience with myself, which is osteosarcoma, an aggressive form of bone cancer. Can you tell me more about your experience with it?

Brenna Huckaby: Of course. I competed in gymnastics for the majority of my life. I had goals of becoming a college gymnast. When I was 13, I started to have knee pain. It was interesting because it only hurt some of the time. I went to the doctor, and they did an x-ray, but they didn't find anything wrong. The doctor said, "Do physical therapy, and we'll go from there." But we didn't have the funds for physical therapy, so I continued what I was doing and made an extra point to condition my muscles a little bit more around my knee.

About a year later, when I was 14, the knee pain never went away. It continued to cycle. It would happen sometimes and not happen other times. One of the times that the knee pain came back up, it was so intense that I was in tears. I went to my mom and I was like, "Mom, my knee hurts." She said, "OK, we can't do this

anymore. We need to get to the bottom of what is going on. We're going to go back to the doctor."

Kaplan: Did it swell up, by the way?

Huckaby: It didn't swell up that much. Honestly, the only way that we knew there was swelling was when we were told to look for it. It was very small swelling and slight discolored red, and then it was warm to the touch. But again, you wouldn't think to look for those until you know to look for them. At this doctor's appointment, they found a tumor on the x-ray. When you go back to compare the two x-rays from when I was 13 and 14, the x-ray when I was 13, the tumor was so, so small that you couldn't see it without knowing what you were looking for. But, honestly, had we even caught it then, the outcome probably would have been the same anyway.

So, when I was 14, we found the tumor. Two or so weeks later, I had the diagnosis of osteosarcoma, bone cancer. And about two months later I had an amputation.

Kaplan: Wow, that's a lot to go through at that age, I imagine.

Huckaby: Yeah, absolutely. I had just started high school. It wasn't how I expected my freshman year to go. But again, I'm super-fortunate because of how long I had my cancer without knowing it, I should not be alive.

Kaplan: I'm not an athlete, but I had a very similar experience. What kind of advice do you have for someone who is going through a similar kind of cancer experience?



Huckaby winning at the 2022 Paralympics

Huckaby: Something that got me through is, just because your life looks different than it did before, doesn't mean it can't still be great. That's something I struggled with a little while as I was adapting to my new life because while I was going through chemotherapy, I remember thinking about my friends, my future, my sports, my goals, everything that I cared about. That's what held me together during my cancer journey. But when I finished chemotherapy, it hit me that that life didn't exist anymore. Everything I once knew was gone and so different.

I had to grieve the loss of that life that I knew and then rebuild and reinvent myself into this new life. It was really scary. I was like, "I don't know if my life can still be as great and as awesome as it was before." But it can, and in a lot of ways it could be better, too.

Kaplan: You said two months into treatment, you became an amputee, and you had to readapt to life. What was that experience having to readapt to something so different?

Huckaby: It definitely took some time. Like I said, I went through a grieving process, a depression period where I didn't have the motivation to live because the life I wanted just didn't exist. I had to have a massive heart-to-heart, intervention, whatever you want to call it, with my family. They sat me down and they were like, "Brenna, every time you lie on this couch, cancer is winning. The more that you're not getting up and living your new life, cancer will continue to hold you back. It's time to beat cancer once and for all and move forward

through it." We knew that gymnastics was my outlet before. So, we were like, "Let's find your new gymnastics, your new sport." I tried gymnastics again, but it didn't give me the light that I had before. That started a whole process of finding a sport or an outlet like gymnastics, just as an amputee. That's how I landed on snowboarding.

Kaplan: What was the motivation that got you into snowboarding?

Huckaby: I was treated at MD Anderson Cancer Center. They used to do a thing called—

Kaplan: I love them, by the way. They're so great!

Huckaby: Oh, I love MD Anderson. I will fly there. If I ever have any problems, I will be flying to Texas to get taken care of over there. Gosh, I can't remember the name of the program, but they used to do a rehabilitation ski trip. On this trip, most people skied, I think I was probably the first who snowboarded. The doctor who organized it, his belief was that if we can get kids who lost mobility through cancer up skiing, then they can see a world of possibilities that they could do with their lives, whether that's getting up and making themselves a sandwich or becoming a CEO of a company. It'll give them that confidence to go out and live the life they used to live with full mobility.

I chose to snowboard on that trip because it reminded me of a balance beam. I wanted any piece of my old life back. I just wanted a taste of it again. And I learned to

snowboard and fell in love with it and moved to the mountains. (laughs)

Kaplan: That's a huge change, from Baton Rouge to over there?

Huckaby: Yeah, massive change. But definitely better for me, I think, in more ways than just snowboarding. Just a better climate as an amputee as well. I don't sweat as much, that's the main thing. And there are a lot of opportunities to be mobile out here.

Kaplan: I'm from Miami, and I get the climate thing. It's the worst to be an amputee in a hot climate.

Huckaby: You had osteo?

Kaplan: I had osteo, yes.

Huckaby: Are you an AK (above the knee) or a BK (below the knee)?

Kaplan: I'm an AK.

Huckaby: OK, so you know the struggles!

Kaplan: Yes, it is rough out there! I understand the sweating problem and all that. It is not cute.

Huckaby: You get it! No, it's not cute. I prefer the less humid environments for that reason. Utah, that's where I live now, it's way better for me.

Kaplan: What drew you to competition?

Huckaby: Honestly, when I started snowboarding, it wasn't in the Paralympics yet. They were in the process of making it into the Paralympics. I wasn't fully motivated by competition when I first began. Obviously, there was a piece of me that would love to do it, but that wasn't my main focus. My main focus was having an outlet and a place to go. It wasn't until I started with a snowboarding team, just to get better and develop my skills and know how to ride a snowboard so I could have more access to the mountains. They invited me to go to a competition and do snowboard cross. And I got on a snowboard cross course and I had so much fun. I was like, "Whoa! I want to do this!" Because I felt that competition spirit that I hadn't noticed or felt since gymnastics, and I was like, "I need more of that!"

That competition was just me and another teammate, it wasn't a big thing at all. It was super-local. After that one I went to nationals, where a lot of the athletes who were there had just come back from Sochi. I started snowboarding and then shortly after, snowboarding became a Paralympic sport for Sochi. That season that Sochi happened was the season I started competing. I just missed competing in Sochi by a couple months. I went to nationals with all of these athletes who had just

gotten back from the Paralympics, and I placed third. And I was like, "Oh, my gosh, I could actually be good at this if I keep training to compete."

I think the possibility of being a top athlete is what drew me to competing in the Paralympics. I was like, "I don't suck, and I haven't been doing this for very long, so I'm excited to see where I can go!"

Kaplan: (laughs) I love that takeaway: "I don't suck!"

Huckaby: (laughs) I mean, I did suck, but I sucked less than other people, and that was exciting!

Kaplan: Is there someone in your ear who says, "OK, we have a potential Paralympian on our hands"? Or is that your inner voice speaking?

Huckaby: Both. Once I got into competing and I felt that drive again, I was like, "I know I can do this. I know I could be good at this." And at that national event, the US team coach invited me to a World Cup that next season. The coaches had seen my potential in the sport as well and were encouraging me. I was 17 at the time. I was just about to turn 18. My mom was nervous about me going out of the country. Obviously, I went and it was awesome. I continued to show up. (laughs)

Kaplan: Can you tell me more about that first time? Obviously, you aced it, you got gold in both categories. What was that like for your first Paralympics?

Huckaby: Oh, my goodness! Honestly, it was the most stressful thing I've ever done. It was because I made it stressful, I put so much pressure on myself to win those gold medals that I wasn't really able to enjoy it. I'm still so proud of myself in everything I've done and how far I've come, but I'm more proud of myself, I think, for my most recent medals because I didn't wrap up my worth in them. Whereas in 2018, I told myself, "In order to be worthy and deserving, you have to win. Gold medals dictate who you are." I felt super-empty and depressed after winning my two gold medals at the first Games, and I was like, "I don't ever want to feel this way again." I did a lot of therapy and personal development and spiritual practices to love myself. My wins this time, I didn't wrap my worth up in them. I was able to enjoy and be present and have a good experience, whereas before, I only cared about the outcome. Yeah. (laughs)

Kaplan: That's good! You talk a lot about manifesting your goals. You set your goals pretty high. What are some keys to manifesting those goals?

Huckaby: Both games, something I do is to visualize. When I'm training, if I'm in the gym on the bike or wherever, I'm like, "I can do this easily." I focus on myself winning the race before I get there. For Korea, I

saw the venue before we raced it because we did a test of it. We were there a year before.

Kaplan: Oh, that's cool.

Huckaby: Yeah, it was awesome. And that's typical. For a whole year after that test of it, I visualized myself going down that course, I visualized the medal ceremony. I knew where everything was going to be, and I was there. I had already done it in my head. And I would feel it, connect with it. And I did the same thing for China, but China was a little different because I had never been there, never seen the course, had no idea what to expect. So, when I did visualize, it was more like what I wanted to feel in that moment. I wanted to feel proud of myself, I wanted to feel at peace and excited and joyful and connected. I sat down with those feelings rather than actually seeing what it would look like. That is huge for me because it calms my nerves once I'm there and it makes the steps that need to happen in order to get there—it just kind of makes everything align. I'm trying to think of anything else I do. Oh, I connect with my "Why?" for motivation. You hear a lot of people talk about that. My "Why?" when I started was to show people that just because your life was different doesn't mean it can't be great. After I had my first daughter, my "Why?" kind of shifted into showing my daughter that exact thing. "Life gets hard. Things get challenging. But it doesn't mean it's not out of reach." Those are things I connect to to stay—I don't know, moving, moving forward, not ever getting stressed out. I mean, sometimes you get stressed out, but for the most part, it keeps me level.

Kaplan: You're no stranger to the Paralympics, having won gold at both SBLL-1 [single above knee amputation, including through the knee] class events. How did it feel to find that category removed this year's event?

Huckaby: I was upset. However, I understand that there were not enough women to make a viable Games for my class. When I had first learned in 2019 that my class wouldn't be in the Games, that's when I was told I could compete up with the other women. I knew that I would compete at a disadvantage, but I've never compared myself—I never mentally put myself at a disadvantage, if that make sense. When I'm training, I'm always trying to be better, trying to find my limits. It doesn't matter who I'm competing against because the mission's the same: to see how fast you can get, how far you can get, how strong you can get.

When I found out in 2019 that I would compete up in LL-2, nothing changed. I was just happy to have the opportunity to compete, even though it was at a disadvantage. But in 2021, when the official written-out guidelines came out for Beijing, I was completely left out. There was no way for me to be eligible to compete. There was no spot, no language, anything written for my class. That was stressful. It was disheartening. It

was—I don't know, it felt like I was being excluded because of how well my performance had been. I can't tell you exactly why this happened. But I just know that it hurt, and I wasn't going to stand for it because there wasn't—it didn't make sense as to why it was happening. Which is why I fought back.

At first, I contacted the U.S. OPC [Olympic & Paralympic Committee] and we went through all the appropriate channels within the IPC [International Paralympic Committee] to make a change to what was happening, and they held firm on their belief that I was not allowed to compete. That left me with no choice other than to fight it in court, hire a lawyer, which is what I ultimately did, and that's how I won my spot into Beijing. Otherwise, I wouldn't be competing.

Kaplan: How did it feel to win that case?

Huckaby: Oh! I'll be honest. I didn't think I would have. I wasn't going to back down regardless. I was going to fight it to the end. But everything I was hearing from the IPC flowing down was not positive for me competing. I remember, it was our world championships when I got the call that I had won my case. I started screaming and crying, and I'm not an emotional person at all. It just broke me. Happiness, relief, excitement. That was the right call all along. It felt really good to be heard and validated in my fight. I think those were the two things I had been missing the entire time, validation that I shouldn't be excluded on the basis of my disability, and also, I am heard and changes will be made because of that. That was an amazing, incredible feeling.

Kaplan: What does it feel like to be part of a landmark case like that?

Huckaby: It really hasn't fully sunk in because there are still other changes that need to be made to solidify what happened in the court. I'm working behind the scenes to make sure those things happen. But they haven't fully been solidified yet. Once rules are in place so that this doesn't happen to someone else, then I'll be able to fully celebrate what we did in court. But until then, I'm just processing and trying to make lasting change with what happen.

Kaplan: Was there any kind of tension at the event that led from that?

Huckaby: I think it was hard for me. I didn't talk to anyone from the IPC. A lot of the nations and athletes and coaches from other sports had come up to me and congratulated me on my fight. They were so excited that I was there. That was really cool and special because they were from snowboarding, they were from other sports, which was really cool. I think for me, going around the village and seeing all these signs about how inclusive the Paralympics are and how diverse and how they lis-

ten to the athletes, seeing all this signage but knowing what I had just gone through to get to the Games, it felt so hypocritical, and it still kind of does. I had to process that a lot while I was there and work through that. I would say directly, no, there wasn't any bad blood or anything.

Kaplan: That's good. So, despite competing in the category where other athletes are expected to "outclass" you per se, for lack of a better term, you came out on top in Banked Slalom. What was going through your mind on that second run?

Huckaby: I compete against the same women all year. Banked Slalom is unique because it's straight time. It's all raw time. I'm always competing against LL-2 women [lower levels of impairment such as above-the-ankle amputations]. I also compare my times against the men, and I'm competing against them in my head. I'm always competing with these other groups because it challenges me as an athlete. The Chinese women we hadn't really seen the last four years. They were never at any World Cups. So, it was a big surprise when they were extremely fast because none of us had ever seen them before.

After my first run, when I saw that I was only .08 off of first place, I was able to relax a little bit because I was like, "Oh, my gosh, I can actually do this!" And when I say "Do this," I just meant podium. I wasn't expecting to win, to be completely honest.

So, I was like, "OK, I can get on the podium." I was standing at the top and there was a lot going on that day outside of just sport. I was in not the best mindset. I thought, "I really need to just work on getting into the flow, getting to myself and just snowboarding." I asked one of my coaches at the top, I said, "Look, I just want to know where Cecile and Lisa—" who are two women I constantly compete against— "where they are, if I'm going to beat them or not." Those were my girls. We are so competitive together, in a good way, and I'm like, "If I beat them, I'm matching up where I want to match up." I had found out that I did. So, I was like, "OK, I did what I can control. These are women I constantly compete against. If these Chinese women weren't here, I would be winning." And that's not to say that they shouldn't be there. It was just a unique situation we've never experienced before.

So, I'm like, "OK, I'm just going to let it all go. I'm just going to go. I'm just going to see what happens. If I blow out of the course, I blow out of the course. I don't even care at this point. I just want to see how fast I can go." Obviously, I didn't blow out of the course. I almost did a couple times. But when I crossed the finish time all I wanted to know was, did I do enough to make the podium? Because I was sitting at fourth or fifth at the time. It was really funny because they were like, "Yeah, you're winning!" And I was like, "What? There's no



way!" (laughs) It was wild.

Kaplan: That quote at the end, iconic! (laughs) "Am I on the podium?" You clinched it within the very end of it, and then you got a tenth of a second?

Huckaby: Yeah, it's insane. Mid-course, I'm almost half a second off of first place, which is a lot. That is so much time. And to make that up in the bottom course is unreal. Honestly, that's the most proud of myself, the biggest part that I'm proud of myself for. That's really hard to do. And somehow, I did it. I still don't know how I did it. I made up half a second in such a short amount of course. But yeah, it was really cool. (laughs)

Kaplan: It is pretty cool. What do you feel is the secret to your success?

Huckaby: I used to try to prove to myself that I was just as good of an athlete as able-bodied people. That was always my fight. It wasn't a positive thing. I was always trying to prove to society, to sponsors, to spectators that adaptive athletes are just as good and we can go just as hard. That was my motivation for a very long time, until I realized that it was more harmful to me. I was destroying my body, my mental health.

The reality is, as adaptive athletes, we have to go through a lot more, and there are limits compared to able-bodied athletes that we do have to overcome. We do have to take care of our bodies for long-term life. I would say now, my success comes from rest, from understanding that my body needs time to recover, to heal. And also, I'm already worthy and deserving and the people who need to see that do, and I can't change anyone else's mind. That's not my responsibility.



Huckaby wins Gold at the 2022 Paralympics

Once I realized that it's not my responsibility to change how people see people with disabilities, my responsibility is to live my life to the fullest and enjoy life and protect my physical and mental health in the process. I think that's when I was able to make leaps and bounds in my training and in my progression of sport, which is crazy. (laughs) You would think it would be the opposite, but rest and recovery has been the secret to my success these last four years.

Kaplan: That's very good for people to hear. A lot of times disabled people do push themselves to prove themselves. Other than that, what kind of barriers do you feel you face or other disabled athletes face on and off the snow?

Huckaby: I still think—there's still change that needs to be made for inclusivity and representation and diversity, whether that's in the media, in the Paralympics, there's still room to grow. I think the hardest part is having a voice because I think that we get passed up a lot, and able-bodied people or people at the top are trying to do what they think is best, rather than listening to the affected communities and what we are saying needs to change. I think that's the hardest part, still feeling voiceless and powerless in the conversation. But I will say, in the last eight years since I've been around, I've seen a lot of growth, and I think as long as we keep speaking out, keep demanding change, keep holding corporations accountable, we will continue to see that change. That's what we've got to do!

Kaplan: I like that. So, you're a role model not just to disabled athletes everywhere, but to two daughters as well. How do you take that on? Is there anyone else you look up to?

Huckaby: It used to be really hard for me. I never asked to be a role model. This was never my goal or my purpose. But now, it's a role that I take seriously and I take huge responsibility for. A lot of the time, most of the time, it's a lot easier to go for something you want to go for if you see somebody else doing it. I want to be that person doing it, but also that person who will reach out a hand and help somebody else get to where I am. It's a role that I take very seriously. And I'm hoping that in that process I can show my daughters how to become that as well, how to become a woman who empowers other women and is lending a hand and building other people up. That's what's important in this world. What was the second part of that question? (laughs)

Kaplan: Is there anyone you look up to or have looked up to?

Huckaby: I try not to idolize people. I feel like I used to do that and I got horribly let down. But there is one woman who I still do, even though she has passed. Bibian Mentel-Spee was one of the legends in Paralympic snowboarding, definitely someone I have looked up to a very, very long time. I hope to be half the woman she was. She was a woman who reached out a hand, always. Always encouraging, empowering other women in the sport, empowering other women to be good humans. I hope that I can continue that legacy.

Kaplan: If you're not there yet, you're well on your way.

Huckaby: (laughs) Thank you! ■ ABILITY

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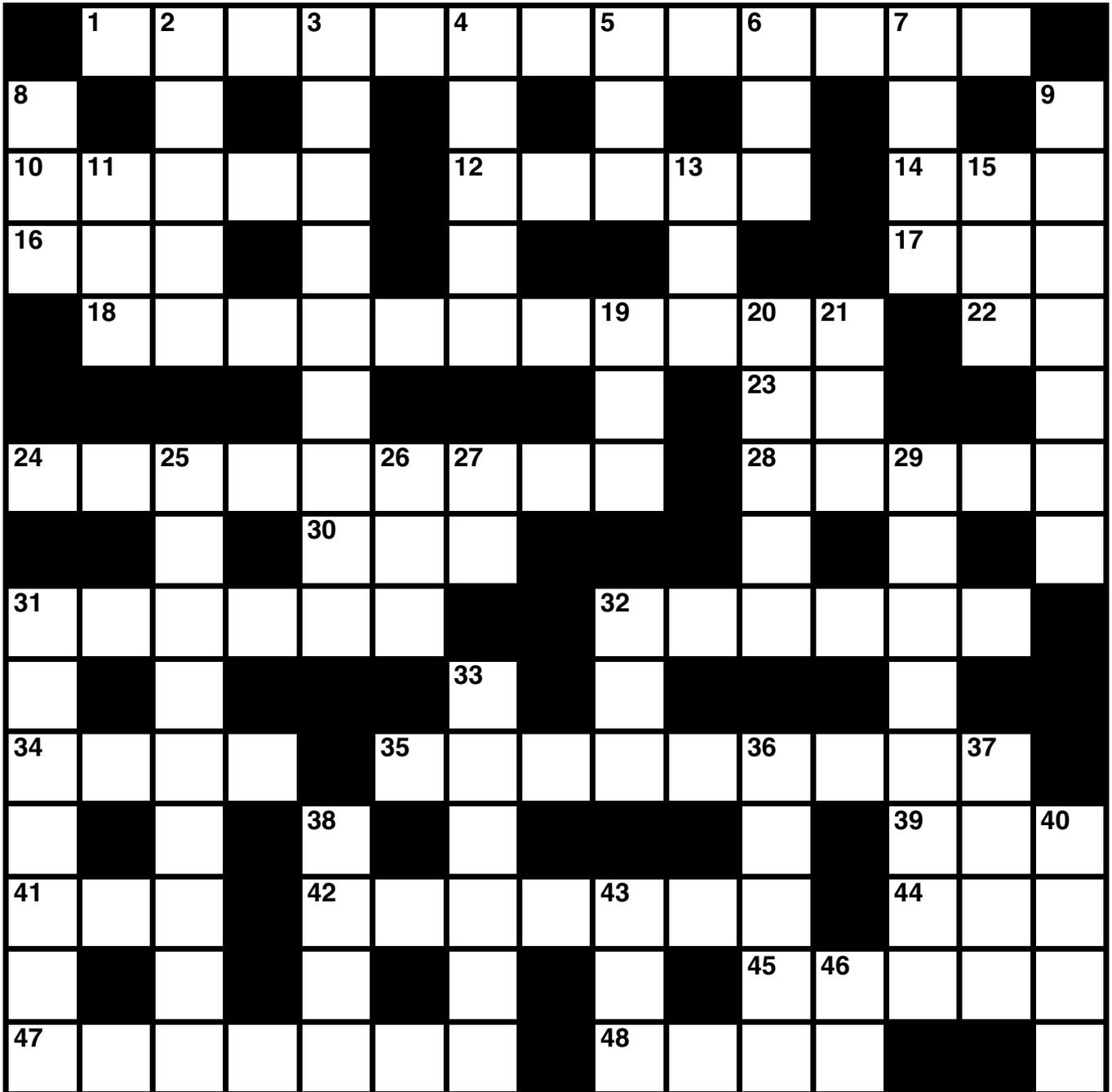
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ABILITY'S



Crossword Puzzle

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A C R O S S

1. "The Walking Dead" star who is an educator and sarcoidosis advocate, 2 words
10. Dakota and Lakota: native American peoples
12. Advocate and policy advocate for people with developmental disabilities, Hannah _____
14. "The greatness of a ___ is not in how much wealth he acquires, but in his integrity and his ability to affect those around him positively" Bob Marley
16. Immigrant's subject, abbr.
17. Get by
18. Producer of the podcast "Proud Stutter"- 2 words
22. Morning show time, abbr.
23. Branch of computer science dealing with programs that solve problems creatively, abbr.
24. Left alone
28. Lustrous fabric
30. Fish-chips connector
31. NZ disability rights activist and founder of the Lucy Foundation Robbie Francis _____
32. Lalia ____: 12 year old who suffered a TBI on her swing who has now launched a clothing line for injured kids
34. Marsh plant
35. "____ Was Here" 2004 film centered on the lives of two disabled men, 2 words
39. Cold draft
41. Panama, for one
42. Actor with cerebral palsy who starred in 2021 film "Triumph" - includes initials
44. "A Beautiful Mind" director, first name
45. Too prying
47. Green Bay team
48. Service dogs, e.g.

D O W N

1. African virus
3. She's a mastectomy bra designer from China, 2 words
4. Doggie
5. Fall back, as a tide
6. ___-do person
7. UK based charity on a mission to bring music to everyone
8. Wear and tear
9. Spring wild flower
11. Philosophy suffix
13. Noah's boat for couples
15. Otherwise called, briefly
19. Bachelor's digs
20. "Midnight at the ____" Maria Maldaur song
21. Going through, in route directions
25. Genuine and real
26. Possible lunch hour
27. Bismarck's state, abbr.
29. Time Long Haul Paul has been campaigning on his motorcycle for solutions to MS, 2 words
31. Adore
32. Coy
33. Watson's partner in crime
36. "___ of a Woman" (Pacino film)
37. Soothing succulent
38. "I am no bird: and no net ensnares me. I am a ___ human being with an independent will." Charlotte Bronte
40. Celtic singer in "The Lord of the Rings"
43. Crest of a hill
46. Operating system, abbr.

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 - Cure for Keratoconus

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18-45

- Thin Flap Lasik
- ICL

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45-65

- Superlasik
- Pi in Eye

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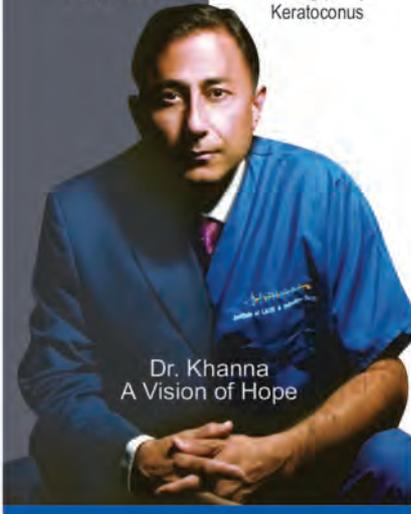
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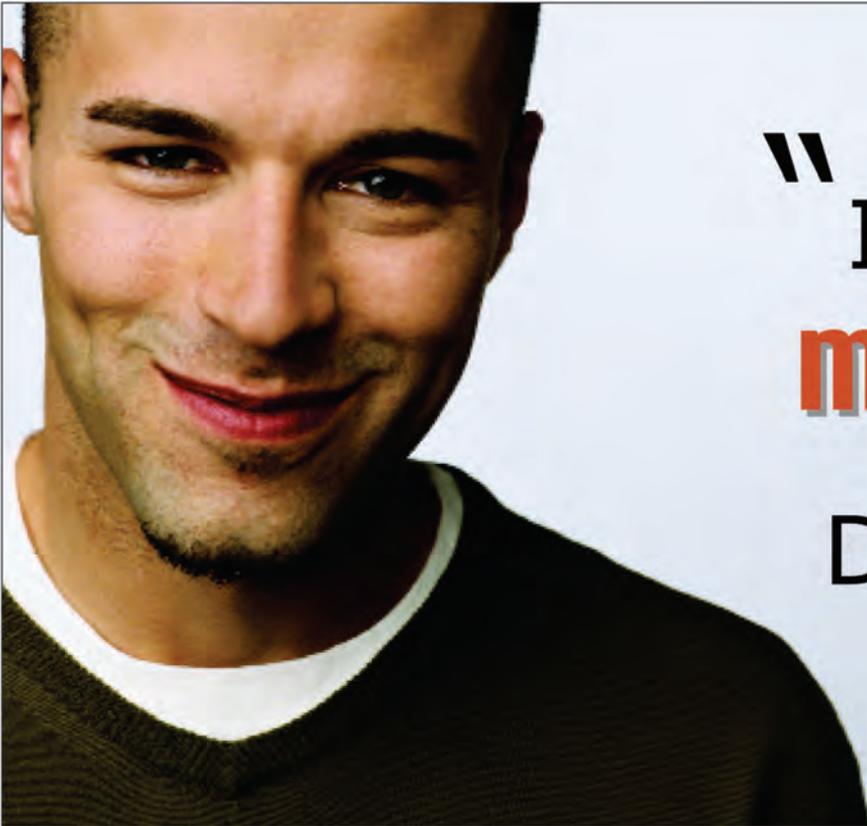
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