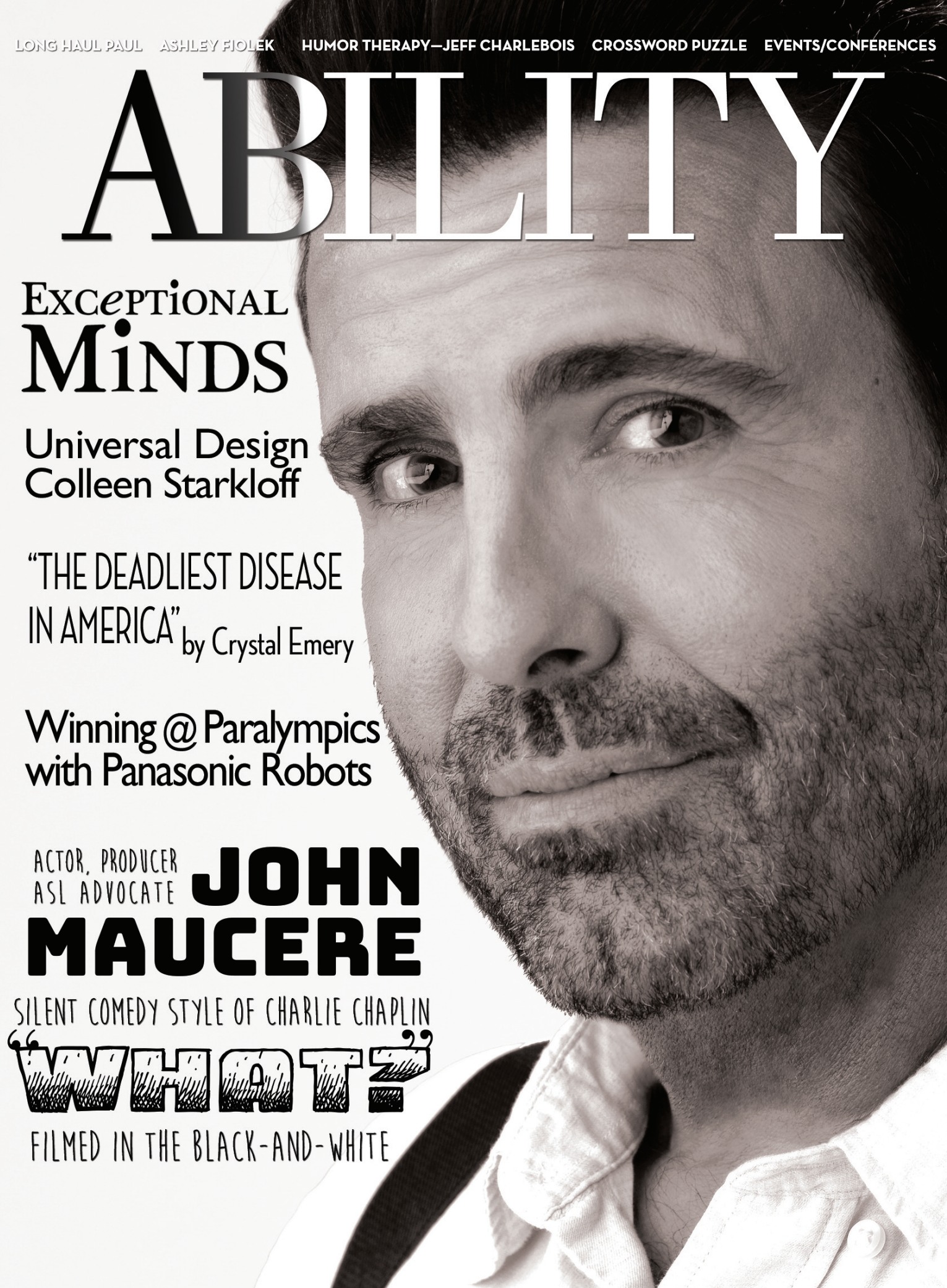
LONG HAUL PAUL ASHLEY FIOLEK HUMOR THERAPY—JEFF CHARLEBOIS CROSSWORD PUZZLE EVENTS/CONFERENCES

# ABILITY



## Exceptional Minds

## Universal Design
## Colleen Starkloff

## "THE DEADLIEST DISEASE IN AMERICA" by Crystal Emery

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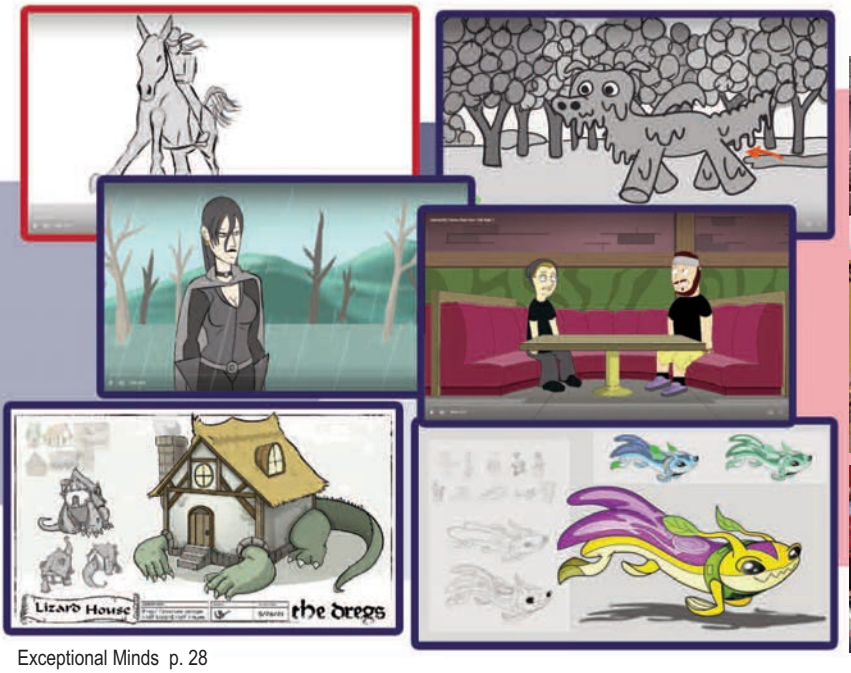
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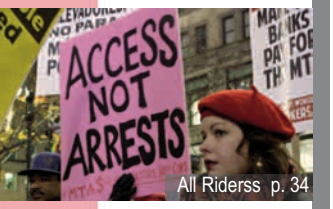
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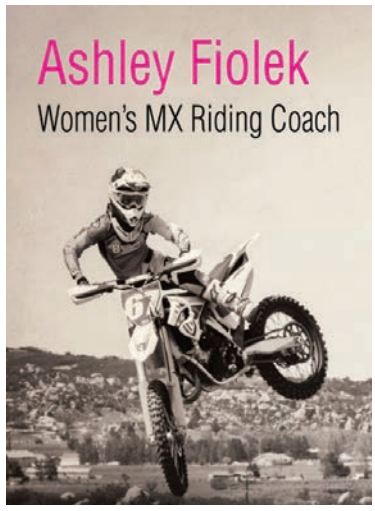

Things are crazy in Utah! A lot has been going on, I have done a couple of classes, went on a few weekend adventures and moved into a house! I will try and fill ya in....

I had a couple of classes in Colorado and also in Ogden Utah. In Utah the class was crazy hot but all of the riders handled it really well and had a great time. I also did a couple of private classes with two little girls which was super fun. The Colorado class was awesome because it was a ladies ride day on Saturday then we went to a different track on Sunday and did an MX school. It was a huge group and there was 20 students! We worked on body position, some braking drills, we rode in circles to practice these techniques and everyone did great. I had fun and I'm pretty sure all of the girls did too. I always throw in some games at the end involving balancing everyone seems to enjoy these or maybe its because its the end of class and they are tired ha ha...




We did some camping at MOAB too while traveling to the different tracks. It was beautiful and we had a good time hiking. My dog, Bambi, is loving life! She loves to travel and being outside is one of her favorite things. Trying to keep her out of the water is always hard to do, she loves to swim more than hiking. Recently, we drove up to Michigan for our friends wedding. It was also my great grandmas memorial service (It's ok she was almost 103!) my parents drove up form Florida and we came from Utah. We all only had a short time so we had to make the trip fast. Our drive was 25 hours and my parents had a 15 hour trip. We managed to see each other a few times (We had not seen them since May!) I made them stay up until 1am on Friday and Saturday. We jammed in all of our favorite Michigan restaurants and a couple of breweries. Sunday was my grandmas memorial by a lake to put her ashes in and then the whole family headed to lunch. It was a very nice time to say our final goodbyes. We talked about my great grandma and what a wonderful person she was.

After the memorial we started our long drives back home. Bambi may have been over it ha ha...
When we got back to Utah Lindsey and I went to our new house rental, it was really late so we just crashed! We spent the next day moving everything from our trailer to the house. We also found a huge reclining couch on craiglist that we needed to pick up. It's going to be quite a change going from the Tiny House to the trailer for 5 months to a full house with a basement and a backyard. Bambi is thrilled with all the space.




Hope to see you guys soon out on the tracks in Utah!
Happy Fall. ■ ABILITY

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# Who Needs A Friend?

Everybody should a disabled friend that they pal around with. There is much you can learn and gain from them. I won't go as far as to say they are like an emotional support animal, but they can open your eyes to a new world. You can do a lot of things with a disabled friend. You can go out for pizza. Enjoy a cup of coffee together. Cruise the mall. Go to a baseball game. Yes! They will gladly do these things with you. There is no need to be skittish around them, only a few bites but, for most part, most of them are well-behaved and make an ideal companion. In short, not only can you help them, but they can help you.

They make you look like a good person. It gives the appearance that you really do care about the unfortunate ones. Down deep, you may not, but it looks good and isn't that all that really matters in this world. To come across to others like you're a genuinely caring person. It's like saying, "some of my best friends are black" but, in this particular case, you actually do have a friend who's disabled. Just think about what a hero you will look like when you post that picture on social media with your arm around the guy in the wheelchair. Your friends will be like, "Gosh, I always thought Bob was a selfish douchebag but look at him with a disabled guy. I guess I was wrong about him." You don't have to put time into a soup kitchen on Thanksgiving. No, you've been helping your disabled friend all year so, damn straight, you get a pass. It also helps when things are all said and done, and you've reached the end of the line. Someday we all will die and meet God face-to-face. God's going to have your file in front of him and be like, "I've got you down here for lying, stealing some clothing accessories a few packs of gum, yada, yada, yada, drunkenness, lust, not honoring your parents and, well there's too many to list and we only have an eternity. I'm sorry, it just doesn't look good for you. You have anything to say in your defense?"

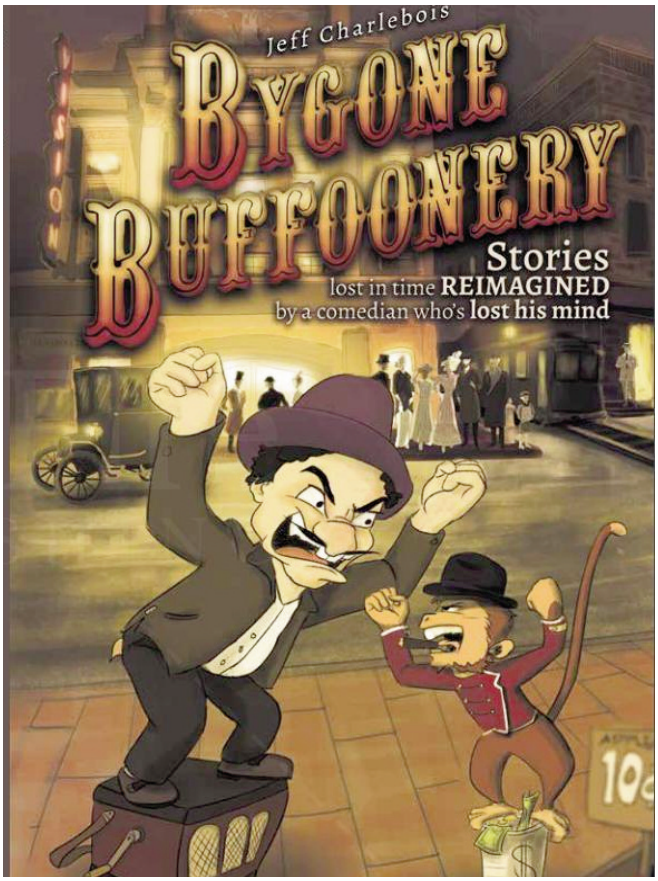
"Well, I think we need to look at the whole and not a few blemishes," you stammer and squirm.

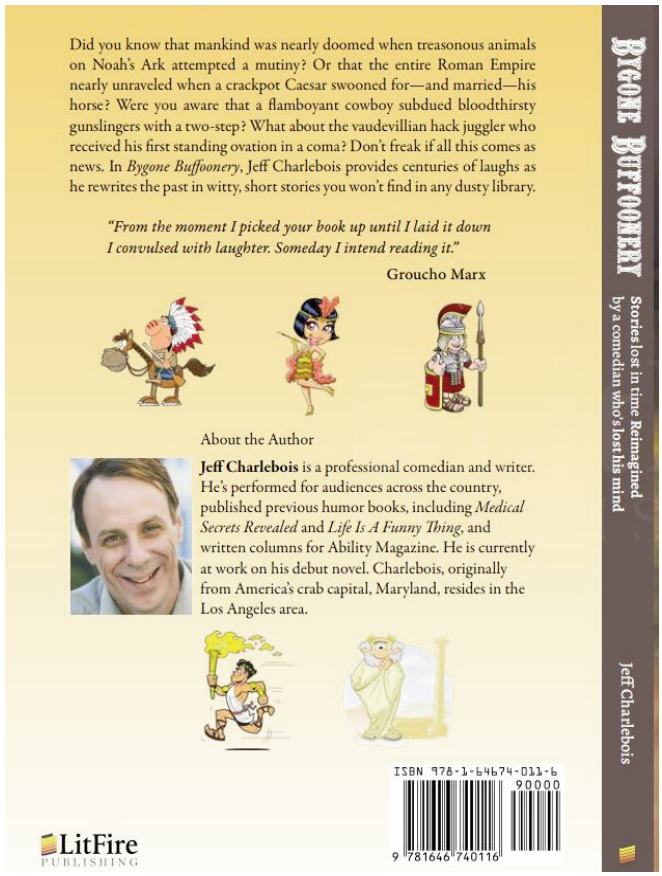
"The whole's not too impressive either," God states.

"Ah, but you're forgetting one main thing, big guy," you assuredly nod, preparing to pull out your ace-in-the-hole. "I had a disabled friend and I helped him out a lot."

"You old sea dog," God beams with smile. "Why didn't you say that from the start? We wouldn't have to go through all this judgement stuff. Come on in. Heaven is all yours. And the drinks are on me, my faithful servant.

You may believe that having that disabled friend sounds like nothing but trouble and a lot of extra work. I can only say, you're right about that. Calls at all hours of the day. "Would you mind picking me up some milk and bananas at the store? Can you fix the flat tire on my wheelchair? If you have spare moment sometime, could you paint my house?" But, think of it this way, it helps fight your laziness which we all must battle. That disabled person gets you off the couch and moving around. In a way, you must do it because, if you didn't, the guilt would eat you alive. And no one that I know, likes to be eaten alive. On the




plus side, you get to feel good about yourself for a change. This nothing more invigorating then helping a fellow human being, but a stiff vodka and tonic is up there.

Having a disabled friend to go around with also has some perks. For one thing, they are a great ice breaker. It's like having that cute puppy that brings people to you. You're viewed as a good person who isn't a threat. Hopefully, if curious people do come up to you, you won't allow them to pet your disabled friend without their permission. Needless to say, the disabled person is good to have around when going to places where parking is hard to find. That placard is a golden ticket. My friends bring me to the mall with them all the time. They get the great parking and they're in the mall within minutes. They only thing that bothers me about it is, they leave me sitting in the car. I guess they don't need an ice breaker. Many times, a disabled friend can get you to the front of a line. Perfect for at the airport or concert. For extra money, I post myself in front of Disneyland with a sign that reads, "Rent Me for A Day – Only $500."

Gratefulness is the key to happiness. The disabled friend is perfect for this. You may be feeling down and depressed because you have no money, no love life, or no life whatsoever. But then, you look at the everyday struggles your disabled friend goes through and you're like, "Damn, I guess things aren't so bad." Us disabled peeps are like that bright light that knocks you back to reality and stops your whining in its tracks. You worry about a car payment we worry about making it over to our wheelchair without face planting on the floor. But the good thing is, when we call you to put us back in the wheelchair you probably won't being thinking about your car payment. So, that's something positive.

The disabled friend is always there to listen to your endless problems. Many times, it's because they're not mobile enough to escape so they're, more or less, a captive audience. But what do you care, as long as he nods and agrees with you that's all you need – someone to assure you that you're not a bad person. A disabled friend is also inspirational. They can change around your pissy mood. You see what they're doing with their life with they have to work with, and you say to yourself, "Damn, I'm a bum" and that motivates you to get out there and make something of yourself. Yeah, you go girl, even if you're a boy.

Having a disabled friend can be a wonderful experience and is by no means a one-way street. It's a beautiful symbiotic relationship. I, for one, have been blessed with awesome friends who have helped me in so many ways. Without a friend who didn't want a disabled friend I'd be dead in the water too many times to count. So, the next time you're out-and-about and you see a disabled person go right up to them and hug them. Yeah, I said it. Hug a disabled person then look them in the eyes and say, "I wanna be your friend". ■ ABILITY



Jeff Charlebois

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# 吴幽 青春的赞美诗

## Wu You The Hymn of Youth

She likes Du Fu's heartfelt openness of "singing in the daytime, indulging in wine, youth as a companion and returning home", and admiring Su Shi's open-mindedness of "the boat passes away from now on, the river and the sea send the rest of my life". In Wu You's view, poetry and literature are both a teacher and a friend, and the poets she admired gave her the courage to face difficulties.

Wu You

Born in Dazhou, Sichuan in 2001, a contestant in CCTV's "Chinese Poetry Conference" (season 6), graduated from Chengdu Special Education School and has been pre-admitted by Binzhou Medical College. She is the first blind contestant to board the "Chinese Poetry Conference".

"My answer is'suddenly like a night spring breeze, thousands of trees and pear blossoms bloom.' Baixue originally represents winter. The Winter Olympics is a very tolerant and open platform, just like the warm spring breeze. Athletes are the pear flowers that are urged to bloom by the spring breeze..." In April this year, on the stage of CCTV's "Chinese Poetry Conference" (season 6), the blind contestant Wu You used a song by Cen Shen "Bai Xue Ge to Send the Military Judge to Return "Beijing" cheer for the athletes of the Winter Olympics, cut from a unique perspective, accurately interpret the connotation of the Olympic spirit of tolerance and struggle, confident and calm Wu You won the support of the "thousands of people" and successfully entered the individual pursuit competition.

As the first blind contestant to board the "Chinese Poetry Conference", Wu You was known to the audience, and the audience was impressed by his talent and perseverance. Without the aura brought by the show, Wu You is just an ordinary senior high school graduate of Chengdu Special Education School. He has been pre-admitted to Binzhou Medical College in 2021, and is about to usher in his university life.

"Ye Lan, Wind and Calm, Flat Patterns"

In July 2001, Wu You was born in Xuanhan County, Dazhou City, Sichuan Province. When she was more than two months old, she still hadn't reacted to the things in front of her, and her eyes didn't seem clear enough. Her family took her to the hospital for an examination. The result was that the optic nerve was congenital dysplasia. The word "blindness" was like A thunderbolt broke the joy of welcoming the newborn in this little family.

When I was a child, because I couldn't see it, the children around me didn't take Wu You to play with. Wu You's father was afraid that she would be bored, so he bought a lot of discs for her to listen to. Poems, English, and nursery rhymes were all available at the time. Wu You, who is ignorant, especially likes poetry and always asks her father to play the same disc for her. "I just thought that poetry is 5 or 7 words, and it sounds very rhythmic."

In order to allow her daughter to adapt to special education as soon as possible, from the age of 3, Wu You's parents took her to the Chengdu Special Education School, where she was fully boarded, and she also regarded this as her second home. Wu You, who has gradually adapted to the school environment, has won the love of teachers and classmates with his optimistic personality. At the age of 4, Wu You, who had just been promoted to preschool, was selected as a representative to give a speech under the national flag at the flag raising ceremony. This experience is still often mentioned by Wu You's Chinese teacher Xie Xiaoli: "She is only 4 years old but has no stage fright. , I thought at the time that this girl is too good."

Under the guidance of the teacher, Wu You's enthusiasm for poetry became uncontrollable. What impressed her was that when she read Su Shi's "Linjiang Immortal: Yegui Lingao", there was a sentence "Ye Lan Feng Jing Wen Ping", Wu You was suppressed at that time,




"Just 7 words , He wrote Quiet to the extreme, especially beautiful. And it was written that Su Shi was drunk in the middle of the night. After returning, the boy fell asleep. He didn't hear the knock on the door, so he simply stayed by the river when he couldn't get in. For a while, listen to the sound of running water. This touched me a lot. It turns out that people can treat the unsatisfactory things in life in this way." She likes Du Fu. The heart and soul of the "hometown", I also appreciate Su Shi's broad-mindedness of "the boat has passed away, the river and the sea will send the rest of my life". In Wu You's view, poetry and literature are both teachers and friends as a delightful way, and those poets she admired also gave her the courage to face difficulties.

"Qiao does not fight for spring, but only reports spring"

Wu You's idea of participating in CCTV's "Chinese Poetry Conference" originated from her Chinese teacher Xie Xiaoli, who was a contestant in the fifth season of the show. After knowing that Wu You also wanted to participate, Xie Xiaoli helped her sign up to the program team. With years of accumulation of poetry, Wu You successfully passed the interview and became a contestant in the sixth season. Under the coordination of Xie Xiaoli's application, the organizer of the "Chinese Poetry Conference" specially produced a blind answer card for Wu You, so that she could interact with The able-bodied players participate in the competition together.

Participating in the festival, Xie Xiaoli took Wu You to the mall to choose the clothes to wear on stage. The two people who usually love their best friends would also go shopping and drink milk tea together, knowing that Wu You likes Chinese culture, can play Ruan, and can sing Peking Opera. After the exam, Xie Xiaoli bought a set of Hanfu skirt as a gift to Wu You. "She is like this, warm and modest, moisturizing things silently. Exchange true heart for true heart, call poetic heart with poetic heart. She is like jasmine, quietly blooming in the corner of the campus, petite but strong, tough and gentle." In this article, Wu You described Xie Xiaoli like this, and said that the two are not like teachers and students, but more like friends.

Xie Xiaoli, who graduated from Mianyang Normal University, became curious about special education when she was in high school because of a TV show involving deaf-mute children. In 2004, when Chengdu Special Education School went to Mianyang Normal University for an open recruitment, Xie Xiaoli resolutely signed up. At that time, Xie Xiaoli had never been in contact with



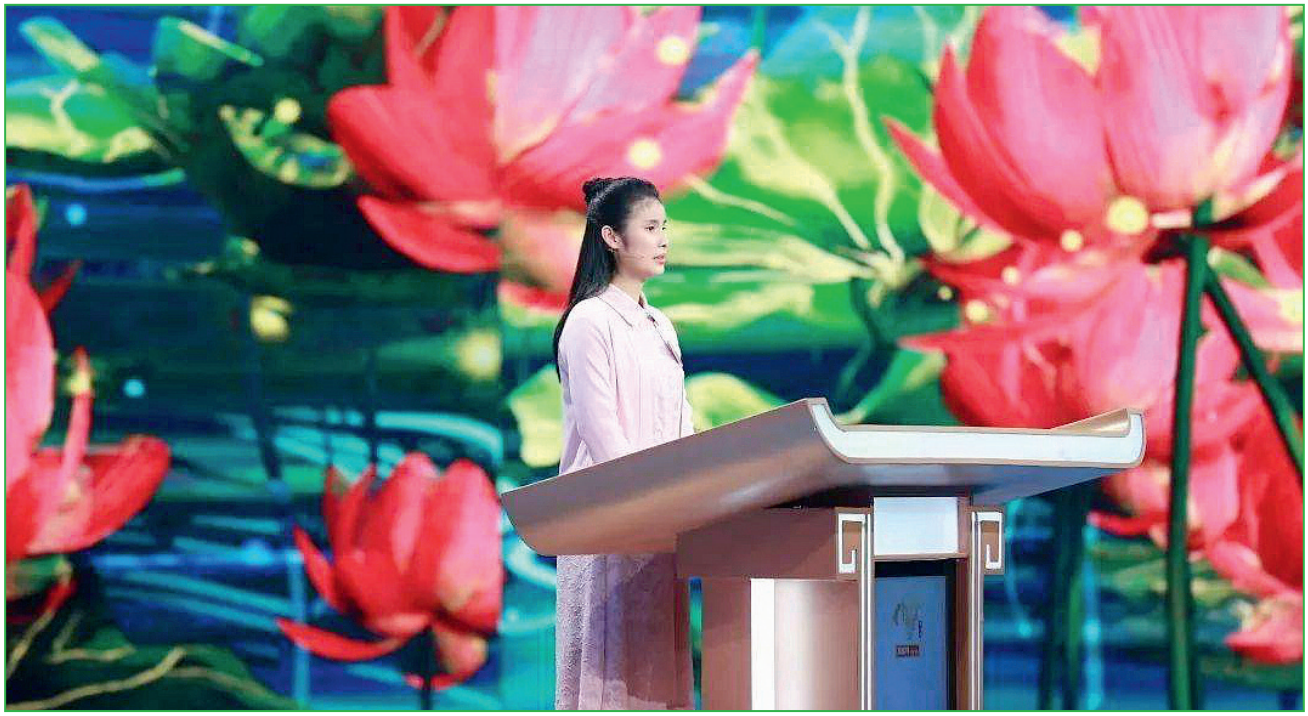

blind children. She had to tell the children "color" in the first class, which was a big challenge for Xie Xiaoli. She closed her eyes and imagined the feeling of each color—blue is the color of the sea, which is broad and cold; red is the color of the sun, which is warm and warm. "I think it's really not as difficult as what others have seen to be involved in the education of visually impaired students. This is a very ordinary job. The beauty of language is not only the beauty of vision, it has the beauty of touch and hearing, but also the artistic conception. The synthesis of multiple sensory combinations."

In her spare time, Xie Xiaoli often organizes her classmates to read poems together. Her teaching is never limited to textbook knowledge, but combines the artistic conception of the entire poem with the poet's dynasty and culture at that time to add more knowledge of Chinese culture. Confucius has already put forward the concept of'poetry education'. It is more meaningful to learn the wisdom of the ancients with them than to memorize them by rote." Wu You is like Teacher Xie's little assistant, acting as a bridge between blind students and teachers. , Add a note on the side.

"It's good to put a little red furnace snow, scattered as a night light in the world." Wu You said frankly that the selfless dedication of the teachers is inseparable on the road of his own growth. "Pretty doesn't fight for the spring, only the spring is reported. When the mountain flowers are blooming, she laughs in the cluster." On the scene of the "Chinese Poetry Conference", she expressed her gratitude to her teacher with a song "Bu Shouzi · Yongmei" . And she has long concealed the idea of "returning to her alma mater" in her heart.

"Wu" Heart From "Secluded" Bright Moon

April is the busiest "college entrance examination month" for students in special education schools. According to the regulations of the Ministry of Education, candidates with disabilities who take the college entrance examination shall adopt the method of enrolling students with separate examinations and separate admissions by the admissions colleges. From April 1st to 15th, in half a month, Wu You moved to Changchun, Beijing, and Yantai to take the exams of 3 universities. Wu You listens to ancient poems on the mobile app every day. Whenever she encounters unclear content, she collects up and asks the teacher. Reading ancient essays has helped her improve her Chinese performance. Her Chinese scores reached 130 in 3 single-



examinations. (A full score of 150 points) and above, the total scores all met the school's admission standards, and finally she chose Binzhou Medical College. "Because Binzhou Medical's acupuncture and massage professional strength is strong, it can meet my dream of practicing medicine and helping the world, and it also supports students in minors. Psychology and special education, I want to study hard in the university, and then cross-professional postgraduate entrance examination."

Blind candidates and ordinary college entrance examination candidates use the same set of textbooks and exam syllabus. Most of the higher education majors for blind students focus on the two major aspects of art and medicine. Similar to Wu You, blind students who did not choose an art major from an early age will basically choose acupuncture and massage majors, and apply for such majors. Science subjects such as physics and chemistry are Required. However, braille teaching aids are difficult to translate and costly to produce. It is difficult to buy in the market. Many exercises have to be read to them by teachers who buy exercise sets, which also increases the difficulty of their practice and brushing.

For the college entrance examination, Wu You made Braille exercises and collections of wrong questions for each subject, and piled them up thickly. As a high school sister, Wu You's notes were circulated by the juniors and sisters of the second year of high school. After the exam, Wu You did not immediately leave school and go home to enjoy the vacation, but stayed at school to help the students with their homework. , To teach them experience, "The braille is Pinyin writing, which makes it difficult to distinguish the homophones in the appreciation of ancient poems. Su Shi has a poem that says'light rain passes, Xiaohe turns', I always thought it was'Xiaohefan' , Which means that the water has risen after the rain, and the water has risen and made waves. Later, I realized that it was the "lotus" of the lotus after communicating with the teacher. I often talk to the younger students about these points that are easy to confuse in the process of touching and reading."

In Wu You's heart, the school has already become a home, and teachers and classmates are like family to her. In the face of challenges and difficulties, she is never timid, and always rises to difficulties. I don't hesitate to show my excellence because I hope that through my own experience and achievements, more students will be encouraged to bravely step onto the stage, tell their own stories, and show off their wonderful life. "I haven't done anything amazing. In addition to love poetry, I am an ordinary girl. The lack of clarity has brought me some inconveniences, but this is just a small difficulty in life. After learning that the ancients can still empathize with the mountains and rivers and live free and easy life under such difficult conditions, I There is no reason not to work hard." In the face of the slowly unfolding future, this talented and strong-hearted girl is bound to trace a colorful picture of life, and her beautiful youth has just begun. ■ ABILITY

by Liu Liu

photography Zhang Ximeng

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


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# Reminders? Forget about it!

Having cognitive issues wasn't always accepted as a common symptom of Multiple Sclerosis. I don't remember when that changed, but it was sometime in the last 20 years. Today Dr. Google claims half of all MS patients experience cognitive changes and deficits and my disease riddled brain would wager the number of patients experiencing memory problems is actually closer to 50%.

My first symptoms were mostly cognitive, memory issues and bouts of confusion, trouble multitasking and following directions. I forgot a lot of important stuff, like my wife's name.
A neuropsych test is great fun if you ever want to feel like a total idiot. The test is designed to measure your failing points in a variety of ways and tasks using different brain processes.

It has been 15 years since my last one, and even with my memory issues, I still remember word for word the test results. I had less than 20% (or maybe it was 25%? or 15%?) Anyway, I was working with the short term memory capabilities of a man aged somewhere between 125 and 150 years old.






Do you rob banks? Make sure I am the eye witness. I sometimes have trouble recognizing the face in the bathroom mirror!

Before you start getting all teary eyed and sending donations in leu of flowers, I have to admit being forgetful has some great advantages.

When I wake up sick and tired, I usually forget to be miserable by the time I finish showering. If my toothbrush is moved ever so slightly however, I will also forget to brush my teeth.

When I am upset or angry with my wife it never last long, fading from my memory in minutes or hours. Unfortunately, when we are having an argument, I can forget in seconds what we are actually arguing about, how it started or even what side I am supposed to be on.

A death of someone you love can be devastating and painful, but when your ram memory is slower than a dial-up modem, you can forget about the pain rather quickly. My memory deficits are often viewed as not caring, but it really should be seen as I just don't care right now.

I think the best use of having difficulty remembering is the unique ability to instantaneously forget. Forgetting I have limitations, forgetting I have a heart condition, spinal fusion, nerve damage, kidney stones ready to drop- none of which has stopped me from continuing to ride my motorcycle raising awareness and funds for a cure.

Well, I do sometimes forget where I am going or that my low fuel light has been on for a while.

I often forget I have a disease that effects my memory. I know I should record or take notes when I do maintenance or repairs on my motorcycle because I always have trouble putting it back together, but while I am working, I convince myself that this time I will remember exactly where each part goes. The next day I would swear on my life I have no idea who took apart the bike. My frustration at my making the same simple mistake yet again lasts about five minutes




before I forget the entire ordeal!

I forget to take care of bills, make doctor appointments, go shopping or to take the dog for a walk. I say I forget, but that doesn't mean it doesn't get done.

The invention of the smart phone and it's ability to remember dates and tasks for me probably saved the lives of thousands of trees earmarked for sticky notes. I often wonder if in 1920 anyone would have believed the telephone would replace both a GPS and a Laptop. Using a smartphone as a portable hard drive allows me to set reminders and use various apps that help simplify my life and keep me up to date and on time with alerts and notifications.

It works great……Except when I forgot to set a reminder to write this column for ABILITY Magazine and the deadline was 8 minutes ago. ■ ABILITY

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# THE DEADLIEST DISEASE IN AMERICA

"Nobody wanted to talk about what racism looks like in healthcare," said Crystal R. Emery, filmmaker, author, activist, and public speaker, speaking of her challenges in making her latest documentary. In "What's the Deadliest Disease in America?", Emery explores the history of racism in American healthcare and exposes the continuing disparities in care for black, brown and indigenous people receive. *ABILITY Magazine* spoke with Emery about her film and her personal experience as a quadriplegic African American woman.

Karina Sturm: First, I wanted to say I love the title of your film. Can you summarize the film for people who haven't seen it and just know the trailer?

Crystal Emery: Well, the film is about racism and healthcare. It is an inside look at how people utilize the words "inequity" or "disparities" and "racism," and they don't really know the meaning of what those terms. And so, the film offers the opportunity for you to experience it in a different way that you can't avoid.

Sturm: Can you tell me what got you interested in that subject?

Emery: Actually, it was challenging. I had become a quadriplegic, and so I said, "Oh, well, if you think you're that great of a director, why don't you make a film about disparities in healthcare?" At the time, I had eight doctors–eight great doctors–and not one of them was a doctor of color. And only one of them was a woman. So, I was like, "What?" And I got very, very sick three months before the hospital stay. And I was in and out of the hospital in a way that I had never really known–that within that time–the overt, subtle racist behavior within healthcare. And that would make the things we would capture were that much more impactful. I had just experienced a lot of it. It was very frustrating.

Sturm: You also made a film about physicians, especially about black women, in healthcare. Can you tell me more about your previous film?

Emery: The film "Black Woman in Medicine" is just that. It's about black women in medicine.

Sturm: (laughs)

Emery: What I loved about making that film is that they did not allow what I call the "ism" word tag, whether it's race, whether it's gender, whether it's socioeconomic, to deter them from reaching their dream. All of these women are major contributors to the health field, and it doesn't matter whether they're black, brown, or white. They're true healers, and I wanted to highlight these amazing women.

Sturm: I remember you said, "You can't be what you can't see." I found that a very fitting quote. Did you come up with that? Did somebody say that to you?

Emery: I don't know who originated that quote. Because you hear it everywhere right now. I heard it from Dr. Jocelyn Elders one time. I made a virtual reality game, "You can't be what you can't see," where the player has the opportunity to be a doctor in the emergency room. And they are the decision-makers, the one who is controlling the game. But you can't be what you can't see.



Sturm: About the virtual reality thing, can you tell me more about that? I don't know anything about how virtual reality works. How did you make the whole experience? Who helped you? What was the process?

Emery: Well, the first thing is that I received an invitation with a goal create a video game. I had never made a video game in my life.

Sturm: (laughs)

Emery: So, I set out. There was an office called Games for Change. I went to that in New York, and I met other people with all sorts of VR and AR, just amazing. Are you telling me you've never played a video game?

Sturm: No, I mean I've played video games, but I don't know how you create virtual reality.

Emery: It's a video game. I wrote a script. The thing about virtual reality, like a film, it's not linear. It is the player–you always have to remember that you're creating from the player's eyes. You don't see the doctor because you are the doctor. So, it is a little different. Creating a character, creating the avatars, their eyes, their noses, their voices, working with programmers who build the back end of the game. It took about six months; and we presented it on the stage of the National Academy of Science.

Sturm: That's quite fast. Six months isn't much. I was really impressed. Your recent film was 10 years in the making. Can you talk more about that?

Emery: I did. I started 10 years ago. I could not raise the money to continue shooting because nobody wanted to talk about what racism looks like in healthcare. Nobody really. But given all the things that are happening in the world right now, we are forced to talk about it. We're forced to look at what inequities, what systemic racism looks like and how it permeates everything around the world, in every society.

Sturm: When did you get the funding so you could continue producing?

Emery: It was a long process. It wasn't like, "Oh, you have the money. You've completed everything." I'd raise a little money, I'd shoot something. Then I'd raise more money, and I'd shoot something else. I had the opportunity to interview Dr. Clara Y. Jones two separate times. That was great because her definition for three levels of racism, whether it's institutional, personally mediated and internalized. It was an amazing opportunity to capture that. And that Dr. Marcella Nunez-Smith who now is one the advisors to President Biden's COVID-19 task force, I had interviewed her last year. So, it evolved as I raised money.

Sturm: What kind of stereotypes, what kind of racism did you experience during shooting? What experiences did you make?

Emery: This is a funny story. I was shooting in a hospital here in New Haven, and my crew–Because we were shooting a reenactment scene, the hospital gave us this infectious disease ward. It was like a little chamber, and it was empty. So, we were able to shoot in there. I got separated from my film crew. So, I wandered around the hospital, and I asked a doctor where this ward was,

and he said, “Oh, no, no, you can’t go there.” And I said, “Well, I’m shooting a film.” And he said, “Oh, no, that’s not the ward you’d need. The ward you’d need is on the second floor.”–which was the psychiatric ward. And I said, “No, no, no, I’m here shooting a film.” And he was like, “Lady, do you need me to get security?”

Sturm: Oh!

Emery: I was like, “Yeah, right, I need you to get security.” He got security. I told them who I was. I mentioned the name of the president of the hospital, and he said, “Oh, you’re the film crew. They moved to—” whatever floor. The doctor just stood there looking at me like I was crazy. He could not imagine that a black woman was possibly shooting a film.

Sturm: Can you elaborate about the historical background of racism in medicine? Where did we start and where are we today?

Emery: Well, where we started was the day that black bodies entered America. I mean, look at the 1800s trials and abuse of people of color, also Native Americans, also Asians, and that just progressed and progressed and progressed. Even now, see Henrietta Lacks, where her cells are one of the leading components in producing cancer drugs, and yet her family does not receive any of that money, those billions that have been made. But the exploitation of her DNA. And even now, we look at COVID-19 and we look at why people of color are dying, and it’s not something that just happened today. There was a doctor last year, a medical doctor, who got COVID and she went through hell in a hospital but not receiving the right care—and eventually she died. She was brave enough to share her story before she died. So, it is ongoing. As long as there is racism in any form, it will exist.

Sturm: What was your own personal experience as a woman who belongs to more than one minority, you’re a black woman, you’re a disabled woman, how did that affect the making of the film, the lens through which you showed all the stories?

Emery: I don’t think it affects the making of the film because what you left out there in all of those titles or identification markers is that I’m a filmmaker first. I was born an artist. I’ve done this my whole life. I think that being a black woman is a wonderful, great. Being differently abled is very challenging, but I don’t think that either of those has to do with the process of making a film. I think I am more the ties in how to tell a story, in influencing the narrative because you are hearing and seeing through multiple eyes, multiple ways.

My crew insisted that I bring my own stories into the film, about how I was denied physical therapy. But that did not influence my choices of stories. It did not influence the hard facts of—because documentaries have to be based not on the particular person, but they have to be based in facts. And whatever you’re dealing with doesn’t mean that someone with that same issue of health deals with it the same way. Not at all.

Sturm: That’s true, yeah.

Emery: So, I try to give voice to multiple voices that are not heard. My voice is my voice. It’s through the lens of my experiences. But as a storyteller, as one who is creating a narrative, it is my job to be very clear.

Sturm: Can you tell me what the most challenging part was about producing this film?

Emery: Money.

Sturm: (laughs)

Emery: The most challenging part is money, amazing money. Convincing somebody that you’re capable of delivering, convincing somebody who doesn’t really want to talk about racism and won’t give you the money. That is always the hardest part for most filmmakers.

Sturm: How about the emotional part? Were there episodes in the film that were emotionally draining for you? How did you deal with all the emotions that come up?

Emery: I’m a filmmaker.

Sturm: (laughs)

Emery: It is my job to take my audience on a journey that does have emotionality. But that is how we process. Originally, it was called “The Audacity of Hope,” which was a play and President Obama’s book. As I was looking at the footage, I said, “Oh, this is the deadliest disease in America.” So, the footage actually dictated what the title would become. As far as my connection to the emotionality of it, I’m a filmmaker. To absorb it, but you look at how best to tell the story. I think that people get caught up in, “Wow, this is a riveting emotional piece!” That doesn’t necessarily mean that that 30 seconds tells a story that can be digested by an audience.

Sturm: What brought you into filmmaking?

Emery: I was born to do that. I directed my first play when I was in third grade. My brothers were Batman and Robin, and my other brothers are Cato and Green Hornet. I was born to do this.

I’ve always been a storyteller, whether it’s theater or film or literary, any form.

Sturm: Are all your films are centered around social issues and change?



Emery: Well, I've produced some actual shorts that are literally on 35mm.

Sturm: Oh, nice!

Emery: These documentaries are what you see because that is what has been in the biggest ones here.

Sturm: What do you want people to take away from your films?

Emery: My goal is to help open your eyes a little more. Recently, there was a young lady there who cried, was crying, because she was a woman of color. I asked her why she was crying, and she told me that she had gone to the doctor and that they had done some procedures that were preventing her from being able to have children. She didn't even know what was done to her.

I want people to understand it's not just about people of color or white people, it's about all people, that racism affects all of us. Either we are the receiver of the negativity or the giver of it, or even when we remain impartial. Because when you remain impartial and do nothing, you really are propelling it forward. I want people to be able to understand what it looks like and then to look within themselves and how they can make change on an institutional level and an individual level. Because we create institutions.

Sturm: What kind of feedback have you gotten so far?

Emery: You always do test screenings. People say different things. There is a part that reaches everyone. Has anyone said, "Oh, hell no, I totally hate this film?" No. But what they all say is, "This has given me a lot to think about. How can I be okay? What can I do today to make a difference?"

Sturm: What can people do to make a difference?

Emery: Start with yourself. Look at how you reference people. Look at how you respond to when you see something that you know damn well is wrong. What do you choose? Do you choose to avoid it? Do you choose to close your eyes? Or do you choose to take a stand and say, "That is wrong"?

We did a workshop in Memphis and a doctor said, "I grew up my whole life with my parents, my grandparents, calling everybody niggers." And he said, "I hear that from a lot of my colleagues. If I cannot stop that in my own house, how could I stop that in my work environment?" I said, "It starts with you the first time you say, 'That is not acceptable,' and being willing to stand in that truth."

Sturm: What do you hope your film will change? Or a little bit more of a loaded question, what needs to be changed in terms of racism and medicine?

Emery: You're making it sound like racism and medicine is its own separate category. It's not. Racism is racism, period. It starts with education, where you live, what tools are available to you. And all of those contribute to negative health outcomes. The film is not

about the negative, it is using medicine as an example or a vehicle. But it's not limited that way.

Sturm: How can we do better?

Emery: We can do better by wanting to do better. Somebody said, when I said, "You can do better by wanting to do better," they said, "Yeah, but I don't know what to do." I said, "There's books out there. There's tons of research you could do. But it starts in your heart."

Racism is in existence because you need to feel better than me. You need to identify a reason why you are superior. And race is easy because it's very obvious. It's a color. We see you. So, to dismantle that, you have to first start looking within yourself at what you choose, how you respond to people. The biggest thing is, "I don't have any friends of color. I don't know any Latin people." I'm not telling you to go out and meet any. What you can do is research. You can look at documentaries like this, so we get to understand what part of this journey is yours.

Sturm: I also know you're very involved in URU. Can you tell me more about the organization and what you do there?

Emery: URU the Right to Be is content production company. We utilize all kind of media at the intersection of arts, humanities, technology, and science. What does that mean? It means that you have to reach people where they are, and we are multi-dimensional people. So, you need multi-dimensional language, literacy. That's what we do.

Sturm: That sounds great. What's next? Another film?

Emery: Right now, we're doing a 10-part series called "Our Humanity" with Dr. Marcella Nunez-Smith. I'm working on a film called "Taking the Pages Down", where I'm utilizing science as a subject. Normally you have some doctor, an expert. I'm utilizing science as the expert.

Sturm: That sounds interesting. When is this coming out? Is there already a plan?

Emery: Oh, you won't see that until late 2022. COVID has held up everybody.

Sturm: Where can we see your current documentary?

Emery: "The Deadliest Disease in America" is coming September 10th at Cinema Village Theater. It will be there for seven days, and then we're working on a distribution plan.

Sturm: Can you share a bit about your condition and how you were diagnosed?

Emery: You don't have enough time for that conversation, let me tell you. When I was 11 and 12, I started falling down. Everybody thought I was just sort of bumbling. And then my hip slipped out of place. And they taped it back together, but I kept falling down. It wasn't until I had slowly started walking with a dropped foot. It wasn't until I was in college that I ran into my old physical therapist (from) when I was 12, who was doing his internship. I was one of his patients. I ran into him in my twenties, when I went to get physical therapy. Now he's running a practice. He said, "I think you have a disease called Charcot-Marie-Tooth. He said I should go to the muscular dystrophy people.

At the time, they knew what chromosome it was. And it really pissed me off because the science community, where they have made great inroads with multiple sclerosis and other diseases, Charcot-Marie-Tooth is one iteration of the peripheral nerve disorder that they have not made any inroads into in the last 40 years.

Doctors and the scientific community are very frustrated about Charcot-Marie-Tooth. In other neuromuscular or neurological diseases, they have been able to make significant inroads. With Charcot-Marie-Tooth they have made very little. So, it's frustrating, not only for the science community, but for those of us who have to live with it.

Sturm: There's someone on our team who has a very similar but even more rare condition, and your stories parallel exactly, same age when she started falling, dropped foot. And she was diagnosed for a while with the same condition, but it turned out it wasn't. She finally got genome mapping to where they found the specific gene that was causing the issue, but it's so rare that not much can be done. Where are you going right now for your—I'll say treatment, but there is no treatment.

Emery: It's very hard to diagnose this because it is genetic, and no one in my family had any symptoms of Charcot-Marie-Tooth. So, I had to get several nerve biopsies in order for them to diagnose it. Now neurobiopsies are not as traumatizing as they were 40 years ago when I had to get them done. I don't really see anyone. I remember years ago I had to go up to the muscular dystrophy clinic for about 10 years. I said, "OK, I'm going to go over there." And the doctor I saw said, "You know what we can tell you to do?" And I said, "Hey, dude, I was here 10 years ago and you said the exact same thing. It's not helping me." I have the severest form of Charcot-Marie-Tooth. I have a series of wonderful doctors who sort of treat the disease individually and collectively because they all talk together. They all come to my movies. They all see my work. It's a team effort. ■ ABILITY

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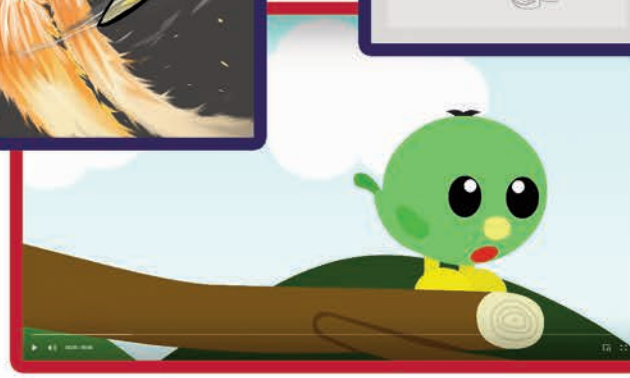


# Exceptional Minds

Part 1



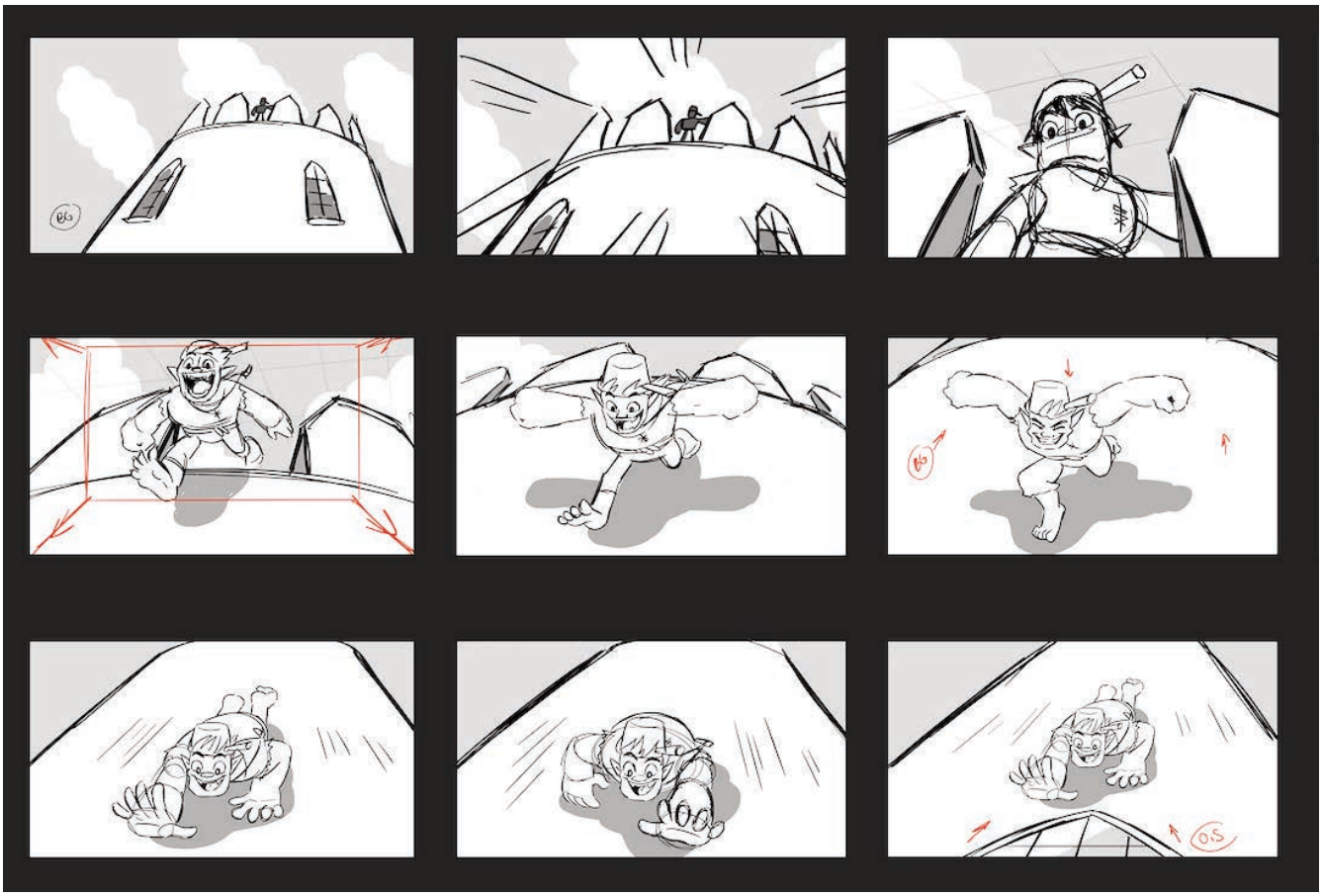




Most people are aware of the low rates of unemployment and underemployment of people with autism. Exceptional Minds seeks to change that, one career at a time. Exceptional Minds is an academy and studio preparing young adults on the autism spectrum for careers in animation, visual effects, 3D gaming and other related fields in the entertainment industry. They provide technical and work readiness training customized to help students achieve their full artistic and professional potential—comprised of a vocational academy, post graduate program, and post-production studios. Exceptional Minds and its partners are building a future where neurodiverse perspectives advance an inclusive hiring culture in the entertainment Industry. In this first part of a several part series of conversations with Exceptional Minds, *ABILITY*'s Priya Iyer met with Morgan Chess, head of marketing, to discuss their model and plans for the future.

Priya Iyer: Could you please give us an overview of Exceptional Minds?


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Morgan Chess: We are first and foremost an academy, a vocational training program. We teach classes in animation, in VFX, in post-production. One of the things that sets us apart is our social skills training. For example, every Monday, all the classes are catered towards work readiness and working with others, social skills, etc. for each of the three years of the course. We help our students find jobs, ensure that they are ready to be part of a team and to be successful.

We also have two working studios. One is the animation studio and the other is the VFX studio. We work on amazing projects. We just finished a short for Sesame Workshop in our animation studio, and then in our VFX studio we work on Marvel films, we work with Amazon, Sony and others doing everything from the end credits to visual effects to editing.

The studios are an opportunity where our graduates work. It also serves as a next step of work readiness training. They're professionals, they're full-time, they're paid, and it helps them get used to that work environment so that they can go off and have long, fulfilling careers.

Iyer: You've covered a lot in there. I'll break it out. The first part is that you educate students. Do you enroll students out of high school or college?

Chess: This is a question we get a lot, so I would like to clarify. For our full-time program, you have to have a high school diploma or equivalent GED and a diagnosis of autism. We do have a part-time program and that starts younger, those are after-school and weekend workshops where hopefully students, when they graduate high school in the future, will join us full-time.

Iyer: You did mention that you pivoted to doing it remotely. Are you scaling up and looking at students nationwide?

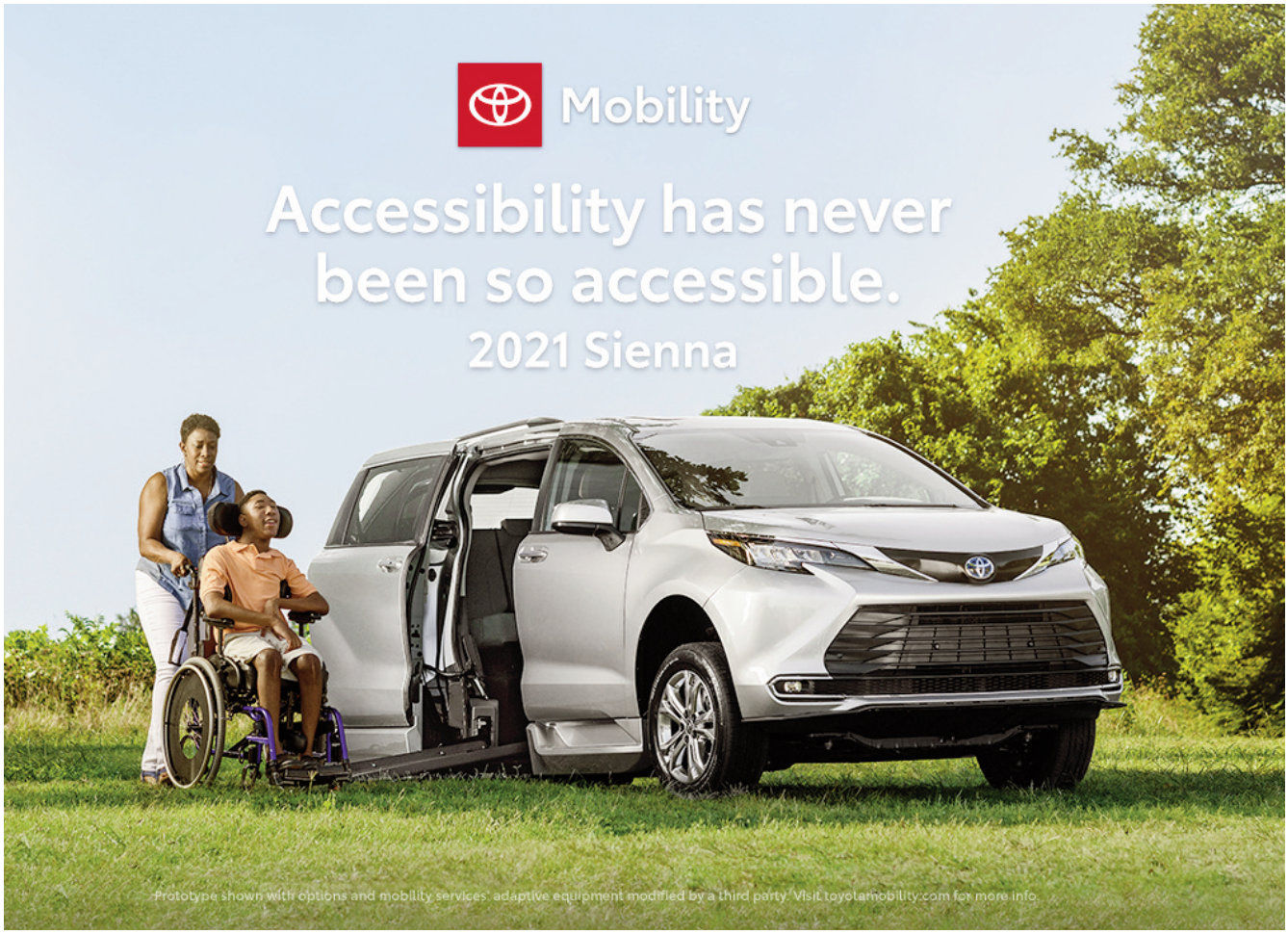
Chess: Yes. right now all of our part-time workshops are virtual. We have students in 28 states and three countries.

Iyer: International!

Chess: It's been very exciting to us. Our full-time program for right now is a hybrid program. They have to be able to come into class, so a lot of students move here or move with family members. We are trying to figure out how to do a virtual full-time program, with the social skills and the interaction the students need to develop in the future.

Iyer: How many students do you have in part-time and full-time right now?

Chess: The part-time is not full yet. It starts on Saturday, so I don't have an updated number, but I can tell you




that for the summer we had 208 part-time students for our summer school program.

Iyer: That's amazing!

Chess: For our full-time students, this week we started with I believe, and I will get back to you with a final count, 37 students.

Iyer: What is your capacity?
Chess: Just about that.

Iyer: So you're almost full?

Chess: The reason I say that in that tone is social distancing. We're trying to keep everyone safe. Kat Cutright, our Academic Dean, has done a wonderful job of getting the school set up and the cleaning requirements completed. We don't know what our current capacity is now.

Iyer: For sure! In the full-time program, students come usually in person, although it is a hybrid model right now. Do they come to you for eight hours a day? And do they graduate out of the program in three years?

Chess: Correct.

Iyer: And you did mention that 30% to 40% of the graduates are then absorbed into the two studios you have. The others, do you help them with job placement in other companies?

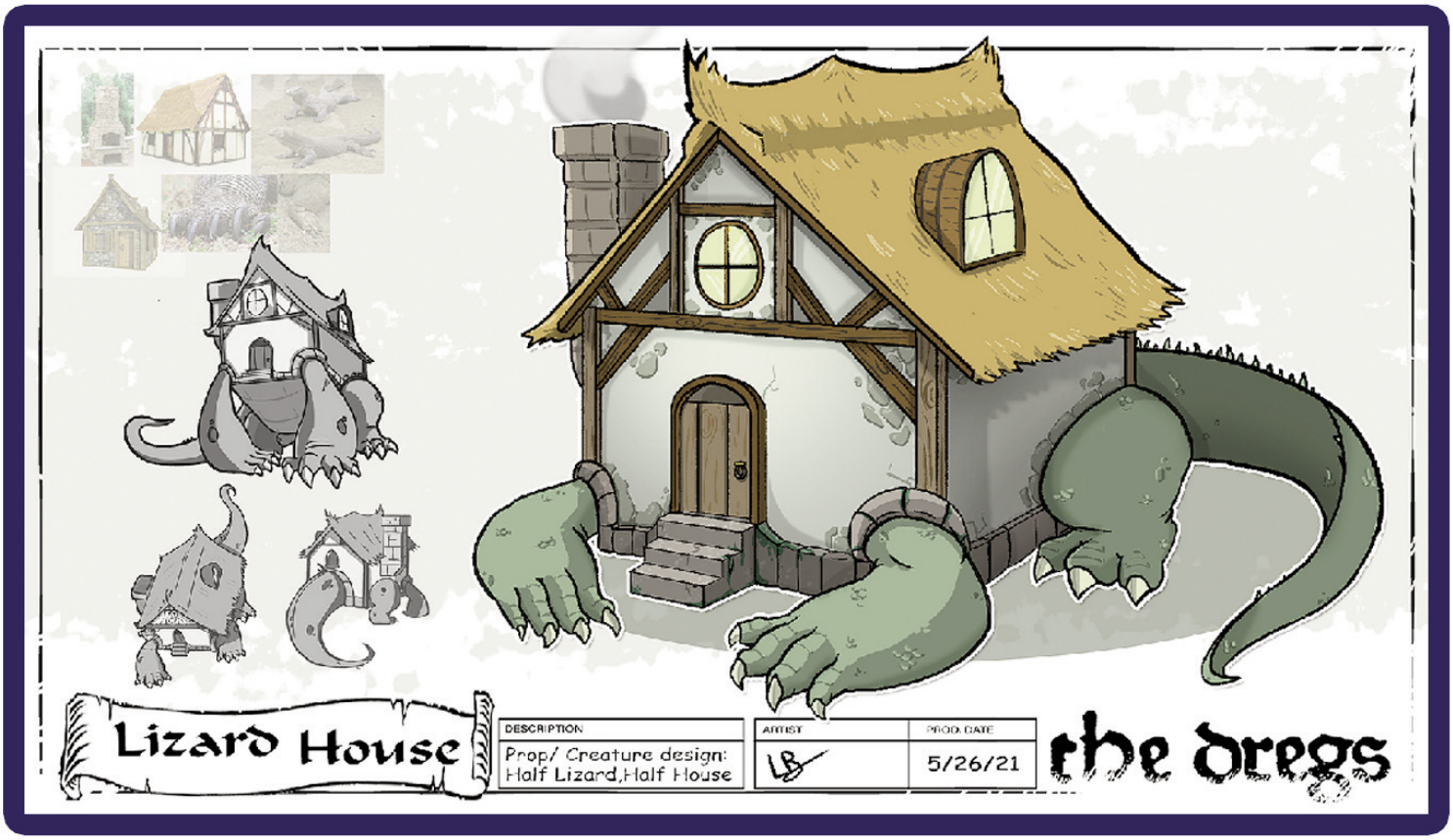
Chess: Yes. That's a big initiative for us, helping with job placement, with opportunities, whether it be internships that hopefully lead to a full-time job, or working with organizations like Netflix to make sure our job posting board is always up to date and we're helping the students get their résumés in and put their best foot forward.

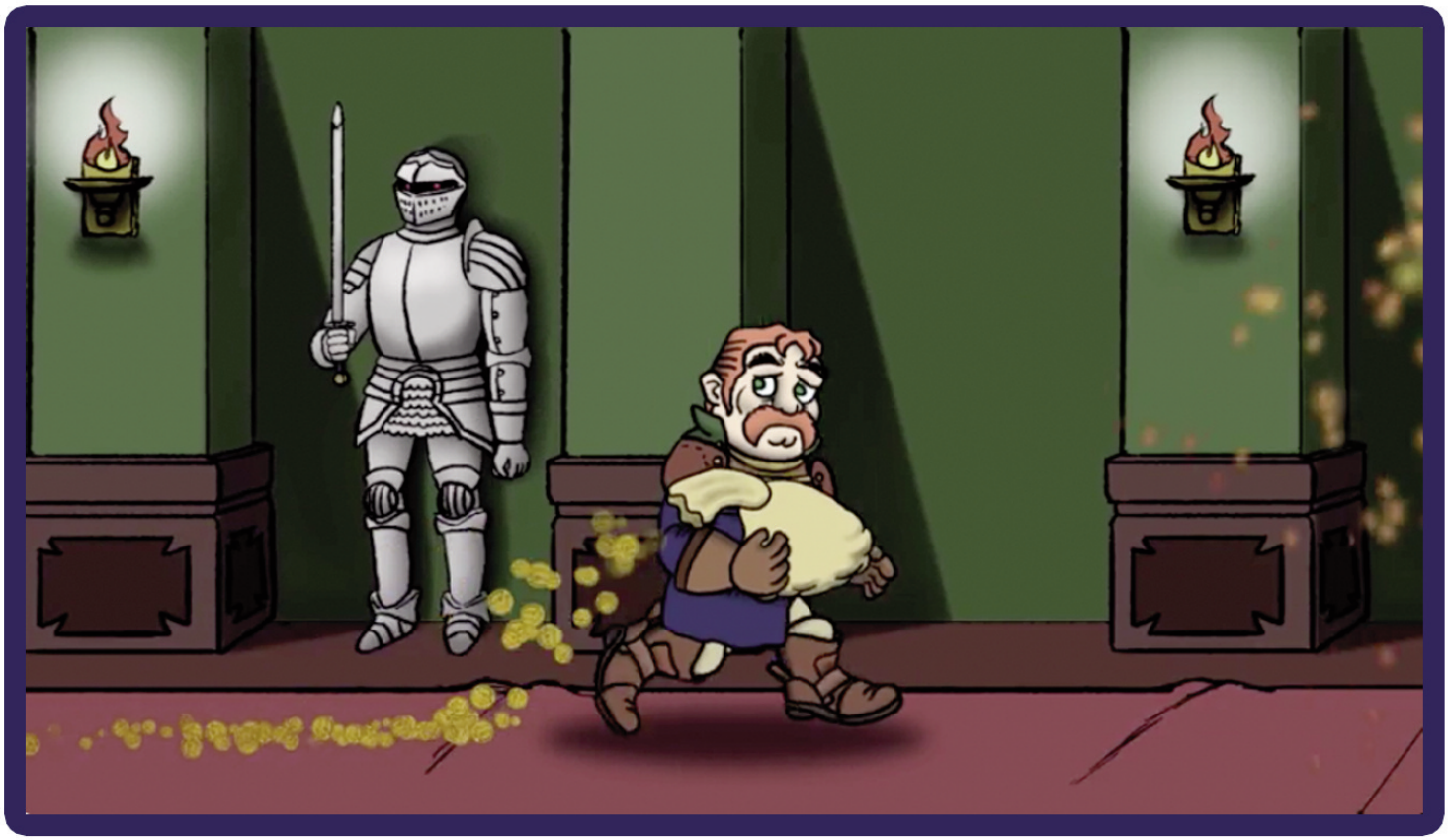
Iyer: It's interesting that you're incorporating soft skills training as well. How did that come about?

Chess: We started that way. Social skills are important for everyone. We do some employer education as well.

Iyer: Is it one day a week that you focus on social skills training for your students?

Chess: The course is personalized for every student. The teachers and instructors and the academic deans are fantastic at this. There is one day that's set aside. As students need it more, there's personal one-on-one coaching and training. Every student is different.


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Iyer: How do you define success for a particular student? I'm sure if they get an internship or find a job, that's success.

Chess: Our ultimate goal is really holding down employment and feeling fulfilled. We can work to get our students placed in a job straight out of graduation, but if they can't hold that job, is that a success for us? That's something we're constantly evaluating, making sure that they're employed. We have an alumni by the name of Xavier Romo who's been at Marvel now for seven years.

Iyer: Nice!

Chess: I'd say that's a pretty good success story! That's not an easy job for anyone to get. He's an integral part of the team. Other graduates have gone into similar roles, they may change, just like the rest of us, but they're employed full-time, they're happy, they're doing what they want to do. That's our goal.

Iyer: How do you keep in touch with alumni? Do they come back? Do they talk to the current students?

Chess: I will tell you, because I run social media, I think it's so wonderful. I constantly get invited to Instagram groups where they're sharing work long after graduation, or helping current students. It's like a family. We are as part of our 10-year anniversary looking to some of our first and second graduating year students to start an alumni network, to help them structure that. I think that's something you get out of a lot of universities that some people find really helpful. I think everybody's excited about that.

Iyer: I'll ask you one more question, and then we'll move to the Netflix collaboration. I'm sure there is a lot more demand than you can take in. I'm sure you get a lot of inquiries from parents, from guardians, from the students themselves. What is the process for figuring out who will be part of the full-time program, the part-time program? What are the criteria that you use?

Chess: First off, I'll just state that we're a nonprofit. We are always constantly doing the best that we can, but fundraising is a big part of how we do that. Giving Tuesday this year will be important for us, it's going towards expansion so that we can accomplish all of those things that we need with this new demand. But there's a process as they vet the people who are coming in. Everything starts with (right now) a virtual tour of the school. That is done in person by our Academic Dean so that she can interact with the students and their families and get an idea of their skills, their personality, their passion. You want the student to be self-motivated. We all want them here for three years and want them to succeed.

Iyer: That's why I think the plans to scale up are important, because then you'll be able to accommodate more students. There's so much demand in this space for employment of neurodiverse individuals. I think we've barely scratched the surface as of now. With all the initiatives around us, there's so much more that can be done.

Chess: Yes.

Iyer: We read that Exceptional Minds is collaborating with Netflix and creating a mentoring program, which is very exciting. How did this come about?

Chess: As they were starting to develop this mentoring program, our head of Vocational Initiatives Steff Farrar was an integral part of those conversations. A lot of these companies come to us, which is something we take pride in, asking, "How do you do this right for people on the spectrum?"

Steff was a big part of making sure that the students get the most that they can out of it, that the mentors were prepared to work with people on the spectrum and obviously provide them with the guidance they need.

Every person wants something different from a mentor. One person may want someone they can entrust with their career insecurities, another may want job skills help, a mentor should be many things. Steff did a wonderful job with our students in finding out what they wanted and making sure Netflix had the information to pair them with the right people.

Iyer: Will they create content for Netflix as well as part of this initiative?

Chess: Not that I know of as part of this initiative, but that is our fingers-crossed hope for the future. As I mentioned, we just created a short for Sesame Workshop. We are creating—we have a program going with _Cartoon Cartoons to create content. Our goal is to really help a lot of these students and graduates from the studio get their foot in the door with these companies and it helps if they have content to show already. That's a big initiative of ours.

Iyer: How many of your students will be mentored through Netflix?

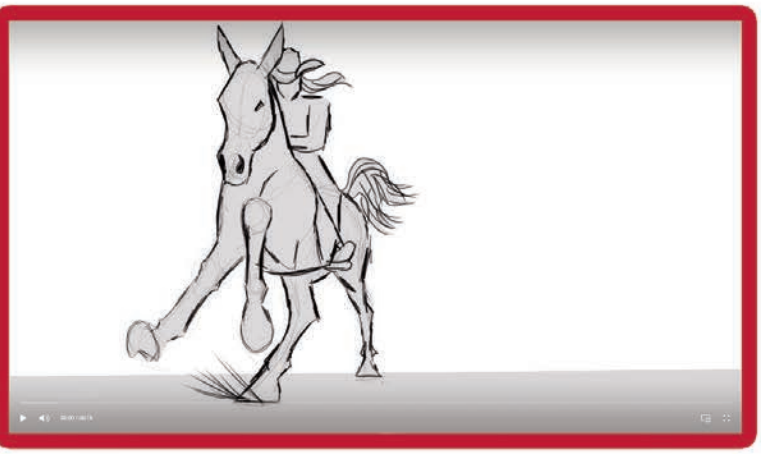
Chess: Right now it's about 33.

Iyer: That's a pretty large cohort!

Chess: Yes

Iyer: That's a good thing.

Chess: And a few of them will be one-on-one mentored, a few of them will share a mentor. They're working through that right now. I know a few of our students










have been notified of who their mentor is at this point, but I know that Netflix is still working through that pairing.

Iyer: Tell me how the program will work. I'm very interested in this. Will it be in person or virtual?

Chess: Right now, and I think this is something that will change and adapt. It's starting off as virtual.

Iyer: This sounds very encouraging. Have you thought about getting feedback from the mentors and the mentees?

Chess: Yes, that's definitely part of the plan, feedback from both sides, since this is our first phase. I think success is that we do this again, most certainly. As with any mentorship program, hopefully the mentees get a mentor for the rest of their career, for years to come, somebody they trust who can help them open doors and give them guidance and experience.

Iyer: When are you launching this officially?

Chess: It's in the works. The mentees are being chosen right now, and I know we're just getting started. We will have more information on that soon.

Iyer: I want to talk about the future of Exceptional Minds. What other programs do you have coming up? What other things are you working on? What other things would you like to see?

Chess: As I said, we're going into our 10-year anniversary, which is very exciting. We're hoping, fingers crossed with everything going on in the world, for an in-person event next April for Autism Acceptance month. What we're working on right now is more programs like Netflix and Sesame Workshop.

Iyer: Can you talk about the teams at Exceptional Minds?

Chess: We are a close-knit team. That's one of the great things about Exceptional Minds. We all help wherever we can. We have a fundraising team that just works on fundraising. We have Steff Farrar, who's doing vocational initiatives, we have faculty and the studios. Everyone is on the same page about what is best for our students.

For the future, at this point, we're set up well to be structured and to grow like we want to grow.

Iyer: And the growth trajectory has been pretty steep in the last 10 years?

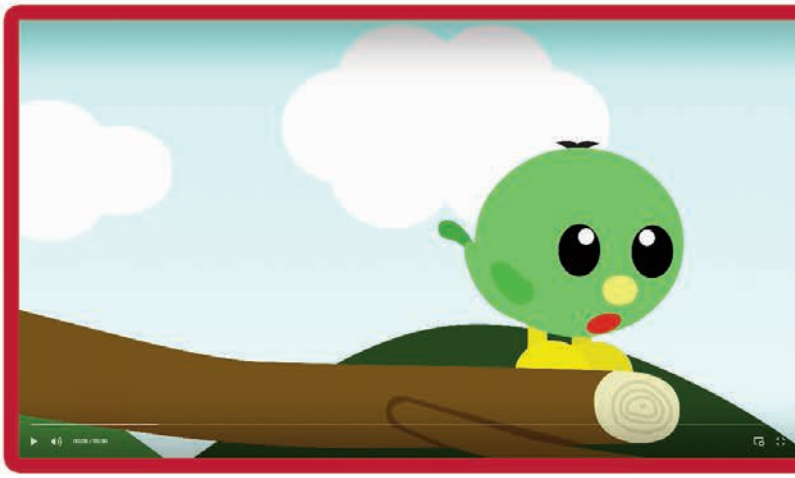
Chess: Yes.

Iyer: It grew from the initiative of a mom to a large successful enterprise.

Chess: Like any school, it took three years for the first class to graduate. That was six, seven years ago, based on the calendar year. They're still active. We still talk to







a lot of those students, growing every year, trying to increase the ability for them to go out and have fulfilling careers.

Iyer: Your plans for expansion, other than the new space, are you looking at other states, other programs outside of animation?

Chess: In terms of physical space, we'll stay in Los Angeles. But virtually, that's something we're working really hard on right now, to be able to help more people in more states. A lot of people can't just pick up and move to Los Angeles. And if they need a parent or caretaker to come with them, that's really hard to do. It's a big initiative for us to be able to do more virtual classes now that the world is more open to it.

Iyer: Are you seeing employers being more open to virtual positions as well?

Chess: Yes, the world is changing, and it's a wonderful time to be doing what we're doing. People are calling us for roles to fill. And we can say, "Absolutely, yes! We have a candidate who would be fantastic for this role, who would love to work in this animation department."

Iyer: You mentioned that during COVID you pivoted to virtual classes and virtual training. How did your students react to it? How did they take it?

Chess: Very well. I think everyone had a hard time with the cultural changes, everyone struggled with the isolation, everyone struggled with quarantine. But the success we had, and I think the pride we all have in our students, especially the class that graduated virtually, is that they adapted so well. The students succeeded, we were blown away by the talent and the will of all the students in the different classes.

Iyer: I'm really happy that your students took well to it and there was a graduating class during the quarantine, which is amazing. That speaks to the success of your program and how quickly you pivoted.

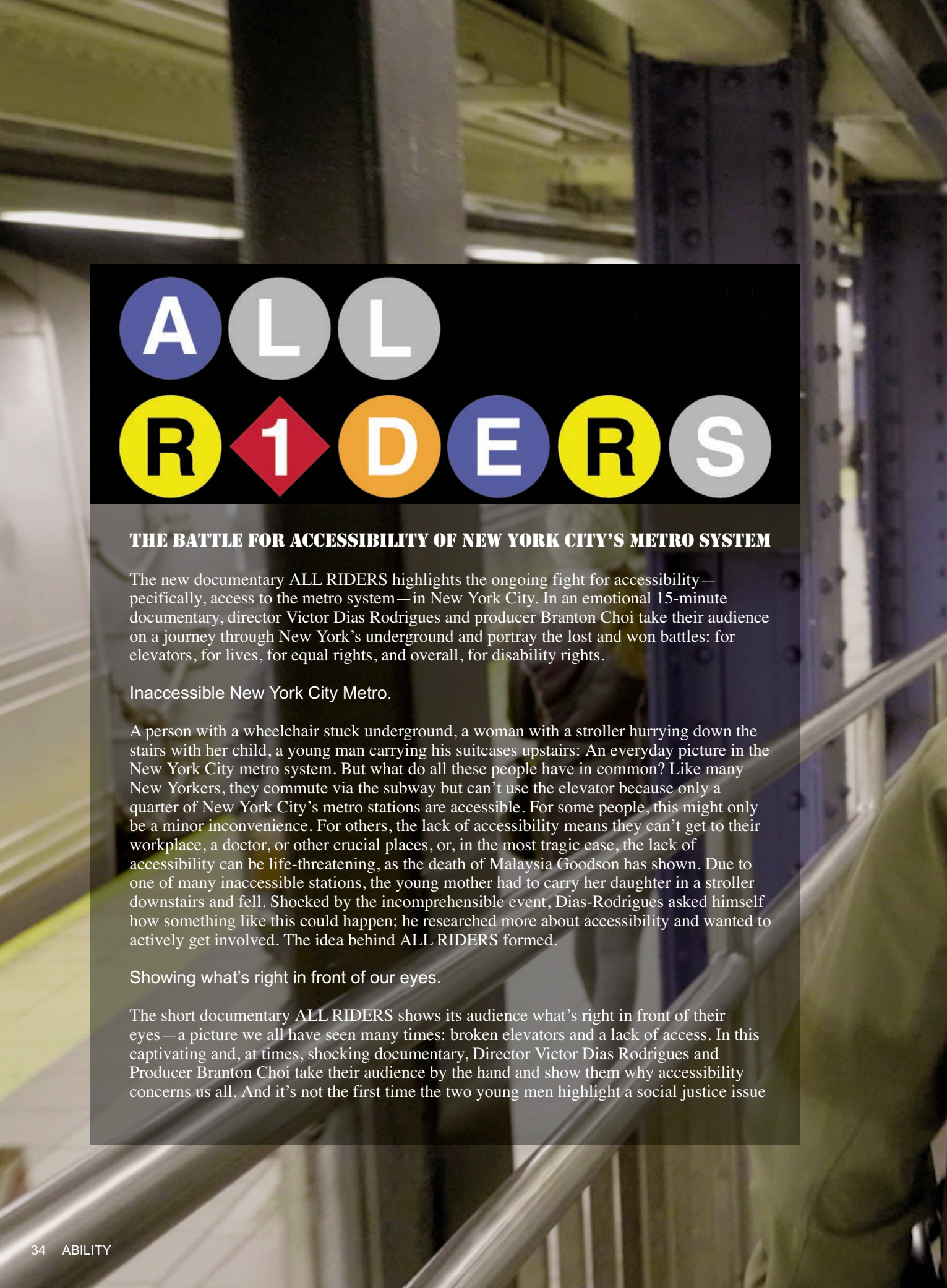
Chess: And our teachers made it work. We're all so impressed and grateful for them.

The ability of these students blows me away all the time. I'll ask students for drawings or content, things I can use on social media, and I am blown away by their talent and their ability to form this family amongst each other, and help each other and give feedback, It's a wonderful thing.

Iyer: It warms my heart, too, when I hear that they talk together and they have a good time. What kind of students do you educate right now- it is only those with autism?

Chess: Right now it's only the autism spectrum. I think that's all we've been able to take on at this point. But who knows for the future? ■ ABILITY

exceptional-minds.org




## THE BATTLE FOR ACCESSIBILITY OF NEW YORK CITY'S METRO SYSTEM

The new documentary ALL RIDERS highlights the ongoing fight for accessibility—pecifically, access to the metro system—in New York City. In an emotional 15-minute documentary, director Victor Dias Rodrigues and producer Branton Choi take their audience on a journey through New York's underground and portray the lost and won battles: for elevators, for lives, for equal rights, and overall, for disability rights.

### Inaccessible New York City Metro.

A person with a wheelchair stuck underground, a woman with a stroller hurrying down the stairs with her child, a young man carrying his suitcases upstairs: An everyday picture in the New York City metro system. But what do all these people have in common? Like many New Yorkers, they commute via the subway but can't use the elevator because only a quarter of New York City's metro stations are accessible. For some people, this might only be a minor inconvenience. For others, the lack of accessibility means they can't get to their workplace, a doctor, or other crucial places, or, in the most tragic case, the lack of accessibility can be life-threatening, as the death of Malaysia Goodson has shown. Due to one of many inaccessible stations, the young mother had to carry her daughter in a stroller downstairs and fell. Shocked by the incomprehensible event, Dias-Rodrigues asked himself how something like this could happen; he researched more about accessibility and wanted to actively get involved. The idea behind ALL RIDERS formed.

### Showing what's right in front of our eyes.

The short documentary ALL RIDERS shows its audience what's right in front of their eyes—a picture we all have seen many times: broken elevators and a lack of access. In this captivating and, at times, shocking documentary, Director Victor Dias Rodrigues and Producer Branton Choi take their audience by the hand and show them why accessibility concerns us all. And it's not the first time the two young men highlight a social justice issue





Dias Rodrigues

and give an underrepresented minority a voice. With his previous film 'The Ending of a Dream,' Dias Rodrigues sheds light on the harsh realities of undocumented workers in New York City. The film director was born in Brazil but grew up across four continents, which shaped his outlook on the complexities of the human condition, as he says himself. When Choi, an independent producer based in Los Angeles, met Dias Rodrigues, he felt inspired by his passion for the issue and immediately wanted to help him create this short film. Choi himself produced a number of award-winning films, such as 'After Class' and 'Red Bean Soup.' "Most producers have a distinction, such as 'I am a documentary filmmaker; I am a fictional producer.' But I am not really like that. I am drawn to stories with a beating heart at the center," Choi explains. "I saw documentary filmmaking as my tool to touch people's hearts with stories that have a universal quality to them, which compelled me to make ALL RIDERS," Dias Rodrigues adds.

Sasha Blair-Goldensohn is a leader of the disability rights movement.

The two filmmakers, who both identify as persons without a disability, early on decided to let the activists tell their own stories in order to represent them accurately. "Most times, I was the only able-bodied person in the room. So it was really important to have the human aspect of the story be front and center without us appearing in any way. It was crucial for us in order to represent the issue fairly and accurately to give the voice to the people who experience the issues every day," Dias Rodrigues says. The team spent a lot of time with New York's disability activists to learn from the barriers they are facing in New York City, but also what they are doing to reduce those. One of ALL RIDERS' main contributors is Sasha Blair-Goldensohn, a passionate disability rights activist based in New York City. Blair-Goldensohn started fighting for access after becoming a wheelchair user in 2009. One morning, while doing what so many New Yorkers do—jogging through Central Park—a large trunk broke off a tree and hit Blair-Goldensohn on his head. Unconscious and heavily bleeding, he lay on the moist ground. As the 'luckiest unlucky guy,' how his mother calls him, he was saved by a doctor who also made his rounds in the park. Blair-Goldensohn survived but experienced a spinal cord trauma. Suddenly, what was once a simple everyday task, commuting via subway, became a lot more complicated, but Blair-Goldensohn isn't a person to simply accept that he cannot use the metro like other people.

Only one-quarter of all metro stations in NYC are accessible.

He began speaking up about the lack of accessibility in New York City and co-founded the Elevator Action Group, an organization fighting for improved access to the metro system. "The purpose of the Elevator Action Group was to make accessibility and inclusion of everyone, specifically, people with a disability, a reality for New York and the subway system," Blair-Goldensohn states. According to the Elevator Action Group, only 109 of the 445 elevators to NYC's metro stations are accessible. That's only every fourth elevator. The organization additionally states that other cities, for example, Los Angeles or Washington DC, have stair-free access to all of their metros. When they analyzed all daily outages in 2014, they found that of the quarter of accessible elevators, 25 failed every day. Right now, the MTA's website says there are 18

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elevators out of service—some for planned work, some for planned replacement, but eight for repair and one that's under investigation.

As a consequence of the lack of access, Blair-Goldensohn, together with several other individuals with a disability and many non-profit organizations, went to court to prove that a significant number of the high-volume station's elevators break down during rush hour and therefore restrict access for people with disabilities further. The case is still ongoing.

ALL RIDERS wants to raise awareness for these common issues.

Access is often something many people without a disability take for granted, and filmmakers Dias Rodrigues and Choi realized that's exactly where they come in. "Our job is to look at places where people don't look. The goal is for people to finally be aware of this issue. Hopefully, as more people see it, the right ones will stand up for it," Choi explains. "But we just cut the tip of the iceberg," Dias Rodrigues adds, "because accessibility is not only in transit. It's in every aspect of life. And that's what we, as able-bodied people, don't realize." Creating a film on such a crucial topic comes with many responsibilities but also challenges. "Building the relationship and gaining the trust of the activists was a very long process. It's a tightened community, and I came in as an outsider. So that was hard but gratifying," Dias Rodrigues says. For Choi, the biggest hurdle was how to pack all the footage in only 15 minutes of film. "The biggest challenge was leaving people out, because we had such great relationships with them."

One person they were not able to include in ALL RIDERS is Quemuel Arroyo, the new Chief Accessibility Officer at the MTA, successor of Alex Elegudin, who makes an appearance in ALL RIDERS, but does not work for the MTA anymore.

"Accessibility is one of our top three priorities!" — Quemuel Arroyo.

Arroyo, who calls himself a transit nerd, is the one person that can and hopefully will improve access in the area of public transportation in NYC. Just like Blair-Goldensohn, Arroyo seems like a passionate advocate for access himself and is now in a position to help make New York City a more accessible place—not a small task to begin with. "Becoming paralyzed from the waist down in a mountain biking accident 14 years ago, I discovered the world of accessibility and disability, and learned about so many voices who are silenced that I decided to reshape spaces that don't work for people




like me, people with disabilities," Arroyo says. Like the "quintessential New Yorker," Arroyo is regularly commuting by bus and subway himself. When asked if that's because as the Chief Accessibility Officer, in order to fix an issue, he first needs to know where the problems lie, he laughs and says: "The real truth is: I commute because I don't know how to drive, and I don't want to learn how to drive. So commuting is the only way for me to move around." As a wheelchair user, he knows quite well what Blair-Goldensohn and his organization is criticizing. "Two blocks away from home, we have a train that is not accessible to me right now. So yes, I am facing the same issues that other New Yorkers—older people, people with disabilities and many more—face within a system that wasn't designed with us in mind," Arroyo states.

### Commuting as a wheelchair user in NY is complicated.

Blair-Goldensohn, who works at Google, commutes by subway as well. Before his injury, he had no issues getting back and forth between his office, that's about three miles from his apartment. "It always seemed natural and not interesting at all to use public transportation at any time of the day; I could change my plans last minute and meet somebody after work, and we would go over to Brooklyn, but once I started trying to get around independently in my wheelchair, I realized it was not that simple anymore," Blair-Goldensohn says. First, it starts with a lot of planning. "Before I go out, I have to think about: What's the weather like today? Is it raining? Do I have a big bag? When is my meeting? Can I be late? Your natural inclination is that you choose the best possibility, but that list gets very constrained when you use a wheelchair, so suddenly, there is really only one subway station, and it's not the closest one. You only have one choice where you used to have many. And it's not even your choice; somebody has chosen for you," he explains. So unlike other people, Blair-Goldensohn cannot use the metro station right at his house, nor can he use the one in front of his office, because neither has an elevator or ramp. He needs to find the nearest accessible station and hope that the elevator is working. But that's not all. When he reaches the closest accessible station, Blair-Goldensohn faces four elevators in total until he gets to his destination. In the middle of his transit, he has to transfer between two trains, which means switching platforms by elevator, "and that elevator is constantly out of service," he says. If only one of those four elevators is broken, he either has to take a long detour—considering NYC winters and blizzards—or he may be stuck underground.

### Redefining accessibility in NYC.

Arroyo not only plans to create more access for people with disabilities, but wants to redefine accessibility beyond elevators and ramps. According to the young man, who grew up between the Dominican Republic and New York City, compared to any prior plans, the MTA is working on the most robust capital plan for accessibility. They are going to allocate $5.3 billion to install at least 70 new elevators throughout the metro network. "Additionally, I am normalizing accessibility and disability at my office so that all of my colleagues that come after me are comfortable speaking about accessibility when I am not in the room. My personal measure of success is: When I leave this position, and I




am the only one talking about accessibility, I failed epically," Arroyo states. He says barriers were built unintentionally, which they now try to break down. One new measure to improve accessibility is that whenever a train comes into the station, accessibility information will be announced so that passengers know if an elevator is out of order before they get on the train. Another accessibility feature is that the passenger load of each of the train's cars will be shown, which will help commuters to know where to find an empty seat.

But why does this take so long? And more importantly, when will all stations be accessible for everyone? A tricky question. "To rebuild a system without ever taking it offline… You want me to replace a plane without stopping it from flying? It takes time to do that efficiently. I worked on a similar project in a previous job, and I gave us a 30-year timeline there, but NYC is so complex, you likely need decades," Arroyo says.

Arroyo stresses several times that he wants to create access for all people, all New Yorkers. "My door is open, and I have a brilliant team here, but in order to deliver the system the public wants to see, we need to hear from everyone. I make that invitation because I believe the best policy arrives when we work with the end-users. I don't want to hear from one group alone; I want diversity: Parents, seniors, tourists, people with and without disabilities."

The MTA's strategy sounds promising if really all happens as planned. However, if not, Sasha Blair-Goldensohn and the behind-the-camera team of ALL RIDERS will surely be there, watching the process closely, and together, they will raise their voices to make everyone aware that "fostering an inclusive society elevates the living standards of all people," to put it in the words of Victor Dias Rodrigues, or, with a bit more pressure, from a person that's directly affected, Sasha Blair-Goldensohn, "If we are being excluded, it is not only wrong and damaging to us, but it is a huge loss to the society at large. The belief that accessibility is too difficult or too expensive is not only morally wrong, but it's factually and economically incorrect." ■ ABILITY

*The film is currently in contention for the best documentary short subject category at the 94th Academy Awards, and versions with captions and descriptive audio will be available as well.*

by Karina U. Sturm

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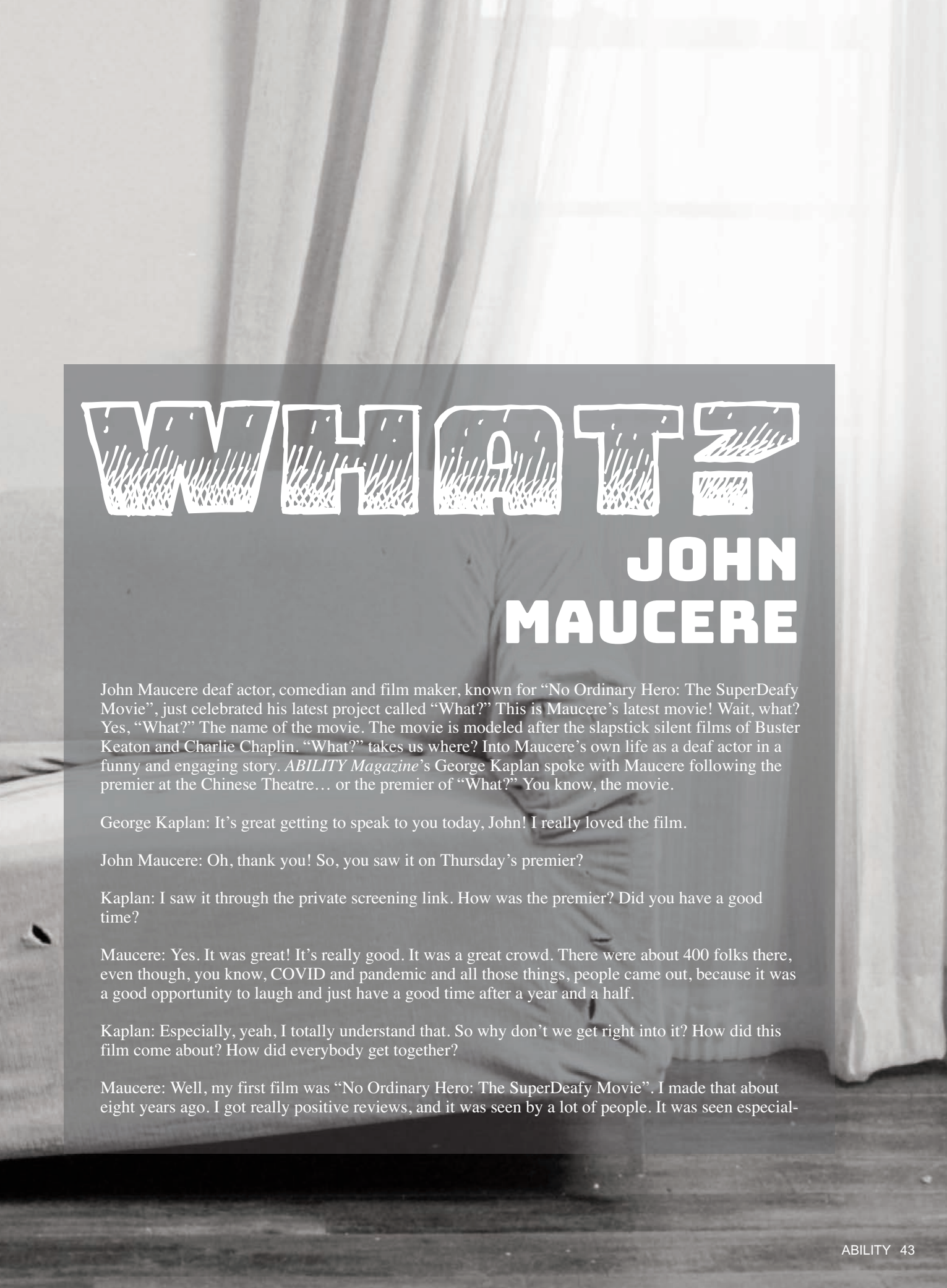
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# WHAT?

## JOHN MAUCERE

John Maucere deaf actor, comedian and film maker, known for "No Ordinary Hero: The SuperDeafy Movie", just celebrated his latest project called "What?" This is Maucere's latest movie! Wait, what? Yes, "What?" The name of the movie. The movie is modeled after the slapstick silent films of Buster Keaton and Charlie Chaplin. "What?" takes us where? Into Maucere's own life as a deaf actor in a funny and engaging story. *ABILITY Magazine*'s George Kaplan spoke with Maucere following the premier at the Chinese Theatre… or the premier of "What?" You know, the movie.

George Kaplan: It's great getting to speak to you today, John! I really loved the film.

John Maucere: Oh, thank you! So, you saw it on Thursday's premier?

Kaplan: I saw it through the private screening link. How was the premier? Did you have a good time?

Maucere: Yes. It was great! It's really good. It was a great crowd. There were about 400 folks there, even though, you know, COVID and pandemic and all those things, people came out, because it was a good opportunity to laugh and just have a good time after a year and a half.

Kaplan: Especially, yeah, I totally understand that. So why don't we get right into it? How did this film come about? How did everybody get together?

Maucere: Well, my first film was "No Ordinary Hero: The SuperDeafy Movie". I made that about eight years ago. I got really positive reviews, and it was seen by a lot of people. It was seen especial-



John Maucere in "What?"

deaf and hard-of-hearing people all over the world because they often don't get that kind of entertainment focused on them. And I thought, "Let's make another one!" And that took another, I guess, about six years to come to fruition.

I met Alek Lev, who is the writer. And my brother, Paul, and I founded our own company, The Maucere Brothers. We liked Alek, and we said we wanted to develop a story about my journey as an actor and my struggles. Back in the '80s and '90s, I was coming of age in Hollywood. So, I've been doing this a long time. We wanted to talk about that and for it not to be some sympathetic, heart-wrenching, "look-at-this-poor-guy in deaf Hollywood". We wanted it to be fun and funny and entertaining, but at the same time have a message. Alek is a silent film aficionado, and that really opened us up to a lot of different storytelling ideas. And from there it came together.

Kaplan: That's amazing! This movie not only features ASL but also Catalan and German sign language. What inspired that?

Maucere: (laughs) Yeah, I'm glad you brought that up. I've traveled all over the world doing my stand-up show. I've been to 40 countries. And a lot of people think that there is one universal sign language, and that's not true. Every country has their own sign language. So, as I've traveled, I thought, "You know, I would love to be able to include some other sign languages in this film." Since we're all deaf, we have a similar experience. And regardless of where we go, we are manual communicators. And there's a very, very rich audience all around the world. So, I decided that I would include some of that.

Kaplan: That was amazing! It was great to see that side of it, and to see the cultural differences while having a big universal commonality, like being deaf, see how different that could be through the different variants. I know we talked about the premier that you had last week. Could you tell me more about it, how the audience reacted? Was it your first time seeing the film?

Maucere: Yeah! Yeah! It was my first time seeing it on the big screen at the Chinese Theater! It seemed huge! I sat pretty close, and I kind of had to (laughs) lean back to take myself in completely. It's nice. I really do—I don't like looking at myself on-screen, everybody hates that. But it was good to see it on the big screen. I'd been working with the director and the editor, and we'd seen a lot of versions on the small screen. I noticed that the energy from the audience with it on the big screen really changes things. It was a great experience. I love that feeling.

The audience reaction was very positive. I have to admit, I was nervous. Because I'd seen it so many times, I had become numb to it. But for the audience to experience it for the first time–My friend who is hearing said, "Oh, people laughed, people were awed, they were touched and moved! They really did go on the ride with you." So, my hearing friend was telling me about the things that he was hearing in the audience. And then they were saying, "Make more! Make more!" (laughs)

Kaplan: That's amazing!

Maucere: It's a lot of work, more than you would think.

Kaplan: Oh, I'm sure. And in this business, I'm sure you're not the only deaf person on-set many times. What did it feel like to be working with a majority deaf cast this time around?

Maucere: You know, I've been in a few television programs through the years. You go away on a six-week shoot or a two-week shoot or even a one-week shoot, and you're there. And the only other person you can sign with is the interpreter. Everybody else is hearing. It's just you and your interpreter, usually killing time in the trailer, spending a lot of time with your interpreter. They become your best friend on-set. And even though the cast is perfectly nice to us, compared to filming What?, nearly everyone, I would say 85% of the folks on the cast and crew and on-set were deaf. The chef, the lighting folks, the production assistants, the hair and makeup, deaf cast. We had deaf mentors all around the set as well. And when you see that ratio slip to the highest ratio of deaf people, I wasn't quite used to that.

Maucere: I also wanted those hearing people on our set to feel comfortable and to have access, so we provided interpreters, and a lot of the hearing people were a little unsure about being in the direction, that it was all being run by deaf, produced by deaf people. And in the end, they were like, "Wow! It's like being part of a family! Everybody just works together." There was so much love and emotion when it was over, it was really good. Just a great experience.

Kaplan: In a previous issue, we had your former collaborator Marlee Matlin with us, and we talked about accessibility and representation in Hollywood, something this film critiques as well. What would you like to see change personally for you?

Maucere: Well, first of all, Marlee Matlin is one of my greatest friends. She has opened many, many doors for us. In 1985, I believe, she came on the scene, and over the years, she has done so much to help improve things for us in the industry. Now, what I've noticed, because you did ask what I've seen change myself, was that the question?

Kaplan: It could be both. I was asking to clarify what you would like to see change, but if you've seen some changes that you are happy with or you think there's a shift, I would love to know about it.

Maucere: Oh, OK. I know you saw the movie and you know it's called What? It's not an indictment of anyone. Through the years, people have tried to hire deaf people, tried to tell our stories and include deaf people, but those writers are not—It's not written by deaf people. It would be nice if there were persons who were part of the creative teams that when they're going to have a deaf storyline, they have a deaf consultant. If there are scenes with deaf people in them and there's conversation, a deaf person can help structure that culturally and linguistically for the production. That's what I'd really like to see.

In the movie, "What?", we found a hearing director—The storyline of the movie is that the hearing director finds a hearing guy to play the role and then has a deaf guy try to teach him sign language. That is actually very common and has been. I've been asked by many, many productions to teach hearing people to sign. And I've turned it down because they're playing deaf roles. I can't do that. So, if the storyline of the movie mirrors real-life storylines, I would like to see deaf people included as part of the creative team, to help develop the storyline, the dialogue for those deaf characters. That would be more authentic. That would bring authenticity. That's what I'd like to see.

Often, we'll go to an audition and meet numerous people in the room–There could be 30 people waiting who are all hearing.–and they'll ask me, hey, how do you sign this? How do you sign that? And I'm like, "It's a role for a deaf person, and the hearing person is asking me at the audition how to sign this?" So that happens. For directors, writers, producers in the audition room, when they're watching people audition in sign language, they typically don't know sign language themselves, so they don't know if it's being done correctly. And sometimes they're looking at the person and they go, "Yeah, that one!" But they're not signing with authenticity.

Now, if you had a deaf person sitting on your creative team or if you had a person who was a master signer, who could sit on the team and say, "This person is not signing with authenticity." If you are hiring someone to speak in a role that's written in Spanish, and no one on your creative team speaks Spanish, zero, like Catalan, and that person comes in and they're just learning how to do it phonetically and they're acting it, you can tell. You're not going to pick a person who's just learned it the day before.

Kaplan: That's interesting. I know that interpreting, too, is its own skill and it takes a while to find an interpreter who matches your energy and who lines up exactly with how you're signing. I know that's a struggle as well. Can you tell me how long it took you to find interpreters who work well with you?

Maucere: That's a good question, a really good question. And an important one as well. My interpreter here is Jon Wolfe. We've been working together on publicity for this film, and Jon knows my sign style. He knows my expression. We have a great relationship. We work well together. It's a good interpretation. I can't just—I don't want to pull just any interpreter off the street who doesn't know my entertainment, hasn't seen my films,

who doesn't know or understand technical signs from the industry. That's an important part for the interpreter to be able to convey for a deaf actor. It makes it more awkward if you don't have the right interpreter.

Now, Jon Wolfe, he is an actor and also an interpreter, and he knows how to sign technically according to the things that are required by the industry. He knows how to be on-set, where to stand to stay out of the way, get off-camera, make sure that the director and producers feel like the interpreter is present and creating that smooth, accessible experience for the talent. And it is very important. Like Jack Jason has done with Marlee for years and years and years. They're always together. He knows her, and that's important.

Kaplan: Yes, very in sync, those two. I saw it in person, and it was amazing, almost like siblings.

Maucere: (laughs) Yes, exactly!

Kaplan: You're a notable alumnus of Gallaudet. What is it about the experience there that prepared you for going on to the real world? What was that like, going back to school there? We've worked with them several times.

Maucere: Oh, gosh. I was at Gallaudet University ages ago. I learned a lot there. It gave me a lot more confidence in having a future, it gave me confidence in my abilities. The education they gave us that we should stand up for ourselves with confidence and move forward makes Gallaudet, I think, probably the best place for a deaf person to go to college because it is the only liberal arts college in the world for the deaf. It's like the Harvard of the deaf world. It just is. What they modeled for us there, the professors and the faculty and the administration, all deaf. All of those folks were deaf, and they were role models for us that we can step up and take positions of leadership as well. I have many friends who graduated from Gallaudet who have gone on to be great successes in their fields. It's because they have confidence, and they have direct communication at Gallaudet in our native language.

There's RIT, too, the Rochester Institute of Technology. There's CSUN in Northridge. I left Gallaudet when I was a junior—I did not graduate from Gallaudet—right after the Deaf President. I left Gallaudet to pursue my acting career. I did that for five years, and then I went back to school at CSUN to finish my degree in Deaf Studies. Then I began working as a certified deaf interpreter in the court system and then did my acting.

Kaplan: That's really cool. What draws you to make your own projects? Is it the frustration with Hollywood itself that brings out this creativity? What makes you seek out to make these kinds of projects and reach out to the community?

Maucere: OK. I'm probably one of the few folks in Hollywood who actually was born here in Hollywood and became an actor. I have been struggling in Hollywood for many years. One thing is, I don't speak. I am a third-generation deaf family. I speak very little. I mostly sign. My acting talent is through my body and my hands and my face. So many roles in Hollywood, especially in the '80s and '90s, required a deaf person to speak. They wanted that person to be able to speak, and that's really frustrating. It's hard to sit around and wait for the right role to come along.

With the advent of YouTube, it became easier for folks to create content. And I found my passion there creating content, and I had a deaf audience. That helped me to find the motivation for my first film, which was "No Ordinary Hero: The SuperDeafy Movie." I probably should send you a DVD so you can watch that one, too. That was the beginning of my journey in filmmaking. Basically, I thought, "Let me create a story so that I can be a hero, do the lead, and not sit around and wait for folks to bring a role to me." And after that one was done, I knew that I wanted to make another, and now I'm working on my third.

Kaplan: Oh! I'd love to hear more about the third one, too. We love What?, but we'd love to hear more about the third one, too.

Maucere: I wish I could tell you!

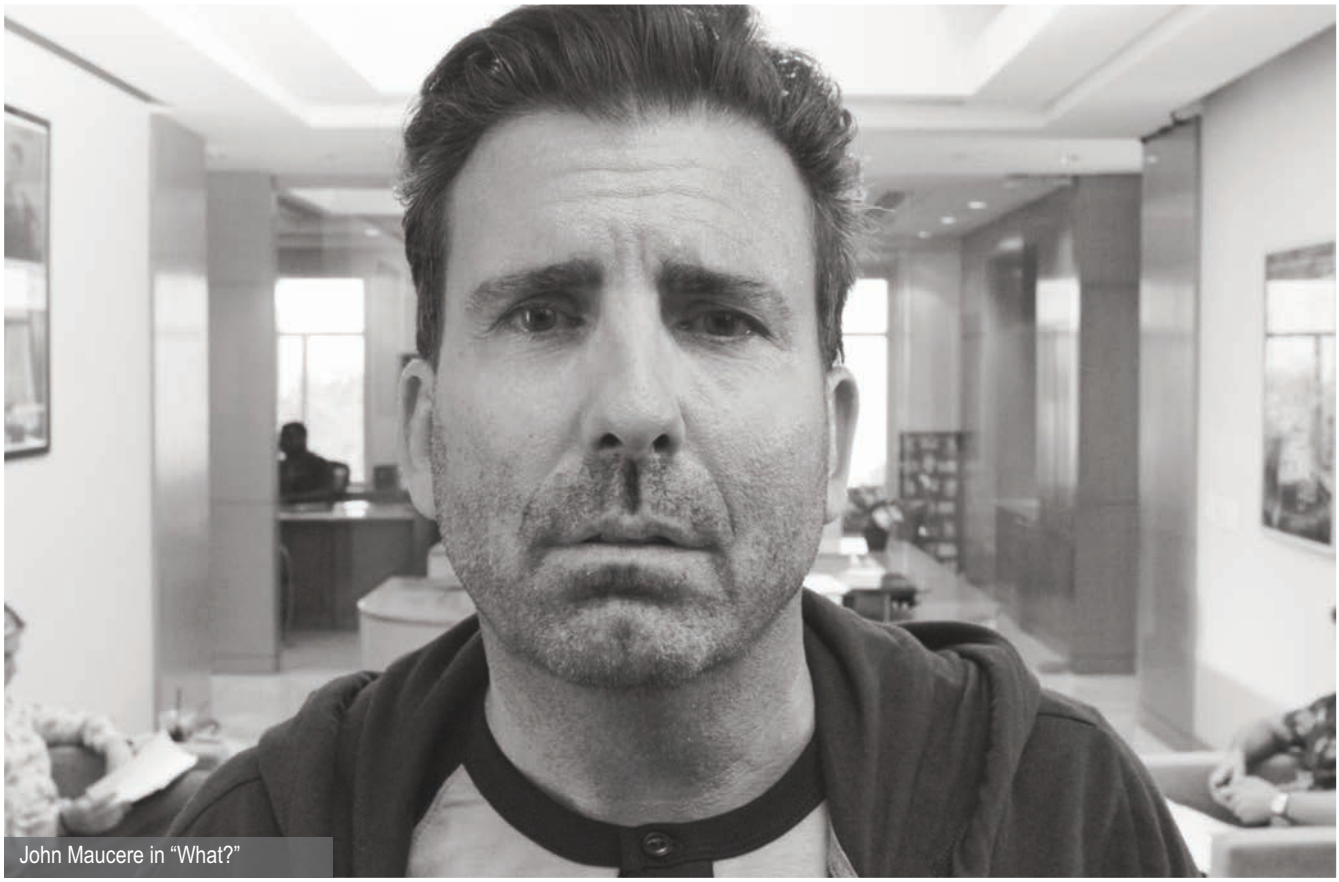
Kaplan: (laughs)

Maucere: But it's one of those things. It's already scripted, things are ready to go. We're waiting for this one to be bought, and then, hopefully, we'll be able to increase the size and scope of our project. We have to start and then grow. We founded our own company. It's called The Maucere Brothers. The goal of my brother Paul and me is to make more films. Also, I want to mention–I was going to also say about that what makes What? the movie unique is that all of the investors were also deaf. All of the funds were raised from deaf people. There was one donor who was hearing, but a person who has a deaf heart for sure. We had deaf folks from Germany and Spain and all over putting money into the film because they want to see deaf people in film.

Kaplan: That's great! What about SuperDeafy prepared you for "What?"? Were there any lessons you learned along the way?

Maucere: SuperDeafy was a great, great film. I had a great director, Troy Kotsur, who is now the star of the movie "CODA" Marlee Matlin was in the film as well, one of the stars of "CODA" Shoshannah Stern, who is a star in her own right. I had a great cast. What I learned from SuperDeafy that I brought to "What?" was to hire PR. You have to have good publicity. I thought, "Oh, we can do it ourselves." And you can't. We want our films to be mainstream for a hearing


JOHN MAUCERE
WHAT?
WINNER
BEST FEATURE FILM
Eurasia International Film Festival
2021
WINNER
BEST FEATURE FILM
Black & White Film Festival
2021
WINNER
BEST FEATURE FILM
Culture & Diversity Film Festival
2021
WINNER
AWARD OF SPECIAL MERIT: LEADING ACTOR
The IndieFest Film Awards
2021
WINNER
AWARD OF MERIT: DISABILITY ISSUES
The IndieFest Film Awards
2021
BEST FEATURE FILM NOMINEE
Paris Film Festival
2021
BEST FEATURE FILM NOMINEE
Rome Independent Film PRISMA Awards
2021
SEMI-FINALIST
Boden International Film Festival
2021
OFFICIAL SELECTION
Dances With Films
2021
OFFICIAL SELECTION
SOMA Film Festival
2021
OFFICIAL SELECTION
San Diego Movie Awards
2021
OFFICIAL SELECTION
Raleigh Film & Arts Festival
2021
OFFICIAL SELECTION
Los Angeles Lift-Off Film Festival
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SHEENA LYLES CHRISTINA SCHÖNFELD LIZ TANNENBAUM MUSIC BY JUSTIN ASHER MAKEUP DESIGNER MAIA WAGLE COSTUME DESIGNER CAROLYN MAZUCA PRODUCTION DESIGN AARON KEE EDITED BY ALEK LEV DIRECTOR OF PHOTOGRAPHY RUAN DU PLESSIS SUPERVISING ART DIRECTOR ROBIN TAYLOR
THOMAS OTTO-BRUC TERRI OTTO-BRUC UWE SCHÖENFELD VANESSA R. VAUGHAN PRODUCED BY PAUL J. MAUCERE CASSANDRA JONES ALEK LEV STORY BY ALEK LEV JOHN MAUCERE DJ KURS WRITTEN AND DIRECTED BY ALEK LEV
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John Maucere in "What?"

audience to enjoy them, and so for this film, we have hired David Robertson, who made this interview happen for us. What we learned from "No Ordinary Hero" was that some things you can't do on your own. We wanted to work with a hearing publicist who could help us access that part of the world, people who had open hearts and open minds and wanted to learn with us what we had learned on "No Ordinary Hero" and that we could do better on "What?."

Kaplan: Great. Going it alone is never—I feel like in independent filmmaking every step of the way you learn that you can't do it yourself and that it takes a team. What lessons did you learn from What? that you'll apply to this next film? Because I know that What? was a huge undertaking. And you shot for two weeks, which must have been something.

Maucere: On Thursday, at the world premier, what was the world premier, and we have now been selected for 13 other film festivals, "No Ordinary Hero" was in three, "What?" is in 13, which is very nice. What I see that we learned from No Ordinary Hero to be What? and now to our future projects will be—that's a good question. Let me think about that. Ask me something else. We'll come back to it.

Kaplan: (laughs) No worries.

Maucere: To be honest with you, I feel like What?, everything has fallen into place as we made the path, and then it makes me thing, to your question, what have I learned for the next film, OK. What I would do next and what I've learned from What? is that it would be nice to have a marquee actor, an A-list actor, for example, Marlee Matlin or another hearing or deaf name. Because that way, buyers are more motivated. I've learned that as well. Other than that, the movie What? is just really great, fantastic. You saw it. What did you think? You tell me.

Kaplan: I thought it was a great way to bring a community together. You start from the experience of this actor. You have beautiful communities of artists who support each other spring up. I thought that was a beautiful aspect to the film.

Did your community show up for you last week? How was that experience of everybody showing up for that premier? Four hundred people, that's pretty wild.

Maucere: Before we were chosen to be in Dances with Films, the film festival, and way before COVID, after the pandemic began to make a resurgence, we were a little concerned. And that was way before we were chosen for the film festival. Would people come out and see the movie? I think it's a testament to those who desire to see films that are in their native language, in their native culture. It really brought folks out. There was an actor party, of course. We were there until 1 a.m. last Friday morning just talking about how much we enjoyed the film, people talking about it, asking us if we were going

to make more—such a great, fun experience. They were so good to us. They're our biggest fans, and they're our community. And you're right, it takes a community to make things grow.

Kaplan: Talking about community, what would you say to an up-and-coming deaf actor, someone who's walking in your footsteps right now and looking at the challenges ahead?

Maucere: When I travel, and I travel all over the world performing–Before I do my performance, I go to schools for the deaf and I talk to the students. I talk about how I got into entertainment. I always say that the number one thing is passion. You've got to have passion. That's number one. You've got to have the dream that you chase after and reach. Don't sit around and wait for folks to hire you. Be on the move. In the movie "No Ordinary Hero: The SuperDeafy Movie" it took about 15 years for that to come together. Fifteen years. It's a tough business to get into. It is. But why do I persist? Passion.

Secondly, don't be alone. Have a team. Work with others. Have a similar goal. What's best about working with a team–I used to work alone, and then I started to gather my cohorts. And I realized that it takes a lot of people–And not just in the movie world or the entertainment business, in any business.–First you have to have passion for what you want to do and you have to have consistency. It's hard because you know that a lot of doors are out there, but they may not be open to you. When one does open, an open door begets other open door and those doors you continue to follow because you bring your passion. I've been doing that for nearly 25 years. Now I'm seeing those young people as they grow up, and they are succeeding in their careers. They do that because I've helped to remind them to always bring their passion.

I tell them that I struggled for many years, but I persist because I kept doing things on my own, having passion.

Kaplan: That's great! I love that! Is there any other project coming up? You talked about the third film, are there any other things that we should be aware of? Besides What?, hopefully we'll have more answers about distribution and things like that.

Maucere: Yes, there's that, hopefully someone will be interested in buying it. There are several projects percolating now. A number of people have asked me to be part of a project that they're working on. Again, I'm not standing around waiting for them to come to me. I'm working on other things, moving forward with creative ideas and collaboration. I want more deaf and hearing people to work together. Of course, it has to be good. We want good content, always. In my third film, it has nothing to do with being deaf. The story itself could be anyone. Any actor could play this role, hearing, deaf, any ethnicity. It's not about being deaf. My first film was about deafness, my second film was about me being deaf in Hollywood, so this third film I'm really excited about.

Also, I was a Deaf Studies major, so I have a B.A. in Deaf Studies. I've been very involved with deaf advocacy, deaf rights, linguistics, access to ASL for years. And doing that, I realized how hard it is to get through. When I made "No Ordinary Hero", that was about schooling. When people watched it–about the boy who goes into public school with no interpreter and struggles trying to read speech, and then when he goes to the right school with the right deaf teachers, surrounded by other deaf students, he begins to learn. I found that storyline through my advocacy for deaf rights, and I was able to put that in the film that people could enjoy, but at the same time, understand that–What do you think is the best school for a deaf person? It's a school for the deaf! Instead of me painting signs and standing on a picket line and having folks march around, the best way is to make a film that's entertaining and that contains a message. Again, we did that with What? in a way.

We've fought for years for deaf people to play deaf roles, deaf characters. The best way to do that is to make a film where all the characters or most of them are deaf, and then that is the message.

Kaplan: What would be the biggest takeaway that you hope that people have from launching What??

Maucere: I think the goal of the film, or the goal of any film, is that there's a message that one gets and that it's important that actors are tasked for authenticity and that they have laughed and that they have had heartfelt moments and that they're not left with some heavy, foreboding sense of, "Oh, that poor guy." That they laughed and it was funny and that they had a great experience, regardless of whether they were deaf or hearing. By the way, on Thursday, probably we had about 75% of the audience deaf and 25% hearing, and I wanted the deaf and hearing people to sit side by side in the theater and laugh together. And "Aw!" together, and have that experience together and be able to leave and talk about the film. We typically don't have that experience.

What? is a black-and-white silent film. The information is given to the audience in various ways, so everyone has access to the story, and it's all there in one place. For years, I've been watching stuff and trying to figure out what's going on and who would laugh and find things funny, always trying to figure out what was going on. In this film, everybody leaves having a simultaneous experience.

Kaplan: That's beautiful, I love that! Also, as a side note, how did you get Keaton Talmadge in those scenes, the painting scene?



Photo by Amy Graves

Maucere: Oh, the actor! The interpreter didn't recognize the name.

Kaplan: The great-granddaughter of Buster Keaton. I thought that was such a cool ode to silent films and a great part to have for her.

Maucere: Oh, yes, yeah. Thank you to Alek Lev. Alek is really a silent film aficionado. He's a big fan of Chaplin, Buster Keaton. He is one of the co-founders of the Buster Keaton Association. He even named his own kid Chaplin, he has a son named Chaplin. So to say he's a diehard fan. He's connected to that network with folks, and he knew Buster Keaton's great-granddaughter. A nd he was honored that she was able to be in the film. It was awesome that we were able to include those actual locations where Buster Keaton performed. You saw the film and you saw the outtakes at the end where we showed you the actual path trodden by Buster Keaton for those specific scenes. It was nice to have her on board. We were thrilled.

Kaplan: That's amazing. I've had a great time speaking with you. I don't know if there's anything else you would like to put out there.

Maucere: I was just going to say one more thing before we close. You know, hearing people also of course are auditorily triggered to emotions in music and sound and stuff like that. Deaf people are attuned to facial expressions and body language. So in this film, What?, deaf and hearing people have a similar experience together. As the film open, we see the film open in color. And then as we get into the story of Don, it becomes black and white, where we see Don struggle and throughout the film he finds resolution and it becomes color again. That's what's music to our eyes, to see those changes, to help us connect with the story, the same way that music would give a hearing person access. Because we're deaf, we're so visual that color helps us feel the connection to the film in a way as it transitions.

Kaplan: I really loved the film. I thought it was a great ode to silent film and an ingenious way to have a movie with mostly deaf characters in that silent genre. I thought that was such a smart move.

Have you been able to travel during COVID with your stand-up?

Maucere: No. I canceled probably 20 shows. I stayed home. I've had the itch to perform! I've done—it's good to have a little break, but it's an itch that needs to be scratched. I'm going to France. Oh, I went to France to perform, and then things got bad again and I've been stuck at home. It's tough.

Kaplan: What about masks? Do you read lips?

Maucere: You know what's great about ASL. People think it's all about the hands, but it includes the face and expression and all of the grammar that we have is in our facial expressions. And half of that is muffled. You're really missing a lot of information. It's hard to understand when you're masked. And it can be very frustrating. Hearing people can hear what's being said, but half of your expression is being thwarted by wearing a mask, so it's really tough.

People are so visually attuned that half the information is going, you can see a person's eyes and that's all you've got. ■ ABILITY

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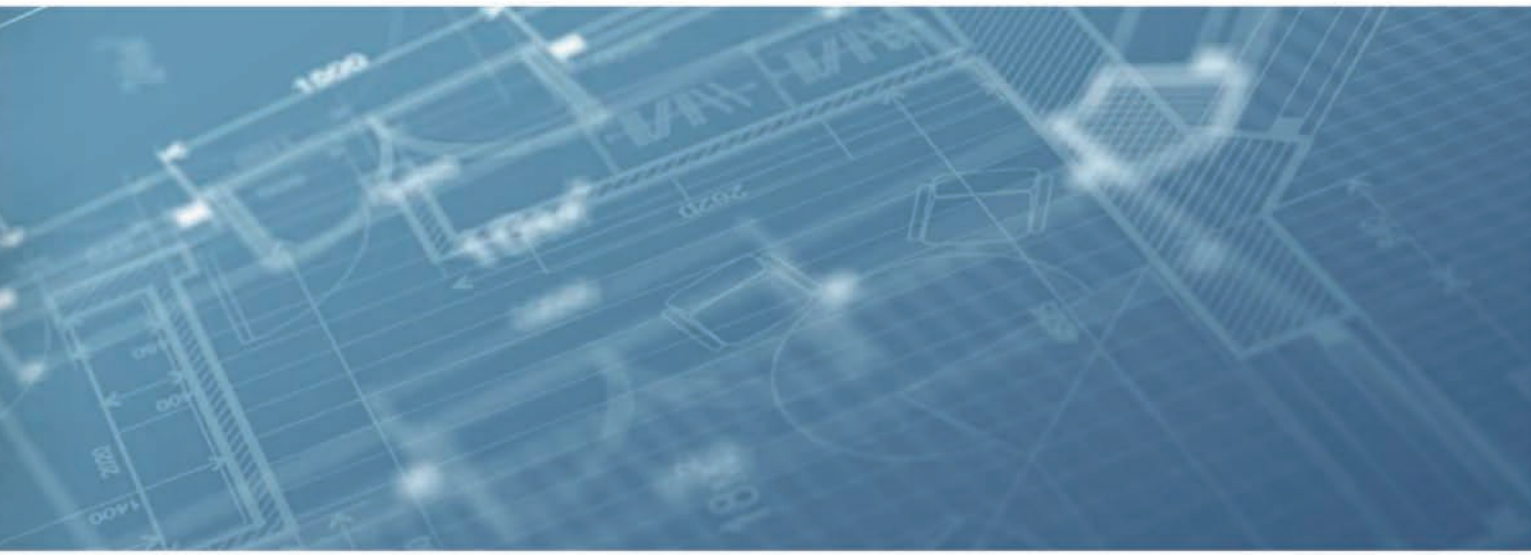
# UNIVERSAL



# A Love Story



# DESIGN



Since the 1970's and long before the passing of the ADA, Colleen Starkloff was part of the disability rights movement of individuals working toward societal change. Her work started serendipitously when Colleen was fresh out of physical therapy school; she met Max Starkloff, renowned activist, advocate, quadriplegic and the love of her life. Together, Colleen and Max founded Paraquad, Inc. and worked to create independent living options for disabled people who wanted to move beyond living in an institution and who wanted to live a full life in society. Throughout the years, Colleen has been teaching, speaking and working toward a broader society of inclusion through housing and Universal Design, a product design method that is accessible to people with disabilities and benefits all. Today, she organizes events that engage various home production professionals in Universal Design in order to bring about more accessible living spaces for everyone. *ABILITY*'s, Chet Cooper, spoke with Colleen about what lead her to this path of disability advocacy and the experience of Universal Design in her own life.



It is important to note that this kitchen was developed specifically to take advantage of the fact that power wheelchairs can now be purchased with an elevator on them so the seated cook can pull under the workspaces, sink, or cooktop and raise their wheelchair to a comfortable level to work on food preparation. For the homeowner who doesn't need the access accommodations, the 36 counter height is attractive and functional for them. Best of both worlds!

Chet Cooper: We have been running in the same circle for years, but I don't know if we've crossed paths? Let's start by sharing a little about your background.

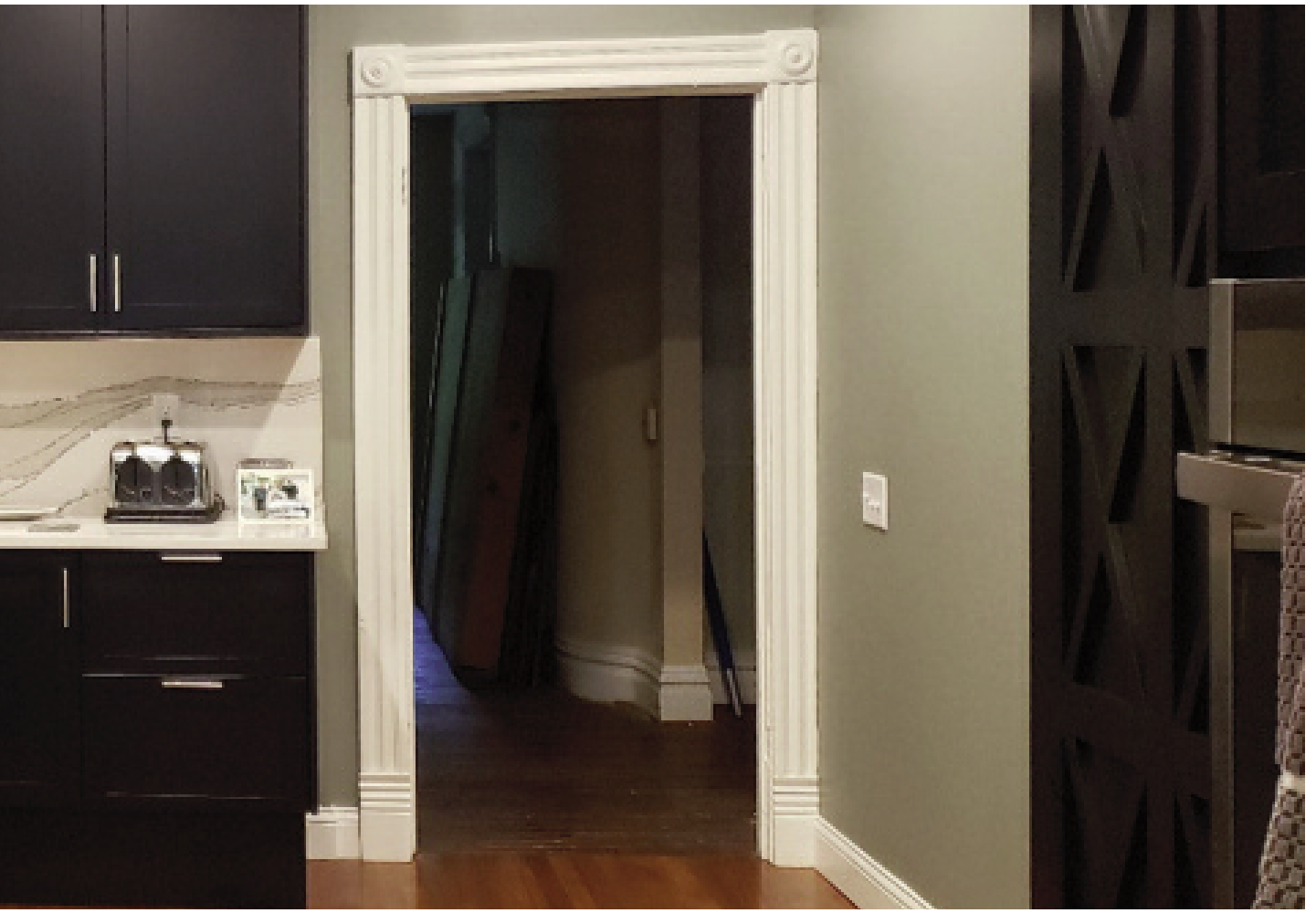
Colleen Starkloff: We have had to have been in the same room as each other at some point—we just didn't know it. Well, I started my career as a physical therapist straight out of school. I went to St. Louis University where I earned my degree in Physical Therapy. The year before I graduated, I was invited to interview for a job as the Chief Physical Therapist in a nursing home in Eureka, Missouri, a very rural area. I must have really impressed them in my interview because I was a year from actually graduating, but they held the job for me. They had a PT who worked part-time, so the plan was for him to stay there until I finished school. And once I completed my program, I was to take over the department as a Physical Therapy student right out of school. But I started my career as an advocate for people with disabilities when I met my husband, Max Starkloff.

Cooper: You must have great interviewing skills.

Starkloff: (laughs) It was a little intimidating, but I've never been one to back away from an opportunity. So, I took it. On the first day there, I saw a man in a power wheelchair, wheeling himself down the hallway with one arm, and he hooked his other arm over the handle on the back of the chair. As he was wheeling down, I never saw his face, but as he wheeled past me, he said to the physical therapist, "Hi, Roger," and Roger said, "Hi, Max". Now, I had heard about this guy named Max Starkloff who was a quadriplegic and lived in this nursing home. My sister had worked there as an aide during the previous summer when she was home from college. And he had asked her out on a date, but she didn't want to go out with him because he was disabled, which ended up being a really good thing for me.

Cooper: That's an understatement!

Starkloff: (laughs) My second day on the job, I heard this power wheelchair wheeling into my office, and when I looked up, I saw this man's face and thought "He's really a handsome guy". But more than that, there was something about his eyes. The look in his eyes and



View of kitchen: The wall cabinets are ceiling height. The lower shelves of each can be reached by a seated cook who uses a power wheelchair with an elevator on it. There is also a closet near the island that will accommodate items that need to be stored in the reach range of a seated cook, as an adaptation for lower storage space. The closet has adjustable shelving installed for this use, should it become necessary.

the smile on his face told me that he was a man of real substance. I'm a face reader, and I could see that he was a really wonderful man. I fell in love with him right there, (laughs) right when he wheeled into my office. He had cooked up this idea with the office staff that he was going to come up to meet me, and then ask them to give him a ride to a lunch appointment he had on Saturday. They were to say, "Oh, we're busy, we can't do it", in hopes that I would offer him a ride to his lunch appointment so that we would have time to get to know each other outside of the home.

Cooper: (laughs) That is some plan!

Starkloff: (laughs) Well, it worked because the staff said, "Oh, gosh, we're really sorry, Max. We're busy and we can't drive you". And that's when I realized he was Max Starkloff. So, we chatted a little bit more, and when he left and went out to the elevator I thought, "Don't be dumb! Follow this guy and tell him that you'll drive him wherever he wants to go on Saturday." So, I went out and told him that I had a couple of things planned for Saturday, but I could take him where he needed to go. I took the chance and he said, "Great!". And the rest, as they say, is history.

We started dating, and two years later we were married. During that time I became very fascinated by a project he was working on to build an apartment complex where people with disabilities could live and work and not have to live in a nursing home like he was. I started listening to his thoughts, and I quickly learned that living within the community was an option for people with significant disabilities, which I never learned in PT school. We just learned how to rehabilitate people. We didn't really know what happened to people with disabilities after they left rehab. Did they go home? Did they go to work? Did they have a family? We didn't know.

Cooper: This before the ADA?

Starkloff: Exactly. I was so fascinated by this man and I began to also learn that there were other people with disabilities all over the country who wanted to see change. They did not want to see people with disabilities institutionalized any longer. There were people who



Hidden pot rack that stores in a base cabinet near the induction cooktop. Works well for standing or seated cook, but is located within easy reach of seated cook.

wanted to fight for the civil rights of people with disabilities, and that's what it ultimately became.

We built the housing complex, but we only could get HUD money for it, so it was a segregated environment of all disabled people living together. We quickly thought that that was not the way to go and started working toward integrated housing and developing an independent living center so that people with disabilities would not have to live in segregated housing. Fortunately, Max and I were able to get some federal grants to help with the cost of building. We were one of the first 10 federally funded independent living centers in the country, and we quickly began working on independent living services so that people with disabilities did not have to live in institutions.

Cooper: That is quite serendipitous the way this all occurred. It's a love story.

Starkloff: (laughs) Yes, it is. I do a lot of public speaking, and that's the story I open with.

It really is a love story. I'll tell you, I was fortunate to fall in love with Max Starkloff.

Cooper: And all thanks to your sister turning him down the year before! Did you know that that was Max when you first saw him?

Starkloff: Yes, I did, because he said, "Hi, Roger," when he wheeled by and I couldn't see his face. I just saw the back of him. And Roger said, "Hi, Max." And I remembered that my sister had worked there a year before and had told me about this guy named Max Starkloff who was quadriplegic.

Cooper: So you knew.

Starkloff: I was pretty positive that was him, so I said to Roger, "Is that Max Starkloff?" And he said, "Yeah, do you know him?" and I said, "No, I don't know him."

Cooper: "But I will know him!" (laughs)

Starkloff: (laughs) As it turned out, he showed up the next day and had this deal cooked up with the staff, and it worked.

Cooper: You should always keep that story as the intro. It's a great story.

Starkloff: He was a very, very, very dynamic man.

Cooper: Oh, he's passed on?

Starkloff: Yes. He died in 2010. We were married in 1975. We were together for 37 years, and I lost him December 27th, 2010. It was a very, very dark day in my life.

Cooper: Yeah, I would imagine that was hard for you.

Starkloff: Max rose to become a state, national, international, and local disability rights leader, and I was right there with him. What I have learned from Max and from my friends with disabilities–not only all over the country, but all over the world–is invaluable. We can't learn these things in school. We could never understand just how difficult things are for people with disabilities. I never would have learned the things that I have in physical therapy school.

Cooper: I think they still have gaps in Occupational Therapy.

Starkloff: They try, I guess, because OT is much more community-minded than PT. They talk about home, how to incorporate things into everyday life to help the patient throughout their daily activities. PT isn't like that though. And to really learn what it is like for people with disabilities to function in the world, you have to walk along side them and see what their daily struggles are.

Cooper: Right, they don't go beyond like you did. You literally built something to improve the quality of the lives of people with disabilities. Schools wouldn't think to teach beyond the individual patient and their specific needs.

Starkloff: You know, I was diagnosed with cancer last year and I've been in the hospitals getting PT and OT, and I'm very sensitive to the fact that most of the time when people see you in that debilitated state—and trust me, I was very debilitated with chemotherapy—they assume that you can't do anything. So, I would make a point, and they'd say, "Are you living with your children?" And I would say, "No, I'm hoping to go back home and get back to my job." "What kind of work do you do?" "I work in the field of disability rights". They look at me, and I say, "I'm all about people with disabilities not living in institutions, living in the community and having families, having a job, having a very rich life." And they always say, "Oh my gosh, that's amazing!" And I'd say, "It is, and it's also really possible." I know that a lot of people like me have not been exposed to what the real options are for disabled people with community living and community participation.

Cooper: Speak about the summit. How long has it been going on now?

Starkloff: I started it in 2002. But, to give you a little background, my awareness of it came from a man named Ron Mace. He is the creator of Universal Design, and was a member of the disability rights community. His contribution—wait, do you know his name?

Cooper: It rings a bell, but I don't think I've ever met him.

Starkloff: Well, Ron created the concept of Universal Design. Other people say they did, but it was Ron Mace.

Cooper: Where was he located?

Starkloff: He was at North Carolina State University at Chapel Hill. He received federal funding to create the Center for Universal Design at North Carolina State University.

Cooper: Okay, now I remember! We've done something with him in the past.

Starkloff: I would be shocked if you hadn't! I would think you guys weren't worth your salt if you didn't cover what was going on with Ron or the Center for Universal Design because you guys are all about disability. So, in the early 1970's, when Max and I were in Washington for one of our disability rights meetings, we had dinner with Ron because we were friends. Whenever we came to Washington and we were all together, our main topic of discussion was, "What are you doing in your state? What do we need to do federally?" It was a kumbaya group of scrubby advocates who truly believed they could change the world—And we weren't going to stop until we did.



View of raised dishwasher in open position.

We were having dinner with Ron one night, and he started talking about the idea of Universal Design. I said to him, "Ron, why are you creating a new concept? You worked so hard on the American National Standards Institute codes (ANSI codes), and getting the accessibility codes into the ANSI standards, why are you doing this? We have enough trouble trying to get people to do accessibility."

Now, Ron was a really soft-spoken guy, and I just loved him. His response was, "Think about it, Colleen. When we create accessible codes and accessible spaces and even accessible housing, we create a segregated environment. Non-disabled people—who will possibly become disabled as they age—won't want to live in accessible housing because they don't want to face the fact that they may be disabled one day. We need housing that works for everybody—disabled and non-disabled—and we call it Universal Design."



View of Island sink: this is a 5" deep x 30 wide Kohler porcelain sink with right rear corner drain. Installed under the countertop, the total depth of this sink is 7" deep. A wider sink with a corner drain was specifically sought to keep the garbage disposal out of the way of knee space of a seated user of this sink. The base cabinet doors, floor and toe kick are easily removed from underneath this sink. The garbage disposal button is located near the front of the counter, along with the single lever water mixing valve. The faucet has an easily pulled down water/sprayer combo that reaches fully around this sink for food prep and cleaning the sink. To the right is a pop up electrical socket that was embedded into the counter top and located near the front of the counter for easy reach by a seated cook.

I was fascinated because I'd been doing a lot of housing advocacy and trying to work on creating accessible and affordable housing in St. Louis and in all of Missouri. And what Ron said made a lot of sense. The independent living and disability rights movement has been about integration from the beginning; it's never been about segregation. So, continuing to create housing that segregates and isolates us–And that won't sell to just anyone–doesn't make sense. But housing that is easily adaptable and is universal for all to live in does.

Cooper: Ron's work was very impressive.

Starkloff: Yes, he was a spectacular man. Sadly, in 1998, Ron Passed away. But I knew there was still work to be done from our conversations. So, in 2002, I contacted his staff who was left at the Center for Universal Design in North Carolina at North Carolina State, and I said, "I would like to do a national conference on Universal Design, and I would like to partner with you guys to do it. Are you game?" And, of course, they said yes. We host the Summit every few years because they take a lot of work and a lot of money; I have the energy for the work, but not the money. So far, we have held six conferences on Universal Design, and at the end of September, we'll host our seventh. But because of COVID, it will be virtual this time.

Cooper: Who's your ideal audience?

Starkloff: It's a really robust audience. First of all, we cannot achieve Universal Design if designers and developers and contractors won't do it. We're just a bunch of advocates. We have a concept in our heads, but we don't have the ability to get the funding and do the drawings and build the homes. So, we're reaching out to architects, interior designers, builders, developers, contractors, remodelers, code officials, disability advocates, Realtors. Realtors are beginning to see the market for housing. A lot of people say, "I'm downsizing, and I want to be on the first floor. I want a first floor bedroom and bath and no steps to the second floor." Because of the aging of America, seniors are starting to ask for this, but a lot of seniors are not aware of Universal Design yet. So, I want to expand our audience this year to also include the consumer who may want to downsize, or change their housing. I want to reach the people who have a child with a disability or a family member with a disability, and they'd like to have a house that is universal so their entire family can fully enjoy their home.

Cooper: Have your heard of Wheel Pad?

Starkloff: No, I haven't heard of them.

Cooper: We did a story on them recently. They're based out of Vermont. They created a house that is very similar to a tiny home, but it's adapted so it connects to a person's "regular" house, and it is, of course, fully accessible. They are having trouble finding funding in



View of main kitchen sink. Items underneath this sink are neatly stored in baskets so that if this space needs to be opened up for a seated cook they are easily removed. Raised dishwasher is to the left. A raised dishwasher is easily used by a seated cook, but incredibly convenient for a standing cook! It was designed to be installed below a wall cabinet and removing dishes to store them in the cabinet above after washing is a dream come true!

Vermont so that people can finance the addition. It comes to them on wheels like a tiny home, but they adapt it to the actual existing house. It is a very interesting concept.

Starkloff: That would be wild!

Cooper: What about visitability? Do you promote that?

Starkloff: I don't. The reason why I don't, and I'll be very honest about this, is that visitability doesn't give us what we really need. What we need is livability. We need homes we can live in, not just visit. It helps you if you go have dinner at someone's house, but I think that disability rights advocates need to be advocating for housing that really works for everybody and doesn't isolate us. I would rather spend my time working on design concepts that create that type of housing. I just did that in my kitchen.

People walk into my kitchen, and they have no idea that somebody in a wheelchair could work in my kitchen. My friend David, who has a power chair, will be coming over this week, and we'll cook dinner together. I don't use a chair regularly, but I did when I was very debilitated through my chemotherapy treatments, and I was able to use my kitchen independently and easily. I believe that when you create a concept like visitability, that just enables people to go visit a house next door but not buy it and live in it. I don't want to spend my time on a concept that doesn't give us what our community truly needs. I would like to spend my time teaching developers how to build housing that they can sell to absolutely anyone, that will convert if the homeowner's needs change. Right now, I think that is most important for me to spend my time on.

Cooper: I agree we should all be doing what we are most passionate about with the time we have on this planet.

Starkloff: Since 2002, we've come a long way. We're not there yet, but we've gotten into St. Louis County and the state of Missouri. We've gotten some Universal Design requirements put into funding for state housing trust funds and community development block grants funding—so that gets into something that's designed to be affordable with public funds. I do see that more and more people are trying to understand it. And when you see models that are really great-looking, and then you see that the cabinet doors will come off of the base cabinet underneath the sink and the floor will pull out, so that if you suddenly can't stand at your kitchen sink and need to sit at it, you realize that's a house you can grow into. Because we all age, but also strive to keep our independence. A house like this is somewhere that allows people to keep their independence—disabled or not.

Cooper: Have you done an analysis on where you are today with your design modes? What is the difference in cost from a visitable home to making it a Universal Design home?



View of pop up electrical socket, ready for use.



View of easy release base cabinet hardware that allows for quick removal of base cabinet doors underneath sinks and induction cooktop.

Starkloff: No, unfortunately, I don't have funding to really see what the cost difference is, but there have been projections before. Ron Mace's center did it years ago and he said, "You're talking about maybe a tenth of a percent of additional cost." However, another measure of success: we're seeing Moen come out with touchless faucets so that you don't have to turn a handle to turn the water on. We see in public spaces where you can put your hands underneath the water and the water comes out. You can put your hands underneath the soap dispenser and the soap comes out. Those are universal features. If you want to put them in your house, that's up to you, but they're becoming sought out more these days. What we are asking for, or what we are saying to developers is that you can broaden your buyer base if you sell homes that will easily adapt so that people who have various types of disabilities can also use them. We're not there yet, but we're on our way.

Cooper: Do you know about the house that was a showcase in Atlantic City on Universal Design?

Starkloff: A Universal Design home?

Cooper: If I remember correctly, Gilda Radner's cancer organization connected with them too.

Starkloff: I knew there was one in Atlantic City, but I have not seen it.

Cooper: We did a story many years ago on it. I don't remember the details, but I remember seeing the graphics for it. It was very cool. There was also a woman in Columbus, Ohio, Rosemarie Rossetti—she raised money and created a Universal home.

Starkloff: I know Rosemarie! She calls it the Universal Design living laboratory. She has a lot of Universal Design features there, and she also has accessibility. Her bathroom is accessible, and I think her kitchen has some lowered sinks and some raised sinks and stuff like that. She's presenting at our next conference. She's presented at two of our conferences before.

Cooper: That's great. We did a story with her many years ago as well. Her home is impressive.

Starkloff: Oh yes, it is! (laughs) We're trying to get as many models of Universal Design out into the mainstream media as we can so people can see it, and understand the value in creating homes like these. I can send you some picture of my new kitchen too. You would never know it's a Universal Design kitchen! Another person who has done a lot of work with that is Mary Jo Peterson. She's an interior designer and is well-known in the kitchen and bath associations network. She's been a big proponent of universal design. You should definitely look into doing an interview with her.

You should also speak with Richard Duncan, who stepped into Ron Mace's role at the Ronald L. Mace Universal Design Institute after Ron passed. He's been working with a lot of product manufacturers to create products for Universal Design. He is a really good guy, a colleague and a friend. He did the first five or six conferences with me. He's a good person to know.

Cooper: Are you familiar with our nonprofit ABILITY Corps?

Starkloff: No, I don't think so.

Cooper: One of the projects developed several years ago is called the ABILITY House, are you familiar with that?

Starkloff: No, but please send me information on it.

Cooper: Briefly, did you know the folks who created Concrete Change?

Starkloff: Yeah, that was Eleanor Smith's organization.

Cooper: Do you know their history with fighting Habitat for Humanity?

Starkloff: I don't know about that history, but I know what she created—I met her when I was going to a conference in Dallas years ago. She and I were talking and I told her about Universal Design, and she told me about visitability.

Cooper: I set up a meeting with Millard Fuller, who started Habitat for Humanity, knowing that Concrete Change was going out and picketing at some of the builds they were doing in Georgia. I created a partnership with Habitat through our nonprofit, and we started building the ABILITY House programs, where we built homes that brought in visitability, Universal Design, and were built by volunteers with disabilities.

Starkloff: How did it work?

Cooper: It worked incredibly well! We built our first one in 1999. We had 250 volunteers with disabilities build a house. It was a blitz build, so we built it in seven days. We got a lot of press; CNN covered our story. We built more houses across the country, in Washington DC, and from there we built more. Then we moved into a scenario where we also do something called the Brush of Kindness. It's a program where we don't build the full home, but we go in and retrofit, or we get volunteers to build ramps for a home. I'm surprised you hadn't heard about that, the ABILITY House project; we have won awards for our work. We were even awarded one at the White House. Part of our push has been to get people with disabilities to be the volunteers that are working on these projects. So they have the benefit of volunteering rather than being the recipient.

We also created the first job board for people with disabilities in 1995; abilityJOBS.com—It's the largest job board in the world. At any time we have over 100,000 job seekers with disabilities connecting with all the major companies and governments and nonprofits looking to hire talent.

Starkloff: Wow! I'm surprised I haven't heard of ABILITY House. Your organization does so much great work for the community. I'm sure you have helped so many people with disabilities in multiple ways.

Cooper: Thank you. From there, we built the first accessible online career fair, ABILITYJobFair.org. It's a face-to-face video platform, and if you happen to be deaf, another video will appear and a sign language interpreter communicates between the recruiter and the candidate. It's been built out with screen reader capabilities and speech to text.

Starkloff: You guys have thought of everything, haven't you? (laughs)

Cooper: Almost! (laughs) We have one more thing we're doing. We've built a pipeline for the entertainment industry to connect talent with disabilities—actors, performers, singers, comedians. We've talked to all the major studios including SAG-AFTRA and Screen Actors Guild of America. It's called abilityEntertainment—abilityE.com. We already have thousands of talented actors with disabilities for in front of the camera, and we're working also to connect behind the camera jobs in the entertainment industry—for producers, writers, crew, etc. who have disabilities.

Starkloff: Oh, I love that! That's fabulous! Are you working with Terri Hartman Squire at all?

Cooper: I've known Terri for about 25 years. I met her, along with Fern Field, as they grew the Media Access Awards. She runs Lights, Camera, Action.

Starkloff: I've known her for forever.

Cooper: She's always trying to push the needle.

Starkloff: Yeah, that's what we have to do. That's why Max and I were in it—we never made a lot of money. We lived OK, we had kids and family, we had everything that we wanted, just like any other family. The biggest difference was that he was a quadriplegic. He had a spinal cord injury. And people would stare at us and wonder why I married him. And to me, that was their problem.

Cooper: It takes a lot to move the needle for attitudes to change. ■ ABILITY

starkloff.org



Power Assist Suit ATOUN MODEL Y

2020 is a year we couldn't forget no matter how hard we tried. Covid-19 took over the world in the blink of an eye, putting everyone's plans on hold, and causing every soul to hold their breath, waiting to exhale into what we would hope to be normality and familiarity of the world we used to know.

We're still waiting for whatever the new normal will be, but in the meantime, we have gone on as business as usual. And business as usual for us includes the 125 year old tradition of the Summer Olympics and Paralympics taking place; athletes ready to compete, and the world waiting to watch. The 2020 games were to be held in Tokyo, one of our planets busiest and most exciting cities. The games were put off for a year, but that didn't dim the fire inside the athletes, and the competitions raged on in 2021.

Panasonic, who has been bringing forth innovative technology since 1918, brought in new products that may change the games from here on out. ABILITY Magazine had a video chat with Panasonic's Tokyo Olympic & Paralympic Enterprise Division, Robot Promotion Manager and their Assistant Chief at their Headquarters in Japan, and found that since our last interview with Panasonic—they are still creating products in hopes to enhance people's quality of life around the globe.

At the 2020 Tokyo Olympics and Paralympics, Panasonic introduced two advanced robot suits, and a robot vacuum cleaner.

The Power Assist Suit ATOUN MODEL Y + kote was created to help with heavy lifting, alleviating pressure and stress from the lower back and arms. Viewers of the Paralympics saw this new suit being used by the spotter and loader personnel who were moving weights and spotting athletes during the powerlifting competition.

Keiji Ogishima, Assistant Chief, explained the mechanics behind the suit. "The suit has a sensor located on the back, and it detects the person's movements so it knows when to give assistance to the person wearing it. When the person is lifting something or they stand up, the suit pulls the person's body upward. Each suit allows for the individual using it to preset their needs before putting the suit on, so it is customizable for whomever wears it."

This new Power Assist Suit has been introduced in airports, factories, farms and construction sites. Takahiro Kurokawa, Manager, said "We created this suit for factory workers and manufacturing sites because in those jobs there is a lot of heavy lifting. We saw how it aided in helping to move heavy items, keeping the pressure off of the body of those who wore it. We then thought that it could be used in more than just factories. There are so many industries and people that could benefit

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- For the tenth consecutive year, readers of ***CAREERS & the disABLED*** magazine recognized Wells Fargo as one of 2021's Top 50 Employers of people with disabilities.
- ***Equal Opportunity*** magazine ranks Wells Fargo No. 15 on the 30th Annual Top 50 Employers 2021 list.



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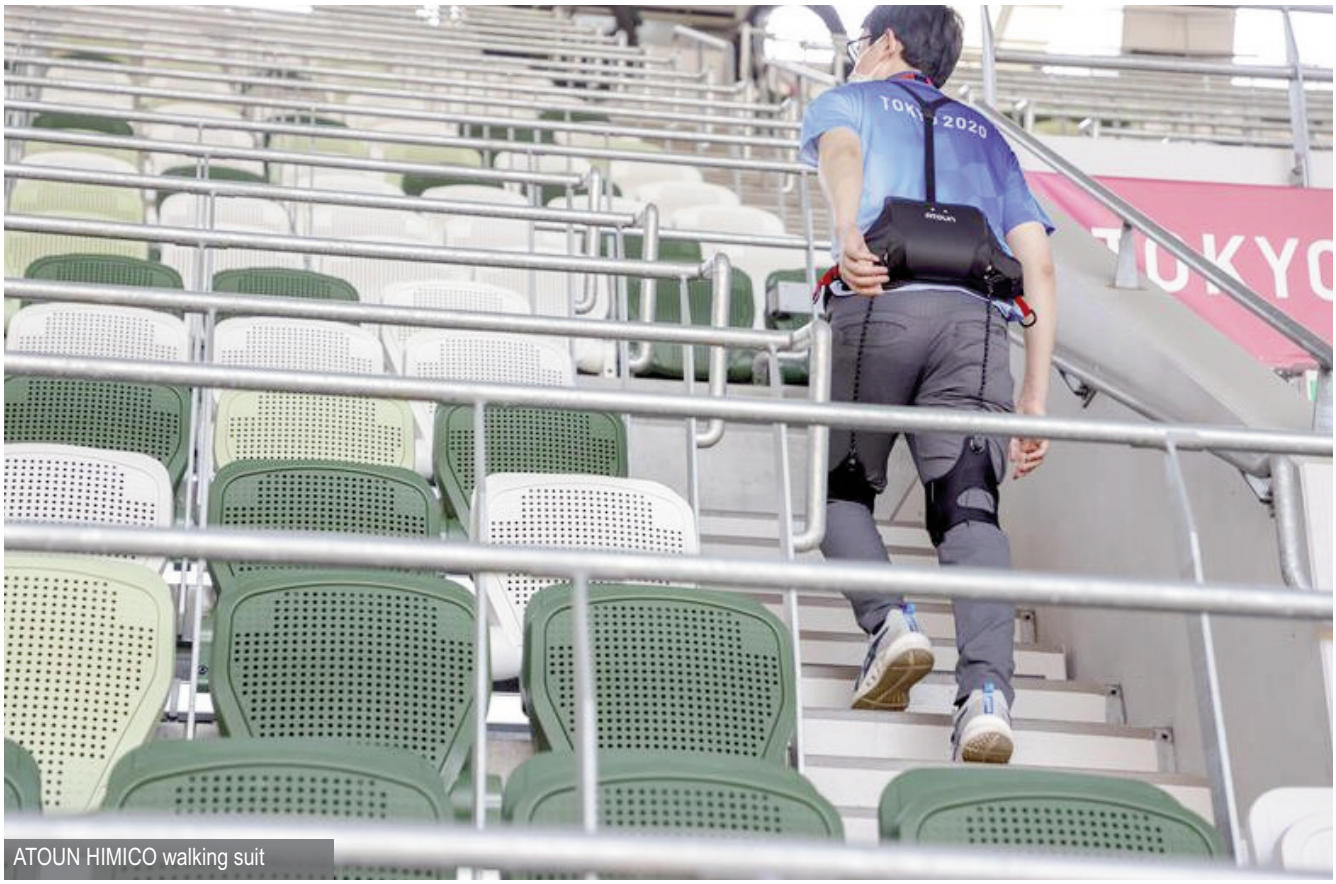
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ATOUN HIMICO walking suit

from a product like this. So we contacted the Japan Powerlifting Committee Association and worked with them first. We then connected with the World Powerlifting Association, and it was used at the World Para Powerlifting event. It was then brought to the 2020 games and we were able to see how it could be helpful for



Panasonic's robot vacuum




more than we originally thought."

Ogishima added, "Since it was used successfully in the Paralympics Powerlifting Competition, we are considering to bring this into nursing care facilities to help caretakers in lifting patients, and in other locations where it is needed as well. Although, it is quiet heavy to wear at this point, we will continue to further reduce the weight so that it's more suitable to bring to other markets who would benefit from having suits like this."

Panasonic also introduced the ATOUN HIMICO, a suit worn by the staff at the Olympics and Paralympics to help lighten fatigue from so much walking. This suit has motion sensors, with a motor at the waist that helps to lift the lower legs while walking, reducing the pressure on the knees.

Ogishima said, "In creating the ATOUN HIMICO, we were thinking of two scenarios—one is for elderly people. They have a hard time getting out of their homes, and this could aide them to go out and walk more, improving their quality of life. Since it takes the pressure off of the knees, this will allow for them to walk further, even go on hikes, without becoming fatigued quickly. The second thought behind this suit is for people whose job requires them to walk around for extended periods of time. It will aide them in becoming less fatigued, allowing them to do their jobs easily and also keeping their body safe. The staff at the 2020 games wore them because they are always walking around for long periods of time and using stairs frequently."

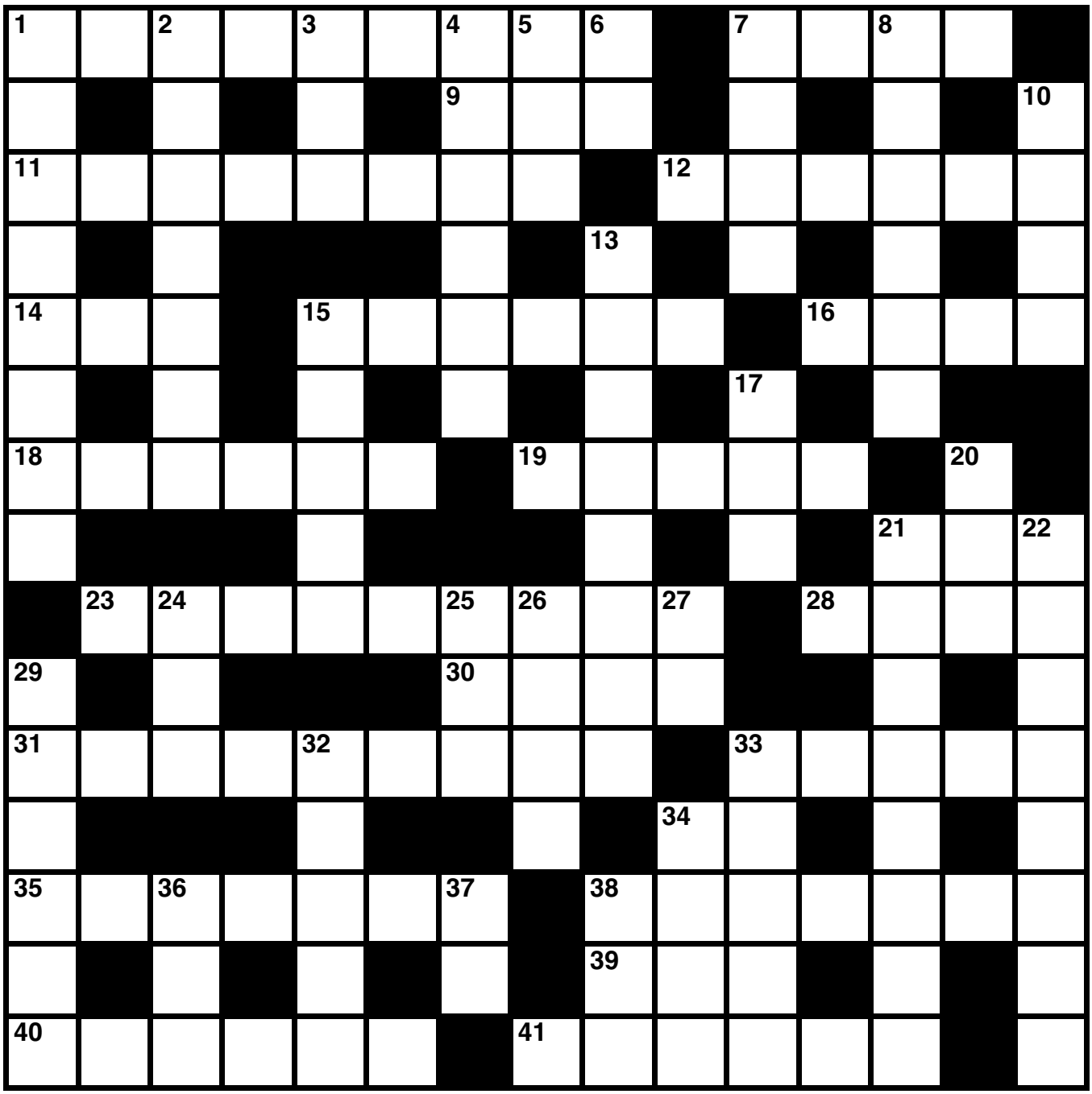
Kurokawa added, "We can see this also being used for people who have difficulty walking. Since it takes pressure off of the legs, this will allow people who have a hard time walking to have assistance in walking, and therefore improving their lives as well."

Panasonic made a clean sweep by introducing their new robot vacuum cleaner. It was first introduced in Tokyo Big Sight, the main Olympics and Paralympics Press Center. "It's AI enabled, and with the Covid-19 pandemic, the robots play an even greater role in society" Kurokawa said. "The robot vacuum is complete with Panasonic's Nanoe TM, our bacteria-inhibiting dust box, which enables hygienic cleaning. The robot vacuum cleaner recognizes their environment by using cameras and LiDAR (light detection and ranging), and knows when it is time for it to clean up, with no preparation necessary. It can detect people and objects with high precision. The one showcased was a prototype, so we hope to keep moving forward to bring this to different markets that would benefit from a product like this."

Ogishima responded "We will continue to be aware of the global market and the needs of those around the world. We hope to contribute products that are accessible to all that need them." ■ ABILITY

panasonic.com

# ABILITY's



# Crossword Puzzle

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# Crossword Puzzle

## ACROSS

1 Latent greatness in every one of us
7 Blind Chinese mountaineer, Zhang ____
9 Pen's tip
11 Nation that gave us Red Curry
12 Creator of the Linwood School, a pioneering environment for kids with autism. Jeanne ____
14 "___ Baby Baby" (Linda Ronstadt hit)
15 American actress and deaf activist who won an Oscar for Best Actress for her role in "Children of a Lesser God," Marlee _____
16 Applaud
18 Problematic situations
19 Change to meet new challenges
21 Hair adornment
23 Kept going, despite all challenges
28 Blind singer, Feliciano
30 Peace of mind
31 Condition relating to kids who have difficulty in social interaction but are very smart
33 Sanctuary
34 British princess, Lady ___
35 Self-regard
38 Classic Aretha Franklin hit
39 Large spreading tree
40 "Rocky Mountain High" singer, John ____
41 Organization with a mission to produce inspiring youth-created documentaries about pressing global issues

## DOWN

1 Co-authors of the book "Expect a Miracle: Understanding and Living with Autism" — Sandy and David _____
2 Gives instruction to
3 Nothing
4 Natural, as talent
5 Assist
6 Dieter's measurement, abbr.
7 One who receives an inheritance
8 Italian staple
10 Invitation reply
13 We all like to be treated with this
15 Runs into
17 Liable
20 Plea at sea
21 Supports and strengthens
22 Surfers' destinations
24 Unusual perception, abbr.
25 Understand
26 Flaky dessert
27 Tour __ France
29 Honest
32 Bring up
33 Co-writer of "The Hidden Child: The Linwood Method for Reaching the Autistic Child", Dr. Sabine _____
34 Furniture from "The Office"
36 Starter's need at Paralympics races
37 Hi!
38 Blind soul singer, Charles

*answers on page 66*

## Crossword Puzzle

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