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ABILITY



The Paper Bag Plan Film

Anthony Lucero + Cole Massey

Interview

Police: Autism Class

CHOC & Chapman Univ.

Meta Glasses

Blind Opinions

Jimmy Button MXer

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CONTENTS

6 **HUMOR — The Squeaky Wheel: Insulin Pump Stuns at Comic-Con**

8 **LONG HAUL PAUL — Canadian Kindness**

18 ***PAPER BAG PLAN* MOVIE — Anthony Lucero & Cole Massey Interview**

24 **JIMMY BUTTON — Motocross and "Pay Dirt"**

30 **META SMART GLASSES — Blind Opinion**

37 **AUTISM AWARENESS — CHOC Chapman/Thompson Training for Police**

48 **ANNIE POTTS — Actor, Philanthropist, Grandmother and More**

58 **LOTTIE JACKSON — Author**

64 **MICHELLE SIMES-KENNEDY — Living & Thriving with Type 1 Diabetes**

70 **CROSSWORD PUZZLE**

74 **MARKET PLACE**

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the SQUEAKY WHEEL



Transformer-Style Full Body Insulin Pump Stuns at Comic-Con



SAN DIEGO — The San Diego Comic-Con Cosplay Contest gave out awards today, and the votes were unanimous. Matthew West and his homemade Transformer armor won Best In Show, Judges' Choice, Best Re-Creation, Best Original Design and Best Workmanship (list abridged for brevity).

"We see Transformer re-creations yearly," said longtime CC judge Charlotte Fey. "This one not only was expertly crafted but also solved a problem." And what was the twist that won West the crown, you ask?

The cataphract is also a fully functioning insulin pump.

The 6-foot-3-inch tall creation resembles Optimus Prime, with the addition of clear tubes wrapped around the arms and legs that insulin constantly flows through. On its back, an oxygen tank has been repurposed as an insulin reservoir, divided into quadrants for different types of insulin as necessary. West hopes to include space for glucagon, a hormone used in severe low blood sugar emergencies, in a future model. The contraption is constructed using various grade-A metals and a Google computer embedded in the head piece's clear screen for convenience. West partnered with multiple tech companies for design tweaks (NDAs abound!) as well as Prada and Gucci for aesthetics. He also collaborated with Shōji Kawamori, Japanese film producer and creator of Transformers.

All of this was still cheaper than paying for a regular insulin pump out of pocket.

"Yeah, my insurance wouldn't cover a pump. I've been diabetic my whole life and it's been hard without one. It was only logical that I made one for myself — and showed it off at my favorite event of the year," West said, beaming.

The San Diego Comic-Con Cosplay Contest was sponsored by Big Insurance, and for his grand prize West received an IOU that read, "idk when we can pay for a pump for u. don't feel like it. iou one tho. xo" ■ ABILITY

by Bea Mienik



Founder Steven Verdile

the-squeaky-wheel.com

Canadian Kindness

Long Haul Paul



In June, I raffled off my 2021 Yamaha Tenere 700 for the MS charity I support. The motorcycle was my 4th since starting my million mile journey for Multiple Sclerosis. Curechaser IV had an amazing 211,000 miles on the odometer and lived a very tough life on the road. The fundraiser raised $15,000 and I delivered the bike to the lucky winner, Fred Swanson in Houston. The final ride from New Hampshire to Texas reminded me of why I enjoyed the bike so much. First of all, it was reliable as a hammer. Traveling as I do, I don't have time to waste. Since getting the bike in 2020, it ran every day without complaint. It never left me stranded. It was dependable and despite still running great, it deserved some time off!

Yamaha Motor USA had provided me with a brand new updated 2025 model to replace it. After spending a month or two setting up the new bike, I took it on it's first cross country ride, from New Hampshire to Seattle by way of Canada. Although taking a 7000 mile ride on a bike with only 200 miles on it might seem like a risky trip, I was very familiar with the bike and all of the accessories I had added because they were similar to the bike I had just raffled off.
What I wasn't sure of was how Canadians would treat an American traveller given the recent political tensions.

One of the things I decided to keep from the first Tenere 700 were the aftermarket tubeless wheels I had



ordered from Italy. They were well used, but because I ride so much on the road, I was not a fan of the stock wheels that require tubes. Tubes are great for fixing damage on the trails off road, but not so practical for getting a flat on the freeway where I can plug a tire in 5 minutes and be on my way. Before putting the wheels on the new bike, I cleaned them thoroughly and replaced all the wheel bearings with new ones. Between the bearings is a metal spacer about 6" long that guides the axle through the center of the wheel. The spacer seemed very tight and put pressure on the bearings so I decided to trim it down a very small amount. The day before I left, I finished up very late and took the bike for a test ride where I heard some noises from the rear wheel. I made some adjustments and it seemed to fix the issue.

The first day traveling on the new bike was an uneventful 900 miles to Sault Ste. Marie, Ontario. On day two however, I started to hear some clicking from the rear wheel as I slowed down to get gas. I was headed for a hotel in Brandon Ontario and thought I would check it out that evening.

I didn't make it. About 80 miles west of Thunder Bay, the bike's rear wheel bearing blew apart and I wobbled over to a small country store which also happened to be the Upsala Post Office. I needed to fix this wheel with new parts or get a new wheel. My best option and only hope of reaching the rally in Washington on time was to have my wife Elin ship me the brand new wheel I had sitting at home. It was all set up



Excalibur Yamaha shop team

and even had a tire mounted on it. It would be a quick swap and I would be back on the road. I knew it would be very expensive, but what other choice did I have?

The very helpful woman in the Post Office explained there was no chance of getting the wheel anywhere near Upsala in the next few days, regardless of whet UPS claimed. She explained they only get mail a couple times a week and if I needed to get something faster, I needed to get to a bigger city like Thunder Bay. Stuck on the side of the road with my brand new motorcycle, I began looking for the best solution. The woman in the Post Office said she would be more than happy to give me a lift into town the following day.

"Sure, we can just throw your bike into the back of my truck and I'll take you into town."
I was completely surprised, and grateful that a stranger would go out of her way to help someone, specifically someone from a country who's government had just insulted their entire country.

When I asked about a hotel I had seen a few miles back, she said, "Nonsense. I have a house in the back where you can spend the night. It has electricity and wifi and I'll get some clean linens for you. I hope you don't mind chickens!" I was surprised again, at this kindness from a complete stranger!

I had my wife ship the new wheel from the UPS Store in our town to the UPS Store in Thunder Bay where I figured I could easily pick it up. Overnight shipping cost nearly $900, and after she paid they let her know it may not make it on time because of customs. That wasn't reassuring, and I began to worry.

My lift into town wasn't going to be until late afternoon, and I wasn't even sure the wheel would arrive or that I would be able to get on the road fast enough to make my destination. My wife suggested posting on social media that I was stranded and need a lift into Thunder Bay.
I carefully crafted a post explaining I had broken down but the new bike was NOT the problem, it was the aftermarket wheels that had 200,000 miles on them. Within a half hour, I had been contacted by Greg Symons who had seen my post asking for help. He lived in Thunder Bay and was willing to hitch up his trailer and come get me. Not only did Greg drive 80 miles each way to fetch me from Ursala, he picked me up from my hotel the next morning and drove me to the local Yamaha Dealer who he thought might be able to help.

Asking a bike shop for immediate service during the busy riding season doesn't usually go well. Most shops are booking weeks or months out. Showing up a half hour before they even open and entering through the back door is a real bad idea, but I was desperate to get my bike fixed and so I followed Greg through the back of the shop.

"Hey Erik, how's it going? I have someone here I'd like you to meet. This is Paul." The door swung completely open and I watched the owner of the shop's face light up.

"LONGHAULPAUL!"

I started to feel a little better about my predicament. He stood up from his desk and shook my hand.

After he exclaimed he watched all my videos and even bought a Tenere 700 because of me, I knew my day was about to get a lot better.

"What can we do to help you?"

I explained my issue with the wheels and the need to be be back on the road soon. Still minutes before Excalibur Motorsports officially opened for business, they were rolling my bike into their shop.

As my wheels were not from Yamaha, the shop did not have access to the correct parts needed and for most of the day, the entire shop was helping me out. Custom spacers had to be machined at a different location to replace the one I shortened and bearings had to be sourced and installed. At one point, three techs were working on my bike to get me back on the road. The owner, Erik Floen introduced me to one of their techs who also was living with Multiple Sclerosis. He explained how he understood how the disease affects people. The tech had been part of their family for 20 years and they made sure he was taken care of with good health insurance and time off if needed. He said he followed my story online and was a big fan because of his close connection to MS.

I kept thanking Erik and expressing my gratitude. "We try to take care of everybody this way. Don't all shops do this for their customers?"

While waiting for my bike, I witnessed the staff helping other customers and a news story being recorded about one of their young customers who had just won a big motocross race. The entire staff was enthusiastic, helpful and supportive.

"No, sadly. Most shops are not like this at all", was my reply.

Erik refused to let me pay and after a round of hugs and goodbyes, I left overwhelmed with gratitude, a fixed



The fundraiser raised $15,000, and delivered the bike to Fred Swanson

wheel, and a new Excalibur tee-shirt!

By the afternoon, I was back on the road, heading west, all because of the help and support of strangers. I made it to the rally just hours before it started and my trip home was uneventful.

No offense to Cleveland or Chicago, but when I need to travel coast to coast I will continue to go through Canada as often as possible because I really enjoy the peaceful roads, the good food and the people are amazing!

If the kindness of its people has a dollar value, Canada is absolutely unaffordable! ■ ABILITY





Interviews with Anthony Lucero and Cole Massey and a surprise guest Michelle Massey



The acclaimed independent film, "Paper Bag Plan," has been earning awards at film festivals across the U.S. and abroad. The movie tells the heartfelt story of Oscar, a father facing serious health issues, who tries to prepare his son, Billy, for independence by training him for a job as a grocery bagger. The film's authentic portrayal of disability, family dynamics and the everyday challenges of caregiving have resonated deeply with audiences.

ABILITY Magazine's journalists, Lia Martirosyan, Olivia Austen, and Chet Cooper recently spoke with Anthony Lucero, the writer and director of the film, and Cole Massey, who plays the lead role of Billy. Cole's mother, Michelle Massey, joined as a special guest, as she took on many roles during the movie's production. In their conversation, they discussed character development, authentic casting and the film's success. They described the significant struggles and obstacles they faced while making "The Paper Bag



Anthony Lucero on the street with cameraman directing *Paper Bag Plan*

Plan." Lucero also shared how his own family experience led him to write the screenplay.

Lia: How's the festival journey going?

Anthony Lucero: It's been great. We started last year, last fall. Heartland Film Festival premiered (the film), and we won the best premiere there. We've won 12 awards so far. We've won, I think, five jury awards and, maybe, three audience awards. Cole won best actor at Santa Monica Film Festival. And Lance Kinsey, who plays his father, won best actor as well at Montreal Independent Film Festival. And now we're releasing this Friday in Oakland, the Bay Area. We're coming out in various theaters around the country. So, about 26 theaters so far, and hopefully a few more. So, yeah, it's been It's a very tough, long journey. It's tough because we don't have much money for this. Got to wear a lot of hats. And Cole's doing promotions for us. Cole's mama, Michelle. Everybody's pitching in, just doing everything and doing so much work to get this out there.

Lia Martirosyan: That's when it means the most, when there's so much support and love, even from the core people.

Anthony: Yeah, exactly. So, it's been fantastic. We love it. It's doing really well.

Chet Cooper: How did you get the seed money to start?

Anthony: Seed money. The brief story is we had funding, which is back when I spoke to Cole and we cast him. We had an investor. It didn't work out. This was back in, I think, 2020. She wanted to be in the film, and I just felt there was a conflict of interest and the film was going to change because she wanted me to rewrite the film for her.

Chet: Was that Lia?

Anthony: (laughs) It was Lia. How did you guess? But the next one, we'll have you in the next one for sure. — No, but it was like a compromise of the screenplay and of the story. I sadly walked away from the money. I felt like I had some integrity, and I had to make the film how I wanted to make it. So, my wife, who's actually sitting behind me, watching every move I do, she actually funded the film. And she could see how depressed I was that I was not going to make this film, "Paper Bag Plan", which was originally called "Between the Ailes." And so, she said, "I'll help pay for this." With all of the decades of work that she's done to save up money, she threw it at me. She said, "Here, go make your film. Go do it." My wife funded, probably, 90% of the film. And that's how we got it made.

Chet: When she threw it at you, was it in the form of coins?

Anthony: (laughs) It was a bag of coins! It hit me over the head really hard. And it was great. I took the coins and made the film.

Chet: (laughs) Well, that's that was really wonderful of her. And you're still married?

Anthony: Still married, yeah. We edited the film together. She hasn't divorced me. But it was a lot of— At night, she'd be like, "Why did you spend 600 bucks on this lens?" I was like,"We needed a lens. We couldn't finish shooting unless we had this lens." Or stuff like that would come up every night. Like, oh my God, you spent this much money on what? So, it was a pressure cooker for sure. But no, she still loves me, which is amazing.

Chet: And then she saw the bill from Cole and said, you must be kidding.

Anthony: Well, Cole was so expensive. My gosh. He was like an A-lister. I could have had George Clooney in my film.

Cole Massey:: (laughs) I mean, I can't speak to what the cost was for me, but I'm glad I got to do it.

Chet: Tell me about the writing of this. What was it in your mind that you had to hold on to that script so tightly that you walked away from the first investor?

Anthony: I feel because it was a bit of a personal project. It was loosely inspired by my mother and my brother, Eddie. Eddie couldn't speak. He couldn't walk. He needed 24/7 care from my mother. So, it was a very personal film that I had written and didn't want to modify it just based on that. It was loosely based on my mom and my brother. And then the other inspiration of the film was my sister Margie. She passed away in 2018 of cancer, and she left behind her daughter, Sarah, who has Angelman's syndrome. So, yeah, my niece is, I think, 39 now. So, the story was inspired by these two amazing, strong, wonderful women and their children, and it just felt personal for me. I didn't want to make too many changes that would affect the tone of the film.

Chet: I understand. How did you find Cole?

Anthony: Cole gave me a lot of money to be in the film. No.

Chet: (laughs) Next question.

Anthony: Yeah, exactly. Next question. No actually, Russell Boast was the one who put us in touch with Cole. He specializes in actors with disabilities. He sent me around 50 or so candidates, actors with disabilities. And what's tricky about the screenplay is I didn't specify what Billy's, the character's, disability was because I didn't know what actor I was going to get, what their disability was, whether they'd have crutches or whether they'd use a wheelchair, whether they might— There were so many variants. So, I kept it somewhat vague. For whatever reason, the actors I was auditioning weren't quite the right fit. And then Cole was the last one. The last one that Russell sent me was Cole. And I'm like, "Yeah, he's great. He's handsome. And let's see if he can act." And so, we had some Zoom auditions with him, and he was the right fit. He was it. I was like, yes, this is my Billy. He was the first person that we cast. And from that point on, everything else could fall into place.

We could find the rest of the actors at that point, but I would not make the film unless I found my Billy. And that was it. It was like, let's just do this experiment, see if we could find him first. And thank God, Cole Massey sent the audition tape in, we met, and he was fantastic and just a star to work with—just amazing in every way. From that point, we decided to cast the father, Lance Kinsey. And on set, I was just mentioning this that somebody, one of the production assistants, had asked if we cast a real father-son for the film? I think we've cast the right pair for this film. But that's how I found Cole.

Chet: Cole, how did you find Russell Boast?

Cole: I've been acting most of my life. I had gotten the audition from my manager. Russell was the casting director for Anthony.

I worked hard on the script. I went in, I auditioned, and I got it. That was pretty much it. Russell knew my manager. She specializes in people with disabilities as well.

Chet: Who is your agency?

Cole: It's EP Talent. My manager was Keely Cat-Wells, but I believe has since left. Now Elle Potruch is my manager.

Lia: You've done these festivals, you're winning awards, you're in a some theaters. What's the next step for getting mass distribution? How does that all work?

Anthony: It's daunting. So, the Cinderella story, as you make the film, it premieres at a major festival, and then Netflix buys it for $20 million. That just doesn't quite happen all the time. So, for us, and it just happened on my last feature, is that we put it on the festival circuit and we just see how it goes. And hopefully it gains an audience, and it did. "Paper Bag Plan," it did. It started off small, and then as it grew, then more festivals hear about it, and they start programming us. I don't know how many festivals. We played in quite a bit. At that point, you're waiting to see what studio is going to pick up this film. It's won a lot of awards. But generally, this is how it usually works—They always see who's in the film. Okay, there's nobody quite famous in the film. So, it's a pass. Studios will pick up a film with a famous

person but not a very good film, as opposed to a film that's really good and nobody well known.

Chet: It's the Catch 22, I guess.

Anthony: It is the Catch 22. Cole Massey is not a household name yet, but it will be.

Chet: Come on, Cole. Come on, Cole. Get going.

Anthony: (laughs) I know, right? It's going to happen. It's going to happen.

Cole: Well, thank you.

Anthony: Yeah, it will. But for now, it's tough. Long story short, we hired a theater booker, and he pitches the film to theaters and gets us in. If the theater likes it, they're like, "Do you think we could sell tickets?" They'll book it. We're in that stage now. We're in 26 theaters around the country as we speak. And then after that, we go to streaming. And we don't know quite when we'll end up on some platform where you could watch it online. But we don't know yet.

Chet: So streaming, hopefully, then brings in some revenue instead of you getting a divorce?

Anthony: (laughs) Oh, gosh. Yes, please. Buy this film when you see it, so my wife won't leave me. Wife and kid won't leave me. Fingers crossed, we do make our money back, and I think we will. Everybody who's seen the film just loves it. They love Cole. Absolutely. And so, we just have to spread it, mostly by word of mouth. It's got to get out there.

Olivia Austin: What impact do you think the film could have on people? For more people to see it, it seems like it could really garner a lot of growth. Was that the goal originally when creating the film?

Anthony: I think first and foremost is I have to entertain people because the script, itself, was lengthy and it got into a little bit more politics and aging out of the system at which Cole, you told me, is now 22. And in the end, you start to pull this stuff back because people want to watch a movie. They want to be entertained. They don't want to watch films about politics. And it's there on the screen. It's just we pull some of it out just to pace it up.

There are a lot of goals with this film. One I mentioned earlier is Cole. We want to get you on the screen more, and we've got to get you some more parts. So, if you could be just a working actor, which is difficult for anybody. I'm not just saying just you. I'm just saying just actors in general. It's hard to get those gigs. So, we watch you on every television across America.

Cole: Sorry, if I interrupt. Though, I will say that for actors with disabilities, it is about 10 times harder. That is changing a little bit, though. But we are often still on the outskirts of people's imagination.

Anthony: Just jobs in general, not just acting jobs. Yeah. The film is about independence. It's funny because I get a lot of parents that don't have children with disabilities come up to me. And they often talk about have they done too little or too much for their child? So, it's spanned across, most definitely, parents that have children with disabilities. It hits them hard. But even parents that just have children without disabilities, it still hits them like, "Oh, my God, I hope I've done enough for my child for when I leave this Earth." So, it's been very interesting, and I have to say heartbreaking at same time to listen to a lot of these stories.

Olivia: And how did you build the dynamic, the father-son dynamic of the characters? I feel like from an acting standpoint, there must have been more to that than we see. Was it chemistry that was built in the casting room?

Anthony: Yeah, I'm going to start, Cole. I'm going to hand this off to you because this is a testament to Cole as being a great actor because we didn't have much time to rehearse. And what did we have, Cole? Two days or something like that?

Cole: If that, maybe a week.

Michelle Massey: I think it was two days.

Anthony: It was two days. It spanned over a week. But yeah, it's a testament to the actors, to Cole and to Lance, making it look like they have this relationship that has been around for 25 years. Cole, you want to add to that? How are you working with Lance?

Cole: Yeah. Working with Lance Kinsey, who is— like I said, I've been acting most of my life.—And he's one of the best actors I have ever worked with as far as skill and talent. Working with Lance is just an incredible master class in subtlety from an actor's perspective because he just does one thing and it changes the entire scene, or it changes one little line. And all of a sudden, it's this masterpiece of a scene. Getting to work with Lance was really extraordinary. He really did treat me like one of his own, one of his own children, when we were not filming. "Are you okay? Are you good?" So, he really not only stepped into that fatherly caregiving role on film, he really did care about me as a human being and me as an actor as well. So, our dynamic and our friendship grew even on set. I hope to work with him many more times because he's just a joy and a pleasure to work with.

Anthony: Well, there are quite a few intimate scenes between father and son in the film. And yeah, it's like they both pulled it off as though they'd been in this relationship for years. I know there's a shower scene in the very opening of the film, which It was very intimate.



Cole Massey in *Paper Bag Plan*

We saved that, I think it was day three because I was like, this is a pretty intimate scene between these two characters. But you're just like, "Just throw me in. Throw me in the shower. I don't care."

Cole: The only thing I asked for was to heat up the water because it was freezing.

Anthony: Oh, I know. I felt so bad for you.

Cole: We filmed it early, early in the morning.

Anthony: We tried to keep that shower scene short because I was like, oh, my God, poor Cole's freezing in the shower. But you're a pro. You did not complain once on this entire shoot.

Cole: I tried. I tried very hard. The magic of it is that the man who did the body doubling for Lance when he lifts me out of the chair is my actual dad.

Olivia: Oh, cool.

Cole: I ended up being both the actor and the disability consultant, I guess, technical director. I don't know how you want me to word that, Anthony, but Yeah, you made sure that we were telling an accurate story, making sure it was authentic. And it really was because Anthony spent a lot of time at my home, and he really said, "Okay, take me through your life."

Anthony: That's right.

Cole: And I said, "Well, okay." I did. And a lot of parts of me, Cole, got added to the script. But I don't think they were far off from what Billy would have done at all. But I think they were exactly what Billy would have done because Billy, the way I see him, is he in this in between of (being) able-bodied enough to do certain things and not able-bodied enough to do others. I think in the disability space, you're either chronically ill or severely disabled. But if you can do some things for yourself, then you are independent. No, that's not necessarily true.

Olivia: People go to the extremes very quickly. Jump to judgments.

Cole: I think this character had a good balance—Anthony, and this is thanks to you—of being truly disabled, but not like he was living on a ventilator.

Anthony: Well, and he had a helicopter dad; and that's part of what was holding Billy back. It's like his dad just wouldn't let him push out of the nest quite yet. And that's just a reality that happens to a lot of parents.



Diana Torres (from Anthony's film, *East Side Sushi*) makes a cameo

They're just like, I have a five-year-old and I do it. I'm making those mistakes of doing too much for him. But that was also a part of it, just this independence, both from the father and from Billy. They both need to try their own independence. Yeah.

Olivia: I see how you were saying it can be an emotional journey to watch as a parent seeing the film, especially if you have a child who deals with a disability.

Michelle: There's also the reality. I could just jump in for a second. There's also the reality of—

Cole: This is my mother, by the way.

Michelle: …of day-to-day living, where it takes so much extra time to do everything for somebody when you have somebody with a physical disability, that you're just trying to get out the door for daily life. You got to get yourself ready to go to work. You got to get the adult child ready to go to wherever it is they're going to go. So, you just do and go because that's the fastest, most efficient way to get it done.

You really don't have time to sit around and wait for them to get in and out and take half an hour to put a sock on. You got to go. And so, there isn't really this space and time to push them necessarily. To do that. If you're on your own, because it just takes too much time and energy, and you're just trying to keep your head low and go forward.

Anthony: I get it. Every morning, I'm putting my son's shoes. He knows how to put his shoes on, but every morning, I'm putting his shoes on because it's so much faster.

Cole: I just want to jump in. We've gotten compliments. We've gotten both compliments and comments from certain people. Most of the comments have been lovely, but some of the comments have been around the sentiment of, "See, if we just push them, they'll be okay. We don't need to pay for services like Social Security disability."

Anthony: Well, did that come up, Cole, or is that just what we were thinking? I think that's what Michelle-

Cole: No, that definitely came up.

Anthony: It came up?

Cole: Yeah. Not while you were around, but there was a gentleman in Ohio that said it. Yeah, I don't know if he…

Anthony: Because that's the last thing I want people to think is, oh, here we go. If we just push people with disabilities, then they'll do it on their own. That's the last thing I want.

Cole: Yeah, that's not what this film is about at all. Right.

Michelle: And he's not working a full shift. He's working three to four hours. This isn't, I'm going off to work eight hours a day and being there all by myself all the time and then coming home and being by myself. It's just he's expanding his universe, he's getting better, and he's starting to excel. But can he be completely independent?

Anthony: Yeah. That's the thing with the movie. It's like it's a movie and you want to show the character have his independence. I don't want to go back and be like, okay, these are all the technicalities, and this is the care that he still needs to have. But we could have gone that direction and showed all the minutiae.

Cole: I want to say in the original script, we did.

Anthony: A little bit. Yeah, it was more. It was more detail. For sure.

Cole: Yeah. Making this film was really a dream role for me. Very rarely do I get roles that are good, where the main character isn't dead, dying, or sick. This was one where it was just a young man with a disability, and his life led him down a certain number of circumstances, and that was it.

Anthony: Were you like, "Oh, my God, I didn't die in this?"

Cole: Oh, I literally said that to you. I said that to you the first day of filming. I filmed it. I'm like, I don't die in this. And I'm like, Okay, this is all.

Anthony: The next script, though, Cole, you're dead.

Michelle: You're out.

Anthony: I'm going to write a death scene in the next one. (laughs)

Cole: But no, what was so fabulous about working with Anthony is that we, as actors, are trained as character advocates. We are trained to advocate for the character, but a lot of directors think this is their baby and they are the be all end all. But Anthony was not like that. In fact, he wanted my input and thought that it was made it was a better film.

Anthony: And it did.

Cole: Yes, it did. So, thank you for that, Anthony. Thank you.

Chet: So, Cole, you're also an artist, right?

Cole: Yes, I do paint and all that. Digitally. Digitally.

Chet: Oh, shoot, because my house needed painting. Darn it.

Michelle: So close.

Anthony: Actually, Cole, some of your paintings, we printed them and put them in your bedroom in the film.

Cole: In the film, yeah.

Chet: Oh, what's that called? Is that Easter egg?

Anthony: It could be an Easter egg. Yeah, for sure.

Michelle: I am in the picture on the desk.

Anthony: That's true.

Michelle: Yeah.

Chet: Oh, you mean like a frame to picture?

Michelle: Yeah. I am an alive mom in the movie.

Chet: You got your mother and your father lifting you at one point. Does he make the film or is he just a stunt person that's not really seen?

Michelle: No, he's in there. You can't see his face.

Cole: He can't see his face, but he is- See his arms and his body.

Anthony: Because originally, the screenplay had a lot of Billy's lifted, Oscar lifts Billy in here. And I wanted more of that. I wanted to show this is what happens every day when you got to lift your child in and out of that chair. Because that's what my mom did up until her late '70s. She was lifting my brother in and out of that wheelchair, in and out of bed. And the reality was Lance had a bad back and he couldn't do it.

Luckily, Cole's dad, Nick, stepped in and they were both the same body type. So, Nick's like, "Well, I'll just do it. Put the shirt on me." And so we had him lift Cole, which also kept it authentic as far as how he lifts you out of that chair and into the shower.

Chet: One thing that I saw in the movie that was just like a real pivoting, I mean, it just changed everything was the purchase of the power chair. Did you have a transition from a manual to a power and changed your life?

Cole: Yes, actually, the power chair that was used in the film is my power chair.

Chet: Cool.

Michelle: Anthony didn't know about it. And that was one of the things he discovered when he came to our house, when he saw that it stands.

Cole: He was like, "Oh, my God, I got to use that in the film."

Anthony: Oh, my God, that's right.

Chet: It's just how it sounded, too.

Anthony: It did. I sounded just like that.

Michelle: When he raises up to stir the spaghetti sauce for the first time. You can hear in most audiences—most of the ones that are parents with special needs.—You can hear the audible gasp because it's such a huge difference to have a piece of equipment like that. It just expands your life. Because, instead of trying to get an apartment that's completely adapted to you, now you can adapt to the counter and the stove top, the sink. And now all of a sudden, you can access things in the cupboard and stand at the counter and make a sandwich. It's truly life-changing. So, we had Cole's regular chair, the power chair. It was also our van in the film. So, it's as authentic as it gets.

Cole: It's as authentic as it gets.

Anthony: Yeah. That chair was, like what you were saying, that was a rewrite when you told me that this chair could stand up. Because I was thinking, how is Billy going to cook in the kitchen? And then one of you, either Cole or Michelle, was like, well, this chair could stand up. I'm like, what?

Cole: I think I remember I was in your kitchen and you



Couldn't get the ramp to deploy crew made it work

said, how is it?

Michelle: You asked me- No, he was in our kitchen, and we- In your kitchen. Took him over to the sink counter.

Cole: Oh, that's right. Yeah, yeah, yeah, yeah.

Michelle: I was like, well, watch this.

Anthony: It was such an Iron Man moment. Like, oh, my gosh. He transforms an Iron Man. It's like, look at this. It's so cool. It's so cool.

Cole: I want to mention the chair. I think in the movie, they sell it for $500 or something.

Michelle: I didn't say.

Cole: The actual cost of the chair, and this was a used chair.

Michelle: Seven-year-old chair.

Cole: It was seven grand.

Chet: When you say used chair, you mean the one you have. Power chair.

Cole: The power chair. We bought it used. That's exactly what I was thinking.

Chet: In the movie, it was used as well. But just in the sense of life and people that can't have a chair, that they don't have the affordability. Insurance won't pick it up.

Cole: Insurance doesn't give a hoot, really. I mean, honestly.

Michelle: Yeah. Everything is no. We have the van that we have now we won in 2009 from Honda. Somebody put our names in, and we won it. Otherwise, we wouldn't have it. And this is the picture car for this movie, and it was hit. We were getting ready to go to set at the handy market, and there was a knock at the door. It had been wiped out, literally from stem to stern, from the front of the van to the back of the van. The whole side was wiped out. And I thought, initially, it was just cosmetic. It was not. The whole van was bricked.

Cole: We had to tow it to the location and shoot it only.

Anthony: I mean, it was like such a huge mess.

Michelle: Now, this is a 2009. We're babying it, but in order to get another one, they start at $90,000. For the people who need it the most, it is the most expensive.

Cole: Yes.

Michelle: So, we're hanging on to it as long as we can. And I'm like, hurry up and get a series so we can buy



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you a new van? Because we're just crossing our fingers that it hangs in there.

Anthony: It's a baby blue Honda 2000. It's such a difficult car to replicate. I remember, I don't know if you were there Michelle and Cole, but I saw a van just like that near the Handy Market, and I'm running after them. Wait a minute. I was like, hey, hold on. I was like, can I use your van for the film? The guy looked at me like I was insane, like I was going to carjack him. And then he just looked. He was like, what are you talking? I was like, I'm making a film, and I need your van. It's the same one. And he didn't contact me. So, yeah, I was stuck. But that van was a symbol of freedom for Oscar and for Billy. And to have it wiped out, I had to rewrite the script itself.

Michelle: But it was also a way to show how Oscar had adapted and done everything on a budget because in the story, he pulls the slide, the piece of wood out, the wheelchair in and out.

Chet: Oh, right. I saw the ramp.

Michelle: It's just a van. It's not a ramp van in the story. So, he's just done everything down and dirty, rough and tumble. This will work. I'll paste this together. I'll by the skin of the teeth. Get a piece of press board and stick it in there. And Anthony was like, I'm just going to use a piece of it. I'm like, "I'm afraid that'll flip," but somehow it worked.

And it also just shows he just made it happen. Made it happen because he had to. He has no other choice. He doesn't have very much money. And he has this kid with a pretty significant disability. And there is no help. There are no programs, there's no grants, there's no anything.

Cole: Well, Billy does go to a day program, but that's paid for by the state. Yeah, even that.

Michelle: But for a ramp van, you're on your own.

Cole: Yeah.

Michelle: And there are so many parents out there who are just lifting. It's a double lift in and a double lift out. You have to lift the kid out of the chair and into the car, and then you put the chair in the back of the car. And then when you arrive at your destination, you have to take the chair out and put the kid in. It's so much because I did that before.

Cole: It's very real.

Michelle: It's really hard.

Cole: Actually, we just recently, maybe five or six years ago, had our bathroom adapted.



Michelle: It's about 10 years ago.

Cole: It was about 10 years.

Michelle: Yeah, because I was dragging him from under the arm.

Cole: She would literally have to pick me up under the arm pits, turn me around backwards, and drag me into the back.

Michelle: And the third time I almost dropped I was like, that's it. We got to go. So, into debt we go. Our house was built in 1925 and not particularly wheelchair friendly. So, we had to to horn it in.

Cole: Well, I'll tell you. At the time of my initial receipt of the script, my mother had been recently diagnosed with breast cancer. And originally, as you know, it was written for a woman with breast cancer.

Chet: I didn't know the original was written for a woman with breast cancer.

Cole: Oh, yeah.

Anthony: Yeah. It was originally mother-son story. And we eventually changed it because, for one, I couldn't find an actress who agreed to do it. I just got turned down. That was crazy.

Chet: And Cole's mother wouldn't do it?

Anthony: She wouldn't do it. She was too expensive.

Michelle: Too much of a diva.

Anthony: Too much of a diva. But like Russell Boast, he would send out the script and whatever. But I said, Russell, you need to specify that we will not have any trailers for actors to go hang out in between takes. They are just going to have to hang out wherever we're filming on set. So, he did. And I think they just probably felt this was going to be a very low budget film, too low budget. And so, we got turned down quite a bit. But then my wife, Kaylo, she's like, "Why don't you make it a father-son?" She hadn't seen very many father-son stories, compassionate father-son stories like this. And she's like, "I think I'd like to see that. Probably a lot of fathers would like to see it, too." So, I went back to rewriting and changed it.

Chet: Yeah, it works. On a lot of levels, I think it's always interesting when you see the more emotional issues coming out of men.

Anthony: Totally. It's funny. I had a comment from somebody saw it, and they said, after seeing the film, I realized how much of an asshole my dad really was. I was like, my dad would never do any of this for me. And We're like, Hold on, it's just a movie.

Cole: Hold on. It's just a movie. Hold on. Making a making a movie like this that's so authentic to me and to us on so many levels was really extraordinary. I would be remiss if I didn't mention that I worked with my mother quite a lot to bring authenticity to this story. And it turned out okay, I think.

Chet: I see she's got a gun to your head.

Michelle: (laughs and makes a fake gun with fingers) I don't know what you're talking about. Just one other very quick thing. I think another reason that he had such great chemistry with Lance is—So, I come from a long line of production people. And my stepmother was married to a man. He's passed now, but his name is Jim Drake. And Jim was Lance's director on Police Academy 4. So, our first day on set, I walked up to him and I said, "You know Jim Drake?" He goes, "I sure do." "Do you know Bridget?" I said, "Bridget is my stepmother." It was like this immediate family connection. And also, Lance is just like, he's such a dad. He's just…

Cole: He just gives off his dad energy.

Michelle: Yeah, such dad vibes. So, that was another really cool little tidbit.

Chet: Well, so you're both in LA?

Cole: Yes. We are both in LA. Yes.

Chet: I was going to ask about the market. Is there a real Handy market?

Anthony: Yes. In Burbank. The owner let us film there for free. We started at 8: 00 at night, and we finished at 4:00, 5:00 in the morning.

Chet: I thought it had closed.

Anthony: Do you know the Handy market?

Chet: No. The movie says it closed.

Michelle: In fact, they're renowned. Right next to it, they have a little area where they do these smoked meat sandwiches. Oh, yeah. They have lines around the block. Yeah, they're really very… It's a very popular market, actually.

Cole: As a matter of fact, the crafty area for that set was right where the- In the smoked sandwich.

Michelle: He gave up their smoked sandwich area for a minute. Yeah.

Chet: You really were able to reduce your cost, Anthony, in production with all the things that you mentioned today.

Anthony: Oh, it's tough. It's like I was doing… It's called DIT (digital imaging technician). It's part of the camera department where they copy the hard drive from the camera to the other hard drive. I was doing that on set, just various. Then post-production here, Cole's dad is Nick. He's doing all of the digital cinema packages, sending those out to the theaters. It's like when you cast somebody, you have to cast people that can help you later on the film and get it done for cheap. That's smart..

Chet: So, when you talk to Russell, you will have all these caveats. They will also need to have family members.

Anthony: (Laughs) Well, I've honestly, I've said this because everybody wears my clothes. Lance, he wears my real clothes. I pulled all my clothes out of my closet. I'm like, here Lance, here's your wardrobe. Here's your uniform. So, you have to cast people that are also your size. It's great.

Cole: The wardrobe person for a lot of it was Anthony.

Anthony: That was me too. I did a lot of the wardrobe.

Chet: Wardrobe, and then you run over there, sew something up.

Anthony: Exactly. I was steaming clothes.

Chet: Makeup?

Anthony: No.

Cole: Did you steam all the —

Anthony: I was steaming some of the clothes, the night before, I was washing some of the clothes, steaming them. It was just ridiculous.

Chet: That's a whole movie in and of itself — a movie about making a movie.

Cole: Making a little independent film.

Anthony: And me crying most of the time.

Michelle: They won the Bill Paxton Award.

Chet: Oh, That's great. Michelle did you work on the film?

Cole: She was the informal scripty?

Anthony: No, you were the script supervisor. Like I said, everybody wore a lot of hats. Michelle did a ton things, still doing a ton of things. Yeah, just so fortunate. So, fortunate people love the film enough to rally around it. It's like, "I'll help you." Absolutely.

Michelle: Yeah. It was very much a little engine that could. Labor of love. Yeah, just pulling for it. The joke is the back of my head is prominently featured throughout the film.

Anthony: Yes. I know. It's like, because we need a body. Yeah, I need a body. Michelle, get in there. You're like, but I was an extra yesterday. Put a hat on.

Michelle: I had a mask on. I put a hat on. I had my hair up. You just plug the holes. You just jump in.

Chet: In the movie, Cole, are you aware that there are some filters that Anthony used?

Cole: Yes. It was in the screenplay.

Anthony: Yeah, that's before I met Cole.

Chet: Well, it worked. It gave a bit more of an insight, not just on the physical issues of Cole bagging, but also the visual of what the character was able to see.

Anthony: Yeah, it just adds a little extra layer of difficulty. Cole has CP, but also visually impaired. Oh, my gosh. Autism. Yeah, it was like, let's do it.

Cole: (laughs) Yeah. I had all the conditions, so…

Anthony: You're hired! ■ ABILITY

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JIMMY BUTTON

RACING FORWARD AND FINDING "PAY DIRT" IN HELPING OTHERS

From his first wobbly laps on a dirt bike at just two years old to standing on podiums around the world, Jimmy Button's story traces the adrenaline, triumphs, and brutal realities of professional motocross. By the time he turned pro in 1989, Button had already made history as one of the sport's most decorated amateurs. His career carried him across continents and through factory rides with Honda and Yamaha, but in 2000, everything changed in an instant. A crash at the San Diego Supercross left him with a spinal cord injury, forcing a sudden end to racing and the start of a new mission. What could have been a final chapter instead became the beginning of Road 2 Recovery—a foundation Button co-created to help injured athletes navigate the daunting financial, medical, and emotional aftermath of catastrophic injuries.

Now, as the sport faces one of its most injury-plagued seasons in decades, *ABILITY Magazine*'s Chet Cooper speaks with Button on his journey, the evolution of motocross, and why giving back has become his greatest race yet.

Chet Cooper: What got you in to riding?

Jimmy Button: I think it's probably a stereotypical story of a dirt bike rider. I started riding when I was very, very young. I believe my first time on a motorcycle was around two, two and a half years old, just in a little field parking lot type of thing by my grandparents' house. That just spurred along. I started racing when I was five. I had a factory ride with Honda when I was eight years old. I was getting paid to race by the time I was eight or nine years old and went through my whole amateur career up until I was 16. When I turned pro in 1989, at the time, I was the most successful amateur racer ever in terms of how many championships I had won. I turned pro at the end of '89 and did a couple of races at the end of '89, and then 1990 was my first full pro season.

Cooper: When you turned pro, did you have a factory ride at that point?

Button: I was a factory-supported rider as an amateur. When I turned professional, I didn't turn pro into the full factory race team. Back then, I was riding for Honda, and Honda didn't do that type of stuff then, so I had to earn my stripes my first year. My first year, I was actually considered a privateer. Then I ended up signing with Yamaha for the '91 season. My second year pro, I was with factory Yamaha, which is where myself and Doug Henry became teammates for the first time. I had a relatively really good career, won a bunch of races, never won the big Supercross or Motorcross Championship, but got second place in those championships on a few occasions. You know, it is what it is. It's hard to win championships. I was lucky enough to be able to win a lot of races, be on the podium for a bunch of races worldwide. Won a lot of international championships, but I never won the big American championships. That's one of those things that happens in a pro career, but it was moving along pretty nicely.

Cooper: Can you tell me about what led you to create Road 2 Recovery?


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Still from *Pay Dirt*

Button: Well, in January of 2000, I had my accident at the San Diego Supercross, just rolling through the whoops–like you'll see in the in the Pay Dirt movie, it shows it pretty well–and I just had a weird, awkward little crash that had massive repercussions. I ended up breaking my neck and suffering a spinal cord injury. I'm a C3-C4, incomplete quad. The career was over in an instant. I was in the hospital for a long time with no real upside given to me. The doctors were pretty adamant about that. I was pretty adamant the other direction.

Cooper: Where did you do your rehab?

Button: My inpatient rehab I did at Barrow's Neurological Center here in Arizona. Once I graduated out of there, I was to a point where–I guess from a clinical standpoint–you could say I was walking because I could shuffle my feet and keep my body weight above ground, but I wasn't really walking walking in the state that I am now. We ended up going out and we found a gentleman in Encinitas, California, by the name of Paul Chek. We met up with him through some advice from Danny Way, the professional skateboarder, who had also suffered a broken neck–no paralysis–but a broken neck. Chek had helped Danny relearn how to move and all these types of things, so I went and did outpatient rehab with Paul for a year. I'd lost 40 or 50 pounds of muscle by the time I saw him, so we went through the whole process with him, and he helped rebuild my body into what it is now. Obviously, I was not going to be a professional athlete any longer, but I wanted to get to a point that I could I could move around and do things as well as I could in society. So, we did the rehab there and going through that whole process–what we were going through as a family, the pitfalls that are out there in in the world for spinal cord injuries and all this stuff that we were dealing with–we decided that we needed to start a foundation because it was so difficult to navigate through all this. I had everything at my disposal. I was very well known. People came from all over the world to give us good advice and good guidance on things to look at, things to do, rehab, to look at whatever it may be. I was financially in a good place, and it just got me thinking, "Okay, this is going to happen to somebody else again because dirt bikes are obviously very dangerous and we need to put something in place that can help the next person that goes through this navigate these waters as best as possible." That was the start of what is today the Road 2 Recovery Foundation. We've been doing this now with the foundation for 25 years. We've donated more than $10 million to injured athletes and helped over I think well north of 200 athletes right now that have had spinal cord injuries or traumatic brain injuries that we've helped navigate the waters of this whole injury.

Cooper: There's so much need that happens that people don't understand when there's an injury. How did you get connected with the film Pay Dirt: The Story of Supercross?

Button: The movie is a story of Supercross, and it weaves in and out of highs and lows of what's happened over the past 50 years of the sport. My injury was pretty impactful amongst my peers. Then with us starting the foundation and what we do now, we're woven through the thread of the sport. In addition to that, I have a great relationship with the guys over at Monster, and I've known Paul Taublieb–who this movie is his child–for a long, long time. When he came to me and asked me if I would be open to sitting down for a few hours and tell him my story, I gladly said yes and was happy to do so to get my story out there and get some more exposure for the foundation because the foundation lives on donations made by everyday people. The more people I can get the foundation in front of to create awareness about the foundation and to raise funding for it will allow us to continue the work that we're doing to help all these guys out that find themselves in the spot that they're in. To give you an example, the 2025 season for us as a foundation has most definitely been the worst that we've seen in 25 years. We've had so many injuries this year. It's unthinkable. I don't think a week has gone by so far this year where we've not gotten a phone call with someone breaking their back or breaking their neck or whatever it is and are going through some pretty serious times. We've never experienced anything like this in this amount of time that we've been doing it.

Cooper: When you say you're getting the phone calls, are they from individual weekend riders?

Button: No, so the way our 501(C)(3) is set up is we cannot help the everyday amateur rider that's out there racing. It's very localized to professional riders so these are just professional riders that we're dealing with. Usually we'll see maybe four, five, or six athletes a year that will get injured, but I think right now we've had north of 20 major injuries already this year, and we're only in August 2025. It is a catastrophic year when it comes to injuries, that's for sure.

Cooper: Do you think that it has something to do with the sport and how aggressive everyone is getting to get to the top and just taking that extra chance to make a pass?

Button: No, I honestly think what it comes down to is this. When I raced, I would say the bikes weren't very good. To go really, really fast, you had to be extremely, extremely talented because the bikes just weren't that great. Now, I look at the bikes that you can just go buy on a showroom floor–let alone the race bikes that the good guys are riding–and the bikes are so good. They're so easy to ride. They're so fast. The chassis and suspension is so much better than anything I ever witnessed. That allows a lesser count of rider to do things that before was only done by a higher caliber rider.

Cooper: You're saying the equipment is so good that a lesser rider can easly go beyond their capabilities?

Button: I'm not saying that the only people getting hurt are lesser caliber riders. That's certainly not it. I just think it's now so easy to go fast, and the bikes are so forgiving, that you almost get lazy because the bikes are so good. You can do so much on them. When your mind is not optimized 100 % all the time, and you just have a very quick lapse of concentration, that's when things are going to go wrong. At the speeds that these guys going now, when something goes wrong, it's huge. It's not something small. It's a huge catastrophic event that goes on. Not that you see a lot of crashes all the time, but when you do see them, they seem to be bigger and more just more damaging than they have been in the past. At least that's my own personal view, whether that's actually what's going on, there's not really a bunch of data to look at to say one direction or the other, that's what's going on, but that's my opinion on this current situation.

Cooper: What do you think about the neck brace Dr. Leatt invented?

Button: There are two or three brands of those that are all fairly similar. I personally look at the injury that I had back in 2000, and I believe had I had one of those braces on, that I would have just gotten right up because of the type of crash that I had. Now, do I think that those braces are going to work in every single situation? I don't. I don't think anything works in every situation. I think some crashes or events that you're going to go through, it doesn't matter what you have on your body. You're going to get hurt. I think that goes for helmets as well. I mean, people think so much about, "Oh, well, if you had a better helmet on, you wouldn't get a concussion." The fact of the matter is, if your head's hitting the ground at 40 or 50 miles an hour and you get a concussion, you're probably just going to get a concussion no matter if it's a Shoei, Arai, a Fox, or whatever brand of helmet that you happen be wearing. I think that some injuries and some accidents, they're just going to happen. It doesn't matter what protection gear that you have on. Some things are just that big and damaging.

Cooper: Where can people go to find out more what the foundation does?

Button: I always encourage people that have questions about what we do or what the foundation does, to jump on our website at road2recovery.com and see what we do and read about us and understand more about us. We want people to donate to the foundation, to the cause, but we also want people to understand what it is that we're doing and be comfortable with spending their money with the foundation and trusting us to do good work with the money that they give the foundation. I always encourage people to go look on it, understand what we do, and if you feel inclined, make a small or a large donation, whatever you're comfortable with, and help us out because we're basically here to help these guys out when they get injured and have nowhere to turn. Trying to just be a good helping hand in the industry.



Cooper: Do you do any fundraisers, events?

Button: We do a number of them during the year. We do two or three golf tournaments a year. We just had one actually on the Sunday after Washougal. We had one on Sunday after the Pala Race in Southern California, and then we'll have another one. It's looking like we're going to do one in Florida near where all the guys ride and train just outside of Orlando sometime in early December. And then we do other events during the year as well. We do events, like sweepstakes events, where you can enter to win prizes or motorcycles. We just gave away a brand new 2025 Triumph 250, as well as a 25 KTM 350 from two sweepstakes that we had been running for the duration of the Supercross season. We'll be doing more things as the year carries on, so anybody that wants to learn about those programs, events, sweepstakes or live auctions can find out all the info on our website. The live auction that's going on right now for August 2025 is actually quite cool. A bunch of the riders gave a lot of memorabilia items for Jerry Robin, who had gotten hurt during Supercross, and those proceeds will go to Jerry.

Cooper: Have you talked to Bob Parsons?

Button: I have not. My dad built his big dealership for him. My dad was Hunter & First Airborne in Vietnam, and so him and Bob hit it off pretty well. My dad had been retired for a while, and Bob came to my father and had my dad go build that huge dealership that he has up in Scottsdale. Then once the dealership was up and running, my dad basically just retired again for the second time. I don't really know Bob, but my dad knows him.

Cooper: Well, he loves golf. He's got a whole business around golf clubs and he sells motorcycles, and he's got money in a foundation that gives to good causes that he likes. I think you should ask your dad to connect you.

Button: He might want to end up sponsoring my son. My son's top 50 in the world golfer.

Cooper: Oh, really?

Button: Yeah, he's sponsored by Callaway already.

Cooper: We interviewed Bob a year or so ago dealing with post-traumatic stress disorder. He had written *Fire in the Hole* talking about his own issues.

Button: I know that a lot of people think he's hard to deal with because he's a pretty strong-willed guy, but him and my dad hit it right off and always got along quite well. ■ ABILITY

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RAY-BAN META GLASSES

Blind User's Experience

The proliferation of assistive technologies for the blind in recent decades, whether it's a smartphone or a specialized computer program like ZoomText or JAWS, has helped connect the visually impaired to mainstream society in ways that were once unimaginable. They enable the blind to perform mundane household tasks, like sorting cat food cans, as well as bigger projects like conducting a meeting while pursuing a career.

Although clearly life-changing, the technology behind many personal assistive devices has often been clunky to wear gadgets with spotty or limited outcomes. Nonetheless, I've maintained a belief that exciting, intuitive and unobtrusive accessible technology for the blind would exist in my lifetime and help me reclaim some autonomy.

Becoming blind as an adult, I conceded certain aspects of sighted life and activities. I created workarounds where I could and I constantly gauged for the parts of the day to forego. That is, until I gained access to and acquired smart accessible technology and learned to integrate new tech lifestyle habits.

I am completely blind. My final vision loss a couple of years ago made my world very small at first. When I got my fight back, I re-engaged with the New York Commission for the Blind and Visually Impaired and received services. While picking up new computer equipment at The Lighthouse Guild, my adaptive technology instructor, Ed Plumacher, showed me the Meta Ray-Bans, the new smart glasses that connect to devices like smart phones and tablets.

While Ed was setting up my new computer, I listened as he received work calls on his mobile phone. He replied to each call with text messages using voice commands, all while his hands remained typing on the laptop keyboard. "How did he do that?" I wondered. Ed read my mind and explained he was using Meta Ray-Ban glasses.

Ed then demonstrated other functions, like the glasses describing the room, including what I was wearing, and live translation from English to Spanish. We had a spontaneous bilingual conversation. I spoke to him in Spanish; the glasses translated what I said to him in English. Then he directed the glasses to provide the Spanish response to my statement. I was struck by the glasses correctly translating an oblique Spanish idiomatic expression I used. Ed said the Meta Ray-Bans also support other languages like French and Italian. With that demonstration, I knew I had to try them out for myself.





Ed reading to his grandson assisted by Meta Glasses



Gina uses Meta Glasses to identify the flavor of a can of cat food.

Ed kindly loaned me a new pair and did the initial setup. Since we are both functionally blind, parts of the setup were especially difficult. For example, there's a point at the start of the process where a blue light shows in order to pair the glasses with a smartphone. This was tough to do when all we had was a tiny bit of light perception between us. We eventually got it set up, but it took us about three hours.—I suspect those with more vision can do the setup in much shorter time.— In the end, it was doable but this was one of those situations that called for extra reserves of patience and tenacity. Off I went with my new Meta Ray-Ban glasses!

The glasses are typical Ray-Ban frames that charge when inside their case and have a battery life of six hours. There are tiny open-air speakers embedded in the arms (temples) of the glasses. Swiping the side of the temple controls volume and tapping the temple can execute commands.

The camera is located on the top right corner of the frames and can capture a piece of writing held in front of it. With the "Hey Meta, look and read this" prompt, the glasses can read or summarize letters, bills, menus. It only takes natural head movements to master this function. The "Look and tell me what you see" command can be used to get a description of everything the camera captures in a room and can locate a specific item. For example, "Hey Meta, do you see a set of keys?" followed by, "Where are they?" often provides accurate visual help finding things if there's no one sighted around to help.

I found a very small learning curve for this and other functions. It mostly entailed learning the verbal commands. When I forgot the precise phrasing, the AI component recognized my intended question and prompted the correct command phrase.

On typical weekdays, I put on the glasses after having my coffee. I then ask for trivial, yet important, information to start the day, like the weather and forecast for the weekend. I then, typically, ask the glasses burning questions that kept me up the previous night, like what was Myanmar's former name and when did it change. The device quickly searches the internet and the little speakers on the frames give me the answers. Then, when I'm satisfied, my brain is ready, I get to work.

I have used the glasses to assist with writing. In one to two seconds, without taking the time to open a browser and type in a research question, the Meta glasses does the searching and reads the information I need. I've also asked it to repeat information, facts and figures so I can type what I need for my purposes, and it does!

Being a non-braille reader, I've lost a crucial tactile knowledge-gathering method I didn't realize I employed to retain and process information. As a blind adult, hearing and typing have replaced visual reading and handwriting. So, having the Meta glasses repeating paragraphs of information over and over to me as I type has been useful and productive for work and for my overall brain function.

The Ray-Ban Meta glasses have also instantly given me access to an extensive array of synonyms, antonyms and spelling, which has come in handy for writing. In fact, my glasses generated, produced, manufactured, suggested many of the adjectives in this piece.

It has taken time for me to acclimate to the experience of not seeing my environment. Being outdoors feels like risky business when I can't see the curb, cars whizzing by or street signs and addresses. Being in unknown places feels disorienting and foreign. I decided to see how much the glasses could connect me to the physical experience of a doctor's appointment.

Sitting in a waiting room at the massive Mount Sinai Hospital, the Meta glasses not only accurately identified the location as a hospital waiting room, it also described the furniture, the reception area and the patients sitting in chairs. When I asked for the location address, it answered and went on to tell me about the hospital wing I was in and other departments it contained. The Ray-Bans gave me more information about where I was than I've ever received from the companions who've helped me attend my appointments.

After my appointment, my friend and I, both serious walkers, decided to walk from Fifth Avenue and 101st Street, all the way home to Queens. It was a lovely spring day and the weather was perfect for a long walk. Along the way, I asked the glasses for information on where I was and the buildings we passed. It correctly told me when I was on the corner of 96thStreet and Fifth Avenue. It correctly identified the Met, although it was snooty about it. It answered my query by saying, "No, it's not the Met. It's The Metropolitan Museum of Art, also known as the Met." The glasses then meticulously described the structure and its architecture. It also told me about the hot dog carts in front. This was marvelous fun.

The New York Commission for the Blind and Visually Impaired eventually issued me my own pair. As of September of 2025, the New York Commission provides Meta Ray-Bans for blind and visually impaired high school seniors, college students, and people who are employed. The retail purchase price point for standard Meta Ray-Bans starts at $300 and can range up to $379 depending on style, color and lens type.

I have a bit of light perception and use the pattern of ceiling lights in my apartment to guide me from room to room, so the commission approved me for a pair of transition lenses. Before, when using the loaner Ray-Bans, I would have to take them off whenever I left my office chair and moved about. Now with the transitions, I can keep them on all day on most workdays. I make calls, answer the phone, send texts, listen to incoming messages from my iPhone and other messaging apps like WhatsApp. I listen to my music subscription or Audible book during a break or at night.

A quality of life function the Meta AI glasses supports is one that I had been reticent to try. Be My Eyes is an accessibility app launched in 2015. It is a service that uses volunteers from all over the world to provide sighted assistance through the use of a smartphone's camera. (Access permissions are required.) I've heard favorable comments about Be My Eyes but have been uncomfortable giving a stranger camera access to my personal space. Encouraged by my positive interactions with the Meta glasses, I finally relented and decided to give it a go.

I connected to a young volunteer named Bianca, who identified the cat food flavors of the cans I held before the glasses. She happily agreed to chat with me about her experience as a Be My Eyes volunteer. According to Bianca, Be My Eyes blew up on TikTok in the Spring of 2025, when someone posted their first volunteer session. That's how she heard about the app. Since then, the pool of volunteers has grown to be greater than the number of Be My Eyes users. Bianca shared that her reason for volunteering is because, "I want to help people like my cousin Austin who is blind from birth."

Curious to know how the Meta glasses came to intersect with the blind community, I chatted with Ed and Brian Fischler, co-hosts of the podcast "That Real Blind Tech Show." According to them, the Ray-Ban Meta glasses became available in the fall of 2023 and were originally designed for sighted working people on the go. In the Spring of 2024, the introduction of the AI component that enabled the user to interact with their environment through the camera caused the blind and visually impaired community to take notice. Once the hands-free utility and ease of use became known, the blind community began spreading the word through social media posts.

Blind techies and non-techies, alike, have said the glasses have made a positive impact on their work and personal lives. Ed described to me how he was able to "read" a book to his three-year-old grandson. First, he asked the glasses to read the text to him and he "read" what he heard out loud to his grandson. Then he asked the glasses to describe the images on the page. This way he could discuss the fantastical characters, colors and shapes his grandson sees on the pages of the book they were reading. I would have loved to have this technology when my son was small, to have that type of bonding moment.



Gina wearing her Meta Ray-Bans with the background of the United Nations

After using the Meta Ray-Bans for a couple months, my daily life feels less stressful and more manageable. I'm still uncovering tools that affect what might seem trivial to a sighted person but are life-altering for a blind person. As an illustration, when I dropped a small poop bag I use to collect my cats' offerings, I wasn't in the mood to get down on my knees and sweep my hand in circles on the floor surrounding the litter box to find it. Honestly, I had a small momentary freak-out. But then I remembered the, "Tell me" function.

I tilted my head down towards the floor in the general vicinity where I thought the bag might be and said, "Hey Meta, look and tell me if you see a plastic bag?" My glasses answered, "Yes, there's a green plastic bag on the wooden floor." I then asked, "Is it at the top or the bottom?" It made my day by replying, "It's at the top, next to the wall on the right." Imagine my glee when I placed my hand where the glasses told me the green plastic bag would be and found it there. I'd forgotten my fan was on and hadn't realized it had blown the bag a bit down the hallway. Inconveniences like this one throughout an average day can feel like a pile-on. The glasses are a significant step towards alleviating these inconveniences for blind people. It's advancements like this that make me glad to be blind now instead of at any previous time in history.

I've become accustomed to asking my Meta Ray-Bans lots of far-ranging questions during the day, both for utility and for fun. There have been times when I forget I'm not wearing them, and ask out loud things like, "Hey Meta, when did Rumi write his poetry?" or, "Hey Meta, what's the latitude and longitude of Ibiza?" I find I'm relying less and less on other talking assistive devices laying around my apartment because of the ease of use, discreet nature of the glasses, and their portability. As long as I'm connected to the internet and my smartphone Meta app is open, I'm good to go. ■ ABILITY

meta.com/ai-glasses

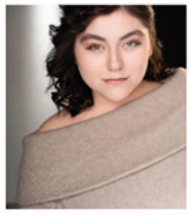
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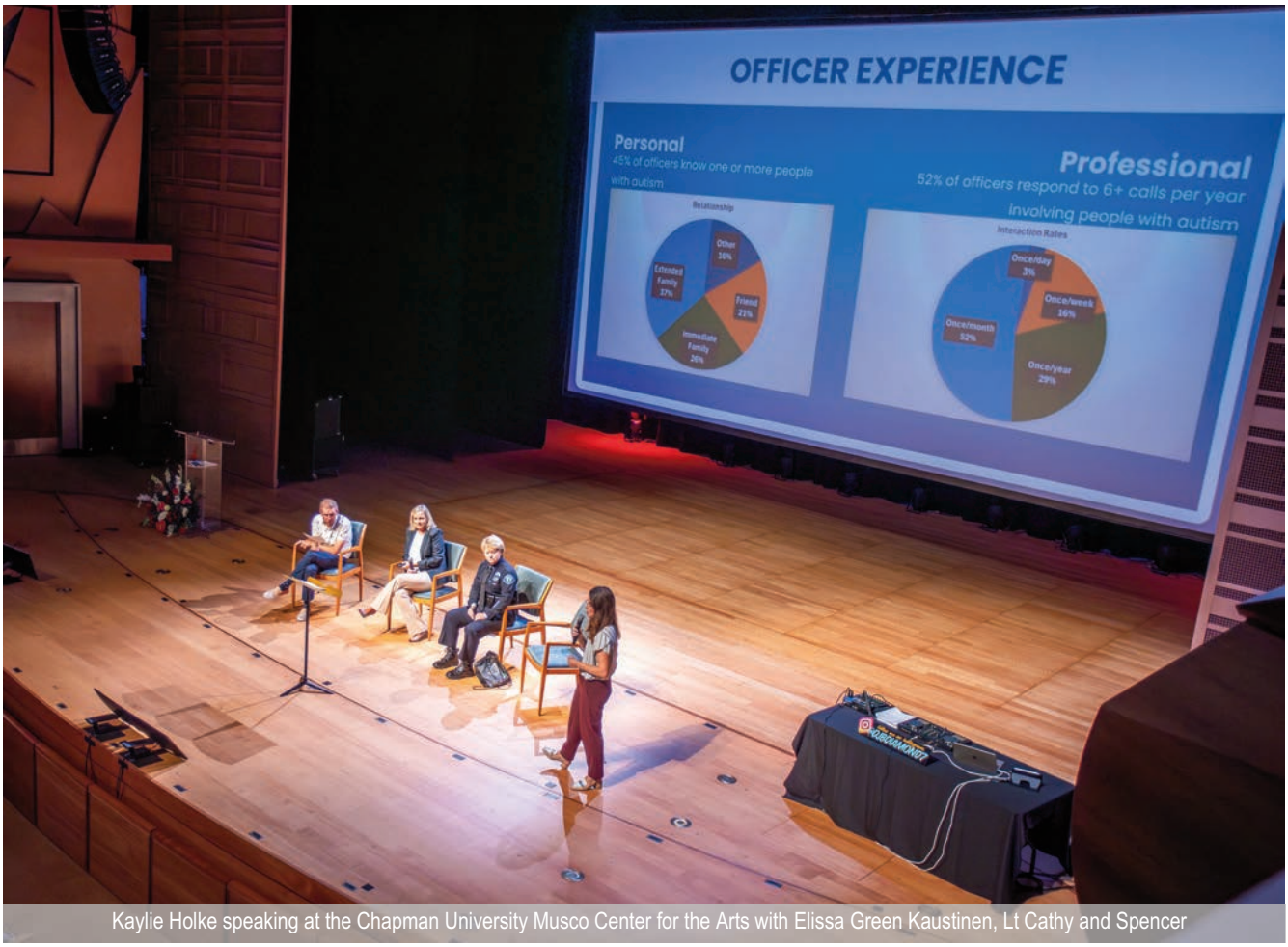
Many law enforcement officers (LEO's) lack the training and resources needed to effectively engage with individuals on the autism spectrum during everyday public encounters—from routine traffic stops to high-stress, critical incidents. This often results in harmful outcomes and escalations that increase the risk of injury for both the individual with autism and the responding officer. To close this gap, a small group of researchers created Autism Awareness Training for Law Enforcement Officers. The program makes a lasting impression by bringing officers face-to-face with a multi-disciplinary team, including researchers from the Thompson Autism Center at CHOC /Chapman University, a fellow officer, and, most importantly, individuals with autism. Elissa Kaustinen and Kaylie Holke from Thompson, and Lieutenant Cathy Scherer of the Irvine Special Operations Division, recently sat down with ABILITY Magazine's Chet Cooper and Diana Pastora Carson, M.Ed., to discuss the program's development, its real-world impact, challenges in law enforcement and some of the surprising positive outcomes they've seen along the way.

Chet Cooper: How did this program come about? Did you create the program and then pitch it to the police department?

Elissa Kaustinen: In a sense, yes. But Cathy was also a part of the development. In development, we were really looking at what the need was and then seeing if there was a police department who was on board in assisting with the development. Kaylie and I did a lot of it, along with John, Spencer and Amy, but also Cathy had a lot of input on it. So, I think the development was really multidisciplinary and really having that officer's lens to it. So, I think Cathy was very crucial in the development. She was just an integral piece of the whole entire thing, and we needed her to present as well.

Cooper: Can you give me the history of the program?


Revisit



Kaylie Holke speaking at the Chapman University Musco Center for the Arts with Elissa Green Kaustinen, Lt Cathy and Spencer

Kaustinen: I would say around maybe three and a half years ago, we were talking with our main donors, the Thompson family, about the need for law enforcement training, the need for officers to be trained on how to interact with individuals with disabilities. I think there were different stories in the news, and so it prompted a lot of conversation. There was another police department who worked in the past with us for an April Autism Awareness. We tried to start conversations with them. I don't recall how exactly I got connected with Cathy, but someone said, Irvine may be interested. They do a lot for the community and are very supportive. Cathy was very willing and graciously met with me and jumped on board.

Cooper: Kaylie, you were part of that development?

Kaylie Holke: Previously, I was a speech pathologist, so I have a lot of experience working with individuals with autism from birth all the way up to young adulthood. Elissa, do you want to give a little bit about your background?

Kaustinen: I was originally a school psychologist within the school system and then a special education coordinator prior to coming to my role as the FAST (Families, Agencies, and Schools Together) Director at CHOC (Children's Hospital of Orange County). My role is really community support, community outreach, not only supporting our doctors and physicians here, but also families. I try to take a holistic approach in working with our families. I go back and forth between using student, patient, individual disability. When I'm here at the hospital, sometimes, I use patients. Other times, it's really students. I think, in order to support the students, we really have to also train the adults around them.

Holke: I'm also a doctoral student at Chapman with an emphasis in disability studies. My role in it was looking at the laws that changed in California in 2022, and then how we could design a training that would support the new mandates for officers to be trained, not just before it was an "either or" of mental illness or developmental disabilities. But now, there's greater focus on developmental disabilities. (We ask) What does that look like? What support can we give? What does the research say? If there is an interest, both from families, from people with autism and also from first responders who say that we need this training, and this is something that we desire. And then we put it all tother.

Kaustinen: I think the one thing that I love about this program is it's actually very unique. Some places do great jobs, but a lot of times they don't do it from various perspectives. To me, our training is unique in the sense that we not only have an officer who has a passion

for it, but we also have our presenters who are two amazing adults with disabilities—And they just shine. I would say they steal the show. When we present, they do just such a fabulous job. I know, in education, we pay for different speakers to come around, but there's not necessarily certain pieces that make it more memorable. I think our training is memorable because they can tie what we're talking about to the interaction that they're also having with presenters.

As a school psychologist, coming from the school setting, I had that lens. We have Kaylie, who is a speech pathologist, having that lens and looking at the communication and the words that we're utilizing, And then additionally, we have John, who is a BCBA (Board Certified Behavior Analyst), who provides input because there are basic things that I think you look at, "What is autism?", the characteristics and the definition... But when we really look at those miscommunications or misunderstood behaviors and the language that we use, having multiple perspectives and how it's viewed have really made an impact.

Cooper: How did John get involved? How did he know what you're doing, vice versa?

Kaustinen: John is a BCBA here at the Thompson Autism and Urban Development Center. I work with him closely. We were trying to actually run a study on virtual reality training. And so, I was training our patients here at the center on how to act with officers utilizing virtual reality. However, that study never took off, but it was a passion of his.

When our behavior group was looking at starting that study—It was around the same time that our conversation started. — I said, "Hey, if you want to help us develop this training, we'd love it to have that perspective and that lens." I still think there's a hope that eventually we'll be able to try to transition and do some study utilizing virtual reality and then seeing if that virtual reality piece does generalize. And I know Cathy was really on board for that generalization. It just, unfortunately, has not taken off.

Cooper: Have you brought in other people who are on the spectrum to see what their views are on the program?

Kaustinen: We've talked to several different people. We really wanted to get some feedback

Holke: I was wondering if this would be relevant, that a derivative of this program being the 'Blue Envelope' program in Arkansas will be meeting with the Autism Society within that? Elissa, do you think that there will be opportunity to present?

['Blue Envelope' is voluntary program that allows drivers with autism to place their license and registration inside a designated blue envelope, which serves as a non-verbal cue to law enforcement about the driver's condition, improving communication and safety during traffic stops.]

Kaustinen: Yes. We do think the Autism Society of Arkansas will have a chance to take a look at it before we start training officers and look at necessary feedback or tweaks that they would suggest or think needs to be made. We've gotten a lot of great input. And even as this evolves and as we grow, it's one of those live documents that is probably going to change or add to or maybe take away. I think we're always looking at feedback. If there are willing participants to come in, take a look, I'm really happy.

Cooper: You said Arkansas. Can you briefly talk about how you moved from local in Southern California, Irvine, specifically, to jump state boundaries?

Kaustinen: Yes. I did a presentation at Tash Conference in New Orleans in December of 2024. We actually presented our training—not every detail but the core components of our training—to a pretty large audience. And one of the gentlemen sitting there was the director of the Governor's Council of Disabilities in Arkansas. He was getting ready to push forward this Blue Envelope legislation. So, conversations started that this would be a great program that would couple with this legislation. It's not something that we'd have to start from scratch. He works very closely with the Autism Society of Arkansas. He's been a part of them regarding the training and seeing what the rollout looks like there and really wanting to connect with people out there so we can then start training their officers. The legislation was passed February of 2025. We're looking at starting training in the academy in October.

Cooper: Are you going to try to tie in some of the work that Cathy has been doing since she's the first to be on the ground utilizing?

Kaustinen: Yes, it's tying in Cathy. It's tying in the Tactile De-escalation (sensory) bags. All of those components are very vital and key. We are looking at a train the trainer model there. One of the key pieces is that you need adults with disabilities to present. That and an officer component are very crucial to it. You don't need me, but I think the adult with a disability and an officer are the two pieces that are the most important. That's because, when it comes from an officer, they have the perspective of boots on the ground. They know what it's like to pull over a car and not have any information. I don't know what it's like to get an emergency phone call and show up. That's not what I do. I think that perspective, to have them talking to officers is very important and informational because they'll have questions, and Cathy has answers that I don't.

I also think it's really important to have an adult with a



Tactile De-escalation (sensory) bag

disability because, with that, comes a lot of experience and their own personal input. Just because one adult thinks one way, doesn't necessarily mean all adults do. I think all of those voices are very valuable.

I also think it leaves a lasting oppression. When officers are interacting, they can go back in their mind and think that Spencer is so memorable. There are officers that I run into after the training, especially with Spencer, and they're like, "Oh, I met somebody and I was able to bring some of the things that we learned. And it reminded me of Spencer. The way I interacted was just a little bit different. It may not have been night and day different, but just those little changes." We want to look at behavioral changes that are sustainable. When you can have that personal touch and you can relate it to somebody personally, you can see those behaviors.

Diana Pastora Carson: You mentioned that you would have an adult with a disability who's one of the presenters. How do you select people? And how do you provide them with training?

Kaustinen: Have you ever met anyone from Glenwood Housing Foundation? We have a very a close working relationship with them. It's an adult-supported living facility in Laguna Beach. They do amazing work. And so, we do things, really naturally, with them. A lot of their residents—They call them G-Force. It's their community or group of the residents who give back to the community because they just really strongly believe in it.

G-force has volunteered with Laguna Beach. We've gone to different activities at festivals within the beach. I've taken some of our patients there. As we were looking at developing, the key piece was that we need some adults with disabilities who want to do this. There were several residents who got really excited about it. Two in particular, Amy and Spencer, were chosen. Now that Amy and Spencer have done it, there are several others who are like, "Can we come do it, too, now?"

We met with Amy and Spencer several times. And they had input on the content as well as the flow, for example, what signal they want on their slide. In our actual training, there are little pink and green dots. They're not very noticeable at all, but it gives them the signal of "this is my slide. I do this one."

We've met several times. I'll go (to Glenwood), and we'll practice. There are still other times where we've

made some tweaks just because they are really out in the community in Laguna, and with different interactions, they realize, "Oh, I don't like that, even though I thought I did like that."

So, there are times where, in our presentation, we do draw from research, and we'll pull in the research piece. But then we also make sure that we have their own personal experience, to give the officers a wide range. Just because one person likes it doesn't mean that everybody else does. But here are some things that can help ease an interaction. Unfortunately, Spencer and Amy cannot travel to Arkansas with me. My task for Arkansas was to find some adults. I think they're working with Autism Society to identify some people.

Carson: What are some of the discomforts in law enforcement, where they wish that they knew more?

Holke: In the literature, there's not a wealth of information of published studies about interactions between officers and individuals with autism. There are some— but also few in number— that are survey-based. For example, what would officers like to see? The outcome is very consistent. They would like to have training. Often training about autism is linked with mental health disorders and in recognition that they cannot be treated the same. Officers would like to have more training.

Then the same thing, surveys that go out to people with autism say, yes, we also want officers and first responders to be aware that I have characteristics that have the potential to be misinterpreted. That stemming behavior has been misattributed to erratic behavior, suspicious behavior, lining up items on grocery shelves has led to conflict, things like that that would be nice if a responding officer was able to recognize signs and say, "Okay, this person does not need to be escorted to the hospital, but we could handle this a different way." So, the research has been pretty clear on that.

To add to the training, we have surveys and interviews with people with neurodevelopmental disabilities talking about what they would like officers to know about them. Then the same question was asked to caregivers, What would you like officers to know about your son, daughter, the person in your care? We pulled together those answers, also with input from residents at Glenwood. For example, provide personal space if possible, turn lights and siren off if possible.—That's something that's big for Spencer; he volunteered that on his own. That one is said loud and clear in the research as well. He also said, "I would like an officer to approach by himself, not with a whole group. I would prefer it be walking, not at a run, that lights and sirens are off, and that the officer narrate to me what they're doing. If they needed to touch my arm, they would say, I need to touch your arm now. And just saying different things and the why, but stating before it's done." For instance, instead of wrapping headphones on his ears, they would say, "I have headphones. I want to put them on you."

I think there was another piece of your question, though, that sparked a thought. For me, one of my biggest ahas was after the first training, how many officers came up afterwards as parents to say, I want to talk to you about my son or I want to talk to you about my nephew or something like that, where I think there's a greater learning and understanding of bringing people together in the same room.

Lt. Cathy Scherer: I've actually had officers get up and walk out of the training. And calling me and texting me later and apologizing, they're like, I'm so sorry. It's just everything we were talking about was just too close to home because their child has autism. And for them, this is just a Tuesday. But when they come to work, it's different. They are working and dealing with it at home. But then they come to work, and we're presenting about it. It just triggered some officers. What Kaylie was talking about was the aha moment for me, too. I didn't even realize how prevalent it is. In one briefing setting, how many people are impacted by it, whether it's their own child or it's their niece, their nephew, whatever it is. And so that was the part for me that just solidified that this is absolutely necessary.

It's having a conversation, but it's also validating those officers that are parents that this training is absolutely necessary. It doesn't matter if you live and work in the same place or if it's two different places. This training is vital because this is occurring in the human race, and it's not differentiating if you're a police officer, a doctor, a lawyer, anything else. I think that part of it for me was very validating.

My passion came from my godson with autism. That's what's driven me to do this and realizing my interactions with him and realizing that other officers are going to have the same thing. And mine is a little bit further away because he's my godson; he's not the child I wake up with every day. And when those officers were coming forward and talking to Kaylie and just getting with me afterwards, it just solidified the fact that this absolutely needs to be done.

I've been in law enforcement for almost 30 years, and it all was training on mental health and had nothing to do with developmental disabilities. The spectrum is what has been on and off throughout the years. But I think that getting very specific neurodiverse training is not happening in law enforcement, and we have done a disservice because we've lumped it all together, which I think a lot of society does. I think, as law enforcement, we have treated it the same because for us, a short-term fix might be taking them to the hospital. But it doesn't help in the long term with the development of that person. So, that's my goal and challenge and willingness to help and train and do all the things that we're doing to try and make it better. And for people to understand that



Spencer speaking at the Chapman University Musco Center for the Arts with Elissa Green Kaustinen, Lt Cathy Scherer and Kaylie Holke

there is clearly a distinctive difference. And you might have a little bit of both, but that's a little bit more rare. But you're going to have more multiple disabilities from a developmental side versus mixing in the mental health and the developmental disabilities. I think these guys have taught me that, and I've learned that through the training. It's just a different level of communication and a different style of teaching.

Carson: What a profound aha for you and for the people that you oversee, Cathy, that you support in law enforcement. Kaylie, how far reaching is the program that you and Elissa are working on?

Holke: Right now, we've done a few different presentations in Orange County. That piece was taken to the Tash conference, and that's where Elissa was connected with the governor's office of Arkansas. Then we also took the data from the first round of presentations and presented at the American Educational Research Association in Philadelphia. So, little sparks here and there. At some point Elissa began doing a part of the training for Orange County Fire Authority, which was filmed. Then to the Falk Ambulance Company that operates in Orange.

Carson: Is there a plan to take this training to every police department in California or nationwide?

Scherer: Yeah, the first step, I told Elissa that she needed to get this class POST-certified, which is an arduous task because they do exactly what we do as law enforcement. In California, we have Peace Officers Standards and Training (POST). It's overarching; all education goes through POST, and that's how officers throughout California are certified to be police officers in California.

They said, "Oh, we have mental health training." And Elissa said, "But no, this is different. This is different. This is different." And she kept having to represent and message things out. It took over a year for her to get it POST-certified, but now it's a POST-certified course, which means you can present to any police department within the state of California. They get training credits for this course, which in turn is important from an agency's perspective because, if I'm going to send my entire police department, I need to know they're getting certified hours for this training.

I think it's vitally important to get that. Not every state has a POST-certification program, and no POST-certifi-

cation program is the same. So, that's the downside. It's just a huge task. When she goes to Arkansas, there are different state laws, there are different parameters. Everything's different. And there's not a national equivalent to this.

Elissa and I went to the Orange County Police Chiefs Association and presented to all of the police chiefs in Orange County, including the Sheriff and the district attorney. And from that, we had the agencies send personnel to the training and take the course. Also, it is something that I suggested to her to go to Orange County Fire Authority because Orange County Fire Authority is the overarching fire authority within the county. Some cities have their own fire departments, but Orange County Fire Authority is the largest fire protector in Orange County. Because we have contract cities, Irvine contracts with Orange County Fire Authority.

Then came the Falk Ambulance. I think somebody heard about it through the fire authority. Falk is a contract ambulance service throughout Orange County. And they wanted the training also, partially, because one of the examples that we talk about in the training has to do with a fire department.

Holke: And about POST-certified classes, at the time that we checked the course catalog. If you typed in autism in the search, the only thing within an 80-mile range was mental illness crisis training. It was embedded in there somewhere, but that that was the only thing that was offered. There were online trainings, but the research that's come out has been pretty consistent that to have disability-specific training, you need to have people up in front of you to be able to just see mannerisms, to look at how people are in space, ask questions and be more dynamic. Having a computer-based module just doesn't quite work for this type of experience. So that's what we were bringing to the table. It's not mental illness training. It is autism specific. We are going to co-present in person, and we're going to be able to be dynamic and take questions and be physically present.

Carson: So do the officers go to this training on a volunteer basis, in your department, Cathy, or is it something that everybody receives?

Scherer: At the time when we originally presented it, it was for research. When we presented it, it went to everyone, every single person who was a sworn officer attended. Then I also have a large portion of professional staff that are in the field and interacting with folks that—They may be our traffic personnel. They take traffic collisions. So, they're involved in a traffic collision and somebody's driving a vehicle and they have a developmental disability or are a passenger in a vehicle, something to that effect. So, our field personnel were present for that.

The sensory bags were developed by one of our DARE (Drug Abuse Resistance Education) officers, Matt, who's in our Youth Services Unit. And he is the one that originally developed our sensory bags. He came to me and said "Hey, we don't have these in all these cars. We only have them in supervisors' cars. Can we get them in all the police cars? And I'll do the training." And so, this was all coming about all at the same time.

Elissa met him and they looked over the sensory bag and said, "Hey, these are the improvements that you can make to your sensory bag and this is why." Then we enhanced it with everything that Elissa's team brought in. And with John, the BCBA and the suggestions that they made, it just enhanced the bag for us. Then we went out and did additional training for the personnel to understand what was in it and how to utilize it.

I still, to this day, get emails from people, from the officers that like, oh, my gosh, this was so helpful. It totally de-escalated the kid. We put the earphones on. He had the sunglasses. He's working with the fidget spinner, and it just totally calmed him down. And they were thanking me for it. It's such a low-cost item that is so necessary.

Carson: All the collaboration you've done to come up with the things that need to be in the sensory bag, all the tools that someone might need. I mean, everybody's different. You meet one person with autism, you met one person with autism. I know you guys have heard that a million times. But to have the tools ready and available, it could make a huge difference. I think it's really important, paired with the right mindset.

Scherer: But I think having those bags as a resource, automatically, in my opinion, sets the tone for that mindset. Knowing that this could make your job easier is what they're going to go to. They're going, Okay, this will hopefully help. And they're looking for those tools because (officers) are there to solve the problem or whatever issue, lack of communication, whatever it is. Sometimes bringing in something from the outside can alter and change behavior for the parent, for the child, so on and so forth. I think that just having the bag accessible changes the mindset of the officer.

I think all of those things go hand in hand. The bottom line is it's all about dignity, compassion, and how you're taking care of people. I mean, for me as a law enforcement officer, that's why I got into law enforcement. I got in the law enforcement to help people. And that is what is the important part. Sometimes, I help people go to jail. It's different help, right? But that's not the primary function. Nobody calls us when they're having a great day. They only call us when they're in some level of a catastrophic event and/or tragedy. And that's when we show up. You can either be the bad news bear or you can be helpful. And that's really what our goal is: taking care of the community. A lot of our calls are taking care of our community, caretaking calls.



Kaylie Holke, Elissa Green Kaustinen, Spencer and Lt Cathy Scherer

Cooper: How do you find the Cathy's of the world within the police departments?

Scherer: Well, a lot of times, they're out there. I can assure you, because there's a lot of people just like me that got into law enforcement, like I said, to help people. And as prevalent as disabilities are, there are people that are touched by it. So, I think you just have to find those key people. Most people that are trainers are very good instructors. Teachers are oftentimes teaching classes already. And so I would when Elissa goes back there and has that initial conversation, it may be a fact-finding for a little bit to get the right person. She took a chance with me and didn't know anything about me. I'll go back to that. Remind me to go back to how we connected.

But I think that once you figure out who those people are, they have to be people that have the confidence within their personnel. If you put somebody in front of them that they don't respect and they don't understand or don't believe that they have the skillset, then you're not going to win them over at that point. But I think there are plenty of officers out there that will have very similar stories to myself or have been touched by somebody with a disability and more than willing to teach and be able to articulate the need and desire of why it's necessary in law enforcement.

Holke: I wanted to say, too, I guess, along with what you were just saying, Cathy, that when the development of the training was happening, I was thinking, "How in the world am I going to stand up in front of a room of officers and tell them how to do their job?" A lot of what helped me see the multiple perspectives and how we all come together for this training is the idea that I can look at body camera footage from a certain angle and think, "Oh, as a speech pathologist, that man did put his arms behind his back. He just didn't put it in the way that was expected from the officer." But he did. His hands were slightly behind his hip level, so he was responding to the direction.

I can provide that input, but it really was great to have Cathy stand in front of her department with the respect that she has and say, "Let's go through this video together. Let's discuss it.", which is an authority and a respect that I couldn't just come in from an outsider and have.

I think that that's something, going to Arkansas, hoping that officers there have that respect and rapport in their departments and say, this is the input I can provide you as a speech pathologist and who's worked on this training. But knowing that it coming from my voice is not going to have the same impact as someone who's embedded in the department.

Scherer: I think part of it, too, is when Kaylie and I talk.

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One part of our training is the officer is tasing someone. I'll review the video and say, "Why did this person get tased?" And the officers are like, "Wow, they didn't do what he told them to do." And I'll pitch over to Kaylie and go, "Well, Kaylie, from a speech pathology standpoint, how did this person do?" She says, "Oh, he did awesome. He told him to put his hands behind his back, and he did. He put his hands right back there. No, they're not touching, but they're behind his body." And then the officer's like, "Oh, okay. All right". And so, it's an aha moment and an aha training for the officers all the time.

Elissa always uses the term "take a seat." Then we show the picture of the girl walking along and she has a chair on top of her head. Well, she took a seat. Then they're like, "Okay, I get it."

But when we can interact and have conversations, and they understand why certain things are happening, it helps them, I think, in the future. I've gotten the emails afterwards, and they're like, "Every single thing you said, I told them to do this, and they did this." They want to share it, and they say, "Oh, it's great. We got through, we de-escalated, and we didn't end up going to the hospital. We didn't end up arresting someone and putting them in a county to jail when that's not what they needed." And so, I mean, every single one of those emails was a win for me. But I have gotten a lot more than just one. So that's the payoff for us.

Cooper: Do you train them to know that sometimes just touching another person, that whole sensory component, and then there's another reaction, another trigger that could occur?

Scherer: Yeah, we do discuss that, and we also discuss not separating the person from the caregiver. Whether it's a parent or a caregiver that's always with them, not separating them from that because those people know what those triggers are. If the officer takes the time and opens up that bag and pulls out the headphones, I can tell you a lot of times those kids are going to go right for the headphones. They will grab them themselves and put them on because that's what they're used to. I've seen them where they take the sunglasses and put the sunglasses on. Those are things that are, often times, in everyday life for a person with a disability. Kaylie, you might have a different opinion of it, but I think that, for us, when you open up that bag, it changes the mindset. And if they see things that they're accustomed to seeing, they gravitate to that. And that's why we developed the bag in the way we developed it.

Cooper: Is this a part of the training where you would literally open the bag to show what's in it? Here's a good approach. We've seen best results. Is that part of it?

Scherer: Yes. And part of what Elissa covers when she covers in the training, she discusses the sensory issues, whether it's the bright lights or the loud noises. She discusses those sensory issues and then breaks it down in ways to help or solve those problems. It could be that they're pulling on their ears or they're just covering their ears or they're screaming louder, covering their ears because they're trying to get your attention. But opening up the bag— and we actually opened the bag up for Amy and Spencer. And Spencer went to one thing Amy went to something different. And it's just different. The interactions with them are just different. We're trying to cover all the bases on that.

Cooper: Are there stats that data are being developed now?

Scherer: No. And that's the biggest downfall I can tell you from law enforcement perspective is that there is not an avenue for us to say, "Okay, we've used this bag many times." I mean, we know when we replenish it because it's a single use, whatever it is. So, we would know from that perspective, but we wouldn't know necessarily the background behind what the issue was going on. Because the data is not there for us in law enforcement because we don't differentiate if this person has a disability. That's not a checkbox on any of our forms, anywhere.

The lack of data is probably one of the biggest driving factors in this training. And I mean, if you've worked in academia at all, you know and understand you live by data, and research lives by data, and grants live by data, and nothing else gets accomplished without data. And unfortunately, law enforcement is not helping their own cause when it comes to data because that's just not something that we track. Unfortunately, I do believe it's an uphill battle in law enforcement because once you track that data and all of our data is open to the public, and then the general public understands and can get certain portions of data that it's not always the data that can be released or that there's certain levels of HIPAA issues, confidentiality, so on and so forth.

So, it is something that is a downside side. But if you look at law enforcement in general, ever since George Floyd, everyone who wants to know how many times we use a baton and how many times we use a taser how many times... And those data numbers are kept now, but they haven't always been kept. And so I think this is an area that at some point in time will probably end up being researched. But at this time right now, the data is not there for us. I know how many calls we respond to regarding mental illness, but there's no other data right now. We'll pull it and group it together with mental illness, and that does a disservice for us. But differentiating developmental disability versus mental health is not a differentiation in law enforcement right now. ■ ABILITY

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annie POTTS

Annie Potts's journey is as much about survival as it is about success. At just 21, a devastating car accident left her with life-altering injuries that required more than 20 surgeries over the course of her life. Yet, instead of dimming her light, those challenges became a backdrop to a remarkable career that has stretched across film, television and stage. From her Golden Globe–nominated debut in Corvette Summer to her iconic work in Designing Women and more recently Young Sheldon, Potts has consistently reinvented herself, navigating an industry not always kind to women—or to actors living with disability.

Offscreen, her story takes on another layer of purpose. Drawing from her own experiences of resilience, she co-founded The Heart Channels, a nonprofit dedicated to supporting individuals and communities through things like helping families in crisis and children in underserved communities. For Potts, giving back has never been a side note but a natural extension of the empathy and grit that have fueled her personal and professional life.

ABILITY Magazine's Chet Cooper met Potts in her Los Angeles home. In their conversation she reflects on the pivotal moments that shaped her—from an unexpected introduction to acting at summer camp, to finding herself on a trapeze in a revival of Pippin, to the quiet but powerful work of lifting others up when they need it most. Through it all, her outlook remains steady: hope, humor, and humanity can carry us farther than we think.

Chet Cooper: You attended the theater program at Stevens College in Columbia, Missouri. What brought you to California?

Annie Potts: Well, I started acting when I was a kid. Because we lived on a farm, there was nothing to do in summer, so our parents sent us away to camp the whole summer. I started acting there. They had a little drama program, and that's where I fell in love with it. And I never wanted to do anything else once the bug bit. I originally came here to do graduate work in theater, but I was in a car accident shortly after I graduated college. I came out to California to do graduate work because I was living in Santa Fe, New Mexico, and California Institute of the Arts had a little advertisement coming through, looking for people for their graduate program. I





Annie Potts as Berthe in Pippin Revival 2014

auditioned for them on a walker. The representative, because I was just a few months away from the accident, was like, “Are you going to be okay?” I was like, “They say I am.” So that's how I got out here to California. I never was interested in doing TV or film, I only ever wanted to do stage plays. But I found myself here, and I didn't stay at CalArts for very long. They'd only been a school for two or three years, and they really hadn't gotten themselves together yet.

Cooper: What was your big break?

Potts: I got a touring play with some old movie stars. They were all younger than I am now, ¬but they seemed like old movie stars—Roddy McDowall and Vincent Price and his wife, the very glamorous British woman named Coral Browne. So, I worked with them, and Roddy said, while we were on tour—He was fond of me.—And he said, “When we get back to LA, I'd like to help you.” I was like, “Well, that would be fantastic.” He knew everybody, and he introduced me to a casting director. A week later, I was starring in a pilot for NBC. And a year later, I was starring in a film.

Cooper: What was the first major show that got you to where you felt like you made it?

Potts: It's a lot of "back and forthing", but I got a Golden Globe nomination for my first film Corvette Summer. And I was like “Oh.” And I just kept working. I've had a few periods when there was a lull in work, but, for the most part, I've never stopped working. It's a miracle.

Cooper: It's great, especially in this industry. There's a lot of ageism.

Potts: It's like, “How old do you want me to be? That's how old I'll be.” When I was going through school and everything, I thought that my ace in the hole would be musical comedy. I had talents for that, and it was the obvious thing. Then the car accident happened and was like, “Well, I won't be dancing.” And that made me really sad. But, on the other hand, it was like, “Oh, well, I'll do other things.” I did, and I've had quite a bit of luck with comedy and drama. Then, 10 years ago, they came to me and (said) they were doing a revival of the Pippin musical, and it had a circus theme. They needed somebody to sing and do a trapeze act. Now, I didn't think that I would be a likely character for that, but I got it and I did it. I was with no harness, and no net. I was up there with a brilliant partner from Cirque de Soleil. My doctors weren't very happy with me, but I did it and it was really fun. It was some serious payback for me. I’d always wanted to do a musical on Broadway.

Cooper: Were you singing when you were up there?

Potts: Yes, upside down.

Cooper: Well, why not?

Potts: (laughs) Well, I mean, as long as you're up there, you might as well! Of course, a lot of friends who came to see me and knew, well, my background were like, “Holy shit, are you out of your mind?” I think that's clear.

Cooper: So did your partner convince you that his grip was so strong that it was safer?

Potts: Well, I was being taught by circus people who the last thing they wanted in the world was for something bad to happen, but I actually felt it was quite safe. I mean, I couldn't have done it if I didn't.

Cooper: So, you were in the car accident when you were 21 and have had around 20 surgeries by now?

Potts: About 20 something. I've actually lost count.

Cooper: You had to have the second knee being replaced?



Potts: Yes, that had to get re-replaced because it wasn't good. Because there's so much damage below my waist, my back has had to make a lot of accommodations so that everything else worked. For 50 years, my right leg was an inch shorter because I had broken my femur and it hadn't repaired itself correctly. —There was a graft that didn't work.—I've just been crooked, so my body was trying to accommodate that discrepancy. It's like that little ditty we used to sing in nursery school. It's all connected. So, once one thing gets goofy, then everything gets goofy. It's like holes in the dam. It just springs out everywhere, and I'm running around trying to fix it. I really hope that this last back surgery is going to be it.

Cooper: Do you have another one coming up?

Potts: I just had one four weeks ago.

Cooper: You walk well for just having surgery. Are you using a cane or anything?

Potts: No, not when I'm around the house. If I went out for a big walk or if I was traveling or something, I would probably have a cane.

Cooper: You've got stairs in the house, though.

Potts: (laughs) Yeah, I've got nothing but stairs in this house! At first I thought, "That's great. It'll keep me in shape!" now it's like, "Man, these stairs are killing me." But we don't have room for an elevator, and I'm not ready to put a stair lift in.

Cooper: So, you've done some homework on the elevators?

Potts: Yes.

Cooper: There are some really small ones.
Potts: I know. Some of the tubes? For the base of them, you still have to have a 10-square-foot area for all of the components, but they're inventing things all the time. I always felt like my injuries were so complex and there was such a multitude of them that I thought, "Well, as I age, then science will either be ahead of me or try to keep up with me." Three years ago now, I got an ankle replacement, which for years wasn't really available, or they didn't work, or they didn't last. I'd been following them closely for about 20 years, and all of a sudden it was like, "Yes, this guy's doing it, and they're great, and there's testimonials, change people's lives." So, I have to say that that was a great fix for me. One of my ankles is fused, and that is the reason that I blew out my knee.

Cooper: Because one part was stronger than the other?

Potts: No, because it's actually fused. So, they cut the bottom of the tibia off and the top of the foot bone–they just cut it off and screw it together–so it moves a little bit, but not a lot. It makes the gait uneven.

Cooper: We're talking about these replacements, and I'm wondering if you're keeping the old ones.

Potts: I have a drawer full. Seriously. I have a drawer full of metal. I asked to keep the old knee replacement,



Dan Aykroyd, Bill Murray, Annie Potts and Ernie Hudson in *Ghostbusters-Frozen Empire*

but they actually don't let you do that. I was like, "Well, it's my replacement." but they said, no. I think that actually might have been a little macabre. It might have been a step too far.

Cooper: I don't understand some rules that are out there with the materials, why not? Why can't you have it? You have probably sold it on eBay. That's probably the thing.

Potts: Oh, God. If I could raise money through charity, I might.

Cooper: That's a whole new industry.

Potts: I don't think there would be many people who are signing up for that, but I hear what you're saying.

Cooper: With all the surgeries, are you hopping around the country for specialists, or are you with UCLA or one of the local big hospitals?

Potts: I tried them all. I think it's about the right doctor, and I try to do due diligence on who the best is. I've had a lot of work done at Hospital for Special Surgery in New York because they're the number one orthopedic hospital in the world.

Cooper: Do you do any hobbies to help with recovery?

Potts: I'm a swimmer. I wish you could swim in the lake by my home but everybody's using pesticides up on the mountains and that goes down the drains, and all of it goes right into that. Imagine it. We've never pulled out a fish that has three eyes or his organs on the outside of its body or anything. I wouldn't drink it, but man, I would love to get in that and just swim to the other end and back.

Cooper: Where do you swim now?

Potts: I'm waiting for my body to heal for a couple of more weeks, but about four minutes from here there's a club that has a lap pool. I've been going there for 30 years.

Cooper: Any ocean swimming?

Potts: In Anguilla, yes. We have a pool here, but it's not a lap pool. You've got to have a lap pool. But swimming has saved my life. I haven't found anything yet that I couldn't swim my way out of with a little surgery.

Cooper: Can you talk a little bit about the non-profit The Heart Channels that you started?

Potts: Yes. It started about twelve years ago now. Every summer we go to a little island in the Caribbean called Anguilla. I met a little boy there who was on the beach and he just wanted my goggles. I was like, "Okay, sure." and then he wanted me to swim with him, so I went to play with him in the water. He was about eight years old, and he couldn't speak. He had some utterances, but not words. He seemed to understand everything.
His mother was close by and she got in the water with us, and I said, "What's going on with your boy?" And she said, "I don't know." I was like, "Why don't you know?" And she said, "I've just never been able to find out here. We don't have the doctors and resources." So, I

got involved with him in trying to find help for him. Eventually—really through the strength and courage of the mother—she got him to the UK. If you're born on Anguilla, you are a subject of the British Crown. She said, "I think I can get him there, and I think he can get treated." So, we helped her get there. I have to say, I called as many people as I could. I was thinking "Is this wise? Can this happen there?" because I didn't want her to get there and then find out there weren't services for them. Where would they stay, et cetera? But England had a wonderful response to them coming there, and had given them a place to live, special needs schooling. And they've been there 10 years.

Cooper: Oh, they literally moved there? I thought there was just some treatment there.

Potts: No, they moved there. She was a woman who'd never been off the islands, and I had serious misgivings about her going there. Because if they were on the island, I felt like I could rescue them. I wouldn't be able to help at such a distance. But the UK has really stepped up and helped him. He graduated from his school.

Cooper: Does he speak now?

Potts: A little.

Cooper: Sign language?

Potts: No, but he is being educated in an ongoing way, and I think they're preparing him to get a job for himself. I think he's been working in a barber shop some, and he likes it. It's a completely different life than they would have had, and really, it's all about the mother's courage there. I'm so happy he's doing well. He has an older sister who's top of her class, and the mother was in college learning to be an aid in special needs classes. It's such a heartwarming success story. It's very different to live on a little island of 5,000 people in the Caribbean and living in Wolverhampton, England. They used to call me, and all three of them would be wrapped up in blankets going, "Oh, it's so cold here. Oh, it's terrible!" Their bones were aching. Their bodies weren't ready for rainy England, but he's done really well. And the whole family lifted themselves up, really.

Cooper: When you go back to Anguilla, do you go to the beach and look around?

Potts: It's a very small island. It's like Hawaii but with just seven families and everybody knows everybody. I've been going there for 30 years, so people know me. I think it was last summer (when) I was on the beach, and a man that I didn't know was trekking down to my beach chair and handed me an envelope. He was a relative—I think an uncle—And it was the sweetest thank you letter. I didn't think anybody knew about my work there or anything I was helping with. It was a long, gracious letter written out in fine hand of their gratitude.

Because of my experience with the boy and his family, my best friend–who's a stockbroker by trade—We both had some cases drop our laps of people in need. She stopped one time because there was a young woman whose car had broken down, It was just around the corner from where my friend lived. She stopped and said, "Can I help you?" and it turned out she was in need of some real help. She was a single mother who had escaped an abusive relationship and was living in a one bedroom apartment with not even a bed, clothes in garbage bags, no job. And so my friend, Mary, called me and said, "I think we really need to help this person. I think that she's had a tough turn, and she's a lovely person." So, we helped her with furniture for the apartment and, eventually, she needed another car. My friend Mary found a job for her.

I'm always drawn to women who are showing extraordinary courage because they don't always get supported. Sometimes we find that people, women, especially, just fall in our laps. They had a job, a lot of pieces of life's puzzle were falling in place, but things would happen like they're getting rid of the apartment or it's being bought by somebody else, and they had to get out. And in order to find someplace else, and put a first last deposit down, that takes a lot of money. Sometimes people are like, "I don't have the money to establish a new place of residence." People end up living under overpasses and in cars because of that. People who are in situations like that or in a moment of crisis, they need that help. We try to come forward and assist with that, and it's been really rewarding. We have found out how hard it is to run a foundation like that. We had thought that we would try to be a 501(c)(3), but they make it very difficult to help people in that way because you have to get audited once a year, and it's like all of us have other jobs.

Cooper: People don't understand not only the complications of running the 501(C)(3), but you have to have enough money because you can't always have volunteers, you have to have some money to pay people and a CPA.

Potts: I have a friend who runs a wonderful organization called Mending Kids, and they have missions all over the world. She gets some heart surgeons or people who fix cleft palates and things like that and it's fantastic. I was picking her brain about things, and she said, "Oh, listen, I have these friends who can be your fiscal sponsor." They're lovely and have been super helpful to us. We've had to keep it small, but we find that the need has been great.

Cooper: So that's under the umbrella of the nonprofit.

Potts: Yes, because we have a fiscal sponsor. That way they keep the books. They're the ones who get audited every year. That's why they open the door and allow that. They were just two women in Pasadena who want-



ed to build a Ronald McDonald house next to Huntington Hospital. They went to the Ronald McDonald people, and they were like, “Nah.” So, they went, “Well, we'll just do it ourselves.” So, they built a fabulous place next to Huntington Hospital. Then then Ronald McDonald came in and went, “Hey, that's great. Actually, we changed our minds.” So, they got hooked on helping. They heard about us through my friend who does Mending Kids, and they said, “We're going to help you free of charge. We'll just be your fiscal umbrella, and funds can go through us.” Their organization is called Charity on Top.

Cooper: They do more than just yours?

Potts: Yes, although we've been a test case for them and other things that they were trying to do. They're doing a lot of stuff, and they're just fabulous women. The people you meet who are involved in this stuff are pretty awesome folks in general.

Cooper: When I looked at what you guys do, I thought, your biggest challenge will be how to say no to somebody.

Potts: Right. Well, we're limited. I find raising funds is so difficult, and we couldn't do it all. Me and my friend Mary were doing most of it, but there's this sweet little app called Cameo that gets people like me and anybody, comedians. They hire you to say happy birthday or give pep talks, and they're really sweet. It pays really well, and they have a mechanism inside the app, so all the money just goes directly into the charity. I never have to touch it, and there's a record of how much. What I'm able to garner on Cameo almost supports what we're doing. I mean, of course, we would like to do more because you'd always like to do more. And, now, with services being cut to everybody, I can't even imagine the measure of the need that's going to be.

Cooper: The stress that's occurring everywhere from what's happening is just mind boggling.
Potts: Well, as Bruce Springsteen said, "In America, the richest men are taking satisfaction in abandoning the world's poorest children to sickness and death."

Cooper: Did he say that in a recent concert?

Potts: Yes, in Manchester. Of course, he's a wonderful writer and a wonderful spirit, and it is so heartfelt what he says. One of the things he said to this audience in the UK is, “The America I’ve sung to you about for 50 years is real, and regardless of its many faults, it’s a great country with a great people. And we will survive





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this moment. Well, I have hope, because I believe in the truth of what the great American writer James Baldwin said. He said, 'In this world, there isn't as much humanity as one would like, but there's enough.'"

Cooper: I'm glad he said it that way. I don't like when they say America's dead, because it's not dead.

Potts: I mean, he's brilliant. He definitely took the edge off it that way. The America that he has been singing to us about for 50 years, and the America that started out in the beginning, we were built on hope and promise, and I think it still exists. We just have to work really hard. I'm hopeful about the future. I have to be. I have children and grandchildren who will be living in it.

Cooper: Speaking of grandchildren, you were in a show called Young Sheldon playing Meemaw, what was that about?

Potts: We were a prequel to a very popular show called The Big Bang Theory, which was about–

Cooper: The origin of the universe?

Potts: (laughs) Not quite, but the origin of a young man named Sheldon who is—I don't think they ever say it¬, but (he's) certainly on the spectrum. Brilliant but a difficult personality. It's about his family trying to deal with having a super special, brilliant child who finishes college at 11.

Cooper: So, it was never mentioned? Do you think they just assumed everyone would know he was on the spectrum?

Potts: Well, Young Sheldon is set in late 1980s. So, it was before people were like, "Oh, yeah, that's what that is."

Potts: So, when did it stop filming?

Potts: A year ago? We did seven years, so it was a proper long run.

Cooper: I interviewed Ed Begley Jr. and he mentioned how wonderful you were.

Potts: He's a lovely guy.

Cooper: So, all the time you were working, and did some of the surgeries affect your work schedule?

Potts: No, (laughs) I always do my surgeries during hiatus.

Cooper: During lunch break?

Potts: I have done that.

Cooper: So, you were able to recover quick enough to recover to not have to deal with too much?

Potts: Well, when you do series TV, generally speaking, you work from July to April so there's always a little two or three-month period when you can shoehorn a knee replacement or something in. (laughs)

Cooper: Had you known that Ed had Parkinson's?

Potts: Yes. I didn't know that he was talking about it. I think when you have what could be defined as a disability–of course, all of us actors think we're never going to work again anyway at any moment–it's going to be over. I mean, I always felt that if people knew that I was as disabled as I was–as I am–that they might think twice about hiring me or that I might be difficult to insure. I certainly have had to be careful. Depending on what was in the script, I might be like, "In that scene where I have to run, you're going to have to get somebody else to run for me because I don't run."

Cooper: What are the other things you're currently acting on?

Potts: Well, they did another spin off of that show called Georgie and Mandy's First Marriage. I can never think of the name of it, it's so long. I reoccur on it. I don't have a regular thing on it.

Cooper: What got you into doing TikTok videos?

Potts: I enjoy doing them. My son, who's very clever, is helping me with those. I think it helps with relevance and also more and more because in the last five or six years, I've had so many setbacks with my physical thing

that I was dealing with that I thought it was more and more like the Cameos I do or like pep talks. I realized that that has value to people who know me and have seen me around for a long time and don't know that I've had disability to deal with. When other people in the same situation see it, they're like, “Well, if she could do it, I could do it.”

Cooper: Can you talk about other focuses of your nonprofit?

Potts: We have a lot of other things we are focusing on. There's a young woman who we're putting through school. We were affiliated with another nonprofit during the pandemic, we were passing out—and after the fires, too—just going out and giving cash to people. I had made a relationship with some of the schools and principals in the LAUSD (Los Angeles Unified School District), which is an incredible system. The counselors knew everybody who about to go down the drain and living in Motel 6 or something. They weren't able to get their relief checks during the pandemic because they had lost their home and you have to have an address if they're going to send you a government check. A lot of people who deserved those checks and needed them were cut out of that.

So, through the LAUSD, we called and said, “Who among you are the most needy?” And she was like, “Oh, my God, this is going to help so much," because there were people sleeping in their cars with four kids, and during that time, the kids weren't in school. They were trying to learn on a laptop. If you're living under a bridge, you don't have Wi-Fi. So, it was just a mess. We did some of that and with the last fires in Altadena, we helped again with that. We just find people. You don't have to do much but walk down the street and there's somebody. I have three partners, my friend Mary, our friend Lindsay—She's a website whiz.— And we have another volunteer who was our script supervisor at work named Robin. About a year and a half ago, I was at a wrap party, and she said, “I don't know if you've heard, I wanted to tell you personally, but I won't be coming back next year. It's time for me to retire.” And I was like, “What are you going to do?” And she said, “I don't know.” And I went, “Oh! I've got some thought.” And she has turned out to be an angel.

Some of our families we got involved with because—After our involvement in Afghanistan went down, those who had been working for NGOs there needed to get out. At that time, the US had been like, “Yeah, you can come to the United States.” And you get in the United States and it's like, “You're on your own.” So, my friend Mary found an organization that was helping refugees. What Robin does for us is she finds housing. She's genius at it.

Cooper: Is that rental housing or purchasing?

Potts: Rental. She's undaunted at it. She makes sure that the checks arrive on time and that everybody's taken care of. Anyway, thank God she retired because we keep her busy. The work is very meaningful to her. Those are the people you want to work with. I will say there is a beauty to just being anonymous, to doing all work anonymously. The only interest I have in press or interviews or anything about this is to encourage other people to take a shot and reach your hand out to help other people, or if people would like to send some funds to let us help people in a broader capacity.

Cooper: How are you going about the fundraising? What is your strategy?

Potts: Well, we haven't been very good at it. I think as a known person, people have been seeing me on TV for 50 years. I think they feel like, “Hey, you're on TV. You're a rich person. Do you need my money?” It's like, “If we're going to support all these people, yeah.” But I found that really difficult. The cameo is the best thing, and people like to do it because they get something.

Cooper: Cameo is wonderful, but it's limiting.

Potts: It is. It's funny, we've tried to give it up so many times. It's like, “Okay, we're just going to get this family through, and then that's it. We can't do anymore.” and something always happens. Somebody goes, “Oh, my uncle wants to give $5,000.” It's like, okay, we could actually take on another family. My friend Mary is the worst. She's a magnet for all this. She called me and she said, “There's a family we need to help. It's another Afghan family. They've just gotten their papers to be able to get out.” They were waiting in Pakistan. This is just literally 24 hours before the war with India started, and I thought that they were family of some other Afghan families that we had helped, and I said, “Okay, whose brother is this?” and she went, “Oh, no, no, no, it's not a brother. I met his brother who was driving my Uber.” I said, “Mary, first of all, you can't get an Uber anymore, all right? Because you're dangerous. What's this going to cost us? No Uber for a month.”

Cooper: So, were you able to fly them from Pakistan? Or were they already coming here on their own?

Potts: They were on their way. I believe I'm not exaggerating to say that they were at the airport. They had been given a go ahead and a welcome, whatever that is legally. But they didn't have the money for air fare, although they were at the airport because this is what desperate people do. This is why they're at the border. It's why they're at the gates with their knuckles wrapped around. It's very hard to say “no” to people with an outstretched hand. ■ ABILITY

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lottie JACKSON

Writer and Advocate

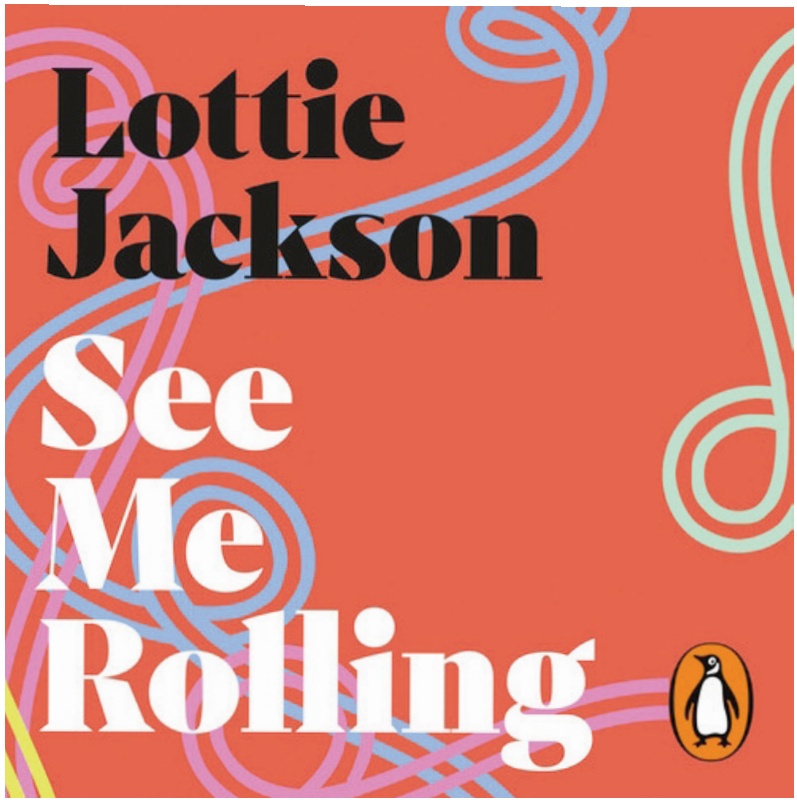
Since 2017, Lottie Jackson has been a freelance writer for publications like British Vogue, Elle and Guardian, writing about fashion, disability and beauty standards. Mid-pandemic, Jackson set out to write a memoir–See Me Rolling. An unflinching narrative about navigating life with a disability and the joys and frustrations that accompany striving for being seen as who you are in a world that wants to see you as "less than".

ABILITY Magazine's Jennifer Woodall had the opportunity to ask Lottie Jackson questions about accepting changes in ability within oneself, the stigmas that affect the disability community and how fashion can serve as a tool of empowerment.

Jennifer Woodall: Can you tell me a little bit about your background and how you became a writer?

Lottie Jackson: Of course. I'm from Bristol (in the UK). Since birth I've had a generalised muscle-weakness disability, a rare condition that affects my physical strength. For a long time, this condition didn't pose many constraints on my day-to-day life. But as I was approaching adulthood, I faced several years of intermittent, severe illness (such as serious pneumonia) which entailed long spells in intensive care. This significantly impacted my mobility and stamina–getting around for example has become more challenging. It has also affected the physical strength of my voice so it is hard to speak at length. Since graduating from university in 2017, I've worked as a freelance journalist for magazines and newspapers (British Vogue, Elle, Guardian, The Sunday Times, Telegraph, CNN). Most of my articles have focused on disability, fashion and beauty standards–analysing why the fashion industry has routinely excluded people with disabilities. It was only during the pandemic, fearing that journalism opportunities would soon dry up, that I turned my hand to writing a memoir. Writing a book is not something I had considered a possibility before, and, admittedly, it was a huge learning curve! I first got the idea while listening to a podcast which mentioned a competition for Penguin's WriteNow scheme for new writers. Winners would secure a place on Penguin's mentoring programme, working with an editor to develop their book for publication. So, in the space of a year, what began as a thousand words for my application eventually led to a book deal, and then gradually evolved into my published book, See Me Rolling.





See Me Rolling evolved a lot throughout the writing process. Not only was I learning about the history of disability and all these incredible activists, but I was also learning more and more about myself. Ultimately, my book was a springboard for self-discovery–a chance to make sense of what I have gained from my disability. These moments of self-realisation were emotionally draining, but I feel as if the investment paid off as I have gained a lot of confidence from the experience–as both a writer and a person.

Woodall: When a person experiences a change in ability, there is often a grieving period that happens where they may be hyper focused on the loss of their previous "norm". I know that I have experienced this myself when dealing with my own diagnosis. Do you have any advice for someone who is in this transitional period?

Jackson: I'm really sorry to hear you have been through this, Jenny. This transitional period is one of the hardest things you can go through. As much as I think it's a personal journey that will look different for each person, I do believe there are several pieces of advice that can benefit everyone. Firstly, it's important to understand the role that society plays on your mindset and the feeling of loss. Coming to terms with your new physical reality is a hundred times harder when you buy into the myth that able-bodiedness is an essential component of a life well lived. It's something we are told by the media, our culture, and it's pummelled into us every time we open Instagram for instance. But, as I explain throughout my book, this simply isn't true. I want to remind others that our physical body is only one part of our experience in the world–there is action and adventure to be found far beyond the constraints of our body. Your everyday experience may look different from the average person, but it doesn't make it any less valid or full of possibility. Finding a new passion can be a great motivator–it's a way of reconnecting with your inner self and imagining a new future. This could be through making art, studying a new subject or helping others…anything that gives you a reason for being. When the world suddenly feels a lot smaller and more restrictive, it takes courage to imagine something bigger for yourself, but I think it will save you. The same can be said for friends and family. I'm grateful to have had the support of my social circle, especially my sister, to get me through hard times. Lean on them, because they'll remind you of who you are and take you out of your own head.

From a practical standpoint, I think it helps to be creative and proactive about making your day-to-day experience easier. Learn how to tackle accessibility issues before they arise because this will lessen the frustration. It will avoid those constant battles that remind you of your new physical limitations and chip away at you. Lastly, I would say don't ignore it. You need to look these frustrations straight in the face and recognise that even if you think you're alone, you're not. Historically, society hasn't been built for disability, so it's not presented as a viable reality. But I hope that my speaking out about these issues and sharing real experiences, disability will no longer be seen as an unnavigable or fringe issue. At its core, See Me Rolling is a book about hope, possibilities and what can be achieved when we expand our ideas about what constitutes a 'normal' body. I hope it will help lots of people.

Woodall: Despite disability being such an intertwined facet of human existence, there is still heavy stigma around it. Can you share some of your experiences with stigma and unconscious bias and the steps society as a whole can take to help reduce it?

Jackson: Exactly, there's still so much stigma that surrounds disability. In part, I think it's because modern life has made us fearful of anything 'abnormal'. Society is a place where everything must be uniform, where people must slot into tick box categories. It's impossible to exist outside of the boundaries, or those tick boxes. Inevitably, this creates a challenge for disabled bodies which may escape categorisation, or defy our need for what's familiar and identifiable. I experience this stigma when using my mobility scooter. If I'm able to go somewhere accessible without a long walking distance, I can go without a mobility scooter and almost exist like someone 'normal'. I sense my body is unstigmatized

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and I'm part of the collective. However, if I'm driving down the street by mobility scooter, this is a signpost of my abnormality. It forces me to be segregated from others. I am painfully visible. While society views any mobility aid as evidence of weakness and frailty… ironically, I'm far more able with it, than without it. These outdated misconceptions and stigmas can distract people from the reality of who I am. Much of this stigma is down to the fact that disability is not seen as an everyday part of life–for example, there aren't enough disabled people in positions of authority or in the workplace. So, I think the first step to reducing stigma is integration. This means creating an accessible world where disabled people are an integral, welcome part of society. It will require more employment schemes to increase disability representation in the workplace; more visibility of disabled people on screen and in the media; more education about both visible and invisible disabilities; more accessible buildings and transport systems; and more advocacy for disabled people's rights in politics. To name a few! But on a more individual level, I think we all need to start having honest and open conversations about disability. One of the biggest barriers facing disabled people is the awkwardness about how to talk about disability. A recent survey, for example, found that 45 per cent of the British public do not even feel comfortable saying the word 'disabled'. If we can remove the anxiety and misconceptions that surround people with disabilities, I think this could go some way to creating a more equal future. After all, inequalities will only breed in silence.

Woodall: In your book you mention a study that talks about how a significant portion of people (particularly in the 18-34 age range) avoid communicating with someone they perceive to be disabled because they are concerned about saying something wrong or they 'weren't sure how to communicate'. Can you touch on this subject a bit?

Jackson: When non-disabled readers have talked about my book, this was the statistic that left them the most shocked and appalled. I found this encouraging, as it shows a real willingness and desire to change the pattern of how disabled people are treated. Often, the avoidance of disabled people is not anything conscious, or purposely unkind, it's just down to a lack of confidence and knowledge. When people come across someone with a visible disability, they see it as the easier option just not to engage or make that first move. Perhaps they are scared to cause offence, or are afraid they should be talking to the disabled person in a specific way. Do they ask about someone's disability or is it offensive to even mention it? Because of all this uncer-



tainty, people may avoid eye-contact and shut down any conversation starters. Obviously, this is very upsetting for someone with a disability–it feels dehumanising and does little to stop the cycle of marginalisation. As the statistic showed, this hesitation is more common among millennial and Gen-Z. Perhaps, it's because face-to-face interaction can be more daunting for generations who grew up with social media and online communication. Younger generations could also be more concerned with how they are perceived by others, and want to avoid embarrassing or cringe situations at any cost. I think as we mature, we become more self-assured and confident about how to navigate unfamiliar social interactions. In terms of improving this statistic, we need more positive interaction between disabled and non-disabled people from the earliest age. New generations must understand that disability is a natural part of life. This could start in schools if classrooms promote a safe environment where disabled and non-disabled children can learn about the things that unite them. For people of my age (millennial and Gen-Z), I think it's a very personal journey that involves educating ourselves about disability. Teaching ourselves that disability is a complex, nuanced thing that should not be feared. Reading books like See Me Rolling is a good starting point, and also watching tv programmes with positive and authentic narratives about disability like Netflix's Sex Education.

Woodall: In your book, you talk about applying for college and some of the pushback you experienced with a career counselor, mentioning how "a study published by the British Journal of Sociology found that disabled adolescents are 15 per cent more likely to have low expectations about going to university compared to able-bodied pupils of similar socioeconomic backgrounds." Can you expand on this topic and what may be contributing to that statistic?

Jackson: It's a very complex issue which has so many possible causes, but it's worth investigating. Firstly, I

believe people with disabilities need more support throughout the school system. When you're grappling with health conditions or facing periods of time away from the classroom (due to hospitalization), it's hard to visualise your future and talk about career aspirations. I think schools struggle to cater to these students who, understandably, can't keep up with strict timelines and examinations. More disability awareness and flexibility from teaching staff is paramount if we are going to improve the situation. Also, the world of university and academia aren't always seen as inclusive or accessible to people with disabilities. The challenge of living away from home for the first time and being more independent feels impossible. The study you mentioned (published by the British Journal of Sociology) actually found that the prospects of young disabled people may be curtailed by the fears of their parents or guardians who are concerned that university campuses are an unsafe environment for a young adult with a disability. But, from a more general perspective, I think there's a lot of misunderstanding about what disabled people can achieve in life. Too often we presume that somebody's physical stamina is a reflection of their mental capability and intelligence. As a result, disabled people are frequently talked down to and infantilised. It takes courage to push against these assumptions and assert your intellect in a society that continually underestimates you. Everybody should have the right to a university education, and the support to get there. I don't think anyone should be underestimated.

Woodall: I really enjoyed reading the essay "Fashionable" from your book. Can you talk about your views on fashion and disability?

Jackson: Thank you so much, it's great to hear you enjoyed Fashion-able. I really loved writing it, I think coming from a fashion journalism background where I've mostly written articles (with deadlines and word counts!), it was interesting to go much deeper into the subject and research things more freely in an essay format. From a personal perspective, I've always adored fashion. I think if I had to pinpoint why, I'd say it's because personal style is all about self-expression. Our clothes are a visual signifier of who we are, or sometimes who we aspire to be. Clothes exist beyond language, and in that sense, they cut through all the stigma and prejudicial baggage that follows disabled people like a dark shadow. Through clothing, it's possible to shake off negative stereotypes about how someone with a disability should look or behave. So, for example, when I did a magazine internship, the clothes I wore were a fun way to express my interest in the fashion world and make a first impression that wasn't just about my disability. On the first day of my internship, my pussy-bow blouse and leather pants gave me courage to enter the editorial meeting by mobility scooter. Or even starting at university–where despite nerves about whether I'd even be able to navigate Oxford's old buildings–a colourful fair-isle knit gave me a sense of comfort and belonging. Or, going back further, my earliest recollection of my personal style was around age 7, an outfit I wore for my sister's birthday party. I threw aside the twin-set my mum had laid out and went for a garish pyjama top, Dalmatian-print leggings, stuck-on earrings and patent Mary Janes–an outfit I thought was the height of sophistication. Let's just say it was hard to separate me from the clown booked for post-lunch entertainment! But, to me, it was a way to express my individuality and character. From the outside, fashion might seem trivial. But so many people fail to see how it empowers people with disabilities like me. Historically, fashion has been non-diverse and unwelcoming to anyone who doesn't fit the mould. But, in recent years, I've watched fashion open itself up and embrace diverse models. When it comes to disability, very disappointingly, it's another story: able-bodiedness remains a necessary feature of what's desirable and on trend. Despite a few notable examples (such as Gucci beauty's casting of Ellie Goldstein, a model with Down's syndrome), disabled people are near invisible in fashion–unrepresented on the catwalks, in magazines and on the shop floor where there are very few disability-friendly clothing options. A study found that, here in the UK, only 4% of TV adverts have featured disabled people (although almost a fifth of the UK population is disabled). When it comes to fashion week, the lack of disabled models is so stark that inclusivity reports don't even feature a disability category.

In my book, I go back and investigate the possible reasons for this erasure–for example, I think it may have roots in the Ugly Laws (1867–1974) when disabled people were unjustly segregated and prohibited from public view. This anxiety around disability is so deep-rooted, it's part of our social conditioning. Right now, urgent change is needed. I believe the fashion industry has a unique opportunity to change our view of disability by presenting disabled bodies as both beautiful and integral. If we want to live in a diverse world where disabled people no longer face shame and stigma, fashion must redefine what constitutes a 'desirable' body. And there are reasons to be hopeful. I think the rise in 'adaptive fashion' is a positive move towards a more disability inclusive fashion industry. For context, when off-the-rack garments aren't designed for disabled bodies, they may be unwearable for those with disabilities (like limb difference, multiple sclerosis or autism.) Adaptivewear is clothing purposely created for people with disabilities and chronic conditions. It includes features like discreet elasticated waistbands that are pinch-free when seated, adjustable hems to accommodate prosthesis and magnetic fastenings for independent dressing. From the design process, to the models and the end customers, adaptivewear is a world where inclusion cannot be an afterthought. ■ ABILITY

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Michelle Simes-Kennedy

Living & Thriving with Type 1 Diabetes

For Michelle Simes-Kennedy, type 1 diabetes (T1D) is more than a professional focus—it's a personal reality she has navigated for more than two decades. As a clinical social worker, Simes-Kennedy has spent much of her career helping young people and families understand and manage chronic health conditions, including her work at the Mary and Dick Allen Diabetes Center at Children's Hospital of Orange County. There, she developed programs to guide adolescents with T1D through the often-daunting transition into adult care. Now serving as a full-time leader at Breakthrough T1D, she brings both her clinical background and lived experience to the forefront of conversations about access, stigma and support.

In her conversation with *ABILITY Magazine*'s Chet Cooper, Simes-Kennedy reflects on why T1D is recognized as a disability under the Americans with Disabilities Act, how accommodations can empower students and professionals and why embracing available resources doesn't have to conflict with personal identity. Simes-Kennedy underscores the importance of reframing T1D, not as a limitation, but as a context—one that shapes how individuals engage with the world while still pursuing their goals and aspirations.

Chet Cooper: Can you talk a bit about T1D and how it relates to the ADA?

Michelle Simes-Kennedy: Sure, my background is as a clinical social worker, and I've been in outpatient practice for many years. A lot of where I come from has been talking with kids and families over the last 10 years, working with chronic condition populations. I've worked with kids with autism, I've worked with kids with neurodevelopmental conditions, as well as I work in the T1D clinic on the CHOC side (Children's Hospital of Orange County) within the Mary and Dick Allen Diabetes Center. Throughout that time, my goal as a social worker working in that capacity for the last about 10 years, has been to make the clinical concepts accessible and digestible to kids and families. When I was working in that role at CHOC in their endo clinic with the type 1 population specifically, I was developing the program to transition pediatric patients to adult care, essentially, and to give them a streamlined way of doing that to mitigate against dropping off in adult care. I say all of that to give some background as to the way that I talk about T1D, which is often geared towards young adults, so a perhaps less engaged population. My goal is always trying to make things more accessible and understandable.

Cooper: What do you mean by less engaged?

Simes-Kennedy: In clinical practice, a lot of my experience is talking with teens or young adults in the type 1 population. Speaking to my role as a social worker in that type 1 clinic for a few years, it was a lot of work around understanding that my identified patient population was this young adult cohort. Technically, anyone ages 12 and up to age 25. But the goal was taking this

clinical information and turning it into something that was understandable to let's say, 16, 17, 18-year-olds, 19, 20, 21-year-olds who perhaps most of them at that point in their lives—I think like any of us at that age–engagement in our health care isn't a top priority.

Typically, it's not the most exciting thing about being a late teen young adult. So, trying to discuss T1D in a real concrete accessible way with this population has been a really interesting challenge that I've enjoyed. I think all of that to say, talking about T1D as a disability, I think, is the goal because we, myself included—I've had type 1 for over 20 years.—We all need to understand the system that we're operating within and the context that we exist within so that we can navigate it successfully. And a part of doing that, as it relates to accommodations of someone with T1D in particular, the American Disabilities Act has certain language, certain criteria, that different organizations abide by.

Part of that is stating that people with disabilities can receive certain accommodations; and T1D has been described as being a disability. I know from personal experience, from working with patients, that many people don't agree with labeling themselves as having a disability as it relates to the type 1. I completely respect anyone's relationship to their T1D, and at the same time, try to give them the knowledge of the broader system that we're all navigating, and how can we leverage it so that we can take advantage of the things that are available to us.

Cooper: Do you transition the way you speak about this information, based on if you are talking to parents or teens and/or young adults?

Simes-Kennedy: Yes. Typically, I like to get the sense of who the audience is. So, at the talk at Hoag, I asked the room as to who had taken advantage of accommodations, who knew what accommodations were. And then also got a sense of who, in the audience, had T1D themselves and who was a parent, which helps me to get a sense of what the needs might be for that group from the talk that I'm giving. I like to include different examples or different language to make the points a little bit more salient depending on who the audience is.

Cooper: Back to the ADA and disability, how did you navigate the stigma and bias around being considered to have a disability?

Simes-Kennedy: I think it's a few things. The ADA is just a player in this broader landscape that we're all, as people with type 1 or not with type 1, but any other condition that they're navigating. We're all trying to figure out how we can succeed in whatever we're trying to do. I have often found myself talking about accommodations specifically, mostly as it relates to school and, usually, as it relates to going off to college. The way that I conceptualize that is that (it) is a huge shift in a family's life. That's a huge shift in a young adult's life. They're now going off, they're going to be in charge of a lot of this daily management that perhaps they weren't in charge of previously. And just like any of us, when we are navigating any life transition.

Whether you're 10, whether you're 18, whether you're 35, whether you're 65, there are things that are going to be changing. Thinking about something concretely, for example, going off to college, I like to highlight what supports are available to us. As a social worker, I'm always like, "What are our strengths here? What are the protective factors that can help us through this transition?", whether it may be challenging inherently or not. Some of that is looking at the university or the college itself to see what they offer first and foremost in terms of accommodations, in terms of support to make that transition easier for someone with T1D.

I am not a part of the ADA. I think referencing their language and the things that they outline is helpful and useful because you can learn to use that to your benefit. So, whether you're advocating for brand new accommodations—Perhaps, the university is not versed in what a T1D accommodations are.—you can bring in the verbiage that the ADA has. You can bring in this bigger entity within this country that you can have to support your request for additional support. I think all of it, ultimately, comes down to whether you feel comfortable describing yourself with type 1 as someone who has a disability or not. Me personally, I'm less interested in that. I think to each their own. My interest lies in how we can leverage the supports that are available around us and understand the context to which all of those exist so that we can navigate this more easily.

Cooper: Where did you start with your social work?

Simes-Kennedy: I got my undergrad in psychology. After my undergrad, I went to Cal State, Long Beach. I did a program called AmeriCorps for 10 months with this inaugural partnership with them and FEMA. I ended up doing a 10-month program driving across the country several times in a van, doing disaster relief and recovery efforts around the country. That program was my first experience seeing what different communities are like and getting to meet people completely different from where I've come from and really hearing and seeing what needs there are out there. And that's what prompted me to pursue my master's in social work.

So, after that, I went and got my master's in social work at Fordham University in New York City. That program was really focused around social justice and how to make things equitable and accessible to communities and paired that with my interest in health care. I've had T1D since I was 13. My type 1 diagnosis predates all of this. For almost everyone that I've known, I think their T1D has played a role in the way that they've pursued work or educational opportunities. So, at the end of my master's program, I did a fellowship in healthcare. It actually



AmeriCorps in Sacramento, CA with fellow Corps members (from left), Claire Shock, Amy Coburn-Sese, Michelle Simes-Kennedy, Mallory Freeman

was in palliative care and hospice, but that was an entryway into the healthcare system as a social worker.

Then the rest is history. I got connected after that to working at NYU Langone in their school of medicine within their child and adolescent psychiatry department, working with kids and families with autism. I love that population. I worked there for a few years and developed some education and programming and then moved to Southern California.—I'm from here originally.—Moved back here, got connected to CHOC and started in their endocrine division working with their T1D patients on that transition from pediatric to adult care program. Then, within CHOC, there's a newer autism center outpatient program.

Cooper: Thompson?

Simes-Kennedy: Thompson, yes! I was there for several years and actually left there this April to join Breakthrough T1D full-time.

Cooper: What would you like the general public to know about T1D?

Simes-Kennedy: I will just say, from personal experience, having worked with patients for the last 10 years and now working in a nonprofit setting that's not only really research-driven, but it's also globally-driven and globally connected, has been a really interesting experience. To see T1D from a micro level, the individual level—what people are doing, how people are experiencing that daily—to, now, the macro systems level of how communities and groups and different cultures are engaging with T1D has been a really unique and incredible learning experience to be a part of, to continue to gain insight holistically into the type 1 community.

Cooper: Do you know You're Just My Type?

Simes-Kennedy: Yes. Laura. I went to diabetes camp with her. It's a small world!

Cooper: Did you get to meet Mary and Dick Allen?

Simes-Kennedy: I don't believe I met Mary, but Dick stopped by the clinic when I was working there at some point. He was lovely. He was really, really wonderful.

Cooper: Do you use Dexcom or Tandem? What are you using?

Simes-Kennedy: I use the Omnipod 5 and the Dexcom G7.

Cooper: Why did you choose the Omnipod?

Simes-Kennedy: I chose the Omnipod because when I had my first child—I have two kids.—The first time I got pregnant in 2019, I didn't want to have a huge tubing system just coming out of my maternity pants, to be quite honest. That was my decision making at the time. I was fortunate enough to be working at that time in the T1D Clinic at CHOC. My colleagues who are now dear friends had all of this wealth of knowledge as to the different pumps and stuff that were out there, which led me to the Omnipod. Previously, I'd been on the same Medtronic pump for forever.

Michelle at AmeriCorps in Sacramento, CA with fellow corps members (from left), Claire shock, Amy Coburn Sese, Michelle Simes-Kennedy, Mallory Freeman
Cooper: Do you know who Earl Bakken is?

Simes-Kennedy: I don't.

Cooper: So, Earl Bakken created the pacemaker, and then he created the first pump, which is the Medtronic. The irony of this guy—who I got to spend time with in Hawaii.—is he had a pacemaker himself as he got older. So, he created something, he invented something that later in his life he needed. He also had a diabetic pump. I wanted to share that story of how bizarre that his life was. He's passed away a few years ago now.

Simes-Kennedy: Wow, yeah. That's amazing.

Cooper: You haven't tried any tandem products yet?

Simes-Kennedy: I have not, no. I hear good things.

Cooper: Dick Allen basically helped create the tandem. He did that because of his granddaughter.

Simes-Kennedy: I will say it's something about the T1D community at large, whether you're working professionally in that space or you're just connected via having it or a family member with it, I think that there really is something to the power of a parent or a grandparent, specifically, and what they can accomplish. I think the most incredible things that I have seen come to fruition have been initially powered by parents or grandparents of kids with T1D.

Cooper: I think in almost all movements, you need champions, and what better champion than a loved one that the needs of your support?

Simes-Kennedy: Yeah, it's incredible.

Cooper: Do you know who Mary Tyler Moore is?

Simes-Kennedy: I do know who she is.

Cooper: How do you know that? You're too young to know that.

Simes-Kennedy: We were big fans of the classics in my house growing up.

Cooper: Do you know her connection with the Juvenile Diabetes Research Foundation (now Breakthrough T1D)?

Simes-Kennedy: Yes, she had type 1.

Cooper: I interviewed her a long time ago now. When I was asking her questions, I was clueless of what I was saying, which I've done a couple of times in interviews connected to Type 1. I recently got Type 1 about a year ago.

Simes-Kennedy: Oh, you I did? Can I ask how that experience was for you? What prompted that?

Cooper: I got it from the immunotherapy treatments I've been getting for the last multiple years for cancer.

Simes-Kennedy: That's a huge adjustment, and unexpected.

Cooper: It's frustrating. In this meeting this morning, there were five people on the interview, and my alarm kept going because my Dexcom expired, and it doesn't like that, right?

Simes-Kennedy: Yes!

Cooper: I was trying to move my phone away as far as possible and while I'm talking, I'm inserting a new Dexcom, and then I'm trying to get rid of the old one. You know the trick, you have to get rid of the other one and move it about 20 feet away.

Simes-Kennedy: What are you on, the G7?

Cooper: G7, yeah. I'm using the Mobi, finally. It's much smaller. You almost forget, and you're able to get the insulin so much easier. There are so many people where their vision is not the best, so for them to have to put a needle into the insulin vial and then suck it out. I was having problems actually getting to the center of the vial with the needle, but with the Mobi, they created a system that you don't to do any of that. It's unbelievably cool technology. The engineers that came up with that kudos to them. Do you know anything about that?

Simes-Kennedy: I don't know about all of them, but I went to a conference and got to see some of the new things out there, including the Mobi. I know a few people who went on to it as a trial, and I've only heard really good things about it, which is great.

Cooper: Yes, it's crazy the way they made it so much simpler, so much lighter, one-fourth the size. It's smart. I did have to buy an iPhone. I now carry around two phones because I'm not getting rid of my Android. Other than that, it's pretty good. I feel so lucky to be able to experience all this later in my life. Because most people get it when they are young, and then the mental health issues of people that get it at an early age, I definitely can understand that.

Simes-Kennedy: Yeah. I think it's tough at any point in time, but for you to view it as something that you're grateful for because of the access to the technology now, I think that that's huge.

Cooper: Knowing that so many people go through this



Michelle presenting at Hoag's Mary & Dick Allen Diabetes Center 2025

every day in their lives. —I've had an incredibly rich, experiential life traveling around the world and doing so many things, and I still ride a motorcycle. I still surf, but you have to think about it, and you have to think about, "Okay, I'm going to go surf there. I know it's not the best condition of the water. This little clip, is it really going to keep anything out of my body?"

Simes-Kennedy: It's always your brain is always thinking simultaneous to anything that you're doing.

Cooper: Can you give a little background of the 180 decisions and how they came up with that?

Simes-Kennedy: Yeah, that's a really good question. That came from work that Breakthrough T1D did. They had it in some really nice marketing campaign they did for T1D awareness. They had this really nice video about the mental burden that T1D can have. There was this video of people always keeping this balloon up in the air for the entire day as they're doing things. The balloon being held up in the air was the metaphor for their T1D management while they're simultaneously on a meeting, doing an interview, doing whatever they're doing.

I think it's important to talk about all of the decisions that our brain is making, either consciously or subconsciously, as someone's type 1. Especially with having had type 1 for so many years, I think that my brain is used to operating in this pretty intense capacity, largely unconsciously. I think I'm making decisions on doing math equations in my head, which is not my strong suit, but things that can really have quite a big impact on my health, while I'm simultaneously trying to achieve things educationally, professionally in my life. So, I think that reminding all of us with type 1 or people around us that on average, we're making 180 additional decisions a day is important to put into context.

Cooper: It is definitely something that you have to be proactive about. You have to change your sites. You have to monitor what you eat. You have to calculate what you're eating, and you have to bolus. You have to monitor that.

Simes-Kennedy: I think it's so interesting because it causes people with type 1 to become aware of our biology and our anatomy, whether we ever ask for that opportunity or not. Now, we're thinking about our metabolism and our digestive system and how a protein impacts us versus a carbohydrate versus sugar. Those are things that most people are not thinking of, and now we are always considering them, even if we're not acting on them. Then also what are the consequences, practically, if we are misjudging a bolus (a dose of insulin taken to handle a rise in blood glucose), and then also emotionally and psychologically, if you misjudge a bolus, does that lead to greater blood sugars? Does that lead to a greater A1c? Could we potentially feel like we are therefore directly causing our future complications? It really can snowball in a person's mind without them really being aware of the magnitude of having type 1 sometimes.

Cooper: Have you ever experienced where you might be having a bad day, bad sleep because of that bad day, and then the reaction to your levels from not sleeping well or having a nightmare or something like that?

Simes-Kennedy: It's interesting because, only lately, have I given myself some time and space to look at my T1D like a player in my life. I'm a middle child. I have a competitive nature. Whether competing against myself or others, to be the top of my class, the top athlete. I just have that in me, and I really have never looked at my T1D as an explanation or a path as to if I'm not feeling up to whatever it is, an assignment or being ready for race day when I did cross country. I never really incorporated T1D into my thinking. I just took care of it. I have always been well-controlled for one reason or another. It's always just been there side by side with me doing its thing. Perhaps it's coinciding with now working in the fully T1D organization. But now, I'm finally giving myself the space to see how a 300 blood sugar for several hours overnight could impact the way that I function for a 7:00 AM meeting. To be honest, it's a newer practice that I'm engaging in.

Cooper: If I'm correct in what I've heard from endos (endocrinologists), those that can't produce the insulin might still have insulin in their body?

Simes-Kennedy: I think there are a lot of variables. Genetics play a factor there, at which stage you got diagnosed with T1D and did you still have different things that were working in your body? Was your body still producing a little bit of insulin, either for a long time or maybe not so long? Cortisol stress impacts all of us differently. Our adrenaline impacts us all differently. There are a lot of different variables, which is, I think, why it's so hard to put your finger on why things are happening. There are so many variables that are coming into play that it's not like you just get to go to the endo and you get a prescription for perfect 24/7 blood sugar and you go home. It's a constant wheel that you're trying to navigate, but also at the same time live a life outside of just managing type 1.

Cooper: What's your perfect level? 110?

Simes-Kennedy: Oh, gosh. I would say if I am within range for a majority of the day and I don't feel totally exhausted by my T1D, that feels like a win. For me, personally, I am all about balance and looking at a picture holistically. Having a target blood sugar doesn't really help me to achieve that, if that makes sense.

Cooper: Are you typically in the 150s-160s, or do you not even look anymore?

Simes-Kennedy: I definitely do look. I think that it's important and it's useful to have targets because those clinically help us to determine, "Are you at higher risk for complications? Are you at lower risk for complications? How are you going to do long term?". Those are really helpful guidelines. I actually don't know my parameters off the top of my head because I'm not really motivated personally by specific numbers.

To give some context, I have two kids. My youngest is a year and a half old. During pregnancy, you have to keep your numbers so tightly controlled that, for me, it was not quite all-consuming, but it really took up a lot of my mental energy to make sure the numbers were controlled, to make sure I was getting them in tight range. Because the insulin needs of someone who's pregnant vary every single day, and they get increasingly more as the pregnancy goes on. Sometimes, I would eat five almonds, or when I woke up in the morning, I'd have to go and do several squats or run around to bring my blood sugar down because for some reason, my blood sugar would skyrocket. I think that moving away from that tight, tight control, and not being in pregnancy anymore, my goal is to be within what's clinically recommended, and also to realize if I'm outside of range, that it's also okay and that I have confidence that I'll be back in range again at some point.

Cooper: When you're talking about the pregnancy, I know there's some complications that could occur, but just the additional stress of just trying to stay in range cause you to be out of range because of the stress.

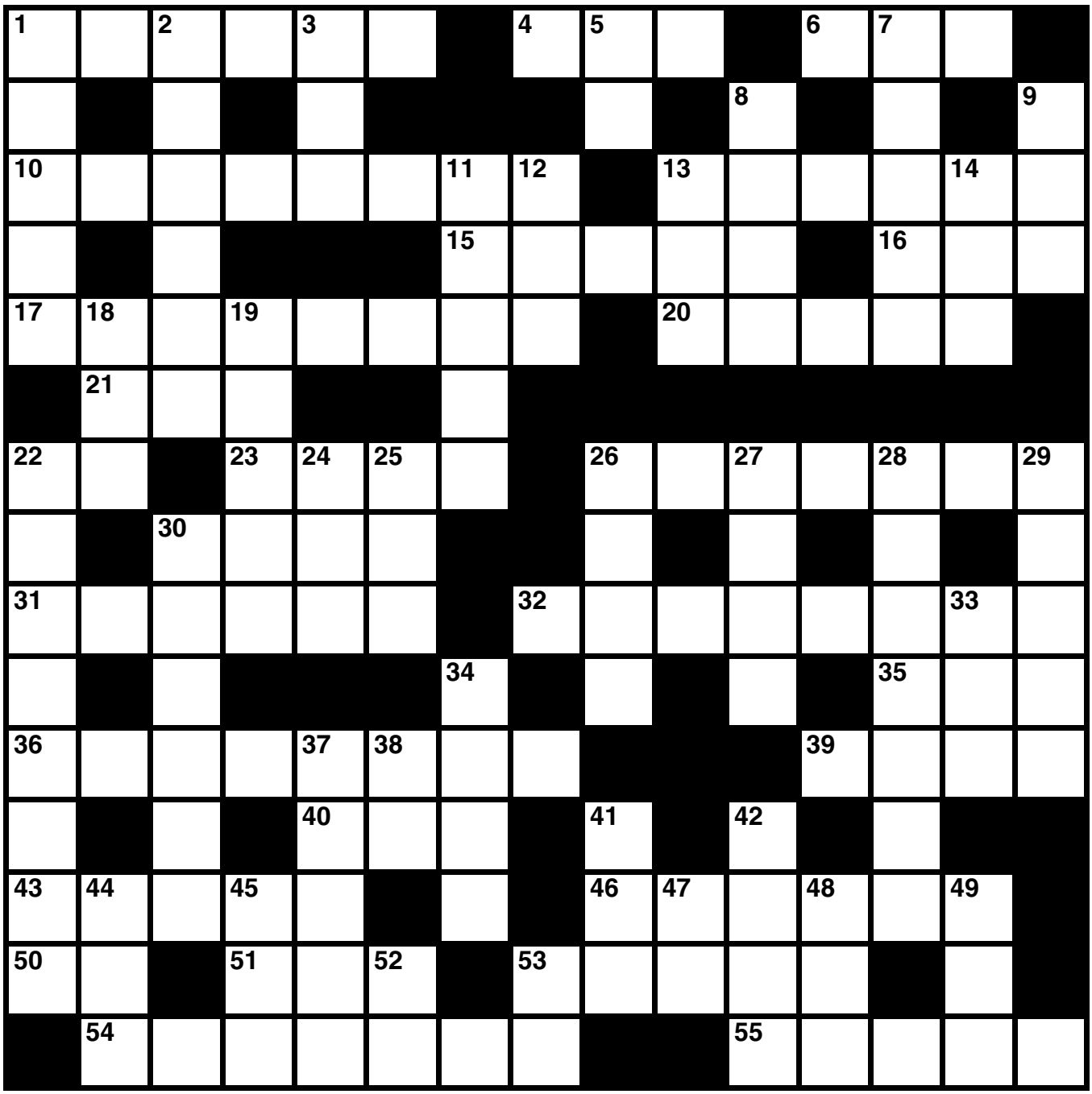
Simes-Kennedy: It's like an impossible task. Yes.

Cooper: The children are good?

Simes-Kennedy: The children are good. They're healthy. Healthy pregnancies, healthy deliveries. They are thriving. They're a year and a half and five years old. But yeah, it took a lot of work and a lot of focus to get them here as someone with T1D. ■ ABILITY

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ABILITY's



Crossword Puzzle

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Crossword Puzzle

ACROSS

1. Internationally recognized adventurer, Paralympian, Everest climber, open water swimmer who is blind, Gerrard _____
4. Law passed in 1990 to protect those with disabilities, abbr.
6. Electric vehicles, abbr.
10. Writer of "The Canary Code", Ludmilla _____
13. Website designer with color blindness, Joshua ____
15. One who provides assistance
16. Very small in Scotland
17. The S in ASD
20. Deep anxiety
21. ___ general rule, 2 words
22. History making pitcher, Young
23. Conde ___ magazine
26. Theoretical physicist motor neurone disease, Stephen _____
30. Los Angeles-based disabled actress who played in Little Shop of Horrors, "The Diviners", "Peter Pan", Marissa _____
31. Coldest
32. Actor who has a form of dwarfism who won an Emmy award for his work in "Game of Thrones", Peter _____
35. Helium or oxygen, for example
36. Doctor and researcher working to support those with spinal cord injury and traumatic brain injury, 2 words
39. "The Green ___" Tom Hanks film
40. Engine need
43. He played Bones in "Star Trek"
46. ____ Potter, a disabled actress in "Glee" who was Sue Sylvester's sidekick
50. Father, informally
51. Appear, with "up"
53. Broadcast on television
54. Harold _____ (double amputee) who won an Academy Award for his performance in "The Best Years of our Lives"
55. Actress with Down syndrome who acted in the BBC TV show "Upstairs Downstairs"- ____ Gordy

DOWN

1. Stares open-mouthed
2. James Ian's award winning song which is a melodic testament to disability awareness and inclusion
3. Nothing
5. ___ Evil (Mike Myers character)
7. Opinions
8. The most decorated Paralympian, Trischa _____
9. Color clothing
11. Secure area in a bank
12. Purpose
13. Beverage from leaves
14. On Soc. Sec., abbr.
18. Take care of a bill
19. River transport
22. Documentary showing a summer camp for teens with disabilities, 2 words
24. Commercial messages
25. Ready, ___, go!
26. Frozen rain pellets
27. Trail behind a motorboat
28. John Lennon's famous song
29. Fliers in formation
30. Enhanced with artificial parts, as in TV's "The ____ Woman"
33. Female friend
34. Surrealist Salvador _____
37. String toys that go up and down, 2 words
38. Roman numeral for 101
41. First person in a wheelchair to win a Tony Award, ____ Stroker

answers on page 72

Crossword Puzzle

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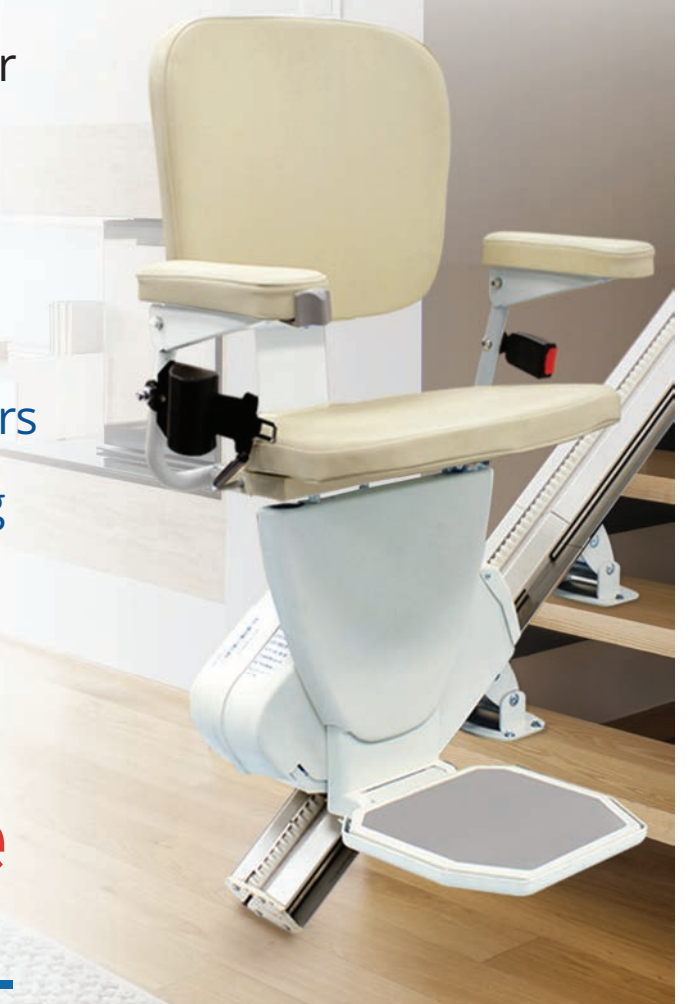
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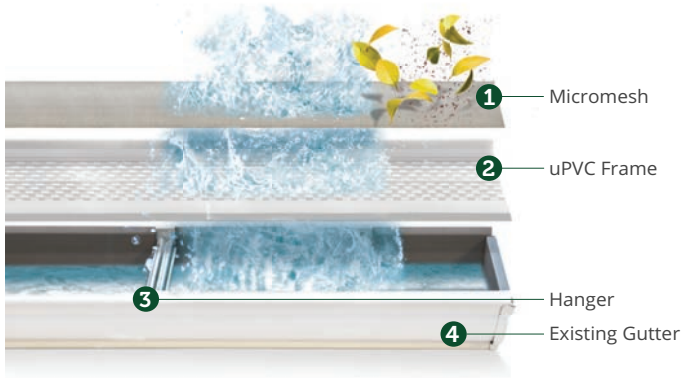
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