JUNOT DIAZ LONG HAUL PAUL FABIAN CLASSICAL GUITAR HUMOR – SQUEAKY WHEEL ALIYA RAHMAN CROSSWORD PUZZLE MARKETPLACE

ABILITY



Dr. Thomas Flynn
Legacy in Sight Pt.2

Junot Díaz
Special Ed to Pulitzer

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"I Am Disabled" Isn't Enough

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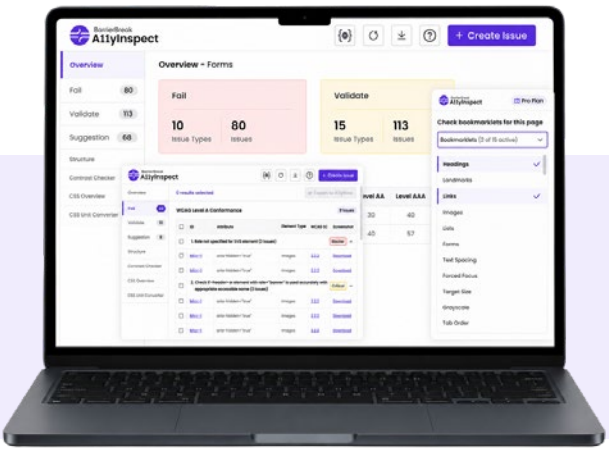
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the SQUEAKY WHEEL



7 New Phrases Ableds are Using to Avoid Ever Saying ‘Disabled’



We all love it when able-bodied people refuse to say the word "disabled" out loud. Just like them, we feel squirmy and uncomfortable when we think about our weird bodies and brains. So here are seven of our favorite new things they're calling us to make sure our experience is never acknowledged — just like we want!

• "Our resident ADA expert"
When someone addresses you this way during a work meeting with a knowing little grin, thank them for being someone who recognizes your expertise, instead of saying that "other" thing out loud.

• "Person with Alternative Movement Patterns"
Person-first language is so important, but sometimes it still lets people think about our terrible problems. So vaguely referring to a consequence of, ahem, —all that — is a great way to say it without saying it.

Popular alternatives: "Person experiencing differing capacities," "Person paying high insurance premiums," "Person with closer parking."

• Cain (because you're not Able)
It's the best when someone is so unwilling to think about "you know what" that they immediately start making jokes about us and, on top of that, bring in religion!

• "[Name of your service dog]"
Our furry lil guys are the cutest stand-ins for our unmentionable troubles!

• "Funcoordinated"
A positive spin and wordplay? Yes, please!

Popular alternatives: "Chairiffic," "Autastic," "Chronically sick as Hell."

• "Short Bus Kings"
It's great how you can say "short king" and never say openly that a guy is too small to be a real man. That resonates with us, and we're stoked you can now hide the reason guys who take the short bus are also not men.

• "Friend of Helen"
We are complete fangirls of Helen Keller, and we totally want to be her friend! Plus her various disabilities and symptoms mean the label can apply to people with a wide range of unspeakable abnormalities.

Popular alternative (until recently): "Homies with Hawking"

Whichever one of these phrases you encourage your non-disabled friends to use, the important thing is we all get to keep feeling that festering body shame deep in our medically interesting bones. ■ ABILITY

by Sy Hoekstra



Founder Steven Verdile
the-squeaky-wheel.com





A Quick Demo Ride

I put over 200,000 miles on my 2021 Yamaha Tenere 700. I didn't wear it out, I raffled it off for a Multiple Sclerosis charity. My 2025 Yamaha Tenere 700 barely has 60,000 miles on the clock and still smells new! Because I travel the country full time sharing my story, I always add accessories that make long days in the saddle comfortable and fun. Auxiliary fuel tank, custom seat, aftermarket cruise control, auxiliary lighting, a taller windscreen, tankbag and hard saddlebags have made my 2025 Tenere just about the perfect adventure touring bike for me.

Yamaha introduced a brand-new version of the Tenere 700 during Daytona Bike Week called the World Raid. It had 50% more fuel capacity, cruise control and more electronic controls for stability and traction. It also had a 35" seat height which makes it interesting for me to sit on considering I have a 28" inseam! They were due to arrive during in the summer. Yamaha asked if I wanted one.



"*Probably not*," was my reply. The new model was tall and didn't seem to have anything special that I hadn't added to my new bike already. *Or so I thought*.

For the first time, Yamaha USA organized an Owner's Rally for anyone riding a Tenere. The Yamaha Tenere Trek Rally took place this past August in Tamarack, Idaho. I had planned to ride from my home in southern New Hampshire to Tamarack, Idaho on my well-equipped T7, when I got the email. The new World Raid model had finally arrived at Yamaha USA's headquarters in Georgia, and I was asked if I would be interested in taking one for a little test ride. The little test ride turned into having me ride a spanking brand new 2026 Tenere World Raid from Atlanta across the country to the Tenere Owner's Rally in Idaho!

I never turn down a chance to ride someone else's motorcycle, and knowing I would be the first civilian to ride a World Raid in the United States, I was happy to oblige. I would be riding the new bike 2500 miles over five days to get to the Rally.

Five days? I could almost walk to Idaho in five days. I secretly decided to add a few side trip adventures along the way. After all, the World Raid was built to go the distance, and why not put it through a real long distance test?

With a million and a half motorcycle miles over the last 38 years, I'm comfortable traveling alone and far from home. I travel loaded to the gills, packing a ton of tools, spare parts and extra riding gear. I have no less than 8 flashlights, two air compressors and four pairs of gloves in my kit at all times. At some point at every national rally I attend, I'm fixing someone else's bike, car or semi truck with tools or parts from my saddlebags. I like to be prepared for anything! For this test ride, however, I would be leaving almost all of my tools, parts and gear in Georgia.

The World Raid I was riding was stock naked and so it felt considerably lighter than my heavily loaded T7. I put what essentials I could cary into my jacket pockets, filled a small dry bag with my medications, phone charger, toothbrush and a set of clean clothes. Riding an hour or two without the tools needed to tighten a loose mirror or to patch a flat tire is one thing, but I was about to log more miles in five days than the average riders travels in two years!

I kept my ambitious extended route to myself. After all, I wasn't sure yet how far I could ride the World Raid with the stock seat without needing to get off to rest my butt.

I said goodbye to my tools and spare gloves and parked my 2025 Tenere in the visitor's lot at Yamaha's headquarters. I jumped up onto the red and white World Raid, posed for some photos, waved good-bye, and at just about 10:00 am, headed west.

It was July 29th and humid as hell. Within seconds, my wet and clammy jacket began to dry off and the faster I went the cooler I became. Escaping the Atlanta humidity quickly was worth the risk of a speeding ticket.

The first day's miles melted away, and I found myself flying smoothly through Birmingham, Memphis and Little Rock. Without the 38 inches of saddlebag width, I am filtering through traffic like a plastic knife through a

pan of hot brownies. The seat height of the world raid is quite an advantage in freeway congestion, I could see far beyond the cars in front of me. As familiar as the 700cc engine was, the suspension was all new. Not heavy, but solid and planted. I kept repeating these two simple words whenever anyone asked me what I thought about the new bike. The front end was solid and planted. Not that I would ever do it, but one could probably set the cruise control, sit back on the passenger seat relaxing, arms riding the waves wind, while watching the miles of scenery blow by. My cheeks were tight from grinning in my helmet.

Do I want a Tenere World Raid? I think I might.

The beauty of having a 300 mile range is that you don't have to worry about stopping in the middle of busy cities to find gas. You aren't thinking about refueling every hour and a half when you are traveling. It's a marvelous way to travel, after all. Would you buy a car that needed to get gas six times a day? A larger tank gives you options and time to plan gas stops where it will be more convenient and quicker to get back on the road. I wish my bladder got the memo!

I rode for 10 hours to the Oklahoma state line and the hotel I had booked the night before. My first day on the World Raid was just under 700 miles. I was surprised the stock seat didn't suck, I probably could have ridden a couple hundred miles more. One thing was certain, I was going to ride the World Raid as many miles as I could, adding in as many cool places and National Parks as I could before reaching Idaho. I called my friends at Yamaha and suggested they bring a new rear tire to the Rally, as I planned to wear this one out! They laughed. I didn't.

I needed to be in Tamarack Idaho in five days. The direct route was 2500 miles. My new route would double that.

I had myself a shower, grabbed a beer and a burger at the Courtyard Bistro and began plotting the next day's ride. Pike's Peak had some incredible views and was only 800 miles away. Unfortunately, finding a hotel that wasn't $400 a night meant riding an additional 100 miles to Denver, and so I booked a room in Denver, set my alarm and fell asleep.

4:00 am came quick, although I was already up when the alarm went off. I filled up the fuel tanks and packed my small dry bag the night before, so 15-20 minutes is all I need to shower, have a cup of mushroom coffee, gear up and be rolling down the street.

Lots of early morning two lane roads and a stop for lunch in historic Dodge City, Kansas. I finally reached Pikes Peak about 4:00 pm. The last time I had been to Pike's Peak, it was so windy, I was unable to put my kick stand down without the wind blowing my bike over. Not this time! I made it to the top without issue, got some great photos and then got stuck behind slowly moving traffic



on the way down. This was the first Tenere World Raid to ride Pike's Peak, and over the next few days would also be the first to ride to dozens of incredible locations.

The next day on the World Raid had me riding all over Colorado. Loveland Pass, along the Snake River, Independence Pass and The Million Dollar Highway. Only 600 miles, but a full day of scenic two-lane roads, on a two cylinder motorcycle built for adventure. The day was filled with lots of elevation, including my opinion of the World Raid version of the Tenere 700.

I only needed two stops for gas!

Do I want a Tenere World Raid? I think I might.

The next day brought on the HEAT! If I was to truly test out this new bike, I needed to see how it would do in the hot weather. Just how would the World Raid handle Global Warming? The weather forecasted 120 F degrees in Death Valley, and I could think of no other place to put this bike to the fire, so to speak. In all seriousness, I live with Multiple Sclerosis and anyone who knows someone with MS knows we do not do well in the heat. Uhthoff's phenomenon is the worsening of neurological symptoms in MS when the body is overheated. Let's just say, it would be really stupid for me to ride a motorcycle through a desert alone in the heat of the summer. A flat tire or running out of gas in such a desolate area would not end pretty.

I got up early and rode through Zion National Park. By the time I got to Las Vegas it was 112 degrees. I didn't stop for the photo I wanted in town. Although riding naked seems like a good idea when it's blistering hot out,



my experience in the desert heat has taught me to keep fully geared up, close all my helmet and jacket vents, gloves tight at the wrists, hydrate constantly and with no skin exposed, keep moving. The three-day old motorcycle couldn't care less, it's temperature gauge never rose above half. Cool!

Red Rock Canyon was next, and I did stop for a few photos, opening my helmet visor was like lowering the oven door to see if the pizza was done. It's amazing how the body's 97 degree temperature can feel like air conditioning when it's 120 degrees outside. The World Raid behaved like nothing was wrong, while my pepperoni was getting cooked. I needed to get moving again and needed to decide if I was going through the desert or around. Did I mention my brain slows down a bit when it gets overheated?

Riding a brand-new motorcycle through Death Valley in August at high noon may not be the smartest route to take when you live with a chronic illness, but I trusted the Tenere motor more than I trusted my own mother. After a quarter million trouble free miles on Tenere 700's, I had zero doubt we would reach the other side of the desert. The 6.1 gallons of fuel meant no stops were needed and if I did stop in the 124° heat, *it was only because I wanted to*.

I didn't!

I blasted through the desert heat as if the last Cuban sandwich on earth was waiting for me at my hotel in Tehachapi. I drank water from the CamelBak I stuffed into my jacket and rode fast, disregarding all the signs, whether they were flashing heat alerts or speed limit *suggestions*. There were only a few other park visitors and certainly no other motorcycles in Death Valley that day.

I was on a mission to cross hundreds of miles of desert and it just seemed wrong to be trusting my life to a horse with no name. I stopped for a quick photo in the park.

With my legs melting into the tar, and barely half my neurons firing, I decided I could not go any further until I gave my strong, dependable workhorse a proper name.

Of the two colors available, Yamaha had given me the Redline White. It may not be politically correct to name a motorcycle after a pack of cigarettes, but the bike was made in France and the French seem to still enjoy a good smoke, so, without a formal christening I gave my 2026 Tenere World Raid a name, *Marlboro - Hard Pack*.

I made it to Tehachapi California by dinner time. The World Raid and I clocked 850 miles of two lane roads for the day, with more than half of it above 110 degrees. I drank 650 gallons of water. I was too worn out and it was still too hot, so I didn't bother to lube the chain. In fact, I hadn't looked at anything mechanical on the bike since leaving Atlanta, 3000 miles ago. It didn't matter, Marlboro was one tough machine and I trusted it.

After a few thousand miles, I really thought I would be missing some of the creature comforts I had on my personal T7. At this point, I couldn't even remember what color my bike was.

Do I want a Tenere World Raid? I think I might.

The next day was Sunday, and my planned route had me riding through the Sequoia National Park, the Sequoia National Forest, up to Yosemite National park and finishing in Carson City Nevada. About 600 total miles of national parks and scenic byways. After fighting traffic in the Sequoias for 7 hours and barely getting through 200 miles, I decided to change my route. After all, Marlboro had never seen the Pacific Coast before!

The World Raid hooked a hard left and we headed for San Francisco where I heard there was a bridge of gold. It had been a few thousand miles since we had been on the freeway, and I was reminded how well the air flowed around the new designed cockpit. The windshield side deflectors are quite a bit larger than the stock Tenere and with the taller redesigned shape of the windshield, provide a calm pocket of air even though I was trying to make up lost time. 52 miles per gallon was my overall average on the entire trip and I don't like to waste time.

The viewing spots for the Golden Gate Bridge were jam packed, but without saddlebags, I was able to squeeze us in for an obligatory photo. Waiting to enter a one-way tunnel in Sausalito was the closest I came to dropping the World Raid. It was a long five minutes, smiling and making imaginary friends with the guy in the truck next to me hoping he would help me pick up the bike after it fell over. It wasn't a question of if I was going to drop it, but when.

Every time I came to a stop over the last four days, I had to make a choice of what foot would make it to the ground. Typically, it was the left, with my



right foot on the peg and rear brake. This particular time, It was the wrong choice and it was so windy, I couldn't swap! 5 minutes seemed like an hour, but, somehow, I managed not to get blown over!

I think we crossed every bridge near San Francisco before heading back east to Carson City Nevada where I had booked a room the night before. This was my longest day on the road, as the morning chewed up so many hours, the Pacific Ocean detour and hitting a roadblock a half hour from my hotel that required a 30-mile detour around lake Tahoe. We rode 800 miles over 17 hours, and we certainly saw some stuff!

I saved the offroad testing for the final day of my demo ride. When I say offroad, I'm talking about dirt and gravel roads, maybe a jeep trail or two. For the first time since leaving Atlanta, I turned off the traction control and rear ABS. There are a ton of rider adjustable aids, but honestly, I forgot they were all there because they just work!

Out in the desert, near Gerlach, Nevada, there is a memorial to long distance motorcycle riders who have died. There is also a plaque listing all the winners of the biannual Iron Butt Rally. Although I have competed in two Iron Butt Rallies, my name will never appear on the winner's plaque as I retired from competition over 20 year ago after getting diagnosed with MS. It was a quick 150-mile ride from Carson City, and I had been to the site before. Sadly, a few more names have been added to the memorial section since my last visit.

The Black Rock Desert is where Burning Man takes place, and, thankfully, I was two months early. From Gerlach to Winnemucca there is a gravel road that Google says is too treacherous of a short cut to get to Burning Man. Jungo Road is 100 miles of gravel, hard packed clay, mud and sand. There are sections that contain jagged rocks pointing up like swat team spike strips. Some reviews of the road say getting a flat is 100% guaranteed. There is no cell service, no houses or businesses; the road is famous for being treacherous and desolate. Perfect!

Standing on the footpegs for two hours was the hardest part of riding Jungo Road. Sure there were a few sandy sections where I glanced at my phone's status to see the NO SERVICE or SOS where the signal bars should have been. There were some muddy sections as well, had I been a foot taller, I may have tried to put my outriggers down, but my feet had no chance of touching the earth unless both wheels fell off! I kept my speed up and weight back a bit and the World Raid glided over the rough terrain like a speed boat over water. It was smooth. The front end was solid and planted. Noticeably improved over my stock suspension. I felt confident and really enjoyed the couple hours I spent riding all 100 miles of Jungo Road.

We were greeted by a group of Yamaha employees as we arrived at the Tamarack Resort in Idaho. The 2026 Tenere World Raid affectionately known as *Marlboro* had 4,720 miles on the odometer when I handed them back the key. I had a box of memories and a giant smile glued to my face.

"How was your ride, can we get you anything?"

"Yeah, I need a cigarette, and I need a World Raid." ■ ABILITY

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JUNOT DÍAZ

Finding Voice in the Immigrant Story

The life of acclaimed Dominican American author Junot Díaz serves as a case study in perseverance and tenacity. After arriving in New York City in the 1970s at the age of seven, Díaz and his family soon relocated to New Jersey, where they began their pursuit of the American dream, a journey familiar to many immigrant communities. Struggling to learn English as a second language, Díaz was placed in special education and faced significant challenges in school. Despite being a failing student, he found solace and escape in books.

Today, Díaz is a professor of creative writing at MIT and the author of several celebrated works. His most renowned book, *The Brief Wondrous Life of Oscar Wao*, earned him the Pulitzer Prize for Fiction in 2008. He has also received the MacArthur Genius Grant and been inducted into the American Academy of Arts and Letters. In a recent interview with *ABILITY Magazine*, Gina Velasquez spoke with Díaz about his experiences as an immigrant in the United States, his struggles with education and mental health, and his insights into what it takes to succeed.

Velasquez: I find it interesting that you're an award-winning author and you struggled to learn English.

Diaz: Yes, very much so. I had great difficulty with it. I was one of those people who was put into special education, which back in the '70s, for someone who did not speak English, was not fun.

Velasquez: Given your facility with language and writing, why do you think you struggled to learn English?

Diaz: It's hard to explain. I do not actually think I have an inordinate facility with language, or above average. This just happens to be the thing that I really plug at, that I really work at. In fact, I've always found language very difficult. I've lived in a number of countries. I've had that privilege. Never had kids and always been lucky enough to be able to take some time and go abroad. And let me tell you; despite living in countries for six months or a year, I can never pick up even a few words. I just don't know what it is, but there's something amiss in my language acquisition circuitry. And it's noticeable to friends because they can always see it. They're like, "Wow, you really struggle to pick up even the most simple terms in other languages." I have friends who are really talented. Wow, man, they just absorb language.

I also saw it because there were four of us siblings. We all came over at the same time. And I was able to see firsthand how I had these others— My little brother came along later. He was born in the States.—And here we are, my other siblings learn language the way you would imagine a kid thrown into that environment would learn it, which was very quickly, very organically. They had no difficulty. They just glided right from immigration to English.

For me, it was just impossible. I don't know what was happening. Teachers quickly figured it out. They had these other three examples, and they're like, "Man, this kid's got a younger sister who's picking it up way faster. And his older brother is just crushing it. His older sister is crushing it." So, they immediately assigned me to classes. I was just basically sitting in the back of classes, not understanding what anything was, anything of it, and just, in some ways, moldering.

Velasquez: What was special education like?

Diaz: They brought a teacher in who I met with, and she began the process of really focusing and getting me to do the necessary drills and the one-on-one attention that you could get in those days when there were still some availability of resources. It's a balance because, back then, it wasn't as widespread, the specialization education, but the numbers were smaller. That really helped to turn the corner. But it was a process, and it was a great struggle for me.

Velasquez: So one-on-one you were able to start picking up English?

Diaz: I think it was more that there were drills that got around my block. It wasn't that I needed one-on-one so much as that (the teacher) really went at it in a different way and got me to think around it.

Velasquez: Do you think maybe you have some learning difference?

Diaz: It's hard for me to say. You know how it is, maybe undiagnosed. We live in this world where everybody is quick to diagnose themselves. I'm from that generation where we're the last people to diagnose ourselves. All I know is that I've never been able to learn languages, and it's been a great struggle. It's been 45 years, 50 years, and I still can't think of it without wincing.

Velasquez: I ask because as you said, this is a generation where people get diagnosed with learning disabilities or learning differences. I have a friend whose child was a bright kid. But somehow he couldn't pick up reading or writing. It took a while to get him evaluated. They discovered that this bright kid has something called disorder of written expression. My friend did what it sounds like your teacher did, like special drills every day for a while. And then suddenly it clicked for him, and then he became a pretty good reader.

Diaz: That's what I'm wondering. Yeah, that sounds very familiar.

Velasquez: That's why I was wondering that perhaps you might have a learning difference.

Diaz: Again, I always think it's extraordinary. From everything that I've seen, it's so hard sometimes to get the answers you need, and especially when you're a parent and you're dealing with a child. I'm at that age where my friends have their kids, And watching them go through some of the steps that they've needed to go through to figure out things that are happening with their children, to get the right expertise, I'm not surprised. Of course, my immigrant mother, very poor, was just glad that we read and kept it moving. She was glad that we could read and write and speak and just kept it moving.

Velasquez: Yeah. I tell my American friends, the idea was just go to school, graduate from high school and go to college. And that was it. I don't know how we did it, but we did okay.

Diaz: Man, hallelujah. How rare and how beautiful.
Velasquez: I understand you also struggled to get through high school.

Diaz: I was a terrible student. Just terrible. I just don't know what it was. I think because I was already a kid who, in many ways, should have been in therapy. Probably should have been medicated. I suffered from tremendous depression starting from probably around sixth or seventh grade, debilitating levels of depression. It probably didn't help anything in my life and anything in my education that these were mental health challenges that went completely not only unobserved but unaddressed. I shouldn't say unobserved. People saw it but misunderstood and unaddressed it.



I mean, by the time I got to junior and senior year— I think each year.—I was racking up to close to 100 absences and just wouldn't do the work. If it hadn't been for the push for graduation of those days, they wouldn't have handed anything to me. But they didn't want me in the classroom. They didn't want me coming back. They wanted to move me along, and they definitely did. It was miserable. Again, I look back on it now and I'm surprised that things worked out the way they did. I was able to turn things around. But my God, I was a mess, a real mess.

Velasquez: How do you think you did that? You went to Rutgers and then Cornell for an MFA.

Diaz: Yeah. What happened was that my mother basically came down on me like a pile of bricks. I get out of high school with pretty much a useless degree. My mother was like, "Guess what? You're either going to work full-time or you're going to start taking classes. I don't care what you do. You've got to take some classes." My other two siblings were in college. My mother was just seeing the road that way. I think she was very wise.

What happened was that I started going to a local school that accepted me. There's always a school that'll give a student like me a crack. I was working delivering pool tables and taking classes at night and on days that I didn't

have any shifts. I loved college. College was a completely different experience for me. I don't know what was going on. I don't know why. Maybe it was also just timing. Maybe my depression lifted that first semester. But I got just perfect grades that first semester and then applied for a transfer to where my two siblings were, which was at Rutgers. They were living in dorms. They were having what looked like the time of their lives. There was ample funding in those days for education, and universities were very cheap comparatively. And lo and behold, one semester at this other school, 4.0, next thing I know, I get accepted to Rutgers. And again, it was a lot different in those days. If I tried to apply to Rutgers with my transcript now it would have been impossible. I would have been laughed out. But those days, things were, I think, a little bit more forgiving. Things were a little bit more flexible.

I got into Rutgers, and I never looked back. I found the university experience very, very different. I think being away from home helped my mental illness a lot, just a lot. I think I was away from a lot of the triggers. I was away from a lot of the pressures. I also was surrounded by people who were very different. The university had people around who had themselves gone through the same struggles I was going through, who were able to point me to resources. It was just night and day for me. I became someone who thrived, where before, school was the worst possible outcome for me or the worst possible experience. I suddenly turned it around, and university life, in some ways, fulfilled me profoundly.

Velasquez: Was that when you realized you enjoyed writing?

Diaz: Yeah, I was trying to figure out what in the world I was any good at. I'm in college, and, for me at least, for all of its joys, there was always the clock hanging over your head and the very practical question: What's next? I had to figure it out. I had to figure out what the hell I was going to do with myself. There was this sense that I really enjoyed history a lot. I thought, "Okay, you know what? I could just go to school. I can become a history teacher. I wouldn't mind that. That would be fun. I'm easy, good with young people."

Then, at the same time, I was doing this creative writing. I thought, "Well, maybe that's possible." When I was getting done with my undergraduate, at the encouragement of one of my faculty members, I applied for MFAs. I applied for five or six of them and got into one. And that's where I went to Cornell. And again, it was another just incredible stroke of luck because I was denied everywhere, from the most local, you would say, the safety schools. All of them rejected me, but Cornell accepted me. I got so lucky. And that was another "never looked back" from then.

Velasquez: I'm sure it's more than luck. They must have recognized your talent. They must have seen something there.



Diaz: I mean, you wonder. But I've been on applications—Listen, I worked at an MFA. I did admissions. What I mean by luck is that, sure, we get a lot of talented young people. But when you're in an application, it's a lot of art. When you're in an application, it's a lot that's arbitrary. People get up at the right time of day or they don't get up. If you've got a committee that's in a weird mood, a kid who would otherwise be in tomorrow doesn't get in today. I guess I was thinking from that perspective. But again, I felt lucky, and I felt like I also took advantage of the opportunity. I really went hard.

Velasquez: And did the depression lift without medication?

Diaz: No, I think I wrestled with it all the way through. I think it was just easier and better when I was at school. I mean, when I was at Rutgers, there were semesters where everything looked to me like it was coming through black and white. I barely spoke to people. If it hadn't been for the fact that I was running and going to the gym every day, I don't know what I would have done for myself. I can remember weeks where I just didn't have any contact with anyone, and my friends would have to come and drag me out of my hole.

I would never say that I just got into college and everything was sunny. I think that it was definitely a struggle, but at least there were some angles and there was some help. And that was the way it was all through school. When I was in grad school, it was the same way. I would have month-long depressions where I was just useless.

Velasquez: Do you think this was related to your experience as an immigrant, living in certain communities or lack of resources and opportunities for kids of color?

Diaz: I mean, none of it helped. Being with no resources, being from a community where they didn't even consider mental health important. Now you can get online and see all the memes like, "Oh, I'm from the immigrant com-



Junot Diaz with John Leguizamo at the Public Theater

munities." Everybody has memes around it. Everyone's, "This is what mental health looks like in my community." And the parents will throw something at the kids.

But let me tell you, it was the silence. The looking away was complete, was total. None of that was useful. And certainly, all of those biases made the matter harder. I was carrying a lot of those biases as well. I was like: You know what? I'm not going to deal with this in the way that I probably should have dealt with it because I was also a product of these kinds of lack of resources. Yeah, definitely, that was part of it.

Look, you don't need to be a sociologist or the person who does this work to realize that growing up in very poor communities, growing up with an enormous amount of precarity, growing up inside of the family I grew up with is just not going to leave you with the most balanced frame of mind. No. I think there're certainly people who could come out of this very stable, but it would have been a challenge, I think, no matter what my brain chemistry was in my childhood.

Velasquez: Then fast forward to what's happening now in immigrant communities with all the news that we see of mass deportations and undocumented people being labeled criminals. Do you think current immigration policies are impacting the mental health of Latino-American kids?

Diaz: There's absolutely no question. I mean, I think that this period, if it continues in the same manner, is going to be another dark valley. If you think about the developmental history of our communities the same way that COVID represented this dark valley, developmentally— The way that COVID in so many places set our students back in terms of their mental health, their resilience, skills, and education. If this continues, I think that this is going to not only be another COVID-like event, but it's going to be much worse because we're talking about communities and families being torn apart at the seams. We're talking about the dystopian "running man" fear.

This is extraordinary what has happened. This sadopopulism, as Timothy Snyder describes it, this desire that so many people have in this country to see other people be sadistically tortured in this way. I think it's going to not only impact the communities that are being victimized, but also I think it's going to distort the humanity of people and populations who are here rooting for this crap, who are thrilling at the sadism. I think it's just poisonous any way you look at it.

Velasquez: You're a professor of creative writing at MIT. Are you seeing it in your classroom at the level where you teach?

Diaz: I have so many students who are struggling with this, struggling with whether they go home, how this is going to play out. But I think, for me, it's more that I'm a member of an immigrant community, the ground zero. My dearest best friend, I visit him in his house, and he has an extended family member who just is so fearful of leaving the house because he has himself a very irregular immigration status, and he's just terrified of leaving the house. His life has just been transformed and completely hemmed in on all sides by his fear, by the very real danger. And that's just one example, but there are many.

I'm that immigrant. I think many of us can know this. Many of us are this. I'm that immigrant who never really strayed too far. I may have gotten this incredible job and all these privileges, but most of my friends are still in this community. As people say about me, at any given moment, you run into him, he's going to be with other Dominicans like him who are immigrants. It's been nuts. It's been fucking nuts. I cannot grasp this. I cannot grasp this. This is so horrible and unnecessary and just vicious.

Velasquez: I completely agree. Like you, no matter where I go, no matter how much I assimilate, you never feel 100% American. You always straddle both worlds. You feel it. It's happening to them. It's happening to me. It's happening to all of us.

Diaz: It's just nuts. I don't know what to make of it. But you know what? What can one make of it?

Velasquez: Do you think there's a recovery in view somewhere within our lifetime?

Diaz: Yeah, I mean, I don't know. I think it's just the nature of human beings. We're not great at predicting. We're not great at seeing the future. And we're also just imperfect and we're suffering. And when you suffer, it's hard to see anything. I don't know. I guess a part of me just doesn't know what— I'm in that place where I just don't know. This is very bad. That I could tell you.

Velasquez: Yeah. I'm sorry I took it to a dark place.

Diaz: We're in a dark place.

Velasquez: I wanted to go there with you because of

your very unique perspective of being an immigrant, struggling to learn English as a second language, going to special ed and going on to being a renowned author, a renowned writer.

Diaz: Well, I mean, listen, I don't know anything except that boy oh boy, are we in for it? We just got to keep the struggle going.

Velasquez: Can you tell me how it felt to receive the MacArthur Genius award and to be inducted into the Academy of Arts and Letters? I mean, for a kid from New Jersey, how did that feel?

Diaz: I think I was stunned. One gets excited, of course, to win anything like that. It's an extraordinary experience, once in a lifetime. But also, I think I am just stunned. Look, I am not that great a winner. Some people are terrible losers. I'm a terrible winner. I get very nervous. I put a lot of pressure on myself. I always think, "God, this makes it harder in a way." On one hand, it was great, but, on the other hand, I think it made it harder for me to do work. So, whatever. It's woe with me, pity, pity. I was glad for it, but on the other hand, it slowed me down. I was already an incredibly slow writer, and it just slowed me down even more. So, glad it happened, but, boy oh boy, I'm definitely one of those writers who do better when I have a lot of time just to be— just a lot of time by myself.

Velasquez: Quietly.

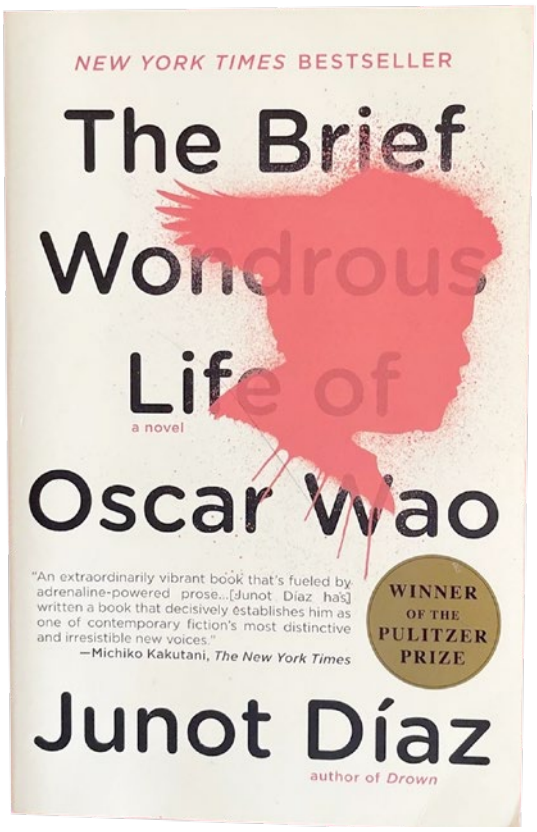
Diaz: Yeah. But one of the funniest things is that when I won the Pulitzer, I tell you, not everything translates to the level of culture. My mother had no idea what the Pulitzer was. You really can't convince people of something being important if they don't know it. My mother just simply asked, "So, how much did you win?" When I told her $10,000, she just looked at me and said, "You were making more than that the year you were doing your newspaper route." I was like, "Well, first of all, that's not true. But thanks, Mom." Because in her mind, she boils it down to that. It cannot be that important if it was only $10,000. There you go.

Velasquez: Oh, wow. Do I know your mom? It sounds like my mom.

Diaz: I know, it's incredible. It's incredible.

Velasquez: Yeah, they bring you down to Earth. How long did it take you to write *The Brief Wondrous Life of Oscar Wao*?

Diaz: It took me 11 years. It took quite a long time. I'm way past that mark now. I think I haven't written a book in 15 years, excuse me, or 13 years, something like that. I just am a slow writer. As a friend of mine said, "You're not just a slow writer. You're the slowest." But we'll see. We'll see.



Velasquez: Are you working on something else now?

Diaz: I am and hoping that something comes of it.

Velasquez: Well, I can't wait to read it.

Diaz: I really appreciate it.

Velasquez: Is there any advice or message you would want to give to the immigrant kid who's struggling out there, to the kid with a learning disability or depression?

Diaz: I'm not sure I'm the great person for advice. I'm also pretty unremarkable on so many levels outside of the visible success as a writer. Whenever I have to talk to my godchildren or my nephews, and I tell them, "Listen, I am nothing special. If I can do the things that I've done, almost anyone can do them."

I think that these lives are so difficult. Our lives are so fucking challenging. But the truth of it is that there's not much that a little resilience and a little persistence can't overcome. It sounds simplistic, but it certainly proved it for me. I don't have magic powers. I don't have special gifts. I didn't have anyone who looked out for me. I wasn't in any special services beyond just the initial special ed. I got to tell you, man, I discovered that just a little bit of persistence and a little bit of resilience saw me through a lot of bullshit, a whole lot of bullshit. If you got people helping you, all the better. All the better. ■ ABILITY

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TARRIS MARIE
BLAQUE
#ANOVEL



Tarris Marie

Fashion, Fiction, and Finding the Light

The journey of a novelist is often one of discovery, and for author Tarris Marie, that path was paved through a life transition. After a career in the fashion industry as a buyer, Tarris faced a life-altering diagnosis of Stargardt's disease. The progressive loss of her central sight caused a transition away from the corporate world and opened a door to a new and exciting passion: storytelling.

This creative pivot led to her first novel, *Blaque Pearle*, a gritty crime drama set in the neighborhood of Compton involving the complex webs of organized crime. She followed this success with her next book, *Empress Creed*, a historical drama set in the 1930s. Both novels skillfully interweave themes from the fashion industry, high-stakes crime, and romance, reflecting the diverse facets of Tarris's own experiences and imagination.

Today, Tarris is a celebrated novelist, proving that a change in perspective can lead to a more profound narrative. *ABILITY Magazine's* Gina Velasquez and Jennifer Woodall met with Tarris, discussing her transition into writing, how she develops characters and the nuances of the publishing industry. She describes the importance of motherhood, a supportive family and the power of "finding the light"—both through digital magnifiers and the support of a community that refuses to accept "no" as an answer.

Woodall: What was it like navigating the publishing scene?

Marie: It was actually a blessing for me when I got started because I started my career off as a buyer first. I was in the fashion industry. I did a lot of things, not just buying, but I started off as an assistant buyer. I saw myself doing that really until I retired. But then when I lost my vision, I had to pivot because of the company I was working for at that time. I just wasn't able to read the numbers as quickly as they would want. It was just a lot of challenges that were going on when I came back to work after I had my devices and things.

To answer your question, when I actually started writing and I hired a writing coach, I first started with an agent. My journey into the publishing world actually started



Tarris Marie at a book signing for *Blaque Pearle*

with, of course, the story. I had a writing coach, and then I found a literary agent who then connected me into the publishing world. I started that journey, really, by just a test. I didn't know where the writing was going to go. I didn't know if someone was going to take to it, or pick it up. But as soon as I sent out my manuscript, I started getting some responses from agents. Then I found the right one who then put me in contact with my publisher.

Woodall: Can you talk about your process as a writer, like how you approach character development and plot?

Tarris Marie: So, really, character development is my favorite part of my writing to be honest. I usually create a whole life for the characters before I even put them down on paper. Where do they come from? Genuinely, I would have to say God. I mean, they just pop up and they start talking to me, and I'm like, okay. When I can't take it anymore, I just start writing it down. I usually start with giving them a life, if that makes sense. It's like I start with them from birth. I write their whole life story. Then once I write their life and what they do, then I actually start the story. So, my story usually begins with the character.

Woodall: You said you had a writing coach?

Marie: Yes, Bruce McAllister. I called him my "Yoda" that connected me to the literary "Force."

Woodall: What was the process of finding a writing coach? What was that like?

Marie: So, when I first started writing, which was in 2020—I can't believe it!—the character started coming to me. The story started coming to me, and I just started writing things down or typing things out. As I was typing, I was like, "Okay, I have a story." So, I tried to find an editor first because I'm thinking, "Okay, I have the story. Now I just need somebody to clean it up." But I didn't. An editor actually recommended that I find a coach because writing is an art form that does have elements that are required, and you have to learn your craft. I didn't realize that at first.

I was so excited to be writing that I just wanted to get my story out there. So, how Bruce came to me was just through research. I started researching and I started cold calling. I talked to different writing coaches and told them a little bit about me and what I was trying to do. He and I hit it off from the start, so that's really how that came to be.

When you hire a writing coach, it has to be someone that matches with you and your personality. Also, depending upon where you're trying to go in your career, you want to find the right match. It's almost like a marriage, right? That's how I feel about it. Same thing with the actual agent, and same thing with the publisher. It's all a marriage. So, you want to do your research. You want to do the interviews. And then you want to be true to who you are as an artist. Then find that perfect match for you. And Bruce McAllister was that match for me.

Woodall: Is *Blaque Pearle* your first book?

Marie: This is my first published novel. It wasn't the first book that I actually wrote, though, but it was the first one that I brought to the world.

Woodall: Do you have advice for writers who are wanting to publish their first book who might not know where to start?

Marie: Yes. I feel everyone has a story to tell, right? So, of course, it always starts with a story. Be true to who you are and the story that you want to write. Then, after you've figured out what that is and after you put that art on the canvas, then you go out and do the research. Just look at books that are similar to the book that you have written. Look at authors that you look up to and see who published them. That's really what I also did as well.

When I found my literary agent, I looked to see who wrote a book that was similar to mine. Who was the agent that got them that deal? Who are those authors? What are those books? What is the genre? All of that. So, that's why it starts with the story first. You have to get that nailed down. Once you get the story on the canvas, then you would find a literary agent. An agent is not required for all publishers, but most of the big publishing houses do require a literary agent. So, that takes some research as well. It's a marriage that you are committed to as you are navigating through the publishing world. You are trying to figure out the best fit for your work and for you as an artist.

Woodall: Did you run into any accessibility issues when you were doing book signing events and finding a good location or things of that nature?

Marie: Oh, that's a wonderful question. I will say that from all the events that I did, everyone was so great. I did not run into any accessibility issues at all. You know that, as I talked about earlier, I stay true to who I am. Being legally blind is one of the things that I embrace, of who I am. Putting that out there into the world and making sure that they know that, of course, is important to me. So, every encounter that I have had in publishing, as far as writing is concerned, I haven't had any issues. Everyone has been just welcoming and kind, and I haven't stumbled into any issues. I use my magnification devices when necessary. My magnifier stays on me at all times in case needed. I just make sure that I stay ready with my devices if any challenges were to come my way.

Woodall: I'm glad to hear that you haven't run into any accessibility issues. That's always refreshing to hear.

Marie: Not at all. That would be another story, honey. That's when I was in the corporate world, so that's when I had to pivot. That was where I ran into issues. But in the actual writing world, no. I use big screens. I use all my devices, and I don't have any issues with that. Just so you know, too, it was important to me that I have my book available in audio, which it is. That's how I write. I speak the words onto the page if I'm not using my magnifier. Being able to utilize my voice to speech is super important for me as a writer, and I make sure that I use that. My publisher has been a great partner. That's something that they also wanted to make sure that my work was available in audio.

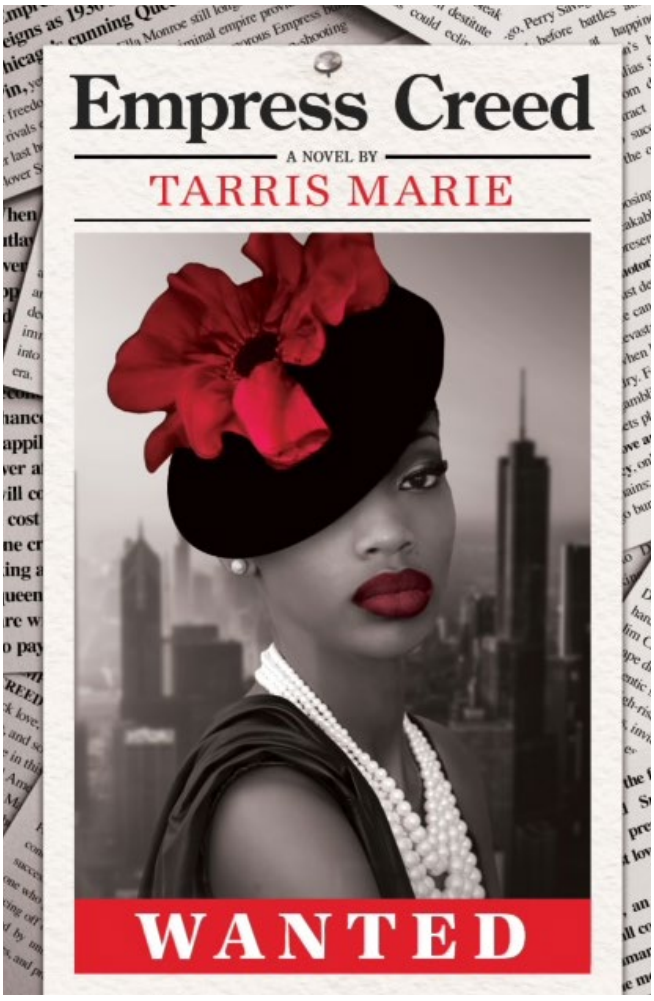
Woodall: Gina and I have both had conversations about audiobooks and the actors and how much of a difference a good audio actor can make for listening to the book. So, do you get to choose who the actor is?

Marie: So, for *Blaque Pearle*, this was my debut novel. I did not have any say in who the actual actors were, but they were phenomenal. They picked the perfect actors for Blaque, Pearle and Goldie. I was super pleased with the actors that were chosen, but I did not have any say in that process.

Woodall: I was always curious how that worked, and if the authors got to make that decision.

Marie: Sometimes they do. But, for me, with my debut novel, I was not a part of that process. I was super pleased with the actors that were chosen. For someone who's been listening to audiobooks for a while, the game has changed and made the experience so beautiful. I love a good audiobook. Oh, my God. Compared to years ago when I first started listening to audio, it's changed so much. The actors put in the work and create the art and bring our books to life. I think that they deserve the credit that they get. Those actors that portrayed my characters in *Blaque Pearle* did a phenomenal job bringing my characters to life in the audiobook.

Woodall: That has to feel really rewarding as an author



to get to experience your characters being brought to life through another person and how they're interpreting that and then being like, "This sounds amazing."

Marie: Oh, my God. I can't even describe it. If you would have told me even five or six years ago that this would have been my life, I would have laughed. I am just continuously amazed. My next book, *Empress Creed*, has gone to print. When I got to see the cover and I got to see the inside pages of the book, I'm like, "I did that." I cannot believe this is just such a blessing. It's so beautiful and fulfilling to be able to tell these stories and to have them on the shelves. As you said, especially as a legally blind woman, I am able to be a legally blind author. I have my book told and brought to life through another human being who then just embraces the characters that I created and made them their own.

Gina Velasquez: So, you and I share several parallels. I worked in publishing for a decade but left twenty years ago because I was losing my sight. Back then, I didn't know about assistive technology or support systems. My main focus was becoming a mother, so I prioritized that before eventually figuring out how to balance a career. Navigating that journey for myself and my child was a long process. Could you talk about that for you?

Marie: Now, that's a heavy question. Well, just so you



Tarris Marie at a book signing for *Blaque Pearle*

know, it's beautiful to be able to talk to another sister in this space. I understand your frustration because when I was first diagnosed, I was handed a Sherlock Holmes magnifying glass at that time. I was just told to learn Braille. I was like, "Oh, okay. Wait a minute," because I hadn't lost my vision at that point. It's called Stargardt's disease. It's progressive, and it leads to legal blindness. My peripheral stays intact, but I have blind spots with the central vision.

Velasquez: I know what that's like. That happened to me, too.

Marie: When I went back to the corporate world, that's where I had some issues. First, I went through occupational therapy. With the occupational therapy, I learned to look through new eyes. I was given bioptic lenses and bioptic scopes. I actually even learned how to drive with these bioptics that I've purchased. I went through that for 12 weeks, and I went back to the corporate world ready to rock. So, what happened to me at that time—and again, this was before working from home—was that the landscape changed. I mean, this landscape has changed so much that I don't know what that would look like, but everything happens for a reason.

Anyway, when I did go back to work, I had my magnifying device and I had my big screens. So, I was ready to rock. Then they would ask me questions, as I did my presentation, like "Tell me what was that number three years ago, week two, day three and four?" When I would try to fumble to find it, it was like, "Oh, God." So, those were some of the things that I ran into. And then it led me into the writing world.

So, press forward, I'm a mom. I have two children, a girl and a boy. Before I started writing, I did the stay-at-home mom thing. For me, it was a great experience, but I felt like something was missing. There was a part of me that was missing. On my journey to figuring that out, I ended up losing my vision. I had lost my job.

I had lost so many things that it took me to the bathroom floor. Then I spun into depression. So, then God told me to get up, and I said, "Well, God. Tell me what to do so that I won't ever get on this floor again, and I'll help as many people as I can to not be on the floor." And he said, "Write a book." So, that's literally how I started. I mean, I sat in front of my blank screen, and then I was like, "Okay. God said write a book, so what is this going to look like?"

It started with the character Pearle, and I started writing what her world was like. The process was very difficult at first as I was getting my bearings and trying to figure out what that was going to look like. I had no clue. I mean, I'm still learning as things go on, as my life begins to transform and as I have to continue to pivot. Some things will happen, then something else will happen, then I'm like, "Oh, okay." I'm still navigating this world and trying to figure it out. Like I told you, book number two is coming. But for my kids, I taught my daughter how to read with my magnifying device.

Velasquez: Yes. That's amazing, right? Because I was almost completely blind when my son was starting school. You know how that Common Core reading is so tough the way they teach it now. I had his little books memorized, so when he got home, I could pretend to be reading them. Actually, it was more from what I had memorized. So, the fact that our children learn to read when we couldn't see ourselves, I find that—now that I look back—a little crazy.



Tarris Marie speaking

Marie: Oh, my God. Let me tell you this quick story. So, I told you I taught my daughter how to read with my magnifier, and my magnifier is digital, right? So, it has a light on it, and it has a screen on it. I would blow it up so that I would teach her how to read. I took her to a party—And this is one of the things when I decided to, I would say, come out the closet. And I'm going to be honest. I was still a little, I don't want to say embarrassed, but maybe that is the word I'm looking for. I was still not fully out, although most people knew that I had vision issues and was legally blind at the time.

But I was sitting there with my daughter, and there was a mom that was reading to her daughter. There were a few moms, actually, that had books out, and they were reading to their children. My daughter was little. She was sitting on my lap. So, then she was looking at the book and the mom said, "You want a book?" So, she nodded her head and the mom gave her a book. Then she handed it to me and got in her reading position to just put her head back on my shoulder. I was like, "All right," and I couldn't see, right? So, I'm like, "Oh, shoot. What do I do?"

So, I started just talking like, "Okay, here is a cloud." My daughter looked at me like I lost my mind. She reached over me, grabbed my magnifier out of my purse, and said, "Light, mommy, light," because she called it the light. And so basically, what she was telling me was, "Take this thing and read to me. This is how we do. You know how to read. This is how you read to me." Ever since then, I take my magnifier out now. If I'm in a restaurant, it doesn't matter. I embrace this. This is a part of who I am. So, my daughter helped me with that journey when she said, "Mommy, light," and then she just put her head back on my shoulder like, "Now get to it."

Velasquez: She showed you the light. (laughs)

Marie: Oh, come on now. Yes. Come on, Gina. (laughs)

Velasquez: For me, it was my cane. When I started losing my vision, I did not want to use my cane at first, and it was embarrassing. Well, not embarrassment. It's almost like you don't want to be different, right?

Marie: That's it. Because it's not embarrassment.

Velasquez: It's standing up for being so different. And maybe people are looking at you with pity. So, it took a couple of stumbles, and it took my son pulling out my cane when we walk out. Because for him, it was almost like a toy. I began to use it, and that showed me how to just be myself. And I don't care what people think. I'm blind, so what? I'm still me. I am just mom, like you said. It's different, but I think it's because he's accepted me. It has now enabled me to model self-acceptance to him.

Marie: Absolutely.

Velasquez: That was so powerful to me when I realized that my disability, if anything, only helped him. I raised a human that accepts all disabilities because he really does.

Marie: Absolutely. I love that.

Velasquez: How old are yours?

Marie: My daughter is nine, and my son is 13. She's about to be 10. So, yes, I have one teenager and a preteen.

Velasquez: And both of them are going on 25, right?

Marie: Oh, my God. Absolutely.

Velasquez: Did you ever worry when they were smaller and you were first coming to grips with your blindness that your children would have some disadvantage?

Marie: I took my daughter to see Lion King. This is before.— I take my bioptics out now. It's not a big thing. —But at that time, even though I was just doing the mom thing, I was still focused on things I couldn't do. There was a time period that I was just like, "All right, well, I'm not going to be able to do this. I'm not going to be able to do that. They're going to miss out on this." I went through a period that I would say I responded to depression. I was so focused on things that I couldn't do, but I'm not there anymore.

But yes, to answer your question, there was a time when I was concerned for them and what I possibly couldn't provide. They wouldn't see me working because my career was very important to me. I didn't think about how I was able to be there for them. I was able to still attend these different things. I wasn't seeing it through that lens at that time when I was losing my vision. I had lost it, but

it's gotten worse. But you know what I'm saying? When I was losing my vision, I definitely went through a time period where I was concerned about that. Absolutely.

Velasquez: For me, I was worried that I wouldn't give him a normal childhood until I realized it is what I give him. I'll give him the best that I can and model for him how even with a disability, I can work. I can find a job.

Marie: Absolutely. I had a doctor that really started changing my perspective on things that I could do. He was like, "Hey, honey, you can do this. You can do that. Let me see your phone." Then there was a free app on my phone where if I didn't have my magnifier, I could magnify on my phone. I just didn't even know that those things were even possible. I was very grateful to have the doctors that I had.

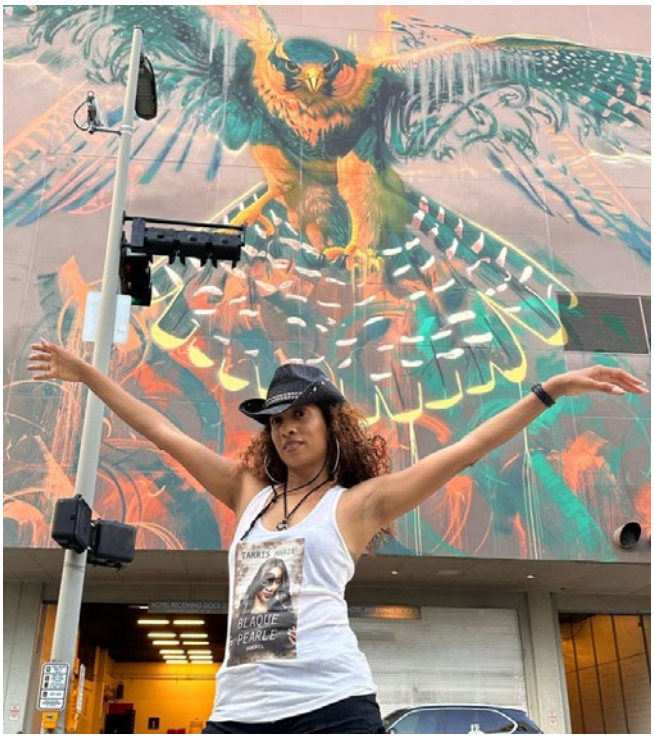
Just like the publishing world was a process because it took me a while to find that support. Before, I was told, "Hey, I can't wave a magic wand and make you be able to see." A doctor actually told me that. It was definitely a process to find the right support and the right doctors to be able to help me navigate.

Velasquez: Right. Normal. That's what we're trying to do, but our lives are normal. We have children. We work. So, yeah, we're just like everybody else.

Marie: Absolutely. We all have a story, and that's why I always say that everyone has a story. You never know the person next to you—what their story is. I'm always trying to make sure that I'm sensitive to that. I don't know what they've been through. A lot of times we wear a mask and we're masked behind the things we've been through. But sometimes, like you said, we're the light, and we're just shining. So, it just depends on where you are and what stage you are in your journey.

I noticed a parallel through my books where it's like, "Oh, my God. I didn't realize how much I talk about wearing masks." And I think it was because there was a time where that's how I was navigating through the world. I was masked in certain ways. Especially during COVID, we wore masks on masks, so it was just a crazy time. I talk about that as I look at characters. I'm like, "Oh, my God, this is a whole theme."

I'm just grateful that I was able to come out on the other side and to be in this space and place and feel good. My kids see me glowing and growing, and I'm just excited and grateful for the opportunities that have been placed before me. My husband has also been a supporter and has been there because he's been with me since college. So, he's also been a part of the journey and has been very helpful as I've navigated into this new—I don't want to call it new life—but as I pivoted in my life. He's been a part of the journey, too. I guess I want to make sure I share that, too. So, it's my kids and just my family as a whole.



Velasquez: Yeah. Family is important when you're dealing with a loss, like vision loss.

Marie: It's so important for the community. The best advice I could give, and I don't want to sound cliché, but I would say, do your research and also just don't accept "no." Don't look at your life as a wall, but just look at it as changing direction. Try to find the pivots instead of the roadblocks. Like, "Okay, this is in front of me. Let me pivot now to the left. Let me pivot to the right." And just do what makes you feel whole. I knew even when that doctor said that to me, that was devastating, right? And it took me off guard. I was like, "Who says that to another person?" That's crazy.

But what I knew was that that wasn't acceptable and that it did not make me feel whole. So, I'm like, I need to find people. I need to do things in life that make me feel whole. So, in the process of finding my wholeness, it took some research. It took some editing.

When you're writing, you've got to cut the fat. Sometimes you've got to cut certain people out. Some people are not part of the journey, but life is a journey, and you just want to make sure that you have the people in your life. You have the health care that helps you move forward and not stop you or take you backwards because it's always about moving forward in the journey. And so, that's what I would do. Definitely do your research and make sure that the people that you have in your life are helping you become whole and helping you move forward in this life. ■ ABILITY

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Dr. Thomas Flynn

The Healer Becomes the Patient

In the previous issue of *ABILITY Magazine*, Gina Velasquez sat down with her former ophthalmologist, Dr. Thomas Flynn, and his daughter, Dr. Erin Flynn, also an ophthalmologist. Together, they reflected on the height of the AIDS epidemic in New York City during the 1980s and 1990s — a period when Dr. Flynn purposefully took on the difficult task of treating patients with Cytomegalovirus (CMV), an opportunistic infection that caused blindness in people with advanced AIDS. Against all odds, Gina survived her terminal prognosis and recently reconnected with the doctor who helped manage her care.

In this continuation of their conversation, the focus shifts away from the AIDS crisis and toward the later stages of Dr. Flynn's career. After relocating his practice to Maine, he anticipated a quieter professional life but, instead, found himself running a busy clinic treating patients with severe and complex medical conditions. In a rural state with limited healthcare access, Dr. Flynn became, for a time, the region's only ophthalmologist specializing in uveitis, an inflammation of the uvea, the middle layer of the eye.

Velasquez and Dr. Flynn then turn to his personal transition from doctor to patient following his own terminal neurological diagnosis. Joined by his daughter, who temporarily stepped in to help run his clinic as his symptoms progressed, he describes the intricate process of identifying his rare condition, his deep discomfort with becoming a patient and the medical legacy he leaves behind.

Editor's note: Due to Dr. Flynn's medical diagnosis, he experiences difficulty speaking. Dr. Flynn's daughter assists in communication and expanding on Dr. Flynn's comments. Additionally, Velasquez's son, Aiden, commanded the audio equipment for the interview.

Velazquez: You moved your practice to Maine. You kept some patients in New York; I was one of them. You were 27 days of the month in Maine, three days in New York. Did you move because you wanted to move somewhere rural?

Dr. Erin Flynn: No, he didn't.

Dr. Thomas Flynn: You got it right.

Velazquez: I think it was because your wife was retiring and she wanted to move to Maine. I'm not blaming your mom. I'm just saying it's like a life decision.

Dr. Erin Flynn: Yeah, he was forced against his will. He was not happy about that.

Velazquez: You moved to Maine and you decided to open up shop there. What was it like to be a doctor in a rural community?



Dr. Thomas Flynn with his family

Dr. Thomas Flynn: There's something very strange about Maine. Sickest goddamn people in the world.

Velazquez: In like health?

Dr. Erin Flynn: I think he's alluding to the fact that healthcare there is a little underserved. The population's very diabetic, overweight. And also, I think Maine's got the highest rate of cancer in the United States, and we don't quite understand why that is.

Dr. Thomas Flynn: That's right, and drug abuse

Velazquez: I know that those other illnesses, I don't know how they contribute to eye health, like diabetes. Did you somehow become the AIDS doctor up there as well?

Dr. Thomas Flynn: Yeah, but there wasn't much AIDS. Most of them had died. The ones who had it, most of them had died. So, I had one exceptional young man who survived. He dressed Ivana Trump.

Velazquez: Who survived in all those years?

Dr. Thomas Flynn: Yep.

Velazquez: Well, by that point, and this is the 2010s, there were antiretrovirals.

Dr. Erin Flynn: Yes, antiretrovirals made AIDS like a chronic illness.

Velazquez: Then your patients who were going blind were going blind from cancer, diabetes?

Dr. Thomas Flynn: The first thing I learned is that I really had a weird specialty nobody wanted to do. Usually when a new doctor comes to a place like Maine, they won't refer patients. But I had referrals from the first minute I showed up.

Dr. Erin Flynn: Because you're uveitis.

Dr. Thomas Flynn: Because they wanted to get rid of the patients. So, I was busy from the first minute I showed up.

Patients in Midtown. Patients in New York. I take it from 40 million people in the tri-state area, Maine has 1.5 million, and I was just as busy in Maine as I was in New York.

Dr. Erin Flynn: He felt like his clinic was just as busy, if not more busy, than his uveitis practice in New York.

Velazquez: Was that because the other doctors don't want to deal with uveitis, just plain uveitis, not necessarily HIV uveitis.

Dr. Erin Flynn: Yeah, a lack of uveitis specialists there. When you came up, Dad, was there anybody else who did uveitis?

Dr. Thomas Flynn: Not really. Not in Maine. So, if they did have complex uveitis, they'd refer down to Boston, Massachusetts Eye and Ear.

Velazquez: And untreated uveitis— Do you go blind from that?

Dr. Thomas Flynn: Completely blind. Yes.

Velazquez: Did some patients who didn't get care go blind?

Dr. Thomas Flynn: Yes. I remember when I did corneas for the very first time. This young woman, and one eye looked like a piece of rock. (The eye) had been lost, and the other eye had—She was very emotional, you know, "What are we going to do? I'm going to go blind. It's horrible." And I smiled and I said, "No way. We can treat this." She pointed to the eye that was destroyed and said, "They could have treated this? This didn't have to happen?"

Dr. Erin Flynn: I'd say uveitis is treatable. It's dependent on the therapy medication. A lot of them aren't particularly pleasant to take. And it's on the importance of following up.

And it's tough to follow up if you're in Maine and the only uveitis specialist is hours away in Boston. When my dad came there, he found a large, underserved community of patients who probably could have had much better outcomes if they'd been properly managed and treated.

Velazquez: There was a lack of doctors who are willing to work with patients with uveitis. But was there another factor for these outcomes in Maine? Was there a good healthcare system, hospitals, insurance?

Dr. Thomas Flynn: Yes. But reimbursements. Reimbursements are lousy.

Velazquez: What does that mean though?

Dr. Thomas Flynn: You spend hours and hours and hours dealing with the eye and the patient. You get paid $5 by Medicaid for that 4-hours. You do a cataract; you don't make any money. $500 for 15 minutes.

Dr. Erin Flynn: He's specifically saying uveitis, as a subspecialty, doesn't make the big bucks in that you spend hours with your patients. You ask the questions. You're managing them, not just their eyes but their body systemically because you're putting them on medications that have implications for the rest of their body. So, it's not a quick visit. And patients get complicated. All the medications come with a host of side effects that impact the patient, all different parts of their body—which Gina, you know better than all of us—And it just doesn't pay well.

So, the patients become your best friends. You spend hours with them. And spending hours with patients—Unfortunately, the American healthcare system doesn't reimburse our long visits with patients. They want us to get patients in and out of the door.

Dr. Thomas Flynn: And in Maine, I didn't have the kind of backup I had in New York. I would start people on deadly, dangerous drugs—And I'm it. I'm the person



Dr. Thomas Flynn with his father

monitoring and take care of them because of busy feeders (doctors) would say, "I don't know anything about these drugs, I can't handle it." I was forced to practice a lot of primary care in Maine because I didn't have any backup.

Dr. Erin Flynn: So, it was hard to coordinate care with their primary care doctors or even rheumatologists in Maine because there aren't many of those as well. My dad kind of had to run the show for the whole body.

Dr. Thomas Flynn: Why is the goddamn ophthalmologist taking care of your liver?

Velazquez: Oh, I see.

Dr. Erin Flynn: So, the doctors would ask this—And I'm assuming that's because methotrexate, which is an immunomodulatory medication my dad puts on his patients can cause elevated liver enzymes.

So, my dad had to become primary care doctor, tracking and making sure the liver was okay while he's starting this medication, making sure the diabetes or their blood sugars were controlled while starting them on high-dose steroids for their uveitis, etc. But he had to be a body doctor.

Dr. Thomas Flynn: And the psych doctor.

Dr. Erin Flynn: Psychiatrist, yeah.

Velazquez: And you served like an entire region, a couple of counties.

Dr. Thomas Flynn: For a while, the whole state.

Dr. Erin Flynn: I think now we've got maybe 2 more uveitis providers in the state of Maine.

Velazquez: Oh, you were the only uveitis provider for a while in all of Maine?

Dr. Thomas Flynn: Yeah. I mean, to give you an idea, I remember one patient was a scientist at the Jackson Lab. That's the place that sells mice to investigators around the country. She was a scientist at the Jackson Lab. She came in and she had horrible eyes due to high blood pressure due to untreated lupus.

I looked at her and said, "We can take care of this. We can take care of your lupus and your eyes." And I made a call to the rheumatologist, saw her, and she was put on a horrible drug called Cytoxan emergently (urgently), which shuts down her immune system.

So, a few weeks later, she was better, but she wasn't. She was funny when I first saw her. She wasn't funny this time. She was kind of sad, distracted. I remember getting a phone call two days later. She died getting surgery.

Velazquez: She died of what?

Dr. Thomas Flynn: Fungus. Fungus throughout her body. Because the steroids are toxic. To treat her lupus, save her eyes, and it succeeded. And succeeded in even killing her.

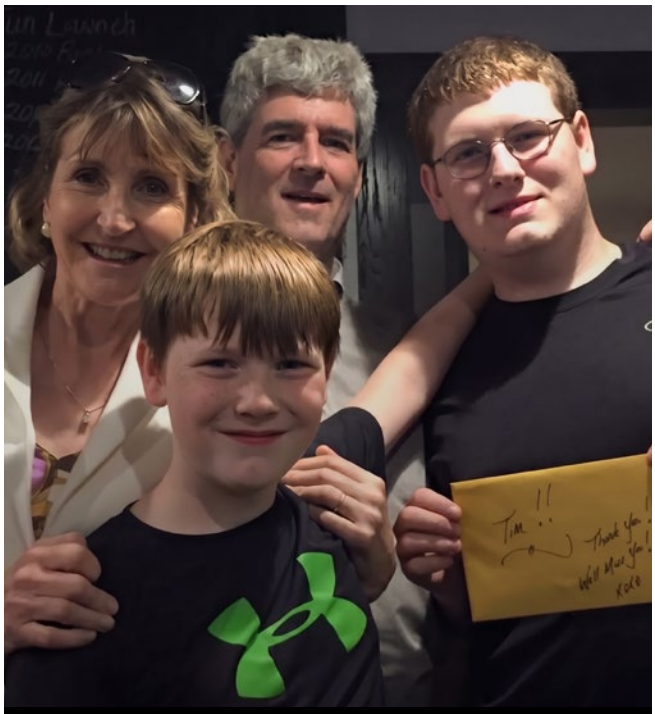
Dr. Erin Flynn: Basically, this woman, who is in charge of a very important cutting-edge scientific institute, walked into his office with eyes ravaged from lupus and she wasn't being treated for her lupus. So, my dad started her on CellCept, Cytoxan. He saw her several weeks later and she didn't seem like herself. She just seemed a little bit off, and a few days later she actually died of disseminated fungus throughout her body because the immunomodulatory drug that he had started her on killed her immune system, which predisposed her to a fungal infection. But it's because I guess she wasn't really seeing another doctor.

Velazquez: That must have been devastating.

Dr. Erin Flynn: She didn't know anything was wrong with her, and she probably didn't think it would be easy to see a doctor about these complaints she was having. It's just crazy in that even somebody who is like the head of a scientific institute like that can die of something that somebody who doesn't have proper access to medical care would die of.

Velazquez: Maine's an interesting place. What makes it interesting is that the stereotypical underserved small communities' image in this country is of southern states, not northern states. You think Appalachia.

Dr. Thomas Flynn: Right, Appalachia. Maine is part of



Dr. Thomas Flynn with his wife and sons

Appalachia. Maine is Appalachia. It's West Virginia with lobsters.

Velazquez: Did you know this before you moved up?

Dr. Thomas Flynn: I found out very quickly. I really thought I was retiring to Maine.

Dr. Erin Flynn: And now, 25 years later, he's finally retiring, but it's not because Maine doesn't need him.

Dr. Thomas Flynn: When they assessed my risk of committing suicide, they asked, "Do you feel worthless?" And I said, "No, I don't feel worthless at all." I know what I'm worth. I just can't do it anymore. I'm not going to commit suicide because of that.

Dr. Erin Flynn: At all of his neurological visits they are screening for suicide risk and they ask him, do you feel worthless? And my dad always answers, no, I know my worth.

Velazquez: When did you retire, if you have?

Dr. Thomas Flynn: Halloween '25.

Velazquez: What brought on the decision?

Dr. Thomas Flynn: Due to the tremor.

Velazquez: Is that what you noticed first? The hand tremor?

Dr. Thomas Flynn: And then I underwent a little neurosurgical procedure to deal with the tremor.

And I lost my voice and I lost my ability to walk. My tremor's pretty good, but otherwise I'm destroyed.

Dr. Erin Flynn: It all started with his tremor, and it's hard to be an eye doctor with a tremor because a lot of our medications are injected through needles into the eyes, or sometimes we do lasers. My dad first had this tremor that started and essentially it would-—Initially it was diagnosed as an essential tremor, which usually in and of itself isn't a big problem and doesn't progress.

But the tremor was getting worse and worse and it was impacting his ability to see patients and run his clinic. So, he got a procedure. He first went to Columbia Neurosurgery and got a procedure called a thalamus ablation. And it's where they use an ultrasound to ablate the thalamus. You got it on the left side corresponding to your right hand because that had the worst tremor.

Velazquez: What does ablate mean?

Dr. Erin Flynn: Ablate means destroy. Essentially, you're giving yourself kind of a localized stroke to try and stop the tremor. My dad got it initially in Spring 2024.

Dr. Thomas Flynn: Yeah.

Dr. Erin Flynn: It worked for six weeks and then the tremor came back. So, he got it done again, but the side effect of the thalamic ablation is it makes you very ataxic or makes your gait very unsteady. That also kind of muddied the waters in terms of his diagnosis or prognosis. And then the tremor came back.

So, my father made the decision to do something called deep brain stimulation, where they put a device in your brain—It's like indicated for Parkinson's tremor—that helps bilaterally reduce the tremor. And it's like you need to get it programmed. And then after that, he started to notice that he began to have difficulty with speaking and swallowing. His gait was already unsteady after the thalamic ablations. It became difficult for him to walk. And he started to have a lot of other symptoms that couldn't necessarily be explained by Parkinson's.

Velazquez: Were you trying to diagnose yourself?

Dr. Thomas Flynn: Yes. trying to ignore it, hope it would go away.

Dr. Erin Flynn: And I think that he really wanted to still be there for his patients and see his patients because that's a big part of his identity.

Dr. Thomas Flynn: I want Jesus to walk in and fix it.

Velazquez: I think it's common for patients to ignore it.

Dr. Thomas Flynn: I've been on the doctor side and the patient side, and the patient side sucks.

Velazquez: I ignored CMV for a long time. I was seeing those floaters months before I reported it because it was just too much. When did you get the actual diagnosis and what is your condition?

Dr. Thomas Flynn: April of 2024

Dr. Erin Flynn: I remember you were diagnosed with Parkinson's, but your actual diagnosis is still kind of muddy.

He was told it's probably not essential tremor and you probably have Parkinson's in April 2024. It was at Columbia and I was a fellow at the time at Columbia. I remember we showed up at the clinic together and I was stressed out because I had surgery that I had to be in. So, I was a little stressed out about the appointment. And I remember that they made him do all these tests and I was shocked at the things my father couldn't do because he'd gotten so good at hiding it from us.

And the neurosurgeon walked in and he said, "I think you know it's not an essential tremor, and I think you know what you have." And my dad said, "Yes, I think I know what I have." And they decided it's probably Parkinson's. But in the months that followed after that, it became very atypical for Parkinson's itself.

Dr. Thomas Flynn: Yeah, it takes neurologists two hours to see me. I'm so complicated. They just spent two hours You don't even know what I have.

Dr. Erin Flynn: He was complicated. He was a bad patient because he really wanted these procedures. So, he said he was fine with the Parkinson's diagnosis because that was the diagnosis that would get the procedures approved. (To dad) So, you were a bad patient. Dad, would you agree?

Velazquez: Was I a good patient or a bad patient?

Dr. Thomas Flynn: You were a good patient.

Velazquez: You can be honest.

Dr. Thomas Flynn: You just had healthful on your head. I mean, remember I had to write a note to say that you weren't faking it. Remember that?

Velazquez: Yes. You had to convince my ex-husband. Yeah, my ex-husband didn't believe it. — I, I don't know if I'm going to include this part because I don't want to tick that man off anymore—But yeah, he kept saying that I was faking it. I had to bring him into one of my appointments and Dr. Flynn kind of read him the riot act.

Dr. Thomas Flynn: How can you fake this? I mean, why would you fake it? Yeah, you know, what's the gain here, right?

Velazquez: Yeah, why would I fake it? Exactly. Then, you weren't really diagnosed, but what is the—

Dr. Thomas Flynn: It's confusing because Parkinson's is potentially a buffet of diseases. I have some of one called B, some they call C. The only way they're going to know for sure is when they scoop out my brain after I'm dead and section it (for a microscope).

Dr. Erin Flynn: He's got basically a buffet of the different diseases, the different neurological diseases. There's one that was kind of kicked around, which was multiple system atrophy, but my dad's a lot older than you'd expect from that. His blood pressure is low, and you'd expect a higher blood pressure. There's the one that his latest neurologist thinks he has, which is progressive supranuclear palsy (PSP), which is a death sentence. Which affects your eye muscles around your eyes and breathing, swallowing, walking.

Velazquez: How sure are they?

Dr. Thomas Flynn: They're not. They're not because I have some features of MSA (multiple system atrophy), some features of PSP, the features of corticobasal (degeneration), some features of Parkinson's. Some features of cerebellar atrophy. I have features of all these diseases.

Because neurosurgical treatments were done. Definitely. What could they come up with? Nothing near surgical treatments that I had done.

Dr. Erin Flynn: Yeah, it's tough too because he's already had those ablations, so that further muddies the water into terms of what is most contributing to the fact that he's having difficulty walking and is very unsteady because he had these ablations and that made him very unsteady as well.

Dr. Thomas Flynn: Was caused by the, uh, by the ultrasound.

Dr. Erin Flynn: Or it could be his disease. You're not quite sure. So, it keeps the neurologist from making an official diagnosis.

Dr. Thomas Flynn: In the course of the disease, your brain picks up misfolded proteins. Like Alzheimer's has misfolded protein called tau. This one has misfolded protein called alpha-synuclein. But PSP has tau. The only way they'll know for sure is after I die. We're very interested to find out.

Dr. Erin Flynn: He's talking about the fact that after he dies, he'll probably want a brain biopsy done to see if he also has the misfolded proteins, the tau.

Dr. Thomas Flynn: The tau destroys the circuits of the brain in Alzheimer's. It also destroys the brain in PSP, which is the disease I might have.

Velazquez: What's your prognosis, do you know?

Dr. Thomas Flynn: Zero.



Dr. Thomas Flynn with his wife and his son

Velazquez: But how long do you think? Will it be a couple of years?

Dr. Thomas Flynn: Yeah, the Meyer curve gives me about a year. I figured, you know, how long. It's already been about a year.

Dr. Erin Flynn: If it's PSP, or honestly any of the really difficult diagnoses, like we've been kicking around, like multiple system atrophy, the crappy part is that a lot of the times they're initially misdiagnosed as Parkinson's. And then you just see them advance much more quickly than you would Parkinson's.

One of my friends is a neurologist, and he always says time is the best diagnostic tool we have in neurology because time will show what your trajectory is.

Dr. Thomas Flynn: And so, I think, Robin Williams, is case in point.

Dr. Erin Flynn: Robin Williams, who had Lewy body dementia. It was initially diagnosed as Parkinson's. I think that just because it's progressing very quickly, that's why my dad thinks it's probably a year. But these diseases are tough because they're just initially misdiagnosed, and then you're not quite sure how long you've been on that trajectory.

Velazquez: Do you get all your healthcare in Connecticut because there's no—

Dr. Erin Flynn: No, actually, he travels. He was in Arizona this winter where my parents have a house because it's easy to get along there. And also, he's

got a great neurologist in Arizona, Dr. Janani at Banner Health. Then he's coming to Maine for the summer due to the climate. And I set him up with neurology here at Yale where I work.

Dr. Erin Flynn: (to dad) What are you smiling about? He's smiling. What?

Dr. Thomas Flynn: You ruined her morning.

Dr. Erin Flynn: Oh. Because I'm sure your new neurologist had to get quite the history on you.

Before our meeting, I checked her schedule system. My dad's appointment was at 10:00 a.m., and the chart said she was still seeing him after 12 o'clock And I was like, "Oh shoot."

Dr. Thomas Flynn: She spent a lot of time.

Dr. Erin Flynn: That's neurology. They should spend a lot of time with patients, whereas I'm retina. I'm just like in and out.

Velazquez: But how amazing it is that you're also an ophthalmologist and you can help your dad.

Dr. Erin Flynn: There are so many ophthalmologists in the family. I guess it's a family tradition. My grandfather was an ophthalmologist. My dad is an ophthalmologist. And my great-grandfather was an optometrist, who hated ophthalmologists.

Dr. Thomas Flynn: Until his kid became an ophthalmologist, then he just puffed his chest out so far.

Dr. Erin Flynn: He hated ophthalmologists until his first kid, my grandfather, became an ophthalmologist. Then he puffed his chest out really hard.

I'm really glad that I became an ophthalmologist because it gave my father and me like a single language to talk about. Like we've got the same world, and we have a similar sensibility. And I mean, it's a big part of your identity to be a doctor.

Dr. Thomas Flynn: The last year, I was deteriorating and I didn't know why, some of it. Erin stepped in and saved my practice. While she was a fellow, they let her head to Maine and take care of my patients. The injections she did.

Dr. Erin Flynn: Yeah, during my fellowship for a year because my dad couldn't do the injections anymore. He just needed a steady pair of hands. I stepped in and I would do the injections or lasers or the procedures he needed done so that he could keep that part of his practice alive. And then he just saw uveitis patients who didn't require procedures.

Velazquez: And how long did that last?

Dr. Erin Flynn: So that was my last like 6 months of fellowship. And I still go up there every two weekends to see his patients.

Dr. Thomas Flynn: They love it.

Dr. Erin Flynn: I think they do love it because they get to kind of still see him in a way, even though he's not still there. And we've got a similar sense of humor, I'd say.

Dr. Thomas Flynn: You've been embraced as being from Maine.

Dr. Erin Flynn: Yeah, I'm from Maine, which, you know, they like that.

Velazquez: Do you live in Maine too?

Dr. Erin Flynn: No, I'm here because I'm 80% at Yale. But when I go to Maine, I'll stay at my younger brother's apartment in Bangor, Maine. I'll have like maybe one or two clinic days every two weeks, just to kind of see his patients. It also gives me a connection with him because I get to hear the stories of when they first met my father and how they initially fought about the meds he was starting them on. I think their stories are similar. They're like, "At first, we argued and I hated him. And I hated his sense of humor. And now he's my favorite doctor and he's the only doctor I want to see."

Velazquez: People hated him? I can't imagine that.

Dr. Erin Flynn: He's shrugging right now.

Velazquez: You're the funniest guy. The comments you made. When I'd go see him up at Columbia, I knew that if my appointment was for 10, I wouldn't get in to see him until maybe noon or 1. I had to be put in the queue and wait my turn. I would just dedicate the day to seeing Dr. Flynn. He'd come out every once in a while, to get his patients, and the way he did it was so hilarious. You made big announcement. You had such a big personality. All the nurses were always laughing. I knew that the minute I walked in, there'd be some quip and you were hysterical. I can't imagine anyone not liking you.

Dr. Thomas Flynn: I lay it on the line. You're going to go blind. Fungus in their eye? I smile and I say, "Listen, I'm a New York doctor, I know how you get this fungus in your eye. Cut the shit. When did you inject heroin last?"

Dr. Erin Flynn: I guess that's a reference to your no bullshit.

Velazquez: Oh yes, I could see that. You are a straight shooter.

Dr. Erin Flynn: Yes. He doesn't dance around when he wants to say something to a patient.

Velazquez: But you know, the honesty is what I appreci-



ated because I always wanted to know. I had a bunch of great doctors, but the ones who were trying to save me from the knowledge of what I was going through, I felt weren't— I know my style. I want to face things and I want to know. I vibed with you entirely. And I trusted you because you were so honest.

Dr. Thomas Flynn: Yesterday, the doctor you sent me to said, "Frankly, you know too much. But on the plus side, I feel like I can talk to you."

Dr. Erin Flynn: My dad definitely knows too much. Dad, I'm sure you had opinions about how she should manage things or diagnose you.

Velazquez: Your style was similar to Dr. House, a warm one because you were so kind and caring. But you were like a House with your quips and your snarkiness and your directness. Now, you're really Dr. House diagnosing yourself. See, that's what House would do, right?

Dr. Erin Flynn: It's definitely what Dr. House would do.

Velazquez: It's been an incredible honor to have been your patient.

Dr. Thomas Flynn: I still remember the day we had to fight to get seats in the clinic for you. I still remember the day we had to fight to get chairs for people with HIV in the waiting room.

Velazquez: In New York City?

Dr. Thomas Flynn: Yeah.

Dr. Erin Flynn: I don't know if Dr. House would fight to get his patients seats.

Velazquez: Dr. Cox from Scrubs would. You're also Dr. Cox a little, you know.

Dr. Erin Flynn: I don't think my dad's seen Scrubs. I want him to, but he hasn't.

Velazquez: Oh, you would love it.

Dr. Erin Flynn: That's one doctor show my dad hasn't watched. Also, watching doctor shows with him sucks because he'd always get the diagnosis right. Like, when we watch House with him, he'd be like, "This guy is a moron, obviously it's like

syphilis." Or this guy, "Jesus Christ, it's like lupus. Like, what is going on?" We always hated watching Dr. House with my dad because he'd be like, "What a moron, obviously it's cysticercosis of the brain. Come on!"

And he'd be like, "fuck this shit." And we'd be like, "Dad, shut up, we've got 45 minutes to go." He'd be like, "Obviously she's sleeping with a prostitute. Come on." I'd be like, "Dad. That was a plot twist that was supposed to come about in like 25 minutes, okay?"

Dr. Thomas Flynn: I will also be an enemy for life. This is a Yanuzzi story. I was late for grand rounds after I had many hours in the emergency room dealing with a patient. I walk in and Dr. Yanuzzi says, "Oh, Dr. Flynn, so nice for you to show up to grand rounds." —And I'm trying to be quiet and sit down. —He says, "What do you think it is?" I said, "Look, it's amyloid." And sit down. Turned out it was amyloid, and the poor student was presenting, it was only 5 minutes into his presentation.

Dr. Erin Flynn: We have this retina society, it's called Yannuzzi Rounds, and the point of Yannuzzi Rounds is to like have cases that stump all of us and make us all look really stupid.

The point of Yannuzzi rounds is to almost be like an episode of Dr. House, right? This poor guy who had spent hours putting together these slides and was so proud of his case and had all these twists and turns in the story. And this poor kid who was probably a fellow or a resident who had like not slept the night before, who was stressed out about this presentation, suddenly got shut down. But that is my dad. He's very quick and smart.

Dr. Thomas Flynn: And Dr. Yannuzzi asked, "Why did you think that?" I said, "Obviously." (rolling his eyes)

Dr. Erin Flynn: Like it was the most obvious diagnosis in the world. I can attest as an ophthalmologist or a dumb retina specialist, that is not an easy diagnosis. And if I was asked the same question, I would probably stumble around and say something dumb.

Velazquez: When I was your patient and my eye trouble became more than just retinal problems, you sent me to a couple of different people. You sent me to Dr. Odrich for my optic nerve, and then you sent me to Dr. Sperber for my cornea, and I also saw Dr. Shrier, I later found out that you guys all went to school together? All my doctors were in med school together?

Dr. Thomas Flynn: They all were. I wasn't. I was brought to D.C. But there's something called a resident instructor program.

Dr. Erin Flynn: They all knew each other from Manhattan Eye and Ear residency program. And then I think that Shrier, Barile, Odrich, Bill Schiff, all went to medical school together. But my dad was a little bit of an outsider. He didn't go to medical school with them, but he trained with them.

Velazquez: You were an outsider? I feel like you were the nucleus.

Dr. Thomas Flynn: Well, I was the instructor. I was head of the group; I became director of residency.

Velazquez: Were they residents when you were director?

Dr. Thomas Flynn: See, what happens is Manhattan NYU selects elite people--doctors who've just finished fellowship--and makes them resident instructors. I'm the graduate from the fellowship. It's an honor, prestigious. I switched to the residency because I'm only a year older than you, but I know how to basically stop bleeding patients. I'm here to help.

Dr. Erin Flynn: So, I guess my dad, Shrier, I'm not sure about Odrich, but they became the resident directors, after their residency. Because they did a great job, they were asked to be supervisors to the residents. So, even though they had just been in the shoes of those residents, they now had the responsibility to oversee these residents.

Dr. Erin Flynn: It's kind of like me at Yale. I'm fresh out of fellowship, so I'm like a little baby, and I'm now watching and supervising others.

Valesquez: You are the supervisor?

Dr. Erin Flynn: I teach surgery and I supervise residents and fellows in clinic, but it is a little bit crazy. When you're like, "I was just in your shoes" and you're telling them this is how you do it, like you've been doing it for millions of years.

Velazquez: But it feels like it's a cadre of just remarkable people. Wonderful people. I mean, Dr. Odrich is the sweetest man and kind and gentle and caring, and so is Dr. Sperber. And Dr. Schiff is just very soft-spoken and knowledgeable. It was huge luck for me to land with you guys.

Dr. Thomas Flynn: The disease that I have has robbed me of a lot, but it won't take the people away.

Dr. Erin Flynn: They won't take that special place for him because you're right. All those people are just salt of the earth people. Just so smart, fantastic doctors, but also so humble and just really good people.

Velazquez: And you're friends for life, and what an incredible group to have as friends for life.

Dr. Thomas Flynn: Yeah, they are. Because we understand each other.



Dr. Thomas Flynn with Gina

Dr. Erin Flynn: They went through a lot of these things together.

Dr. Thomas Flynn: Yeah. Including AIDS.

Dr. Erin Flynn: When my dad asked them to do all the things possible just to save the vision. And they asked him, "Why are we doing this, Tom?" And he said, "Because we gotta save the vision." And they roll their eyes and say, well, you trained me, or we trained together. So, let's do it.

Velazquez: Yeah, wow. So, um, do you have any final thoughts, anything you want to share that we didn't cover that you want to want people to know?

Dr. Thomas Flynn: Well, the field has sort of devolved to almost nothing. For a while, it seemed that I might become the chairman of the department or something. But then the disease kind of went away. And I was never so pleased in my life to see my opportunity to leave. I couldn't stand the way it was in the '80s again. I couldn't stand how grim things were. This is a disease we've managed to do away with.

Hopefully, nobody gets CMV right now. In fact, one of the things I was doing at Columbia was— I was kept in the freezer —When somebody saw a peculiar-looking eye, they'd bring (me in). "Let's get Flynn. He remembers what it was like." When they're seeing me right now, they see some old guy. So, this is a disease that we've largely cured.

Dr. Erin Flynn: Yeah, I think something that I remember my dad would mention to me when I was a kid was he kind of poured his life and his passion into the manifestation of AIDS in the eye. And he really sweat a lot of blood and tears into it. And it was a huge thing he contributed to, both in his personal life and in his academic life. And now it's pretty much been cured. It's gone. So, in a way, I think he would express this feeling like, damn, like I poured myself into this cause and now it's all gone. And he's so grateful that it's gone. Thank God.

But, but for him, it's like, that was like everything to him. And the big irony, though, is that because he threw himself into it and now that it's all gone. It's like a big part of his work, right, you know, is almost for naught in a way. But he's still so grateful that it's for nothing, but a large part of it does feel like "poof," it's gone.

Velazquez: What an incredible time to be practicing, huh?

Dr. Erin Flynn: If we compare him to Grant, my grandfather, contributed to Retinopathy of Prematurity (ROP), and his work is still very much used every day. There's even a depressor, a scleral depressor for babies, which is called the Flynn depressor.

Velazquez: The Flynn depressor?

Dr. Erin Flynn: Yeah, But my dad, his legacy is not something we use every day because, you know, the CMV retinitis and the AIDS has been almost eradicated, which is great, but it's also like, damn, Grandpa gets more of a sustainable heritage. My father's grateful that his heritage is mostly unnecessary right now. It's almost dead, and that makes him happy in a way.

Velazquez: Also, your legacy is your patients. Your legacy is your children. Because of you and the work you did, I'm here and my son is here. We all looped in together for this, and that's because of you.

Dr. Thomas Flynn: Yeah, I wouldn't go back to the same stuff.

Dr. Erin Flynn: Well, thank you for everything. Thank you, Gina.

Velazquez: Thank you, Erin. Thank you, Dr. Flynn. Thank you, everybody here. It's, it's been incredible.

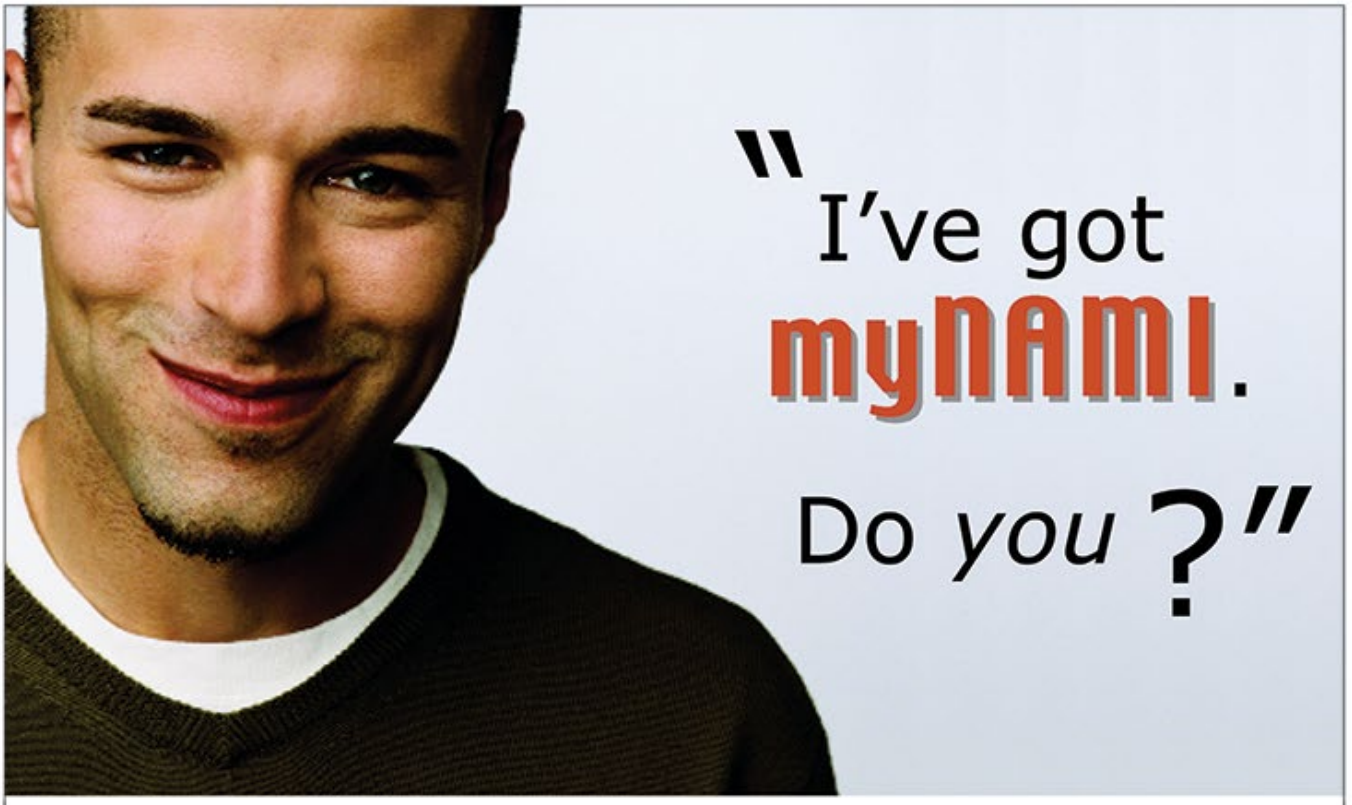
Dr. Thomas Flynn: (To Aiden) It's a good thing your mother didn't listen to me.

Velazquez: Yeah, because we wouldn't have an audio engineer. What would we do? We can pull the table and just figure out, was it a good decision or not?

Dr. Erin Flynn: oh, my dad is smiling. He's nodding. He's got this sassy look on his face like he had to think about it.

Velazquez: That was the face you gave me when you walked into my (hospital) room, and I'm there literally dying. And you said, "I'm here to see your eyes." ■ ABILITY

Dr. Thomas Flynn profile



NAMI

The Nation's Voice on Mental Illness

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TAL Anderson

THE PITT

AND DISABILITY REPRESENTATION

Actor, author and disability advocate Tal Anderson has built a career bringing authenticity and depth to neurodivergent characters on screen. Audiences may recognize her from *Atypical* and *As We See It*, while her latest role as Becca King in *The Pitt* has earned her an Emmy nomination as well as a DARCY nomination in the inaugural Easterseals Disability Arts & Culture Awards. Through Becca's story, the series explores independence, caregiving, relationships, sexuality and bodily autonomy—elements of disabled adulthood that have often been overlooked or simplified in film and television.

Anderson's commitment to representation extends beyond acting. Alongside illustrator and fellow autistic creative, Michael Richey White, whom she met while working on *Atypical*, she created the children's books *Oh, Tal! Not Today* and *Oh, Tal! Not Like That*. Her books draw from shared experiences to help children, who feel different, see themselves reflected in stories. Having begun acting in local children's theater, Anderson has also witnessed the entertainment industry's gradual shift toward authentic casting and greater opportunities for disabled performers, while recognizing how many aspects of disabled and neurodivergent life remain largely absent from mainstream storytelling.

ABILITY Magazine's Gina Velasquez and Jennifer Woodall spoke with Anderson about developing her characters, the complicated relationship between independence and caregiving in *The Pitt*, dating, bodily autonomy, writing for autistic children, and the evolving state of authentic disability representation in Hollywood.



Jennifer Woodall: You were recently nominated for a DARCY for your role as Becca King in *The Pitt*. Before that, your breakthrough roles were characters in *As We See It* and *Atypical*. Can you talk about your approach for developing those characters?

Tal Anderson: Sure. Regardless of what the role is, I've been taught to analyze the scene and the script before I even start to figure out who the character is and to try to make choices for them. Ultimately, the character exists how they're written, but the writer doesn't always give you everything about the character. Especially when it's a small, minor role like my role in *As We See It* and, initially, in *Atypical*. I've learned that every character has a backstory, even if you're not given one.

I try to look at the stakes for the character to understand where they're coming from and also take into account whatever comes next in their day. For example, for *Atypical*, (my character) Sid was written specifically as a character who was there to help Sam. In season 3, where she was introduced, she was just this girl working in the accessibility lounge, so I had to fill in her backstory. I could develop some perspective and get a feel for who Sid was as a person and not just in the scene. Sid is strong-willed and smart and a little bit sassy.

When introduced in season 3, Sid was just starting college and was meeting Sam for the first time, and she was sort of smitten with him. But, by the time Sid got to season 4 and her next year in college, she had things a lot more figured out, and she developed a friendship with Sam and had goals set. Hopefully, all the character work I did helped to get her personality across. I also needed to find a place where Sid and I could share experiences, so that way I could play that authentically. Because I had recently graduated from college myself and was familiar with the disability accommodations that were offered, that was our common ground.

For Gia in *As We See It*, my character didn't get the chance to develop past the initial introduction before the show was canceled. My main scene was with Rick Glassman, and the two characters were performing a scene from *Notting Hill* for an acting class. Within the script, there was an action line that said something like, "she performed the scene surprisingly and shockingly well." This was meant as a contrast to Rick's character being completely disinterested in playing his part in the scene, but for me and Gia, it was amazing because we were able to put our heart and soul into that scene despite his disinterest. In that way, Gia and I share a bond. She took her role in that performance very seriously and performed her best regardless of what was happening around her. I guess our common ground was acting in the situation.

Woodall: I really enjoyed *As We See It*. I was sad to see it get canceled. We actually got to chat with Sue Ann Pien as well, so it's really cool to get to talk to you also.

Anderson: Yeah, Sue Ann is amazing. I love Sue Ann.

Woodall: I appreciated how your most recent show *The Pitt* handled your character Becca's personal relationship with her sister and caregiver Mel. Can you talk about the struggles that can come with gaining independence for both the caregiver and care recipient? Do you feel like that mirrors your own experiences in life?

Anderson: As for the independence storyline this season, it doesn't totally mirror my experience, but I can relate to it. Throughout my life, people have been more protective of me, and they still are. I think they probably worry more about my safety, for instance, or they worry about me being taken advantage of. And I imagine it must be hard for my family to always be worried that something terrible is going to happen to me. Like Becca, I have a great support system, and my parents are still very much involved in my life and provide a lot of support to me.

You know, Becca and I are definitely not the same person. I live independently and I drive and I work. Even though our level of support needs is different, we both still need support from a lot of places and people to func-



Tal backstage of HBO Max's *The Pitt* in front of her trailer.

tion and to be as successful as possible. I think the difference between Becca and myself is that Becca lost her parents, so Mel is all she has. She's in a position where she's lost so much, and in a way, she's also lost her sister because her sister felt forced to become her caregiver. So, my life isn't as tragic as Becca's.

Woodall: I thought the show's inclusion of the topic of sex and dating within the neurodivergent community was super refreshing. Can you speak on that a little bit?

Anderson: Sure. This concept of bodily autonomy is such a giant struggle for all disabled people, and it's something the community has been battling forever. You know, it goes hand in hand with the infantilization, that adults with disabilities fight every day, even from strangers. So, being able to shine a light on that issue through Becca's storyline has been pretty amazing. I agree it's definitely refreshing to see stories like this that so many people can relate to and see themselves in. *The Pitt* is very good at doing that for all sorts of marginalized communities.

Woodall: Are there life topics within the neurodivergent community that you wish you saw portrayed in film and television more often?

Anderson: Yes. There are so many things that don't get shown for whatever reason. Things like the high unemployment rate within the disabled community and the current situation with healthcare and Medicaid cuts for people with disabilities. There's also topics that non-disabled people probably don't even know about, like the fact that if you're disabled and getting government disability benefits, you're not allowed to have money in savings or to be married without losing those benefits. There are major issues that are disrupting the livelihood of disabled people every day.

Beyond that, approaching the concept of neurodivergent people having to mask every day to hide their disabilities so their behaviors are like more acceptable to non-disabled people. Or even the fact that most neurodivergent people are living with multiple overlapping disabilities and are managing so many things externally and internally on a daily basis. The list of the realities of living an authentic disabled life is endless. I personally think that all of those stories are valid and important to see on screen, not just for validation to the people who have that lived experience, but also to educate everyone who doesn't.

Gina Velasquez: You're also a children's author, and you wrote *Oh, Tal! Not Today* and *Oh, Tal! Not Like That*. What inspired you to write these books, and what is the message for children living with autism?

Anderson: Well, Michael Richey White, the illustrator,



Tal backstage of HBO Max's *The Pitt* with co-star Fiona Dourif



Tal in in a Florida Rep Youth production of Stephen Schwartz's musical, *Captain Louie* (Fort Myers, FL)



Tal backstage of HBO Max's "The Pitt" with co-star Noah Wyle

and I met while working on a set of *Atypical*. Michael is the award-winning Hollywood production artist responsible for all of the artwork for the main character, Sam, in the series. We bonded over both being autistic, but also over having so many shared lived experiences. So, we talked about that and we decided to create a series of books to start a conversation with younger children who feel the way we both did as kids to help them feel okay about being different and encourage them to be themselves. There just aren't enough books out there for young kids who live with differences to relate to so they can feel seen and encouraged to be creative and to feel good about themselves.

Velasquez: Are you going to write another one?

Anderson: I just recently released *Oh, Tal! Not Like That*, but the third book is coming soon. We also have another book unrelated to that series, that we finished, and it's being edited right now about a careless clown. The drawings are beautiful!

Woodall: So, you started as a child actor in Local Children's Theater. What were the attitudes you encountered surrounding actors with disabilities when you started, and was there any pushback regarding authentic casting?

Anderson: When I started, I don't think I was aware of any discrimination, but I think there probably actually was. I think it was more like there were no roles for disabled characters, so I didn't get many auditions. But now, I actually get auditions for disabled and non-disabled characters. I think that looking back, there is definitely a difference between the general understanding of disability and the openness of viewers to watch disabled stories. That is improvement, you know. I just think I was young and new and wasn't aware of the discrimination.

Velasquez: In your opinion, what is the current state of authentic casting in the entertainment industry?

Anderson: You know, I think we're making strides towards improving representation, but I also think it's a very slow process in that it'll take more time to see real change. We're still working on achieving equity on screen for all marginalized communities in general, even for gender and race. I think, or at least hope, that we'll get there eventually.

One area where I think representation is greatly lacking is the intersection between the LGBTQ and autistic neurodivergent communities. It's really not a story that has been told on screen that often and leaving out that representation is leaving out a very large part of our community identity. There are definitely positive things happening, and I think what *The Pitt* has done throughout the last two seasons for all disability representation has moved the needle. The show is very popular, and that proves that people want to see stories told authentically. ■ ABILITY

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DARCYS

The Next Evolution of Media Access Awards

After more than four decades of advancing disability representation in Hollywood, the historic Media Access Awards—co-founded in 1979 by veteran TV producer Fern Field and legendary producer Norman Lear—have officially rebranded as **The Easterseals Disability Arts & Culture Awards (The DARCYS)**.

Co-produced by Easterseals Disability Services and Film Independent, the reimagined awards program marks a major expansion in scale, visibility and global reach. Designed to celebrate storytelling that reshapes narratives and eliminates stereotypes, the DARCYS honor authentic inclusion across film, television and digital media.

Guidance for the revamped initiative is led by a Disability Advisory Committee co-chaired by advocates Emily Ladau and Nicole Lynn Evans, alongside a lineup of prominent disabled industry leaders.

"Inclusion must be a movement, not a moment," said Ladau and Evans in a joint statement. "The inaugural DARCYS will be a joyful celebration of the disability community's contributions to the media landscape and a bold call to action for a true disability representation revolution."

To ensure authentic inclusion behind the scenes, a majority of the nomination committee members are individuals with disabilities. Furthermore, submissions require substantive, sustained disability involvement, with accessibility features like captioning and audio descriptions integrated directly into the review process.

"The Easterseals Disability Arts & Culture Awards are about more than recognition—they're about redefining what inclusion looks like in entertainment," said Mark Whitley, President & CEO of Easterseals Southern California. "By celebrating and honoring authentic voices and experiences, we're helping set a new industry standard where disability representation is not the exception but an essential part of great storytelling."



Actor, comedian, activist, author and speaker Geri Jewell



Stand-up comedian, speaker, writer and disability advocate Tina Friml

Shawn Davis, Executive Producer of the Film Independent Spirit Awards and the DARCYS, echoed the vision for systemic industry change:

"For over four decades, Film Independent has championed a culture of inclusion in storytelling. Partnering with Easterseals Disability Services... is a natural reflection of this mission—amplifying authentic representation and ensuring that diverse voices shape the narratives of not only our industry but the world, too."

Comedian and disability advocate Tina Friml headlines the event as its first host. The first-ever DARCYS Legacy Award honors trailblazing actor and activist Geri Jewell, recognizing her career work transforming the cultural landscape for people with disabilities. The celebration brings together leaders from across entertainment, media and advocacy, reaching global audiences via live broadcasts on YouTube and PBS SoCal, along with national rebroadcasts on local PBS stations.

Competitive categories for the awards include Best Feature, Best Documentary, Best Performance in a Feature, Best Scripted Series, Best Unscripted Series, Best Performer in a Series, Best Social Creator, Achievement in Casting Ensemble and the Christopher Reeve Emerging Talent Award. ■ ABILITY

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Aliya Rahman

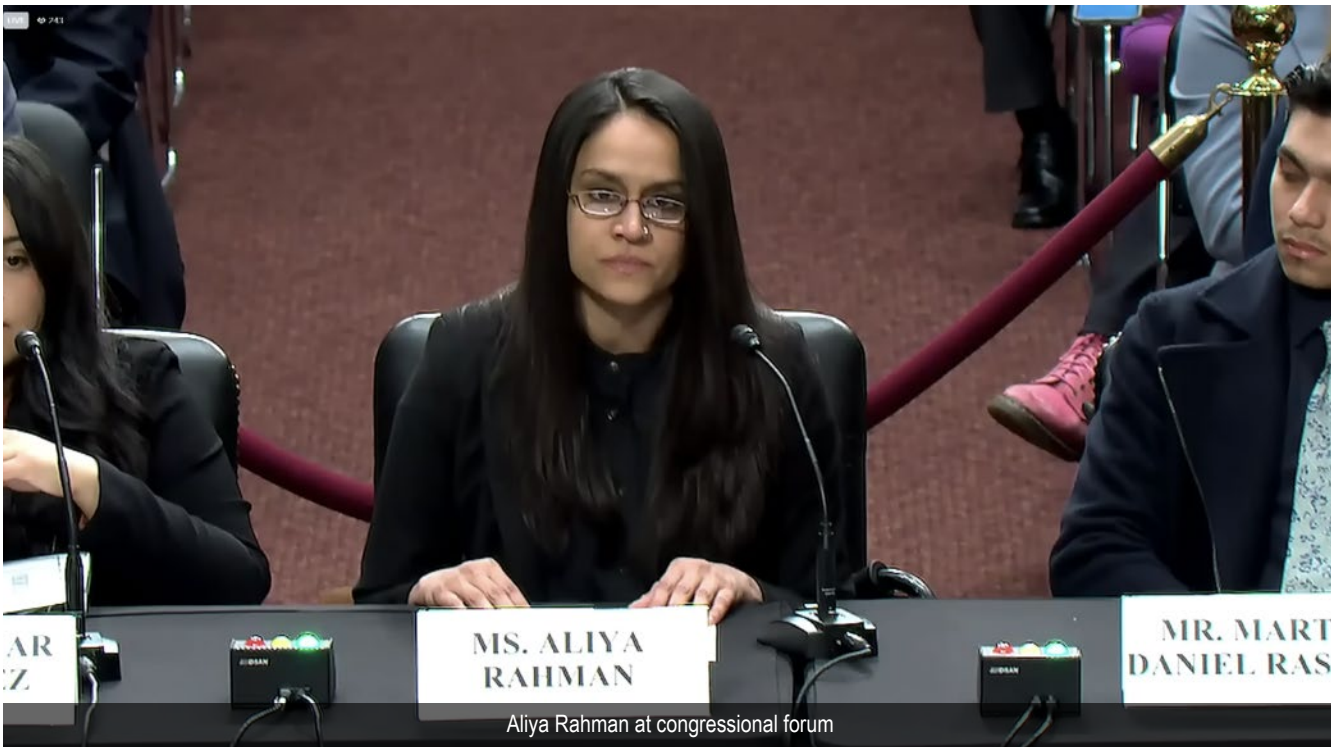
CRASH AT THE INTERSECTION OF DISABILITY AND AUTHORITY

Aliya Rahman, a software security engineer and former engineering manager, experienced a life-altering traumatic brain injury (TBI) in August 2024. Long navigating the tech industry as an autistic, queer, woman of color, she brought a unique perspective and a strong keen awareness of structural patterns to her work. While on the challenging road to recovery, Rahman found herself at the center of national attention after a viral video captured ICE agents stopping her and forcibly removing her from her vehicle while she was en route to a therapy appointment. The high-profile encounter marked the beginning of an ordeal that thrust Rahman into public advocacy while raising immediate concerns for her personal safety.

In a candid conversation via Zoom with *ABILITY Magazine's* Jennifer Woodall, Rahman reflects on the trauma of having her disability disregarded during her encounter with law enforcement and her subsequent time at the Whipple Federal Building detention center. She also delves into her career as a software engineer, representation within technology and her identity as a neurodivergent individual. Throughout the interview, Rahman highlights the pervasive lack of accessibility accommodations and the steep personal costs of speaking out against systemic authority.

Jennifer Woodall: Can you give a bit of background on your traumatic brain injury?

Aliya Rahman: I sustained a traumatic brain injury in August of 2024. (My) brain took a while to recover the ability to speak, to walk, to do other things that came with that brain injury, like to open my jaw and chew. A lot of other things came along with that. The brain-specific part was classified as a medium to mild traumatic brain injury.



Aliya Rahman at congressional forum

Rahman: And I'll say for those who may not know much about TBIs, if you have a severe TBI, you are not on this Zoom call talking right now, generally speaking. That's where the classification is. So, saying that somebody has a mild or moderate TBI does not mean that they aren't seriously impacted in life. Folks who have support needs that are real, and they're able to do some things for themselves.

So, in my case, I eventually got to the place where I could drive again. I encounter balance issues related to my vision and the occipital nerve. And that is why I walk with a cane. It is not for my legs; it is not for something musculoskeletal. It is because of my brain and balance issues. I have vision that's been impacted in terms of close-up vision and the ability to track lines of text or unfortunately look at a computer screen for more than a couple of hours a day. Even that usually requires breaks.

After this interview, I will go and close my eyes for a long time before the next conversation I need to have with folks. So, to treat that brain injury, I am in a great city for that because Hennepin County has a traumatic brain injury center where they do something that you should do for anyone who has a brain injury, which is they coordinate a lot of your data for you. You don't have to do what I was doing when I still lived in Iowa—the injury happened in Illinois, but I lived in Iowa—And I really encountered a lot of challenges of access to care because of defunding that's happened there and just other policy changes around how life is for you as a nurse, a doctor or a medical student.

So, here, I go to cognitive therapy. I go to occupational therapy. I go to physical therapy. I go to a neuro-optometrist. I see an ophthalmologist. I've seen a neurologist. I have had many MRIs or CT scans or other forms of measurement of my brain and neck. As we all know, the brain is not just up here. It extends all the way through our body, actually, if you think about it that way.

All of that stuff is absolutely like a part-time job. I go to that traumatic brain injury center at least once a week, sometimes 3 or 4 appointments a week because I am trying to get back to work. It may happen. It may not, but I have a lot of awesome support. And helping me think about how my new brain functions. That is where I was going the day that I was detained by ICE. And it really speaks to some conversations that have happened here locally about what was the extent to which people impacted by ICE, like financially, was their own fault for deciding to stay home. Look what happened to me when I didn't, all in the interest of trying to get back to work.

And so for a person with a TBI—I won't speak for everyone—But for myself, part of what comes with that is having to add a new variable to the calculation I make every time I step out of my door as a person of color, as a disabled person. When I know that we have unaccountable people in uniform with guns who are really showing inconsistent regard for people's bodies—lives, warrants—Whether there's any kind of crime being committed that's actually in their jurisdiction and where there's been no accountability for their actions.

Yesterday, we decided to file a lawsuit against them for the deaths of only a couple of people in the case that's happening there. But otherwise, this is part of disability for me, living in an occupied city.

Woodall: What did you do for work before your brain injury?

Rahman: I am a software Security engineer. The last job that I had was working as a software engineering manager. (Pauses) Sorry, I get pretty intense eye socket pain from the brain injury.

So, I was a software engineering manager at a place where we were still transitioning back from what it was like to staff during COVID. As we were stabilizing our software team, I had meetings all day to support other engineers. And sometimes I wrote code. And sometimes I did what is called DevOps, where you're actually working on the cloud infrastructure that code runs on. I'd have to log into a server sometimes and fix like, "Oops, we're using the wrong encryption algorithm." and stuff like that. So that was my most recent job with private sector company that essentially managed all the tech stuff, software, apps, websites and data for the parent real estate company of a lot of the real estate brands that people know, like Coldwell Banker and so on. Before that, I worked for startups in the private sector. I wrote the encryption daemons, which I think is such a cool thing. And there's no actual little daemon. It just means a software background process that it's the thing that tells you you've got email. Or that puts up a notification.

I wrote that for an encrypted file sharing and email company, kind of competitor to like Proton Mail. It was a combination of writing code, checking other people's code, making sure we're up to security standards. And then, in my spare time, I had conversations with community members who were worried about their own digital safety. Either they felt they were being surveilled or just wanted to know "How do I talk to my family members who aren't on the internet as much as me?" About what we should and shouldn't text. Or like, "What are the correct settings for privacy when I'm using Gmail?" Then the occasional phone call that would be like, "My husband doesn't agree with me about what we need to do with the cable box, so I need you to break this tie." That was my life.

Woodall: Being a woman of color and a member of the disability community, did you have any issues within the tech industry related to that?

Rahman: I think that that defines my entire career. And pretty much every move I ever made out of a tech company was related to something around not being able to get a team to act on racial discrimination, sexual harassment. And the disability piece is interesting because you know, I didn't have a TBI until August of 2024, and I haven't worked as a software engineer since then, but I've been autistic all my life. And I have had employees with disabilities. As a manager, employees are coworkers.

As a manager or coworker who had some understanding of racial justice, disability justice, it's very important to me that that's part of my everyday work. And even if you don't care about anything but profit, that's something you should want in your employees. And, yet, it is a real challenge to get to happen. My experience working on



Aliya makes machines and needs to solder circuit boards to do that. The eyewear with light makes small pieces possible to work with.

tech teams in the private sector is that I was very often, especially at the senior engineer level, the only woman working as an engineer. I would say that, so I am a woman of color. I'm not Black, I'm not Latina and I'm not indigenous.

South Asians and Asians, I do encounter those folks in the private sector. In startups, no. In startups, I was often the only person of color, the only woman, the only out queer person, the only person talking about my disability. I think it's really important to talk. When we talk about race in tech, we have to talk about anti-Blackness, not just racism. And there were no senior Black engineers that I ever worked with closely, except for maybe once a year, crossing of paths at interdepartmental meetings, like at my last job for sure. And the last couple of startups, none. I think it's a real issue.

And so how that shows up for me is trying to make sure that people are titled and paid correctly, and that we don't disproportionately not title and not pay people correctly when they are Black folks, when they are Indigenous folks, when they are Latinx folks. And that was always a fight. So, I think that's probably the thing I would raise up. The other thing I would mention is that I saw, at one of the places I worked, what I would call predatory practices towards women that men believed were being sponsored by their company, like on a visa level. And I think they may have assumed that about me, but I'm not being sponsored.

Woodall: Sounds like a challenging workplace culture to navigate.

Rahman: Yeah, and I think we should—the conversation of the moment is about AI. Which is not new tech. It's not actually even a distinct technology. It is marketing. It's a brand. It's like a marketing phrase for some things we've had around for a long time. But with that, there's also this realness to who is doing that. Look at who the sort of tech gods that people are afraid of right now or who or they think our geniuses are? It's not people like me identity-wise.

These people are weighing in very heavily on public policy. And we even have one who is neurodivergent and is not showing up for the autistic community in any way around that. If anything, the opposite. I think the last thing I would say about tech is that you actually have a lot of people who don't identify as disabled or don't identify as autistic or really have language around neurodiversity. But many of the techniques that we use to make sure they're successful are the things that I would do if someone said, "I'm autistic, I need the following thing in my workplace."

Woodall: Do you think they don't want to talk about it because of stigma?

Rahman: Look what happened to me when I was arrested, when I told them. And both times, both arrests, significant issues around how disability was handled there when someone actually identifies out loud. And this is an important conversation, absolutely.

Woodall: Autism is different for everyone. How does your autism impact the way you process things that are happening around you?

Rahman: Yeah, absolutely. I'm so happy that you asked the question in this way because through what's happened over the last two months—When you watch public discourse about what happened to me, it's very clear that our public either lacks understanding of what autism looks like or they are only able to think about that through the lens of one or two examples that they have seen. I actually think it's important for me, too, to not make that problem of understanding worse because I'm verbal. And this is a conversation in the autism community—who we are and what we need—is taken up by people who are verbal. That's one way that it shows up for me is in my speech. So, I would say that from the time I started speaking when I was little, I went through periods of essentially being mute, probably more related to trauma and autism than anything else. I have challenges, sometimes, staying on the highway instead of the side road when I'm having a conversation. I don't always find that to be a challenge, but it is for teachers in schools.

When I was in kindergarten, there was this moment where my teachers and parents sort of didn't know what to do with me because I was very bored in class. I would complete worksheets quickly and then start doing whatever I was interested in. Because of my identities, because of how my school had absolutely no idea that



Nakshi kantha, a Bengali quilting style done on old and often personally significant clothing. Aliya practiced this technique until pausing due to her TBI's impacts on motor and visual function.

maybe they should think about neurodiversity—This was in the mid-'80s.—They said, "Let's just have her skip a grade. Let's do that." No attention to social skills.

To what you're asking about, which is how I was actually processing my world. They were sort of like, "Let's try to keep her busier and intellectually challenged." And that is a marker of privilege right there because other kids would have been tracked into like the bad kid track and that was also a part of my life. I don't think that I was necessarily seen as not having discipline issues. I think that because I had an aptitude for math specifically, they were like, put her in a different grade.

I think my kindergarten teacher was like, "Well, she's not in my classroom anymore." I was mercilessly bullied in school. Anybody who knows me and knew me as a child can tell you they had various words for me, like awkward, ugly, never gonna get married, doesn't fit in. And those things were huge challenges. I don't think until I left my home environment did I have the ability to choose a home environment or a path that actually worked for my mind.

I struggled with mental health through my entire life until I was probably—well, there's no until. Life is hard right now. but I don't deal with depression symptoms all the time. I don't deal with suicidality. I don't deal with a number of things that I think would be part of my life if I hadn't had access to like language around neurodiversity.

So, you ask me how my brain functions, and how my brain attaches to patterns. You know what I did for fun last night? I read news articles about all of the people

in Minneapolis who are concerned about the increase in drone traffic in their neighborhoods. And city council has figured out that they don't belong to the cops; they don't belong to a Minnesota entity. People are really worried about the level of surveillance that up ticked here when we were occupied (by ICE). Last night, I was writing code—I can do this in like 10 minutes at a time and then have to stop after three iterations—How to get data on where the surveillance cameras are that belong to Flock Safety, the license plate readers that the ICE agents have. And then also, when you register the signal from a drone in the air using a radio, how do you parse that into intelligible signal and actually get the radio ID? Because I want to know. Whoever's drones those are, what is the radio ID that they are putting out? They're supposed to put out. Or are they not compliant? That's how my brain works. You know, I love math. So, I'm a stereotype in a lot of ways. I don't really try to raise that up a lot, but, to me, math is not about numbers, it's about patterns.



Footage from ICE arrest Video by Amanda Moore

I also think that is why people are constantly asking me, "Are you an agitator? Are you an activist?" I am a person who doesn't run from truth when I see a pattern about something that is wrong. I'm an engineer, guys. And if something is happening around me, I'm like, "This is not correct" This is not what I'm seeing with my eyes and ears. I have a very hard time believing the lie. I think a lot of people are not consciously believing a lie. Who does that? But, instead, are responding to social pressure that is a bigger factor for them than like, "uh-uh-uh, incorrect." And so, rhetoric around what's happening in our country right now works. I don't get those kinds of social rewards from responding to that rhetoric.

I'll say that about my brain, too. I live alone. It helps me manage my environment. And even when I was a little kid, my mom said it was really hard to get me to eat if my brain was busy doing something else. So, right now, my brain is busy doing something else. And there's a lot of data and patterns around me. Around what is happening to us. And I feel that one of the better ways to use the privilege of a case that actually got covered is to try and make sense of those patterns and tell people about it.

Woodall: I have OCD, not autism, but I relate to what you're describing, getting stuck in pits of thought loops. Does your autism work that way for you?

Rahman: It definitely does, particularly around verbal audio information. I experience the world through my ears and through touch in a really serious way. I think maybe, to a greater extent, I think a lot of people are very sight data oriented. If I hear verbal information, my brain perseverates on it. I mean, this was a large component to what happened when I was arrested by ICE. Swimming pools of loud, contradictory verbal information. And I think now the best video evidence of that is actually the video that Zoe Lofgren played in Kristi Noem's hearing, where you get a view that I actually hadn't seen this video before or heard it, more importantly, where you actually can hear what I heard—when an agent smashes the glass of the passenger side window. The other one was open. The other window was open because they said they were going to smash it, so I was like, let me take care of that for you and lower it. Smash that glass, and the agent standing next to him points down the street and says, "Get out of the car!" And then points again and says, "Go!" And that was like the 50th command I had been given.

People who know me will know that if we're having a conversation and there is TV or music on in the back that has lyrics, I can't track what they're talking about. And so, I am less impacted by just the loudness of sounds and more by what you're talking about, about pits of thought. That's my life, friends. That is my life. I have to really control my environment at home in order to be focused.

You see a whiteboard behind me. I have to organize my thoughts. I have to-do lists on my phone that literally look like pick up toothpaste, put toothpaste on toothbrush. And that is how I navigate a situation where new information might be introduced to my brain. That's how I have to get through my every day. I have worked really hard to develop those systems. And when I am trying to tell people I am getting data overwhelmed, I can't handle new data right now, when those people react with frustration and provide even more verbal data, it's not going to go well for anyone. And usually I'm not saying that— I mean, I'm never saying that with the intent to invalidate what they're saying. Not once did I say anything to those ICE agents that sounded like, "I hate your mom. I don't like you."

Everything I said, even in my most frustrating moments, was related to their instructions and how unclear they were. I just think this is such an important thing around what accommodations are. And I saw both the ICE agents and the Capitol Police in DC who arrested me during the State of the Union react very poorly to ask for accommodation. Laughter,







Footage from ICE arrest Video by Amanda Moore (FreedomNewsTV)

ridicule, anger, taking that as trying to make their job harder, potentially, in the case of the ICE agents, telling me they believed it was a lie.

The moment that I was pulled out of the car in Minneapolis, I said, "I am disabled." And they said, "Too late." And pulled me out of the car. And I just think that identifying our disabilities and what we need as accommodations—Until officers learn what that actually means on a deep level, we're trying to walk across a bridge half built. Because if I get this far and you then see the thing I did to make your job easier and compliant as a threat, look where we're at now.

I have been charged with nothing for both arrests. I have huge medical bills. I have a great cost to my life. My whole future plans have changed, and this has not gone well for the arresting agencies that did this.

Woodall: Can you take us through the day that ICE pulled you from your vehicle, that whole experience, if you're okay with that?

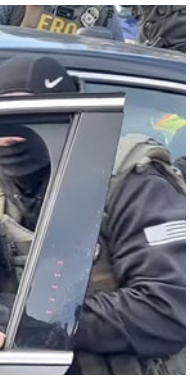
Rahman: Sure. Yeah. On the morning of January 13th, I did something very routine. One is a long-term routine; one is short. The longer-term routine is that I got in my car to go up, literally, one road. I take one turn from my house and then turn onto Park Avenue. That connects me to the parking lot of the clinic up the street. It was my 39th appointment at the Traumatic Brain Injury Center that I was going to. And along the way on Park Avenue, just south of 34th Street, there is a roadblock on Park Avenue. You'll see on the propaganda video released by DHS afterwards that they chose not to show the actual roadblock. They take a video of a different street to say that I'm a liar. That is a street that I was redirected onto because these ICE agents were really failing at managing this traffic jam that they had created. And to my understanding, I got there after these folks had removed the people from the houses that they had gone there to get. So, their job was over, I believe.

When I arrived there, it wasn't obvious what was happening when I first crossed into the 3400 block of Park, you kind of wonder, this is a multi-lane road that's a thoroughfare here in Minneapolis. And it's not uncommon that there would be traffic right before 10:00 AM. So that was my first thought. And then I slowed to a stop behind a couple other cars. Cars were stopped for a while because the side streets were blocked when I first got to that intersection. And you just saw this mess of people in the intersection. And you start to slowly see they're wearing big vests. Like, their bodies look shaped funny is the first thing you see. And then nobody is shaped funny, but they have an implement on them. And oh, it's like a military-style vest. And as you get a little closer, you can start to see the acronyms. So, I'm seeing ERO. I'm seeing ICE. I'm seeing HSI. This is the alphabet soup of militarized occupation that people in Minneapolis really encountered at that time and that people all around the country have encountered.

So, there are no signs. There is no clear, "this is what's happening, this is what you should do." the way that any road construction crew would do. ICE doesn't do that. It's a mess. And so other drivers are getting out of their car. They're whistling, they're honking, they're filming. I am kind of single-track minded right now trying to get to a doctor's appointment. And, you know, I am mostly trying to make sense of the situation. I start to text my doctor like, "Hey, something's going on. I might be pretty late." because I'm like, "Oh no, I'm going to miss the 15-minute, like you're too late and you have to reschedule mark," which is like a thing in my mind I'm always thinking about, trying to manage time. And then people start banging on my windows. People start—and by people, I mean ICE officers—yelling, "Move! I will break your fucking window!" And there's no like, "Hi, this is what's happening. I'm so-and-so. We're going to try to clear this intersection in the following way.", Or, even, "Move your car." There's no information around that. It's hard to see because I remember my car feeling very dark because there's that many agents surrounding it.

And so, there are cars moving into the side streets, stopping there, moving out, in this kind of mix. I get directed around the corner. I mean turned. I turned a corner. I go into the intersection. I did not want to go into that intersection. It's full of guns. This is six days after we learned how these specific officers behave. Again, I'm looking for patterns. And I have patterns about how police behave around people of color.

So, I'm running this subroutine in my head. What happened to Genoa O'Donnell? What happened to other autistic people when confronted by police? And then what new information do I have about these officers in Minneapolis right now? Oh, they shoot people in the face if you don't get their instructions right. So, I'm doing what I've been trained to do. Slow down. Just don't try to do this






Footage from ICE arrest Video by Amanda Moore (FreedomNewsTV)

quickly. I wasn't quick enough for them. After they first told me they'd smashed my window, I rolled it down, my driver's side window, to make that act not necessary. And also, that act in the first place is not an instruction, it's a threat of violence or punishment or something.

When would you actually break a window? I'm either drowning in a lake, there's a fire, you're trying to rescue me, or I've barricaded myself into the car and you can't get me out, which is also not happening. And things just escalated. They get louder. You cannot tell if the things they're yelling at you or at protesters because their mouths are covered. All you see from me, audio sorting in my mind, which is sometimes associated with autism. If multiple people are talking in a space, it's like what I said about trying to have a conversation with music on in the back that has lyrics. I am looking at people's mouths and other facial clues to see who is the one talking to me that I'm supposed to be tracking right now. It's impossible in that situation. And I don't even think that that's a need specific to my manifestation of autism or my ears or my brain.

But nonetheless, I failed to pick which instruction they wanted me to follow. People have replayed the clip a lot of when they pull me out of the car. But again, I think Lofgren's video is very instructive. And it's so instructive that they threatened me again over X that night by name because it makes them look bad. So anyway, you then have an officer smash my passenger side window. I say I am disabled.

As they're grabbing at my body, they said, "Too late." They pulled me onto the ground outside my car. They stood me back up. They started to cuff me. The whole time I am saying, "I have a brain injury and I am autistic." And it really looked like they escalated after hearing that information, which is important to note because when I reflect on this—My friends, we are living in America where violence from law enforcement was already a big problem. And now you have even less excuse to deny that we have footage from that shows federal law enforcement begin with violence.

I don't want to scare everybody. However, we have to get really active around accountability for how they treat disabled people. What is DHS's protocol when someone tells you they are disabled? It is not up to the feelings of the officer to decide if that is a lie and then unleash violence. That is not who we are. Well, actually, it is who we are. That is not what our law says is correct protocol, but we have kind of gray areas in this country around to what extent are officers held accountable for following the Americans with Disabilities Act? Is that applicable?

Are they allowed to say, we feared for our lives, therefore it doesn't apply? This person is a threat. But I'm sorry, photos of me from the State of the Union and videos of me from that day, I am doing nothing violent. Nothing. And in those circumstances, I think the conversation around disability and arrest is even more profound in some ways than I had the State of the Union. You didn't need to cuff me to the wall for as long as you did in Capitol headquarters. I'm not a threat. Automatically pulling at someone's cane and dragging them by their arms is not correct protocol.

A sergeant even intervened. And I know the question was about the day of my arrest of ICE, but in my mind, linear time just isn't really a thing right now for me. I am able to recount exactly what happened in linear fashion. But when I actually reflect, this is just the story of what's going on in our country. I think people can read in the rest of the press that after I get pulled out of my car, absolutely nothing related to my disability is regarded. It's not asked about.

I end up on the ground face-first behind my car again. An officer gets on top of my body, which is not something you should do if someone says they have a brain injury. In the upper area (of my body), I have exacerbated symptoms now. From that, I have two bilateral shoulder braces today. Both of my shoulders are torn, cartilage and tendon. The occipital neuralgia on the back of my head, which is like nerve-related pain, is worse. My vision, I just got a new test, also worse after January. And so, you know, I'm carried through the street face down, the whole time saying, "I'm disabled. I have a brain injury."

When I get put in the car, it was taunting and ridicule for those things. Whatever lies you're saying about your doctor's appointment. I'm told I'm a liar. I'm not told when I'm asking for disability accommodations, what is the accommodation you need? They keep saying somebody else will do that. That'll happen later.

And this is how it goes in the Whipple Center as well. In the Whipple Center, there are a lot of things to talk about, but for the purposes of our conversation, I continue to

ask, “Did anybody bring my cane along?” Nobody knows the answer to that. Typically, I put it in the back of my car, in the backseat of my car. And I don’t know, I don’t know where that cane went. I just know that it wasn’t returned to me.

So, I got to the Whipple Center and I’m asking for a conversation navigator. I do the same thing, by the way, when I’m being hidden in a stairwell in DC when I’m arrested the night of the State of the Union. And I’m asking for a conversation navigator. My speech in both circumstances, it’s slowing down.

I’m saying, “I am autistic. I would like help managing these very high-stakes questions that you are asking me in this moment of arrest.” Nobody seems to know what that is. First of all, there’s a mix of disbelief and just not even knowing what that is because it’s actually not a hard thing to do. As we have now seen from airport footage, there are many ICE officers bumbling around pretty much anywhere they go. If you all have whatever funding and hours to have these many people walking around doing nothing, how hard is it for you to get a social worker or a disability advocate or someone who even knows anything about conversational navigation? The way you would in a classroom or something else. It would make everybody’s life better. And it would even make the ICE officers’ processes go better, unless the process is punishment and harm.

Hmm. Let’s ask that question. What is their actual job if you won’t provide a conversation navigator? So, they don’t do that. At that point, they’re asking me things like, “What is your Social Security number?” And the way I’m able to answer that with the speech effects I’m having at that time, sounds like this. 3…5. Like, they’re seeing that they’re being asked for a navigator, nothing is happening around it. And I’m also asking for a mobility aid, and, instead, they choose to pull me up by my shoulders and drag me around Whipple, transport me that way. Or they pull me up and then they go, walk, push my back. “You can walk faster. Go on, you can do it.” Laughing.

The whole time I’m worrying I’m going to smash my head on the ground. Or, you know, I’m feeling this pain in my shoulders and it’s getting worse. When, finally, I wonder, “Oh, let me try a wheelchair.”—because I don’t typically use a wheelchair. I do in the airport or where it’s a very long walk. I think a lot of people who don’t live this life don’t understand how that works either, that some wheelchair users are not full-time wheelchair users. But it doesn’t mean they’re faking. It means they’re using the right mix of mobility aids for their body and for everyone.

When I finally asked for a wheelchair, the answer was, “We don’t know if we have one of those.” That is a very telling piece of information. We don’t know if we have one. I have to beg multiple people to try to answer that question for themselves. “Can someone find out if you have a wheelchair?” And I’m doing this through very, very slurred, difficult speech that is putting cognitive load on a brain injury that my brain needs for other things right now, like thinking about how I’m going to survive this situation where they’re calling us all bodies. I never heard an ICE agent inside Whipple say person, detainee, man, woman, they. Body. Look at all these bodies they’re bringing in. We don’t have space.

If you are a disabled person and you are used to the world that is uneducated seeing you as a discardable piece of flesh, it is very frightening to hear people calling you a body. You are pretty sure that your chances of living through that experience are not particularly high. And when someone is like, “You know what, I’ll go look for a wheelchair.” and that is not a DHS agent, that is someone who is wearing like the private security insignia on their polo, who I think, in these detention centers, we have a mix of private security companies and DHS officers functioning there.

This person goes and gets a wheelchair, and when they put me in it, the person wheeling it took the time to stop and said, “You were driving, right?” This is a confusing question. And I said, “Yes, I was driving.” And he said, “okay, so your legs do work.” Like, he was taunting me. “Sir, have you ever seen a disabled parking spot?” And this is not your job. That thing you just did; that is not your job. And the only function of it is somebody taking out their feelings on someone they believe is lying.

As they wheel me towards interrogation, I shift my focus from asking for— because it’s clear they can’t manage my request. They don’t know what I’m talking about. —I shift my focus from asking for accommodations to asking for emergency medical care. Because the pain at that point in my head is astounding. My vision is blurry; my speech is getting worse. And long story short, nobody even takes a pulse or does eye tracking while I’m still conscious.

The only person who actually did that was my cellmate, who’s not a doctor. And that cellmate put herself in danger start banging on that door and saying to those DHS officers, “Do you want an American citizen to die on your watch?” Because at that point, it had been hours of asking for accommodations, of asking for medical care. Nothing had been done.

And I don’t think it’s uncommon that when you don’t provide accommodations, you can expect the next problem to be “We need emergency medical care.” But they wheeled me into a cell and just faced my wheelchair at the wall and left. And said, “You can press that button on the wall if you need anything.” I couldn’t reach the button. And then when my cellmate got in there and we tried to press the button, there was no response.

Imagine if I had been nonverbal. My cellmate took time to get information from me about what was actually happening so she could ask these folks that, finally, because of the intervention of who I believe was a local

employee, said, "This is a problem what's happening in this cell." Right before he said that, I heard voices saying, "They asked for emergency medical at 11."

It's now 12. Like, I don't remember the rest of the number. "Why hasn't this happened?" I heard people say, "We don't want to step on ICE's toes." That means you probably did have the ability to provide care, but you wouldn't. I have thought a lot about those people who said that. That sounds to me like someone who knows this is not right and is, for some reason, at a level of intimidation around providing medical care because of real things that they've seen and been told that they're now not doing it.

What I'm telling you tracks with every story that you hear about denial of medical care and accommodations. I am so happy that this little nonverbal 5-year-old Gael was released from Dilly (family detention facility). Miss Rachel should not have had to get involved with a viral video for people to be regarded as real people when they're disabled and have medical needs. This is not okay.

And I just want to read you something. Part of my life now is a daily process of filtering for credible death and assault threats towards me. Because after I testified to Congress, the level of harassment and graphic physical language and some things that were credible enough threats that I lived in a safe house for five weeks after I was arrested. A little bit because of my medical and disability needs, but mostly because of the level of high-volume threats and violence, mouth-breathing phone calls that are left behind, people physically going to my ex's house. People, strangers commenting on my mom's Facebook who doesn't live anywhere near here.

I just want to read you something very specific. When I look for threats—and this is related to like what I'm just talking about, about how I was treated as a disabled person—you see people like the officers have absolute rage, laughter, ridicule, when you say you're disabled and need something. And I really wanted to understand what that's about. You know, with the officers, it's like their default is this person is lying to manipulate me. So, even mentioning disability makes you more seen as more of a lying threat, criminal to them. And it really makes me wonder whether I should disclose and tell people that I'm disabled.

It seems to bring more violence. So, when I look for threats, I have written a little bit of JavaScript code to help me identify if a comment is from a bot, a likely bot account or not. It's a browser sort of plugin that I made to help me more quickly go through this. And one comment that was from February 4th on Instagram about someone who had put out a supportive video going, "This shouldn't be happening in America," about my arrest by ICE. One comment from an account that I believe is not a bot, but is definitely like a troll who just has a lot going on for them. This is a study for me in identity and how



One of many comments Aliya receives on social media

people think about my disability in this context. This is from thatlyssa77 on Instagram. February 4th. "Aliya Rahman. I wish you were in Iran right now. You would have been beaten down with fists and a machete, stomped on, murdered, your dead body mutilated and raped. Then could you cry mentally disabled? The Iranian regime wouldn't have been so nice. Boo-hoo, you fucking cry-baby bitch. I hope you choke. Disgrace to people with ACTUAL mental disabilities." Which part of me you mad at, friends?

Woodall: That's it. It's wild to me that they put so much time and energy into that, leaving comments like that. It's so fueled by hatred. Where's that coming from?

Rahman: There are thousands of comments about "this person's not really disabled." And even supportive people—Somebody said to me, after I testified to Congress, "I never would have thought that you were disabled. You're so tough." And I said to them, "Disabled people are tough. We shouldn't have to be, but we still get through life with all these kinds of things people think about us." And I think that this comment is something that I would call "know your place violence." If I'm disabled but powerful—If you are perceiving me as disabled but not staying in my place, not shutting up in the corner, I'm a giant threat to you. You will come after me. Don't you know disabled people aren't supposed to be able to do anything? That's what that comment sounds like to me. Disabled people aren't supposed to be speaking up. People are like, "I don't believe she's disabled, she put on eyeliner."

People normally say to me, don't regard these comments. I read the comments to understand what non-bot people are using to attack. Because trolls are actually useful to listen to in terms of like, what are the narratives that are out there? And people are like, don't pay these comments any mind. The comment I just read you—If somebody said that about you, would you be able to just move on? There are hundreds of comments like this, and they happen every time I speak up. Every time I say people like me should not be treated this way. And I am not going to stop fighting while things are like this. Those are the days that Markwayne Mullin goes on Newsmax and talks



Aliya at State of the Union address

about me. Those are the days that ICE tweets from their own account on X with criminal code and my name.

I've never been charged. That stuff is reaction to you being afraid of the power of disabled, queer, Muslim, immigrant women, brown people of color not letting you behave the way you want to and make the assumptions you want about us. And your fragility is showing. That is a kind of fragility you can bet on. It sees its own emptiness and mortality, and it lashes out without regard for harm. So, we got to get together and fight.

We got work to do. That's what I'm doing now.

Woodall: We spoke about it briefly throughout the course of this conversation. Can you cover what they said you were arrested for at the State of the Union address?

Rahman: Yes, standing up. That is what I was told. And I had actually stood up a number of times at the State of the Union, including alone. And, you know, to me that I wasn't protesting, I was having an experience of the event, which everyone is allowed to do. And I care about the people around me. I wasn't insulting the two people sitting next to me who were continuously standing up for the conservative talking points and cheering. It's gallery seating, like way up in the balcony because we, the guests, sit separately from reps. I didn't go to an aisle. I didn't have a sign. I didn't say a single word. I was even wearing a mask for a number of reasons, but one of them was I have pretty telling facial expressions about how I feel about things. And I didn't want people to think I was scary.

This is a huge part of my life. About people misinterpreting like puzzled face or upset face as a threat. So I wasn't even displaying my whole face, There were a number of stand up and sit down moments throughout the night. At the State of the Union where reps sit down, stand up, sit down, stand up, that's happening in the gallery as well with guests exactly the same way and at the same moments too. You don't get like a list of instructions about that. And so I had done that a couple of times in my seat. Not disrupting. I don't think anybody was aware that I was standing up. Certainly not disrupting the business of Congress, like people in the past who have been removed and the only one who's ever been arrested and charged were yelling and interrupting a speech.

As I'm standing up, I hear this person say, "you can't stand up." And I say, "I'm sorry, people have been standing and sitting all night." And then this person with the sergeant at arms says, "Well, you can't stand, you can't be the only one standing up." And then right then tons of people stand up and start clapping. Well, it looks like we solved that problem. And as all these people are standing up, making noise, and I'm standing there not making noise, I'm

told sit down you know, I'm trying to understand what is going on because that's not a clear instruction either. So what, sit down for the whole speech? When they grab me by my arms and I start to tell them I have two torn shoulders, that is not necessary, and they won't stop. And they're starting to grab and try to take my cane as a default. You can go watch the Instagram reel that Dr. Anita K. Patel put out about how she tried to intervene and say to them, this person is neurodivergent, has a brain injury and two torn shoulders. She was told she'd be dragged out with me if she didn't stop trying to advocate for me. An attorney tried to stop them or ask me what was happening or tried to accompany me. She was not allowed. A pastor behind me also tried to come with me. She was not allowed. A community organizer behind me from Colorado tried to accompany me because they saw how these people were like yanking at my body. She was not allowed.

We learned the government's filing no charges. Obviously, never in the history of the United States has anybody at the State of the Union been removed for what I was removed for. Or charged. And these folks were staring, like the sergeant at arms, from the moment I was sitting silently before the speech even started, when I would look up at the door and look around, they were staring at me. So, I knew I was being watched. I don't know why they were watching me, but I knew they were.

They open the door of the House Chamber and then they hand me over to the Capitol Police who immediately slap cuffs on my arms. And then they start having this conversation. Someone said, "Is she being arrested?" And someone answered, "Yeah." And I keep asking, "Why am I being arrested?" And the cops said, "We don't know. We weren't inside."

And there are police all up and down that aisle, Capitol Police. And I keep saying, tell Rep. Omar's staff I am being arrested. Tell Rep. Omar's staff. I want to talk to Rep. Omar's staff. And they're dragging me down this hall by my arms, again, yanking at my cane. And I'm telling these two Capitol Police officers, stop doing that. I have torn shoulders. I am disabled. I am walking with my cane. Just let me walk with my cane. You don't have to drag me by my arms. And they're telling me, "Don't resist," yanking harder.

Finally, they open this door and put me in this back stairwell access hallway thing, like a non-public area. And a woman in like a sergeant-looking uniform pops out into this hallway and says, "Stop moving her like that." We're going to call for EMT and get a wheelchair. So finally, they stop like being rough with my body.

And the arresting officer who later in Capitol headquarters cuffs me to the wall and cannot figure out how to fill out forms correctly and accidentally checks the wrong box around whether it's a custodial arrest or not. This man laughs a couple of times when I'm like, "My shoulders are really painful because they're pulling on them." That's how these folks are acting. And when I'm asking for a conversation navigator, I'm getting intimidation when I'm asking them to call Rep Omar's staff. And they're telling me, "Oh yeah, well, what's the number?" I'm like, "I don't know, but you do because you're security for this building. Call, her office. They told us they'd be there. I want them with me." I don't see them until they pick me up after I'm released, like right about 4:00 AM.

I can't get them at the hospital. The cops try to get them to give them my phone. So, we just say, fine, no phone until later. I'm begging for a long time, asking for a conversation navigator again. And my speech is getting slurred and stressed out and slow again. They have me cuffed behind my back and I'm begging "Can you please at least move the cuffs to the front?"

That can't happen for some reason. This team of EMTs arrives and started asking me questions. I asked, "So you guys live here in DC?" They said, "No, we were flown in separately from Utah just for this event." Then the real EMTs get there, who said, "Who are you guys? What's going on?" The real EMTs' faces are really creeped out.

And then I get wheeled to this parking area in the back of the Capitol building. The cops finally hold a phone near me and said, "This is, this is Rep. Omar's chief of staff." And I said, "Connor, I've been arrested. I made no sounds. They will not tell me why specifically this was considered a problem." And the cop goes, "Hey, hey, hey, hey" And I'm like, "Connor, they're getting upset that I'm talking to you." And he goes, "That's not what I said. You said you needed a conversation navigator and now you're going off about what happened." And I'm like, "Okay, I'm sorry. I didn't realize I wasn't allowed to talk about what happened." That's part of the navigation. But okay, can you please call him back and I will speak only about providing assistance and they wouldn't do it.

So, I'm concerned about my shoulders. I'm about to miss my next meds because of how long this is taking. And I have a 6mm tear in this tendon. There's only like a couple millimeters left before muscle detachment.

Finally, you know, they move my cuffs to the front right before I get put in the ambulance— I'm not posing a violent threat to anyone. This is not necessary. But I think, you know, from the jump, the assumption was I'm some kind of dangerous threat. The Capitol Police officers felt very much like ICE, and the people in that balcony felt very much like our observers here who are trying to get them to behave in any kind of compliant way.

Woodall: I know this is speculation. Do you think they recognized you as Aliya?

Rahman: What I can tell you is that I was handled in a way that was disproportionate force, again, for not acknowledging disability. And I was a congressional guest, and I was not making any sounds. So, you know, I don't have any information to know about what they believed about me. I do know that the conservative press have been posting all day about various guests.

I had been doing press throughout the day, and press had been putting out stuff. DHS had been putting out things on social media all day, saying negative comments about people's guests. Because they were like, people are bringing illegals to the State of the Union. And, you know, Markwayne Mullin said on Newsmax that Representative Omar bringing me there was a joke. "How could she defend these lawfully arrested people or lawfully detained people?" None of her guests were lawfully detained.

It's very clear from my engagement with the world after I testified that my body alone is resistance to people. Other people cannot handle me speaking or not speaking. Even just standing is too threatening to this regime. And it's happened a number of times in my life. So that's the context. That's what I can say.

Woodall: You're currently being represented by the MacArthur Justice Center, related to the injuries and trauma you experienced. Is there anything you can share about it that?

Rahman: I'm going to say stay tuned and that the MacArthur Justice Center are working hard to look into this situation and to consider our options. You cannot sue an ICE officer. What you can do is file a federal tort claim against the federal government. And what's distinct about that is that that is compensatory. It doesn't have punitive damages. Like against an officer. So those are the things I would say. Once again, here's the legal context in which this is going on, where people who have been brutalized by ICE cannot sue those officers the way that you could try to sue a police officer. And of course, we see that that's a very hard thing to do as well. But that's the context we have here. And there are active efforts in Congress to end qualified immunity for those officers in situations like this and to make it possible for citizens to sue an ICE officer. Or, you know, just any federal law enforcement agent, really.

Woodall: Is there anything else that you would like to add that we haven't covered here today? It can be anything.

Rahman: I will just say that this is not easy in any way. And there are a number of days that I am like, "Do I have the spoons to have another conversation?" And some days I don't. I have thousands of dollars of extra costs associated with these two arrests that came with injuries and no charges. But what I saw through my experience that these two arrests were, for me, yet another set of lenses into the larger systemic issues that we have in this country around law enforcement, racism, xenophobia,



Aliya with her attorney Alexa Van Brunt

ableism, and how unaccountable law enforcement is around how they're supposed to behave. With people who have identities like me, or how they're supposed to behave with people whose families have been brutalized for generations by law enforcement, which is not a weight that I carry. I'm first generation brutalized by law enforcement on this soil.

That's the reason, by the way, that we had the kind citizen response that we did here because this city has been practicing for a long time at how to make accountability and justice real. That's where this came from. That is what I want to happen next. It's the only thing that's going to help me sleep because every night I see the people who don't have the privileges I do. Even with everything we've talked about, I'm not worried about my housing. I have food. I speak English and people want to hear from me. I lived and I was not deported. That is very uncommon. The brutality that happened to me is extremely common. My ability to get through that and the people that supported me, that's not. It's not as common. And that to me is a work assignment. You were given this thing. Get to work for everybody who wasn't. ■ ABILITY

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Dr. Fabian Carrera

Composing a life Without Limits

Music is the throughline that carried Dr. Fabian Carrera from his earliest memories in Ecuador to a career as a classical guitarist, music-therapy practitioner and university professor. What began as a comforting sound filling the hospital room of a small child in Quito became the discipline, resilience and purpose that shaped his life's work. The music animated the small child with polio who grew into a dedicated student, renowned performer and person of service.

ABILITY Magazine's Gina Velasquez, also from Ecuador, recently sat down with Dr. Carrera to discuss his musical journey, family and faith. Their heartfelt conversation traced the medical challenges of his early years, the influence and support of his father and the bold leap that brought his talents to the United States. They also spoke of his profound work in music therapy, exploring how a simple melody can soothe patients in palliative care and even helped solve a heartbreaking medical mystery.

Velasquez: Can you talk to us about your early life in Ecuador?

Carrera: These topics are very heavy. I can talk a little bit of how tough it was, how beautiful it was and how amazing the provision of God was in my life. By no means this is religious or preference for anything. I consider God in a very wonderful personal knowledge. It was really tough because we had to overcome a lot.

Velasquez: Can you talk about your experience as a child with polio? How old were you?

Carrera: Nine months old. My father was in the army, and my uncle was also in the army. He was high up in the military. And he said we needed to be at the military hospital. So, we went from Cuenca to Quito. It was like 10 hours' drive on dirt roads. Highlands, very difficult to drive.

When we arrived at the military hospital, they said "He cannot be here. If it's polio, we cannot let him because he's going to be very contagious for all the kids that are here." They set me up in an old military hospital in San Juan in Quito. It's in a very old part of the city. So, behind the hospital, they have some tool sheds. They created a space for me to stay there until, finally, the polio broke down. And then I was able to enter the military hospital.

I don't know how I survived that. They got me into the hospital and gave me the medications that I needed. And the physical rehabilitation that was required. (There were) a lot of processes because my two legs were compromised, my spine was compromised. I had to be fitted with two braces. The braces were from the toes to my hips connected together for both legs, connected at the top of my waist.

Besides that, I had to use two crutches, which made it so difficult, so painful. And then the therapy process. I continued my rehabilitation for five years. I had to be in the hospital because I had lung complications. I was also confined to an iron lung for a season.

It was a very hard case of polio. I grew up five years in the hospital, I didn't leave. The doctors used to always tell me, "You are my king." I was like, "What are you talking about?" They said, "All the kids that had polio died, and you are alive. That's why you are my king." Of the kids in 1966 that were affected by polio, from 75 to 80% died. They didn't arrive even to one year old.

Velasquez: What is your earliest memory and what kind of mobility did you have then?

Carrera: My first memory, I would say, was music because my mother left a radio next to my bed. A radio station that was constantly playing music. I start listening to music and start moving my head side to side, left, right, left, right, left, right. And then little by little, start moving my shoulders. That's why I'm a firm believer that music therapy has power.

I would say, without being the beating or playing violins next to me, it was a lot of pain. It was a lot of crying. It was a lot of tears. And the nurses that they used to work at the hospital, some of them, were nuns. They were in the military. I don't know what branch, but they used to take care of us all night long.

And I understand completely, there were a lot of kids that



Fabian Carrera as a child with his family

were in pain and they needed to sleep, the nurses needed to sleep. And then they used to come at us and tell us, "Shut up, we need to sleep" "What do you want?" And start yelling super loud. I couldn't understand what was wrong with these people. When you yell at a child, it makes the brain lock. You don't hear anything else. You don't follow any more orders.

That was the part at night. In the morning, it was a different story because we had different nurses. I was able to see my mother. I was able to see my father. My mother used to come and read books or magazines to me. And singing songs for me.

Velasquez: And those are your first memories?

Carrera: Yes. I don't remember anything about Christmas, about my birthday or anything. That was since I was six years old. That was the first time I could say, "Oh! This is Christmas." Oh, my birthday. Oh, nice.

It was really tough in those stages, even my mother told me something disturbing. She came with a camera and the nurses and the soldiers that used to care, "Excuse me. No. We don't allow this." "Why not? He's my son." They said. "This kid is going to die and what are you going to do with his pictures afterward? Cry more? That's why you need this? No, put it back, we cannot allow this." So, I do not have pictures of me as a (young) child. I have pictures of when I got to see my family. It's a beautiful picture in black and white. I got to experience this wonderful thing of being with a family. I went home and what a surprise! I met my big brothers. I didn't know I had brothers. My big brother is five years older than me and the middle is three years older than me. And it was tough for them too because they have to stay all those years with my grandparents. They forgot about me and they started calling my grandparents mom and dad.

So, when we came back, my daddy came back and talked to my grandfather, "I'm going to take the kids." "What? No, you're not taking the kids. I love them." And the kids didn't want to go with him. It was a tough story though. Finally, my father reunited all of us. I will say this was like a traumatic encounter though.

Velasquez: When you finally left the hospital and went back to Cuenca, what was your condition then?

Carrera: The doctors told my father not to go back to Cuenca because they don't have hospitals there. "We need to have special treatment for him, and he eventually is going to need two major surgeries on his legs." My father talked to my uncle, who was high up in the military. They transferred him from Cuenca to Quito.

With therapy, I thank God, I recovered the mobility of my left leg. Unfortunately, my right leg is still paralyzed. Because I did recover the mobility of my right leg, the doctors told my father they were going to put staples on my kneecap because he said this leg is going to grow and the other won't. And we needed to stop the growing of the left leg, so when I got to puberty, the difference would be minimal. The doctors said, "We learned because we didn't do this before. The patients that got polio had 8 to 10 inches difference between legs."

Velasquez: So, what happened?

Carrera: The surgery needs to be when you're a child. If you already passed that threshold, it's too late. I was in the perfect stage. I think I was 10 years old. When I had the surgery, the first surgery, they put eight staples—four on the left side and four on the right side of the leg. They were going to stop the growth plate.

A year later, I was playing with my friends at school and I fell down. And one of the staples came out. I was scared. I forgot completely that I had staples on my knee. They took me to the hospital and they did x-rays. They saw the staples were opening up already. They couldn't hold the growing.

By then I was maybe 11 or 12 years old. The doctor said this is what you're going to get—my height—and we need to remove the staples. Today, I only have 1.5-inch difference between both legs.

Velasquez: That worked out. That's great.

Carrera: When I was a kid, a teenager, I only used the right brace. The shoe had a sole like one inch. So, you can even look at the difference between shoes.

Velasquez: Right.

Carrera: Yep. That was it. And then the doctor said, "My king, this is how far we can go with you. You are alive. Of course, you're going to limp a little bit but continue doing your therapies. As far as this polio, this is how far

we have gone. Enjoy your life and follow your dreams." And then he hugged me and kissed me on the cheek. And here I am.

Velasquez: It worked. And you regained use of your arms?

Carrera: My arms weren't affected as much as my legs were. What was affected was my lungs and my legs because that affects the muscles. When they realized I had polio, it was too late for the right leg. They tried to, they put needles in the bottom of the heel, and they didn't find reactions like the nerves. They poked me on the other leg and started having reflex of the nerves. That's when they said, we need to take this kid right now to the military hospital Quito.

And then a new chapter begins. I was going to regular high school. We didn't have to go to kindergarten. You went straight to first grade. (The school) said, "No, he doesn't deserve to be here because he's mentally challenged." They assume instantly, right? I needed to be in a school they call Artes y Oficios. It's a school for kids that have mental challenges.

Those kids were going there to learn how to be carpenters, how to do plumbing, or things like that. After maybe three years, you're ready to work, or some carpenter will hire you, plumbers or something. And my dad said, "Wait a minute, he has a physical disability. He doesn't have mental disability." He fought for me to get into regular education. That's when I finally went to a regular school. Elementary school.

Velasquez: Were you behind? Did you miss out on a lot of education?

Carrera: I was the oldest in the classroom. Because I was the oldest, I needed to sit down in the back. If you learned and didn't ask questions, it could be better if you just stay invisible. So, the years went by, and when we finished 6th grade, this teacher said to me— I was excited, I was like, yes, I want my diploma because I'm going to move into high school.

Carrera: But then the teacher said, "You're going where? This is it for you, man. You just need to go and shine shoes in the house, in the bus depot. Look at you."

Velasquez: This is what your teacher said?

Carrera: Yes, I went to tell my dad. I considered him, when things like this happened, I unleashed the lion. I said, "Dad, this guy said this." Oh boy, he had an interesting talk with that teacher. So finally, he said, "We just need your grades, grade reports, and then we're ready to move to high school. So, forget about this man, you're not going to see him anymore, and everything's going to be different now." So finally, when I was in high school, well, it was a different time. I was— That was my connection with music already.

Velasquez: You were exposed to music when you were very young. Were you already in high school, was it before high school that you started to learn to play guitar?

Carrera: Yeah, the guitar, let's put a pause in the guitar because my mother left that radio station when I was a kid in the hospital that was constantly playing music. I don't know if you're familiar with the Spanish singers like Rafael, Leonardo.

Velasquez: I love Rafael. I grew up on Rafael from the '60s.

Carrera: I listened to that music every day. And then I started singing and the nurses started laughing at me. I was like, "Why are you laughing? Was that bad?" They said, "No, you sound like a parrot. You imitate those guys to the T." I was like, really? For example, I used to listen to Leonardo Favio. I got all those people to the T. I'm going to go fast forward 10 years. My mother bought me a guitar.

My father played guitar. I listened to how he played music. That was so beautiful. Just when he put his hands on the strings, that really captivated me. I was in shock. I was like, this is so beautiful. Teach me. So, I was practicing all the regular songs, all the traditional songs that he knew about Ecuador.

Velasquez: Yes, my father loved pasillos.

Carrera: We started playing all of that. We played Julio Jaramillo, and my father was also in shock "You just sound like Julio Jaramillo." I started playing that and then I stopped. As beautiful as this was, for some reason it didn't move me.

There were three radio stations that I used to hear in the hospital. It was HCJB, it was *Radio Nacional Espejo* and then *Radio Musical*. HCJB used to play traditional folk songs, pasillos, alabazos, tonadas, all that stuff. And then in the afternoon, they used to read the Bible. They used to tell Bible stories, which was amazing. And then I moved to *Radio Nacional Espejo*. It was soap operas like *Calimán, Por Fin*, things like that, *Calimán, El Hombre Increíble*. So, I was listening to all of that. And then at night, I put it on *Radio Musical*. They started playing the Top 40s, started playing Deep Purple, they were playing rock. They started playing music by The Doors.

I was like, this is unbelievable. I didn't understand what they were saying, but this was my thing. Well, a flash forward, in this case, to my years in high school, it was pretty much rock music. Everything—hard rock, heavy metal, progressive. Pink Floyd, Deep Purple, KISS, all that beautiful stuff.

That was my mission. And then when I was 16 years old, I saw a TV program— they were featuring Maestro Andrés Segovia from Spain. Blew me away. He played music called Asturias, when they have different voices in



Fabian Carrera playing with the National Symphony Orchestra, led by Russian conductor Andrei Vasilevsky

the guitar, very fast piece. That's when I knew. As much as I have that passion for rock, I said, "This is the way I'm going to go." So, I told my dad, "Listen, I'm going to do this. He said, "Sure, let's get you in the conservatory then. And as far as I can see, this style of music is very difficult. And the teachers have to be a very skillful, trained musicians, refined musicians because not everyone's going to be able to teach this." So, perfect. So that is my beginning with the music and the guitar.

Velasquez: Did you audition for the conservatory?

Carrera: Yes, but the situation is this. Do you have an ear? Yes. Do you play an instrument? Yes. Do you read music? No. I was at an advanced stage by then. Because people, if you go for 16 years old and they do not have music, they don't read music, they don't play instruments, they might say, "Sir, you came here too late." "What? But I'm only 16." "You should have come here when you were eight. Next." What?

In my case, I have that advantage. It wasn't that difficult for me because I used to sing the songs. I used to play the songs. I had an advantage because I had already started playing classical.

So, the only thing I had to start working on was reading music. I started taking lessons at the conservatory. They call solfeo, teoría, dictado, which means music theory, ear training and then instrument principal and secondary. And I had to be enrolled in the choir as well. A lot of requirements. It was a very demanding schedule. We had classes from Monday through Saturday with performances every three months. And don't you dare play the same pieces for the second semester. So, very demanding.

I was studying like crazy. I was also taking private lessons at Consejo Provincial de Pichincha. That was across the street from my high school because I wanted to go faster with my studies.

Velasquez: Right, but you were there 11 years.

Carrera: Yes, right, 11 years.

Velasquez: Was that your choice or was it because you were adding new techniques or different types of training, or was that mandatory by them?

Carrera: The level of musicality is way advanced, especially when you play music by Johann Sebastian Bach. Spanish composer like Isaac Albeniz or Manuel de Falla. It requires years of training. No one's going to jump and say, I'm going to play *El Concierto de Aranjuez* by next week. No one will do that.

If you don't practice that concert at least 5 years and you're already a solid guitarist, that will happen. That was what my father saw; he said this is what you need to do. You need to have the instruction. And finally, I graduated in 1996. I played a concert with the Symphonic Orchestra of Ecuador called *Raíces*. It's on YouTube.

This was one of my biggest challenges. It gave me identity. It gave me a voice. It gave me a channel to express myself. I wasn't anymore in the back seat. I was now always in front. I was always invited to different events, different parties, different trips. Come, we need you here, but bring your guitar, by the way. "Oh, I thought you were inviting me because you were nice to me." "No, bring your guitar."

So that was a wonderful experience with the guitar. And



Fabian Carrera With Ana Vidović, one of the world's leading classical guitarists

in 1997, I got invited to play in New York and New Jersey by, at that time, president (of Ecuador) Fabiana Alarcón.

We stayed in New York for a month. We had a wonderful time. I played in different places, different universities, different auditoriums of banks. I played even in the Ecuadorian consulate in New York. And we had a chance to meet the mayor. I couldn't believe it. It was Rudolph Giuliani.

Velasquez: Giuliani. Oh, you met Giuliani?

Carrera: Yeah, from New York. And then we finished in New Jersey, and that was the inspiration for me. Ecuador, as beautiful as it was, in my career, I don't think it was going to offer me more. I need to keep growing. I see the amazing teachers that lived in New York or the United States. I had to do that jump. I'm going to fast forward a little bit. In 2002, I got invited by the ambassador of Ecuador in Washington, D.C. to play a concert there. And then I knew that was my moment. This is when I decided to take that jump of faith. I did a concert, amazing. I started making connections. I started finding amazing guitarists, amazing friends, and among them I found my wife.

We used to work together. She was a music teacher. She's retired now. So that's why I decided to continue and project my studies in the United States, keep growing. I have a long list of teachers that I had here, the master classes that I was honored to attend., continue my education in music. I studied in Miami at Miami Dade College.

I finished and then I continued to Florida International University. I decided to continue my music studies. Alternating with psychology and social work. This was going to be my connection to trying music therapy. And then, I am a performer. It's going to be tough because I was doing social work, psychology and music. When I look back, I say, "When did I have the time to do this?"

I always said I had an advantage because I already mastered the instrument. I was very fluent in reading music. I don't need to sit and learn that. 20 pages long. I just put the papers in front of me and beep, next and next. So that was a done deal; to continue my education, I went to finish my master's in Florida International University, and I got accepted at the University of Miami.—I used to work there. Every summer they have music guitar camp. I was one of the instructors. They knew me very well, so when I made my application, they accepted me, full scholarship. Thank you, God, because that school is very expensive.

So, the pandemic came. It was a challenging time.

Velasquez: You started teaching in 2011, and then the pandemic happens.

Carrera: Yes, but listen, when the pandemic had already hit, I had two masters, I had a minor in psychology, and then I was thinking to go completely (into) music therapy. But then I saw all the things that I had to write, all the practicums I had to do. That was very demanding.

Velasquez: What is a practicum?

Carrera: Internship. An internship was too much because I already did an internship as a social worker. It was to be from 8 in the morning until 5 PM, and then you had classes around 7 PM. I was like beyond exhaustion, to the verge of burning out. And then I said, I'm just going to continue my degree. I'm going to get my doctoral in musical arts in performance because this is what I've been doing for years.

I am not a certified music therapist, but I have major

experience in music companionship, which is the same thing. I have been working with patients with palliative care, dementia patients that are in hospice. Sometimes those patients we have only for 29 days, and then they pass away. So, we continue with different ones.

Velasquez: Can you explain a little bit about what you do when you provide the music therapy?

Carrera: I consider myself a poster child for music therapy because that is what helped me to move my arms, to recover my leg. For example, I go to the patient— I had a conversation prior with the nurses or the doctor who's treating them. And I try to find out what could be the most effective treatment in music with this person. Because, as you know, there is a part in the hippocampus that is only focused on music. People don't remember their names, but they do remember ♫ Happy Birthday to You. ♫

They remember the lyrics, they remember all of that stuff to the T. And then I say, what was your name again? "I don't know." So, the process that I do with the patients is according to their needs. For example, there were a couple of old ladies, African Americans. When I entered the rooms—They were devoted Christians. That is telling you hints of what you're going to play, what you're going to do. I cannot go there and say, "okay, lady, I'm going to play a song by Metallica called *Creeping Death*.

Velasquez: (Laughter) I'm sorry, the image of that just made me laugh.

Carrera: Thank you. So, I sat next to them, with the guitar very soft, just playing the melody. ♫Ti ri la ra ri ra li la. ♫ You should have seen their faces. They started opening their eyes and looking at me: "What is this, so beautiful? Thank you." I remember I played Christmas carols for an old lady. She said to me, "Did I die?" She passed away after that.

It's pretty much you feel led to the needs of the patients. There were patients that the only power they had was just to say "no." I had other patients that I knocked at the door and said, "excuse me, would you like to hear music?" And they say, "no." "Okay, thank you. I'm sorry." I close the door and leave. I cannot impose myself. No, you need to listen, or if you strum the guitar too loud and they cause them to stutter. Yeah, that's no good. I try to create an environment with soothing music. And I watch them when I play.

There was an old gentleman from Cuba. I remember playing for him "Guantanamera."

Velasquez: Oh, "Guantanamera," yes.

Carrera: And then he started singing. ♫ Guantanamera, yo vengo de todas partes. ♫ And the nurse that was in the other room dropped her tray with stuff and said, "What is going on here? He doesn't talk, you know." I was like, "What? He has been here a year; he doesn't talk at all?" No, he's singing "Guantanamera."

Unbelievable. And little by little, we found out that he was run over by a car. He was 80-something by then, and he forgot completely. He had a stroke and nobody knows even his name. So, little by little, I spent 6 months with him. We have a card with letters. And we play "Guantanamera" and all Cuban songs, all boleros, things like that.

We asked, "What is your name?" I showed him letters, and then letter O. O. And then what is next? Omar? No. It was Orlando. Orlando. And then he nodded his head yes. Now your last name, brother—because by then he was in the hospital as an unknown.—His name was Orlando Moreno. And guess what? We found his brother and sister. They were desperate. What happened to him? Nobody knew. And in the hospital, he couldn't talk. Just remembering this made me cry. What a beautiful moment. We found him.

I don't know if you know Miami. There is an area called Hialeah. So, we asked there, "Do you know this guy?" And they said, "Yeah, actually his sister and his other brother live down the block, brother." So, we went and they were, "wow." So, we took them to the hospital. "Is this the guy?" We cried for a month. These are the rewarding things of music therapy. And I see the beautiful results.

Velasquez: That's beyond music therapy. That's remarkable. You're a performer, you're a professor and you do music therapy. You do all three?

Carrera: At this time, I'm focused 100% on my teaching because I was hired at the university in September 2024. I have students that I connected with hospitals here. They started doing music therapy themselves, —not like I used to do with patients.—They play in the main entrance of the hospital where people are going to see and take patients for evaluations. Then they have exposure to music. It could be a piano or classical guitar. At this time, I play a little at home because I'm in the process of recording. I record an album every two years.

And this is my second year. I'm going to start focusing on all this project. And it takes a lot of time, a lot of selections and a lot of practice. I need to be very ready when we have the studio because I don't want to keep repeating or messing up or continuing with the same thing.

Velasquez: Are you working on a solo album or is it with other musicians?

Carrera: No, it's a solo album.

Velasquez: Did you compose it?



Carrera: I see myself as a performer. I tried to compose, but, for some reason, I couldn't find that. I did compose once for my mother, though.

Velasquez: You are recording and you're also a professor. Is the music therapy work on hold for now?

Carrera: At this time, yes. I was planning to do music therapy in June, July and August, but this time I focused on recording because I do recordings every two years. I did one of the last music therapies last February with a friend of mine. It was sad, though. All of a sudden, he had stage four cancer. I had a special request from his wife. "He wants you to play for his funeral." And I did. Very sad, but I did. So, he had music even at his funeral. very sweet guy and his family.

Velasquez: So, is there anything else that you'd like to mention about all the steps that you took to get here where you are?

Carrera: I would like to say that what brought me here is my faith—and I'm not here to promote churches or religious movements at all. I'm just talking about our relationship straightforward with Jesus. This ride has been very tough, but I have beautiful moments, beautiful rewards, beautiful times when I see the provision of God in my life.

I have seen God taking care of me, and that has given me strength to continue. For example, when I, in the middle of this pandemic, decided to go for my doctorate. Deep inside, I was like, you're not going to do this. This is going to kill you. This demands a lot, the papers that we need to present, the projects. But I did it. I graduated. I got my doctorate in May 2024. Unbelievable.

So, I did it, and I didn't die. I had energy, I had the album. And then, with that degree under my belt, the doors start opening, different universities. So, we decided to move here with my wife. I have a stepson. He lives here in Spokane. What a sweet guy. And we are next to him. We spend time with him a lot, many years that we haven't been able to because of the distance. And now we spend every Christmas, every Mother's Day, my birthdays, New Year's, and July 4th, and all that stuff we spend together. Because finding family is everything.

Velasquez: You're making up for all the holidays and birthdays you didn't have when you were a child.

Carrera: Exactly. This is pretty much how this jump of faith has been. I'm very pleased.

Velasquez: Even the difficulties can be beautiful because of the way you overcome them and all the stories you have.

Carrera: And that is part of my resilience. Thank you for the support of my parents, my mother, my father, my brothers and the constant support from my wife. That I can be here and playing music and talking to Gina Velázquez and beautiful things like this.

Velasquez: And ultimately, all the ways you've impacted people at the end of their lives.

Carrera: I fulfilled my mission. Just to show you that we can do this. Even if you are disabled and, in a wheelchair, we can do this. I would say I'm living proof that. I've been playing with three symphonic orchestras. Amazing. If you ask me these things years ago when I was in Ecuador, I would say, "Me?"

It was like how God is opening doors for me. And in the classical guitar area, I was so blessed. I've been in master classes, in concerts with all of them, with all of the heavy players, all of them. They know me, they know about me. I have the chance to play for them. Beautiful critics, encouraging critics. That makes me so proud. Every time I go to bed, it really makes me very happy, puts a smile on my face. I put a board here on my desk and I have pictures and I look at those moments. I'm like, ah, yes.

Velasquez: People can do things that they didn't know they could do.

Carrera: Exactly. No limitations. I cannot walk. My legs don't work, but my fingers do. They fly; they dance. They move fast. I have a good ear. I have wonderful students and encourage them to continue teaching, performing, taking the baton from me, doing the music therapy stuff, doing the performing, the teaching. And that makes me very happy. I said every second that I invest in this, totally worth it." ■ ABILITY

Fabian Carrera facebook profile



Neurodivergence and Higher Education

We all know that physical and mental reasons for disability occur along a continuum. The increase in mental reasons for disability has introduced terms into everyday use that previously were unfamiliar to most people. Terms like neurodiversity, neurotypical, and neurodivergent are becoming more common.

Australian sociologist Judy Singer coined the term "neurodiversity" in the 1990s as a social justice term affirming the great variation in how the human brain functions, and as a way to move beyond the medical model. Neurodiversity includes people who are neurotypical and others who are neurodivergent. In 2000 activist Kassiane Asasumasu coined the term "neurodivergent" and "neurodivergence" for those who are not neurotypical. Neurodivergence in a non-medical umbrella term and not a formal designation. It includes a range of conditions like dyslexia, dyscalculia, Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and more. Also in 2000, an influential British article estimated that 15 to 20 percent of the population are neurodivergent (Doyle, 2020).

As the prevalence and patterns of disability have changed, these terms serve as a useful way to understand differences that move away from the negative and stigmatizing language that has long plagued people with cognitive and mental disabilities like anxiety, depression, and bi-polar disorder. Today, "cognition" is the most common type of disability in the US.

Many college students experience disability

In higher education, the dominance of brain-based reasons for disability are even more striking. The U.S. Government Accountability Office (GAO) reports that 69% of reasons for disability are in the behavioral and emotional category.

Unsurprisingly, educational institutions have responded to this reality by building awareness and capacity with a suite of practices responsive to these students' needs in order to support their academic success.

These practices include but are not limited to:

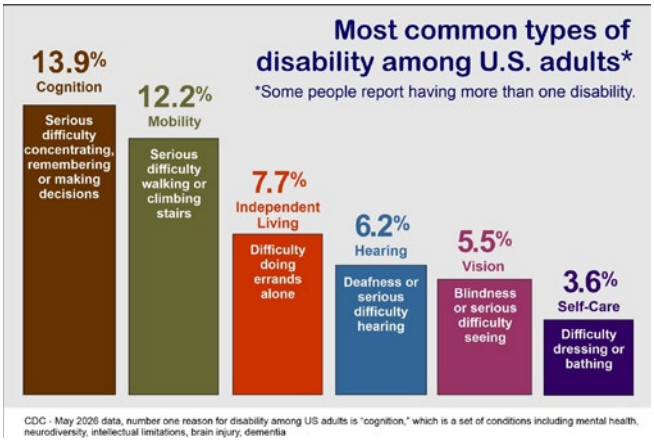
Innovative instructional strategies.
- Grading flexibility.
- Note-taking.
- Providing a complete syllabus at the start of the semester.
- Allowing students to record class lectures.
- Universal design for learning methods: Multiple means of engagement, multiple means of representation, and multiple means of action and expression.

Modifications of policies and procedures.
- Grading.
- Hybrid flexibility for live and remote attendance.
- Single dorm rooms, sometimes allowing pets.
- Specialized testing centers.

Effective communication:
- Offering verbal and print instructions.
- Providing on-demand audio options for print materials.
- Avoiding unfamiliar sayings or phrasing.

Colleges and Universities Embrace Neurodiversity

Colleges and universities of all sizes and in all parts of the nation are experiencing the same patterns of neurodivergence dominating disability services. Many of these



institutions are committed to finding new ways to engage students to plan and to evaluate tailored accommodations. For example, Louisiana State University (LSU) in Baton Rouge has carved out a new Disability Services Testing Center in an existing building. Tracy Blanchard, LSU Director of Disability Services, created a "Reset/Regulation Space" in the Testing Center as a priority before the new testing space opens for the fall 2026 semester. She and her team created a digital QR code-based form for students to complete before and after using the space to measure its effects.

The University of Washington has a pioneering commitment to welcoming and supporting neurodivergent students and training faculty to teach these students effectively. In 2025, the Canopy Foundation made a $15 million grant to establish the Neurodiversity and Employment Institute at the University in 2026. It's a savvy strategy that recognizes employers, especially within science, technology, engineering, and math industries, see strengths and assets in candidates whose brains work differently. Businesses want to employ these alumni, and are making commitments to designing workplaces that support comfort, confidence, and control for the neurodivergent talent they seek to hire and retain.

The College Autism Network (CAN) is an independent non-profit affiliation of scholars, practitioners, employers, and self-advocates founded in 2016. It has a partnership with the Frist Center for Autism and Innovation at Vanderbilt University and offers an annual conference and membership opportunities.

Neurodivergent people often grapple with sensory processing difficulties, both too much and too little in the eight sensory systems: Visual, auditory, tactile, smell, taste, vestibular, proprioceptive, and interoceptive. No amount of other supportive measures can fully compensate for physical environments that fail. To date, there are no U.S. design standards for physical environments that support neurodiversity though there is a growing body of peer reviewed articles on design for neurodivergence. Research Design Connections has a compendium of searchable articles.

The phenomenon of neurodivergence is not limited to the US. There is a particularly valuable tool that offers substantial evidence-based guidance from the U.K.: *Design for the Mind – Neurodiversity and the Built Environment – Guide*. This is a Publicly Available Specification (PAS), but is not a formal standard. The PAS method allows guidance to be rapidly developed in order to fulfill an immediate need in industry. As a testament to that urgency of understanding design approaches for neurodiversity, this PAS was made available for free download with funding by U.K. public and private entities.

Universal Design for Learning was grounded in neuroscience. We know our brains respond to the physical spaces around us, including in the spaces we create for learning. Finnish architect, dean, and author Juhani Pallasmaa, in *The Architecture of Empathy*, affirms the neuroscience basis for why the built environment matters: "When designing physical spaces, we are also designing or implicitly specifying distinct experiences, emotions and mental states. In fact, as architects, we are operating in the human brain and nervous system as much as in the world of matter and physical construction."

Colleges and universities are waking up to the opportunity to use their capital funds to build and renovate buildings and outdoor spaces that neurodivergent students need. With the tools available today and through the engagement of neurodivergent people, it is time to create holistically inclusive campus communities. ■ ABILITY

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by Valerie Fletcher
Principal Investigator from the New England ADA Center and Executive Director of the Institute for Human Centered Design

Additional charts from Census data



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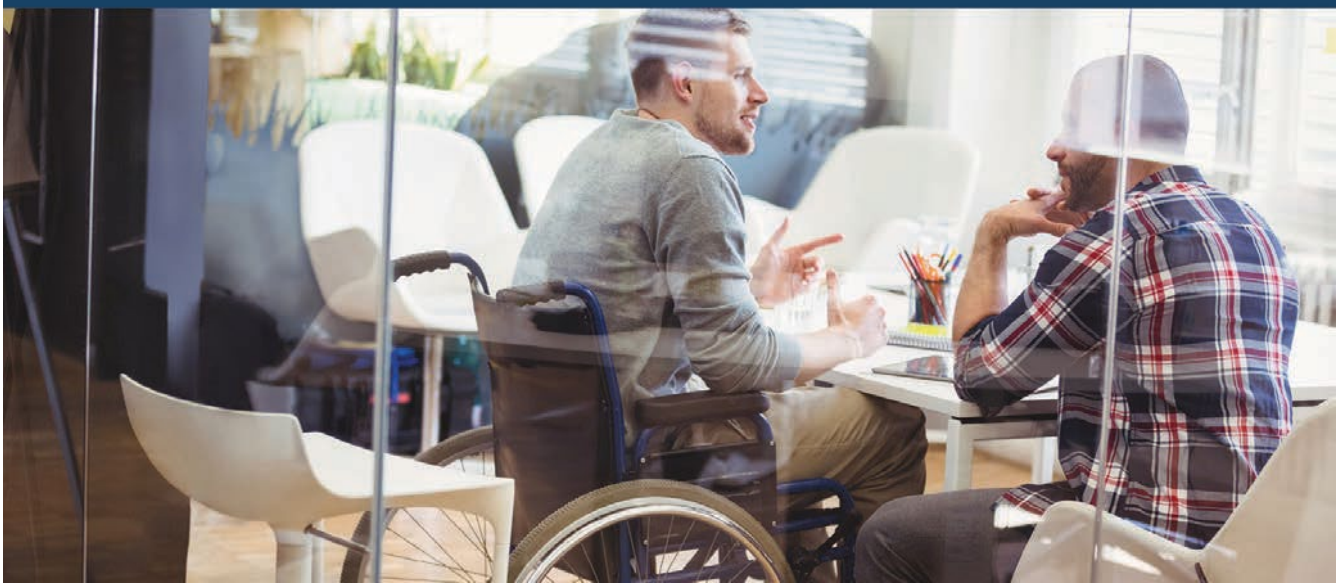
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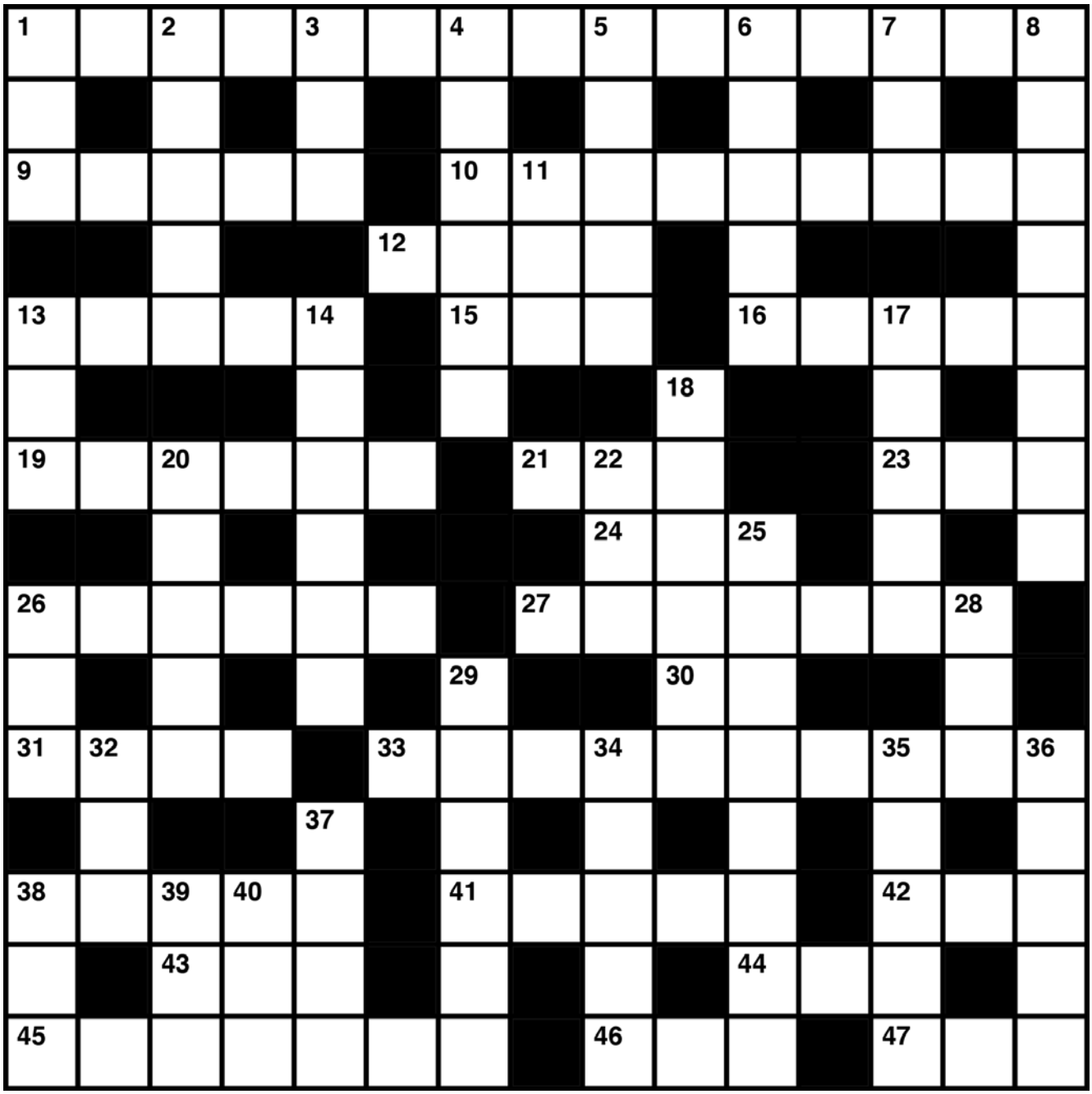
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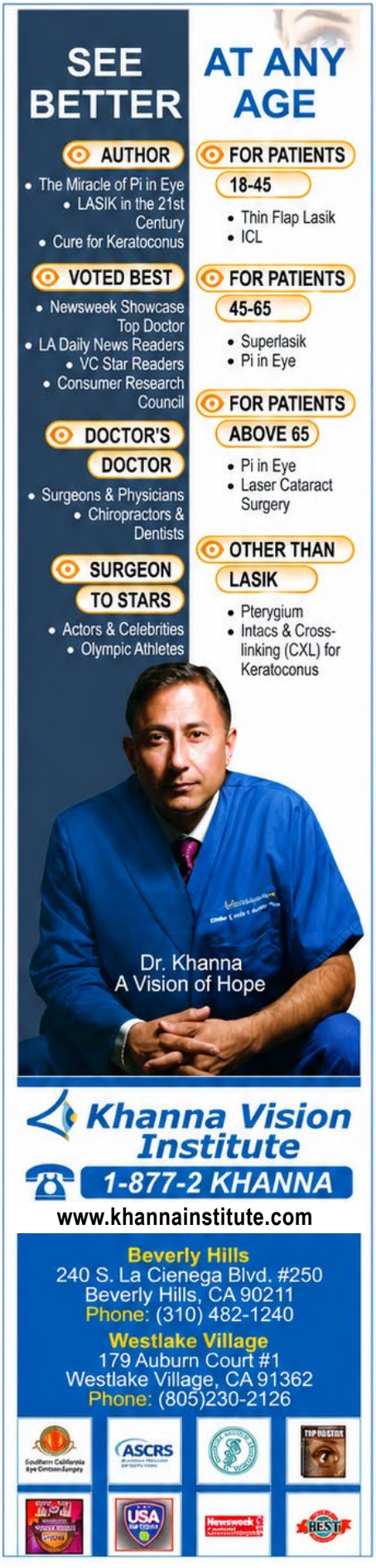
ACROSS

1. Innovative organization dedicated to bridging the gap between the hearing and Deaf communities, founded by Matt Maxey, 2 words
9. Prestigious medical research institute ____ Wasted on Objectively Obvious Observations
10. 2018-2019 TV series created by and starring Deaf actors Shoshanna Stern and Josh Feldman, 2 words
12. Transport goods over a distance
13. Face danger courageously
15. Weep
16. Grammy-winning singer of "Hello"
19. Director of the film in 27 across, Sara _____
21. Hot dog go-with
23. Part of the foot
24. Cleaning equipment
26. Is jealous of
27. Dance film created by individuals living with ME/CFS, long covid and other chronic illnesses
30. Internet address, abbr.
31. Award-winning film about a child with deaf adults starring Marlee Matlin and Troy Kotsur
33. Venture capital fund dedicated to early-stage, disability-centric innovations, founded by Brittany and Rich Palmer, _____ Ventures
38. Iowa State Senator born with spina bifida, now running for a US Senate seat, John _____
41. Hearing-related
42. US aviation controller, abbr.
43. Vote against
44. Dog's warning sound
45. She won four gold medals in para cross-country skiing ansd biathlon at the 2026 Winter Paralympics 2026, Oxana _____
46. In the past
47. BBQ residue

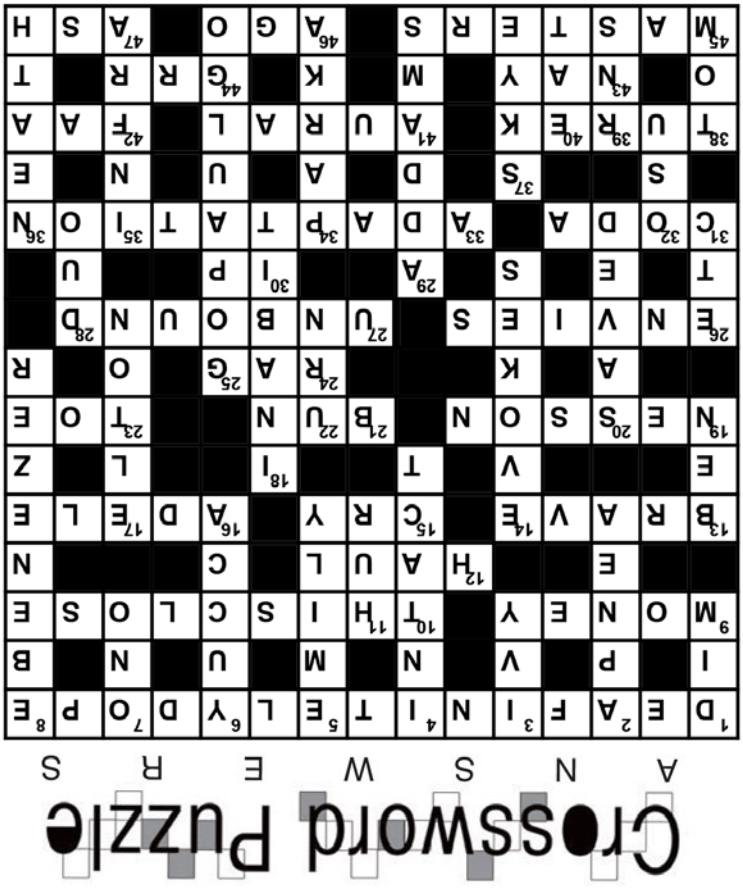
DOWN

1. Not bright
2. Sleeping disorder
3. Climbing plant
4. Not damaged or broken
5. One of the stars in "The Devil Wears Prada", _____ Blunt
6. Desert plant
7. Beatle's wife
8. Dickens' miserly Scrooge
11. Charlton Heston epic role, Ben-__
13. A well-known author, journalist, and disability rights advocate based in Los Angeles who was born with spinal muscular atrophy (SMA), ___ Mattlin
14. Brings to mind
17. "Candle in the wind" singer, first name
18. Shortly, 3 words
20. Rescued from danger
22. Big coffee dispenser
25. Long Haul Paul's T-shirt logo, 3 words
26. And so forth, abbr.
28. "Squirmy and Grubs" for example (they are a interabled couple on Tik Tok)
29. Eccentric family on 60s TV
32. Buckeyes' sch.
34. Hooded winter coat
35. Prefix with red
36. "Out to the road, out ____ the stars" Bob Seger lyric loved by Long Haul Paul, abbr.
37. Scottish island in the lyrics of the Outlander TV series musical intro
38. Male cat
39. O.R. workers, abbr.
40. Consume food

answers on page 78





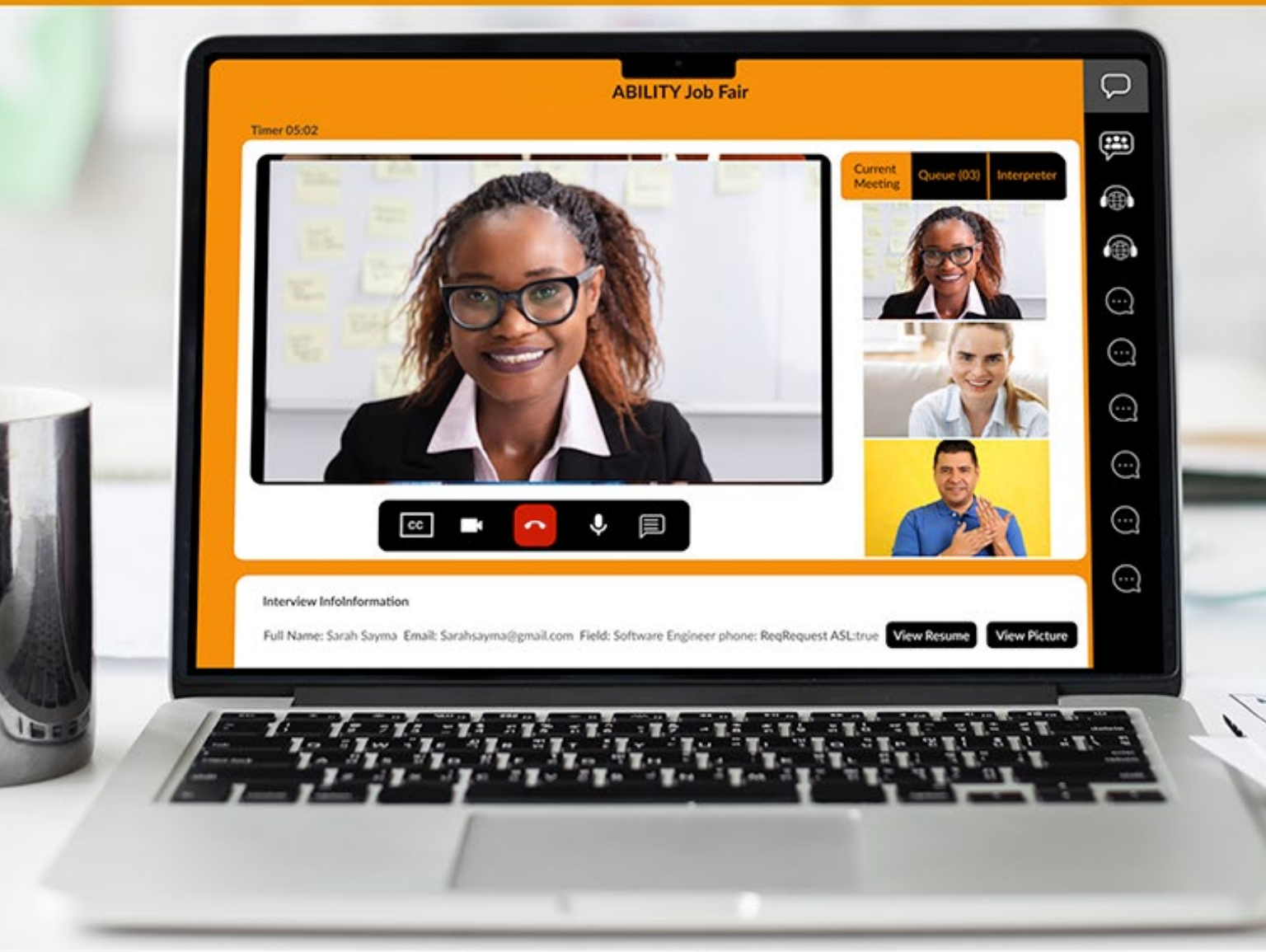


Crossword Puzzle

A N S W E R S

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