

LONG HAUL PAUL JOSH TOWERY JAMES IAN SQUEAKY WHEEL CROSSWORD PUZZLE EVENTS/CONFERENCES

ABILITY

GERRARD GOSENS

GD

BLIND AMBITION

Dr. Cindy Cai &
MSKTC
SCI • TBI • BURN

The
Canary
Code *by*
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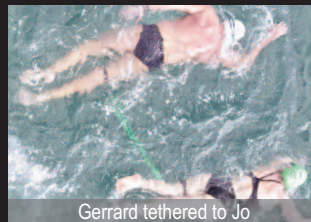
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RFK Jr. Outlaws SSRIs, Approves New Plant-Derived Treatment
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“You really feel like you can conquer the world when you’re on this stuff.”

Robert F. Kennedy Jr. and a Make America Healthy Again scientist held a press conference to announce their latest administrative changes. Here is a transcript excerpt.

RFK Jr.: The government has been harming Americans for too long. Therefore, I have reclassified SSRIs as schedule 1 drugs with no medicinal value. From this day forward, we will treat depression homeopathically with cocaine.

MAHA scientist: We’re going back to the good old days, specifically 1885.

Reporter: What are the side effects of cocaine to treat depression?

MAHA scientist: Serotonin levels and feelings of grandiosity quickly spike in patients, but they do not engage in any deeply regrettable behavior. So ... having too much of a good time?!

Reporter: What statistically significant findings from replicable systematic inquiries support that statement?

RFK Jr.: No one can answer that question.

MAHA scientist: Actually ...

RFK Jr.: No, I’m saying — Don’t answer that question. You’ll be fired.

Reporter: Isn’t processed cocaine a dangerously addictive substance?

MAHA scientist: We use a gentle refining technique. We mix the coca leaves with a purified petroleum, basically organic gasoline, add a sprinkle of baby powder and then allow it to dry in the Sun of America.

RFK Jr.: For the nonscientists like me, he’s saying cocaine is safe for babies.

Reporter: What’s next for MAHA?

RFK Jr.: We’re exploring cocaine as a vaccine alternative. You really feel like you can conquer the world when you’re on this stuff. ■ **ABILITY**

by Mia Ocean



Founder Steven Verdile

the-squeaky-wheel.com



My Best Friend KONA

We had to say goodbye to our dog Kona last week. He was almost 14.

Kona came to us at the very start of the covid pandemic, a sort of rescue from my daughter-in-law who was struggling with two animals who couldn't stand each other and fought continuously. Kona was half French Bulldog with Cattle Dog and a few other breeds mixed in. To be honest, my wife Elin and I didn't care much for Kona either, as every visit to their house was met with a slobbering chaotic canine who just wouldn't leave us alone, jumping all over anything and everyone. Our daughter Ayla knew one weekend dog sitting Kona away from her home would change our opinion of him. After pet sitting for a weekend, she casually mentioned she couldn't keep him anymore and begged us to take him in. We certainly saw a totally different dog during those couple days and that was the only reason we agreed to take him in.

Weeks of social distancing from the rest of the world that first winter he came to





Paul and his best friend and best wife

live with us led to a special friendship between a man and a dog that I could never have imagined. He really was a totally different animal. With all my public events cancelled, I didn't know how I was going to survive without income, and not being able to travel on my motorcycle put my whole life on hold. Kona injured his hip early on and was unable to walk for weeks. So the two of us laid on the floor together for days on end trying not to disrupt my wife who was trying to continue doing her job as best she could while working remotely.

Making sure he was carried outside when he gave me that look, cemented a unique and special trust. We spend our days watching Youtube videos, scrolling Facebook and wiping down groceries with rubbing alcohol. We even made a series of dumb videos called the Kona Corona Chronicles. For me, Kona was the very first pet I ever had and he truly became not just our dog, but my best friend. We survived the early days of the pandemic together and we bonded.

When I wasn't traveling the country on two wheels, a better part of my day was spent hanging out with Kona. He followed me everywhere I went and got angry at me before every motorcycle trip I took. Whether it was watching me mount tires, change the oil or pack the

bike or pack a bag with clothes in my bedroom, He knew I was going to be riding away, long before I even left! Boy, it was clear why he hated motorcycles!

Kona was smart. We had lots of wildlife visit our backyard and as Kona was a herding animal, any sound or smell of a chase was a reason to be excited. He eventually realized he needed to trick us by pretending he just casually needed to be let out to do his business when he actually knew there were deer outside. He remained composed and hid his excitement until the moment he heard the latch on the screen door released and he shot out like a bat out of hell! He fooled me every single time. Kona knew the names of his stuffed toys and when asked, he could retrieve five or six different toys from a basket of 20.

My dog was kind. Kona would normally bark goodbye, standing on the foot of the bed, looking out the window over the driveway when my wife left for work, except if he believed I was sleeping. Instead of barking, he would just whimper very quietly she drove away. He consciously was making an effort not to wake me up.

Kona was thoughtful. Playing fetch in the house often had a toy flung into an end table with drinks or food on it. As he was charging to get the toy, he would pause

for a second, then with Ninja-like precision, extract the toy from around the legs of the table, without ever spilling a drop. Unlike us, Kona never once spilled anything while playing fetch in the house.

He was trusting. As his hearing started to go, a roll of my eyes, a hand gesture or a pointed finger was all he needed to know where we were going or what we were doing next. As his health was failing he would need just a look and a nod to assure him I would pick him up and carry him to wherever he wanted to go.

My dog was loyal. I will never forget the afternoon Kona and I were sitting outside on the back lawn when the mosquitos arrived. He would snap at the ones buzzing around his head or twitch his ears. I had one buzzing around my face that I kept batting away. Kona watched me for a moment and then jumped up and snatched the pestering mosquito just inches from my face.

Kona was patiently polite. No matter how hungry he was, he would wait for permission to eat his dinner and despite drooling a bit, would never eat food that fell to the floor without the ok from us. Of course, he knew what facial expression to show us and usually got the green light!

He loved to walk in the morning and wanted to visit all the neighbors he knew, even when they were not out in their yard. Every afternoon was a car ride to the park or the school ballfields and another adventurous hour hopping to meet new human friends along our walk.

At the end of most summer days, even from a sound sleep on his favorite spot on the couch, Kona recognized the sound of my wife sliding the freezer door open as time for a little ice cream.

A diagnosis of congestive heart failure over the winter was followed by weakness in his limbs in April and eventually inability to walk. His desire to chase the turkeys, rabbits and deer across the backyard each day was finally stifled by his body giving up on him. He no longer had any interest in his favorite position looking out the living room windows which were at floor level. He let us know in various ways that he was tired and ready to say goodbye.

We may have only had Kona for five years, but he quickly became a central part of our family and he will be missed dearly.

Kona truly was this man's best friend. ■ ABILITY

Kona Corona Chronicles

facebook.com/longhaulpaulusa/videos/
kona-corona-chronicles/740514528497566





In the vast and often complex landscape of rehabilitation and life after injury, navigating the scientific jargon and understanding the nuances of ongoing care can be a daunting challenge for individuals with disabilities and their families. Enter Dr. Cindy Cai, principle researcher, and the Model Systems Knowledge Translation Center (MSKTC) who are on a mission to disseminate critical medical and research information.

Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the MSKTC plays a vital role in supporting those living with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injuries. While the name might sound technical, Cai's work is profoundly human-centered. She spearheads efforts to transform complex medical research from "benchside" scientific discovery into "bedside" practical, patient-friendly resources. Along with its numerous medical resource centers, NIDILRR ensures that the wealth of knowledge generated by Model Systems research centers genuinely serves the needs of individuals on their long-term rehabilitation journey.

ABILITY's Dr. Tom Chappell and Chet Cooper met with Cindy Cai, PhD to delve into the workings of the MSKTC and how they are making essential health information more accessible.

Chappell: How would you describe what it is you're doing?

Cai: I'm with the Model Systems Knowledge Translation Center. The name has "model systems" and "knowledge translation," and the "center" is self-explanatory. Model systems are competitive grants funded by the National Institute on Disability, Independent Living, and Rehabilitation Research within the Department of Health and Human Services. NIDILRR, which is the funding agency, funds three model systems programs, one in spinal cord injury, SCI, another one is in traumatic brain injury, and the third one is burn injury. The Model Systems Knowledge Translation Center is set up to work with the medical researchers from these model systems centers to develop patient-friendly resources, to support their rehabilitation process.

Dr. Tom Chappell: So, the term was created by the National Institutes of Health, that subdivision, I guess that's their term for the programs that they fund?

Cai: Mm-hmm, model systems.



Chappell: So, is most of what you're doing the translation work? Are you doing other things?

Cai: The translation work, the translation aspect is so interesting, it's a funny story. I grew up in China and was a translator there, and I never thought I would be working for a translation center. (laughs) The translations were different than what I did from English into Chinese and Chinese to English.

Probably you have heard that this knowledge translation is a framework that was first coined by, the Canadian Institute of Health. Don't quote me on that. (laughs) But the Canadians, our colleagues, our neighbors. It is a dynamic process to make research more relevant for end users. Their goal is to shorten the distance between the bench side, where the scientists develop the intervention, and the bed side, where they implement the new discoveries in clinical practice.

Cai: So, knowledge translation is a whole very interesting scientific-based process to engage the stakeholders from the beginning to the very end, to make the resources more relevant for the end users. We're here to support the model system researchers in their knowledge translation, in their research process, to apply the knowledge translation framework or principles in their process and then to develop resources that are more relevant to the stakeholders. So "translation" is a different term than just simply language translation. (laughs)

Chappell: We gathered that, and it kind of makes sense, because, as I'm sure you'll agree, in science and medicine we actually are mostly speaking another language, and that's what you're talking about, translating more technical and scientific language into language that lay people can understand. Is that correct?

Cai: That's correct. And we also use their input to develop resources. It's just like marketing. I actually was trained as a researcher, on the other hand, my father was a businessman, and he always wanted to know the markets. And I didn't know that until—I didn't learn how to appreciate them until I went into knowledge translation, that we have to understand what our patients' needs are. What are some of the topic that they're very interested in? What kinds of formats do they want to receive information in? And then we do all of these called market research, to use assessment results to identify topics and then packaging the way that would be useful to them. We also test our resources with the end users before we publish them to ensure that they're really user-friendly.

Chappell: This probably covers a broad spectrum of the end markets, both inpatient, outpatient, anything and everything, right?

Cai: The National Institute on Disability, Independent Living, and Rehabilitation Research, NIDILRR, is dif-

ferent from NIH or other agencies. They focus more on rehabilitation. As you know, it's a very long process. It's chronic illness. They're being discharged from the hospital is a really long recovery process. So we focus on rehabilitation.

Chappell: Inpatient and outpatient, though, I presume?

Cai: Uh-huh. And community.

Chappell: So, long after the injuries typically and dealing with more chronic impairment and needs. Give me some specifics as to how it might go for a particular patient with a particular set of needs. Are you coming to them with different types of therapists, with different expertise? Are you providing literature? I assume that's some of it. And maybe other types of resources? How would it work for a typical spinal cord injury patient?

Cai: I was being incorrect when I said "patient." Some of them have been discharged and have been living in a community for a long time, and they're not patients anymore. So, let me just use the broader term of "individuals living with a spinal cord injury, SCI, TBI, and burn." We have developed many resources on spinal cord injury, for example, autonomic dysreflexia, driving after a spinal cord injury, adaptive sports, exercise and through exercise enjoy life. We have about 24 topics on various aspects of rehabilitation for people with spinal cord injury. We use our survey results. Those are basically collected from individuals living with spinal cord injury and also their caregivers because we understand the caregivers play a very important role in their rehabilitation process. We've developed resources for both the individuals living with the injury and also the caregivers.

Cai: We identified those topics that are really critical to them, which include psychological, like depression, mental health issues and also some medical issues like wheelchair use, safe transfer. Those are important topics for them, also bowel and bladders, that's another important topic. Sexuality, we focus also—we want to make sure that people still live well with all these conditions. We identified those topics and worked with medical researchers to develop the content, and then we packaged them in a way that's engaging, using plain language when we write those. We also use cartoons, comics, to develop those resources to communicate to people who may be interested in learning—have different learning styles.

Cai: We also have video format as well. So we developed the content and we also test the content with consumers and then we disseminate, we post everything on our website. If you like, I'd be happy to give you a tour of the website and show you some of the resources that we have.

Chappell: Sure. I was going to ask you to name a few of



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the more esoteric issues off that list of 24, but why don't you do it with a tour of the website?

Cai: OK. Let me just share my screen with you. This is our website, Model Systems Knowledge Translation Center [mskctc.org]. We've organized our resources your injury area, SCI [spinal cord injury], TBI [traumatic brain injury], Burn, and also just the knowledge translation tool kit, with tools to support scientists to apply knowledge translation process to better help patients and families. And also if you want to learn more about model systems, we have resources about model systems, and also there's the database that they've created, which is the world's largest database in SCI, TMI, Burn.

Cai: We're organized by different types of resources as well, so "Living with SCI" and "Research Opportunities." We have an ambassador's program to try to engage people to help us spread the word. And we have fact-sheets, narrative slide shows, and useful comics. Others are storytelling to communicate health information. We have videos and hot topics, which are topics that people are interested in where we compile the resources, create a suite of resources in each of the topics, online course and quick review are the plain-language summary of model system publications. We have a research database, we have systematic reviews, and the model systems directory with all the resources we have.

Cai: We have "Adaptive Sports," "Adjusting to Life," "Aging & SCI," "Depression," Bladder Management," "Autonomic Dysreflexia," "Driving," "Employment," "Exercise & Fitness," "Gait Training," "Bowel Management," "Pain Management," "Opioid Use" for people with SCI, "Personal Care Attendants," "Pregnancy," "Respiratory Health," "Safe Transfer," "Sexuality," "Skin Care," this is one of the popular ones, "Pressure Sore," pressure injury, "Spasticity," "Surgical & Reconstructive Treatment," it's also for people with pressure injury, "Understanding SCI," there are two parts in that, "Urinary Tract Infection," and "Wheelchair Information."

Cai: Those are the 24 topics we have. We're developing more.

Chet Cooper: Where are you getting those outside resources to provide to people.

Cai: Our main vehicle is the website. We have a vibrant website, with 22,000 links from 3,000 unique websites across the world linked to our website. Our main vehicle is the website. And then we also work with United Spinal Association to disseminate their networks. Many of the resources are on the United Spinal Association's website. We also work with the local chapter systems as well.



Cooper: If I was a person with SCI who was looking for employment and wanted to find a resource, where would I go on your website right now?

Cai: Oh, how to find a job? That's such a good question. It's more of a factsheet about some of the things people need to know after a spinal cord injury about engaging to get back to work. "How the law can protect you," and how you can get started. I think our resources focus more on the resources that are available to people and they can use.

Cai: We also provide some tips for people to use as well. I think that you're probably asking the questions of how people can do it, right?

Cooper: No, resources to find a job. I'm seeing a lot of language there that talks about like you said, law, and other resources, but it's like resource to resource, but where does the rubber hit the road where I could

actually find a job?

Cai: That's just such a good point. That should be included when we update this fact-sheet. This one was developed before we had the Center.

Cooper: I see you have a link to AskJAN.org. That does have resources for people, but it's taking them to another place to find another resource. Ask Jan is a great resource, of course

Cai: Uh-huh. I think I see what you mean, more resources where they don't have to go to another place for it. That's a good point. Thank you.

Cooper: You do this with TBI and Burn as well?

Cai: Mm-hmm. It's the same organization for people with TBI, I think we have about 27 topics. I really love the one about "Voting Tips." We just developed that last year. It would be applicable to a lot of people with disabilities. We also have Spanish resources too. And I understand there are a lot of people using mobile phones, so we have a web page for people that's mobile-responsive, and we also have PDFs. We talk about "Why vote?," "What's Your Responsibility?," "What's Your Right?," "How do I prepare to vote?," "Where to Register?," lots of practical things.

Chappell: Is much of that very specific to the impaired, but is it more what you might tell anybody about voting?

Cai: I think it's taking brain injury into consideration because a lot of times they need a ride to get to their place. If they can't go, they need to know. And also being informed of certain topics and where to get help.

Cooper: It's not just accessibility issues; you also are talking specifically to TBI?

Cai: Mm-hmm, yes.

Chappell: Cognitive dysfunction as well?

Cai: Mm-hmm. And also, with burn as well. We have about 20 topics on burn injury. We focus more on the moderate to severe burn injury, like the severity of the brain injury. Exercise, how you can get back to exercising, healthy eating. We developed a whole series, just recently published, on sexuality and intimacy after a burn injury. It's a factsheet with a suite of videos. We

won five Telly awards for our videos.

Cooper: You produced the videos?

Cai: We do. We work with local and state TV and radio stations on videos. We have one video on couple's relationships after TBI that won a Telly award as well. We focus on hot topics. We have a main story typically, and then we have little video clips of the story. We engage real people with brain injury, consumers, their families, and we engage with clinicians as well in short video clips to go with them. The sexuality after burn injury is the most recent one. We have employment after burn injury, exercise, and this is the sexuality and intimacy after a burn injury, which won the Telly award.

Chappell: You just mentioned systematic reviews. What do you mean by "systematic reviews"?

Cai: They are scientific. —It's a systematic process to conduct literature reviews. We have worked with the model system researchers to develop systemic reviews. Sometimes we do scoping reviews, depending on the topic. And then to focus on more TBI, SCI, and Burn injury. Those are systematic reviews.

We publish in peer-reviewed journals and then also we use the results from the systematic reviews to develop consumer products. For example, the sexuality and intimacy after burn injury video is based on a systematic review on the topic by the Burn model system researchers.

Cooper: You're creating consumer products that you're marketing? How does that work?

Cai: All of these resources are consumer products. To clarify, we call our individuals living with all the injuries and their family members the consumers.

Chappell: You're calling them "products," but you mean a production of your work, really?

Cai: Mm-hmm, that's correct.

Cooper: On the knowledge translation, how does the input of the knowledge come to you? How do you vet that knowledge?

Cai: You're asking about our knowledge translation process, not necessarily the knowledge translation tool kit?

Cooper: Let's say I created a product that can help SCI. How do you know that I've created that product? How do you vet that product to disseminate it into your model system to let people know that it exists?

Cai: That's a good question. It's basically the process. We first work with the model system researchers to con-

duct needs assessment, to see what some of the topics people who are living with SCI, TBI, and Burn are really interested in. Then, we work with medical experts to develop content into fact sheet format, typically. The factsheet is basically the bedrock product we have. Then, we translate the factsheet into other information, such as comics and narrative slideshows. We use the fact sheets in developing the information.

For example, one factsheet we've worked on is the loss of smell and taste after TBI. Lots of doctors out there try to save their patients' lives and work very hard. After they get discharged, the loss of taste and smell may not be their top priority when they're trying to save patients' lives. Later on, during rehabilitation, it's truly a very important quality of life indicator.

Based on consumer input and clinician input, we know this is really important, so we developed a factsheet on the loss of taste and smell after TBI.

The content is based on research and expert consensus because there's not a whole lot of research to be found. And still, we need to provide some guidance for people living with the injury. So, we use the consensus from the model system researchers, their project directors, medical doctors, and medical researchers to develop the content, and then we test it with consumers. We test it with the end users, that would be people living with SCI, TBI, and Burn, and their families, and we ask whether the information is presented in a way that is easy for them to understand and whether the information is presented in a way that is appropriate, sensitive, and empowering.

Cai: Our goal here is to develop a resource to empower people living with these injuries and their families because they have to know how to make medical decisions. They have to be informed consumers. You have to make them understand what this condition is, what it means and what typically presents as this condition. Then we talk about why this happens. We present tips for them to try and we present tips and strategies for their caregivers to try. Finally, we provide additional resources for them to try.

During the interviews, we don't just ask them, "What are some topics you're interested in?" We also ask them, "How would you like to receive the information? In what kind of format would you like to receive the information?" That is also part of the marketing research as well. We have to know the format they want to receive the information in and what types of information. Lots of people are still interested in the print resources because, based on our needs survey results, I think still close to 70% of people still want print resources. About 40% want video resources and about 20% want to have podcasts and other resources.

Based on their needs, we package these resources for



Cindy Cai at the North American Brain Injury Society's 17th Annual Conference

them. Lots of people say, “Oh, we wanted to hear from our doctors.” So, we work with rehab hospitals to include our resources in their discharge packages. There are displays in patient waiting rooms. We also work with—lots of times they receive just from word of mouth—their support groups, so we recruited people to serve as ambassadors for us. We work with associations that have local chapters to share our resources. I spoke with the United Spinal Association’s chapter leaders about resources. I go to conferences to show our resources. I go to local conferences as well, like the chapter conferences. Lots of people can’t afford to go to national conferences. So, we bring our resources to them.

We understand that a lot of people from low-income families don’t have a high-powered Internet connection. We make sure our resources on the website are not only accessible but also mobile-responsive. People are using smartphones to receive health information. So all of these factsheets, the PDFs are for them to print it out, but we’ve created a web page for each factsheet, for each product, so it’s all mobile-responsive. That’s how we disseminate. We also have the Spanish portion of the website as well. People from Spanish-speaking communities can have access.

Cooper: We got a press release from a company called LoopPlus.com. It’s a new company with a system set up for wheelchair users to monitor their pressure. For example, if you’re sitting too long in a wheelchair, it will give you this data. My question is, how does that company get into your system so that people who need something like that can find it? It’s definitely of value. Is that outside of your wheelhouse?

Cai: We’re funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). It’s the federal government. We are here to basically promote the work, working with model systems, and to promote the work of model systems. We don’t promote the work of commercial products. We typically do not promote or endorse any products.

Cooper: How does that work? Even though a consumer product is helpful to the consumer because it’s a business, are you not able to include it?

Cai: That’s such a good question! I wish we could be a hub for all of the resources on SCI, TBI, and Burn. We also have a set of scope of work here as well. I think that our goal here is to develop resources that can help people. We provide general strategies to help people. We have limited budgets, and we have also a limited scope of work that we focus on.

Cooper: So, you’re trying your best while still in the silo?

Cai: I think we’re trying our very best within the scope of work that is set for us by the funding agency.

Cooper: Your work seems to be more with the different centers, communicating and bringing data from those different centers into a readable format for your consumers?

Cai: I think that’s an accurate description. I also want to clarify that what we do here is not driven by the work of model systems so far. I think it’s a two-way communication. We communicate with our consumers, and we bring the needs of consumers to our model systems, and then the model systems researchers and resources.

And also, if they want to develop resources, we’ll make sure there’s a need, that it’s not just a scientifically good idea from scientists’ perspective, that there’s a real need of consumers.

Chappell: Does a lot of the work fall under the purview of social science research? You go out and you poll a population of people? Do you have a population of consumers you have access to through these centers and you’re collecting and some of that’s sort of a social science sort of approach?

Cai: The work we do here is social science, a part of social science, that’s correct. The model system researchers do medical research and psychological research as well.

Chappell: Are there existing standing databases into which hordes of various types of information are fed

and can then be harvested or examined later for compiling and maybe even publishing?

Cai: What kind of data are you referring to?

Chappell: I would think a lot of it would be what these consumers are demanding, what they're getting, how it's helping them or not? Is anything like that going on?

Cai: Oh, yes, absolutely. We do ongoing consumer needs surveys and assessments. We constantly have this on our website, and we just started a new cycle where we're revisiting our survey instruments. We're also working with our partners to develop and disseminate our surveys. We periodically analyze the data to use the information to guide our work.

Since you've brought up data, there's another interesting fact about the model systems centers. There are 14 in the SCI program and 16 in TBI and 4 in Burn, who also collect data from patients with SCI, TBI, and Burn. They've created the world largest comprehensive database in these three injury areas.

Chappell: Are these centers that you're calling them typically based in a brick-and-mortar facility? Can they be more diffuse than that?

Cai: They are medical schools and medical facilities. The University of Alabama Medical School has a TBI one, and Craig Hospital: Neurorehabilitation Center Colorado. Indiana, Massachusetts, University of Michigan. In Minnesota, we have the Mayo Clinic. JFK University Medical Center in New Jersey, TBI model system. In New York we have Mount Sinai, in Ohio State University, Baylor in Texas. Virginia Commonwealth University has a TBI model system as well, and the University of Washington Medical School. Those are hospitals and medical schools.

Chappell: So, these centers are compilations of multi-modality involvement at each of those institutions? For TBI, neurosurgery would be involved, neurology would be involved, psychology would be involved, rehabilitational medicine, etc.?

Cai: That's correct. The model system was created in the 1970s. Instead of a fragmented rehabilitation, the model system centers are designed to provide comprehensive rehabilitation from acute, post-acute, into community living through a multidisciplinary team.

Chappell: So, it is still for the consumer, we're calling them, institution-based and it sounds to a great extent, although at the beginning we kind of got away from that a little bit, it's not medical care per se maybe, but it tends to be medically-based and accessible through physicians and nurses and therapists, am I correct?

Cai: They do provide inpatient rehabilitation. Meanwhile,

they provide inpatient rehabilitation model system centers, and they also conduct research.

Chappell: And outpatient, of course, too?

Cai: Mm-hmm. Outpatient as well.

Chappell: I guess it's sort of a two-way street. Many of your clients, your consumers, get to you via having been cared for in one of these centers, but do they get to you in other ways?

Do you have outreach as well beyond just having the website available?

Cai: That's correct. The model system patients at model systems do reach out to us. We've been receiving a lot of inquiries through our website each day. They leave comments for us, and we respond to them with our resources. They want to be part of our work; we talk to them to see how they may engage with us and how we can help them.

Chappell: It sounds like someone at each of these institutions, for example, has decided they want to apply for one of these grants? Is that how it works? It comes from within the institution?

Cai: That's correct.

Chappell: More than likely, in most instances, they would be from the department of rehabilitative medicine? It's through medical center research-based applications, just like one of the labs might apply for NIH funding?

Cai: That's totally true as you described it. It's a great description of how the grant works. You submit a grant, it's a competitive process, every five years. It's a five-year grant, typically.

Chappell: Are you part of more an umbrella of organizations that oversees this and provides resources to each of the centers? Is that what you do mostly?

Cai: I work for the American Institutes for Research. It is a nonprofit, nonpartisan research organization in the Washington DC area. I want to say nonpartisan and nonprofit because we're in the DC area. (laughs)

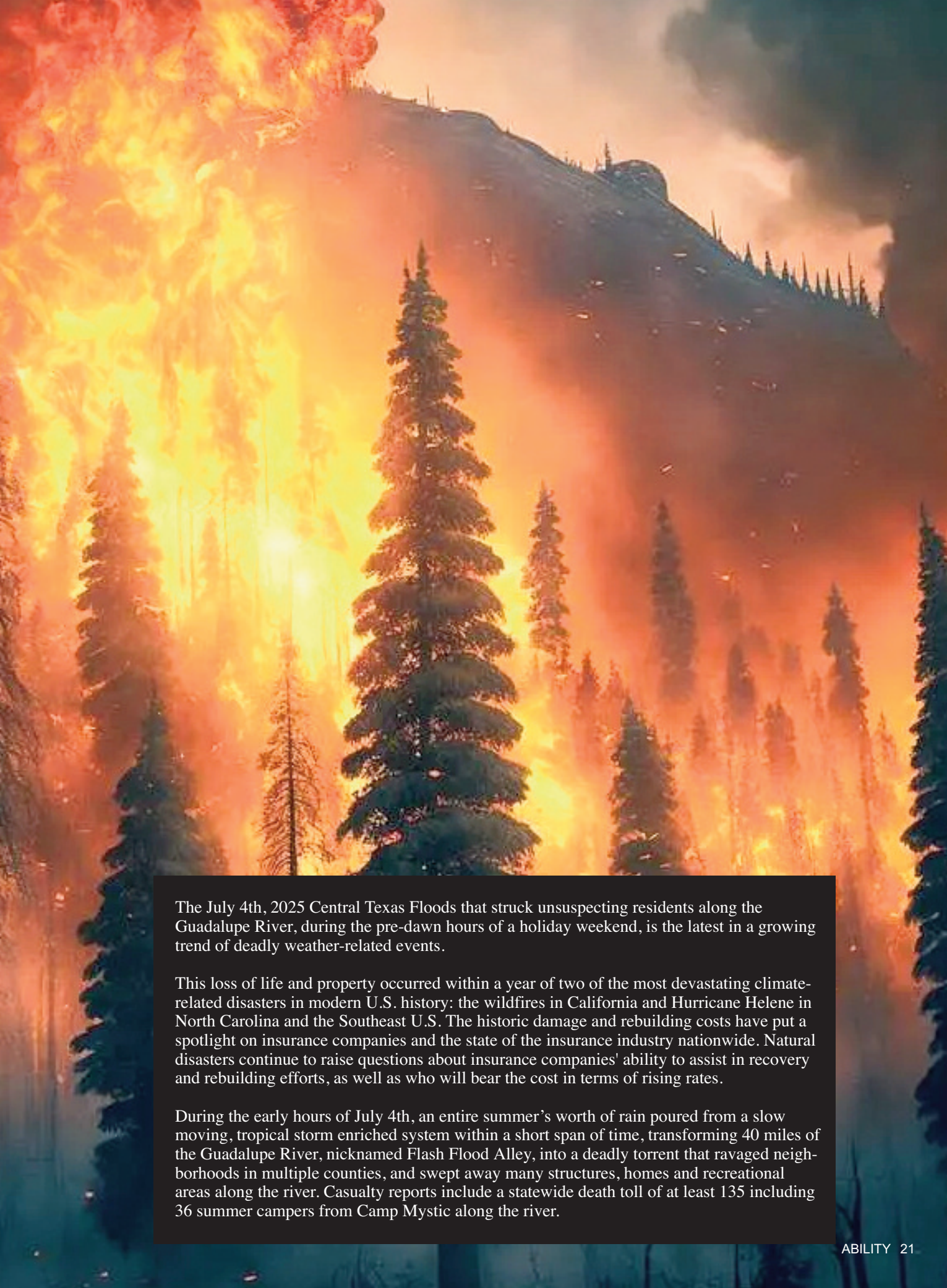
This is a grant that I applied for with my team of researchers from the principal investigator on this grant of Model Systems Knowledge Translation Center. It is a grant that the funding agencies set up to work with model systems, to reach out to the stakeholders to support model systems in their work and then to develop resources to help the end users, people with injuries. ■ ABILITY

air.org/experts/person/xinsheng-cindy-cai



Climate Change vs Insurance Rates

Fires, Floods, Hurricanes, Drought, Sea
Rise, etc...



The July 4th, 2025 Central Texas Floods that struck unsuspecting residents along the Guadalupe River, during the pre-dawn hours of a holiday weekend, is the latest in a growing trend of deadly weather-related events.

This loss of life and property occurred within a year of two of the most devastating climate-related disasters in modern U.S. history: the wildfires in California and Hurricane Helene in North Carolina and the Southeast U.S. The historic damage and rebuilding costs have put a spotlight on insurance companies and the state of the insurance industry nationwide. Natural disasters continue to raise questions about insurance companies' ability to assist in recovery and rebuilding efforts, as well as who will bear the cost in terms of rising rates.

During the early hours of July 4th, an entire summer's worth of rain poured from a slow moving, tropical storm enriched system within a short span of time, transforming 40 miles of the Guadalupe River, nicknamed Flash Flood Alley, into a deadly torrent that ravaged neighborhoods in multiple counties, and swept away many structures, homes and recreational areas along the river. Casualty reports include a statewide death toll of at least 135 including 36 summer campers from Camp Mystic along the river.

In January 2025, Los Angeles experienced its latest in unprecedented wildfires in the region to date, spurred on by extreme drought and high sustained winds of up to 100 mph. Fires across Los Angeles and Los Angeles County saw a death toll of 28 by the end of January, scores missing, 200,000 forced to flee, 38,000 acres burned and 15,000 structures destroyed.

2024 was an above-average year for Atlantic hurricanes. In late September of 2024, hurricane Helene hit Florida, Georgia, and the Carolinas, dropping more than a foot of rain in its path, devastating rural communities and causing more than 230 deaths. North Carolina, alone, estimates more than 200,000 people were impacted and upwards of 100,000 homes destroyed or damaged.

With increasingly extreme weather patterns, catastrophic events like the Central Texas floods, the fires in Los Angeles and hurricanes in the Southeast US are becoming more frequent. The growing financial burden on residents, communities, governments, and insurers has raised concerns and, occasionally, outrage about the long-term viability of private societal institutions and public safety nets.

In Texas, despite the state's Office of Emergency Management issuing a number of National Weather Service updates warning of dramatic spikes in expected storm surge along the Guadalupe River throughout the early morning hours of July 4 in Kerr County Texas, a concerted effort to effectively alert residents of the imminent danger proved inadequate.

In the aftermath of the deadly flood, inquiries into the failure of emergency management systems have prompted local and state officials to claim there was no way to foresee the magnitude of the event. Texas Governor Greg Abbott refused to point to responsibility for failure, stating in a July 9th press conference, "Know this, that's the word choice of losers. The way winners talk is not to point fingers."

However, there has been ample statistical data to refute the assertion that extreme weather events, including flooding in Texas hill country, were not predictive. According to data collected and published by NOAA (National Oceanic and Atmospheric Administration) between 1997 and 2010, billion-dollar disaster events per year averaged \$6.6 billion. The average significantly increased to \$17 billion disaster events per year between 2011 and 2024.

[Editor's note: NOAA's National Centers for Environmental Information (NCEI) will no longer be updating the Billion Dollar Weather and Climate Disasters product.]

Although FEMA data analysis indicates that Texas annually sees the most damage due to flooding, in terms of loss of structures, population and agriculture, approx-

imately 5 million Texans currently reside in areas prone to floods. According to Texas Public Radio, state officials have known the risks but have been slow to address the issue. TPR points to a Texas Water Development Board report published December 2024 which estimates a staggering 54 billion dollars required to address Texas's most urgent flood prevention needs. To date, the state has allocated a fraction of the estimate, \$669 million, towards this goal.

Increasingly, data scientists are finding FEMA mapping and weather modelling, which are based on old and limited data, woefully inadequate. In response to the denials and unpreparedness exhibited in the wake of the Central Texas floods, multiple news outlets have turned to data published by private companies like First Street, a non-profit climate risk analytics company that quantifies and reports climate risks for individuals and communities. In an interview with NPR, data scientist Jeremy Porter of First Street, found FEMA data to be outdated and that dangerous flood zones were more expansive in areas like Camp Mystic than originally known.

Accuweather estimates the disaster cost between \$18 and \$22 billion in damages and economic losses. In a CNBC article, Loretta Worters of the Insurance Information Institute state that about 2.5% of Kerr county homeowners have flood insurance. Respectively, First Street estimated that more than 20% of homes are in flood danger areas. This is emblematic of homeowners being uninsured or underinsured across the US. Over the past 20 years, 99% of US counties experienced a flood event. It's estimated that 40% of national flood insurance program claims are from outside high-risk zones."

It's too soon to know the ultimate impact Texas floods will have on insurance coverage, however some locals have already assessed the financial burden of rebuilding. In an interview with NBC News, Kerrville resident, Cynthia Thomas, states "None of us have flood insurance because my next-door neighbor got a quote for his new house, and it was \$6,000 per month for flood insurance... I know people who are not going to be able to rebuild.

While flooding continues to strain communities and insurers with mounting recovery costs, another threat has emerged with equally alarming potential. "A couple of years ago, when KCC released our first wildfire model, it showed insurers that there were large-loss scenarios in the tail of their loss distributions from wildfires that were comparable to hurricane losses," Karen Clark, founder of Karen Clark and Co. tells the Royal Gazette. The implications are stark. Wildfires, once viewed as regional anomalies, now rank among the most costly catastrophes in the way insurers evaluate disaster risk today.

California is experiencing an increasing number of

wildfires that require significant effort and emergency resources to contain. In 2024 alone, the state recorded 8,024 wildfires, burning over one million acres. Future modeling predictions for the state are materializing and proving accurate. Researchers studying long-term extreme climate pattern changes have reported an alarming increase in fire damage over the past 40 years. A study jointly conducted by The Nature Conservancy and emLab, UCSB, finds that between 1979 and 1988 the total acreage burned in California was 3.37 million. The figures rose to 7.08 million total acreages burned from 2009 through 2018.

Losses of natural lands and communities have prompted seven of California's largest private property insurers to withdraw from the state, reduce coverage, or limit new homeowner policies. This response from insurers, including State Farm, Allstate, Farmers, USAA, Travelers, Nationwide and Chubb, has contributed to the uncertain state of the California home insurance market. According to the California Association of Realtors 2023 Annual Housing Market Survey, 17% of home buyers had difficulty obtaining insurance and nearly 7% of real estate deals fell out of escrow because buyers were unable to obtain insurance.

To understand California's complex insurance landscape, one must look back to Proposition 103, the Insurance Rate Reduction and Reform Act, passed by voters in November 1988 with a 51.1% majority. According to Insurance.CA.gov, Proposition 103 aimed to protect consumers from arbitrary insurance rates, encourage a competitive marketplace, and ensure fair, available, and affordable insurance for all Californians.

Proposition 103 instituted a regulatory system known as the "prior approval" system, where the Insurance Commissioner must approve rates proposed by an insurer before the insurer can implement property and casualty insurance rates. Thorough, impartial review by the Department's rate regulation experts has saved Californians billions of dollars in premiums while helping to maintain a solvent market able to pay consumers' claims.

But some believe that Proposition 103 has proven to be a rigid set of regulations that, instead of stabilizing the California homeowners insurance market, it has been the cause of major insurance players withdrawing or reducing coverage. Lawrence Powell, R.J. Lehmann, & Ian Adams in the paper "Rethinking Prop 103's Approach to Insurance Regulation" (International Center for Law & Economics on November 6, 2023) conclude that "Prop 103 has created an insurance market that struggles to work efficiently even in the best of times and is virtually impossible to sustain in periods of acute stress." They assert that Proposition 103 has become a set of strict regulations that, instead of stabilizing the California homeowner's insurance market, has caused major insurance companies to withdraw or



reduce coverage. They conclude that Prop 103 struggles in the best of times and is likely unsustainable during periods of high stress.

Leyman and Adams highlight outdated legislative ideology that relies on historic modeling instead of forward-looking climate predictions and weather modeling. They also point out the difficulty of amending Prop 103, which requires a new statute voted on by citizens. The state legislature can only vote "in furtherance of the statute" and cannot overturn it. They state, "The recent story of California's property & casualty insurance market has been one of uncertainty and induced dysfunction."

Prior to the COVID-19 pandemic, California's market was saddled by insurance availability issues stemming from a series of historically costly wildfires.

In the aftermath of increased fire events, Prop 103 appeared untenable for California homeowners insurers. They posted a combined underwriting loss of \$20 billion for the massive wildfire years of 2017 and 2018 alone. In comparison, this loss was more than double the total combined underwriting profit of \$10 billion generated from 1991 to 2016.

In response to those losses and the inability to adjust rates quickly, the number of non-renewals of California residential-property policies increased by 36% in 2019. Additionally, new policies written by the state's residual-market FAIR Plan surged by 225% that same year. The FAIR Plan serves as the last-resort insurance for those unable to obtain coverage in the voluntary market.



To slow the surge in FAIR Plan insurance policies, California Department of Insurance in December 2019 enacted moratoria barring insurers from nonrenewing approximately 800,000 policies in ZIP codes adjacent to specified major wildfires. As of November 2022, nearly 2.4 million policies statewide were in ZIP codes under nonrenewal moratoria, many of them added following additional catastrophic wildfires in 2020.

In September 2024, Governor Gavin Newsom issued an emergency executive order directing California's Department of Insurance to implement reforms designed to stabilize California's rapidly crumbling property insurance market and to attract insurers to re-enter the market.

Insurance Commissioner Ricardo Lara has instituted the Sustainable Insurance Strategy, that features a faster rate approval process, forward-looking catastrophe modeling, reforms to the California FAIR Plan, and allowing insurers to factor reinsurance costs into rate hikes. Consumer advocates have warned these reforms will benefit insurance companies over property owners and may result in higher costs for homeowners.

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As reported by local San Diego CBS 8 affiliate, Commissioner Lara defends the reforms in his interview with CBS 8. "It's necessary to maintain a thriving insurance market in the state... I have to make sure insurance companies are making a reasonable amount of money to be able to stay in business, grow and be able to maintain their solvency."

Dave Jones, former California Insurance Commissioner and current director of the Climate Risk Initiative at UC Berkeley's Center for Law Energy & the Environment, forecasts a gloomy future for California residents after the destruction of recent fires. In a January 16 interview with UC Berkeley News, Jones declares that the California insurance market is the "canary in a coal mine," for the country, and that "the canary is about to expire." He states that despite September's emergency reforms designed to stem the tide of insurers dropping or limiting coverage, the LA wildfires highlight the continuing effect of fossil-fuel related climate change.⁴

Jones tells UC Berkeley News, "Insurers are not able to rate increase their way out of the climate crisis... Before the LA wildfires, insurers said they would be filing for

substantial rate increases under the new regulations. After the LA wildfires, with a projected \$10 to \$20 billion so far in insured losses, insurers will be filing for even higher rate increases.... The fact that this occurred is not something that the insurers did not predict at the time they asked for and got the regulatory changes. So, the LA wildfires should not be a basis for insurers to renege on their commitment to start writing and renewing more insurance in California. But they might nonetheless do so.”⁵

UC Berkeley News reports that the warming planet's impact on weather patterns will lead to more natural disasters, outpacing the insurance market's ability to thrive or survive. They argue that there will be more severe weather-related catastrophes, causing greater loss of life and destruction of homes, businesses, and communities globally. Growing risks and losses from climate change-driven events will outrun rate increases and other regulatory changes granted to insurers in the longer term. All of this means that we are marching toward an uninsurable future in this country and across the globe.

The stakes are especially high for the most vulnerable populations who are unable to evacuate. Of the 27 victims of the Los Angeles wildfires, there were three recorded deaths of people with disabilities. CNN reports that Altadena residents Anthony Mitchell, an amputee who used a wheelchair and lived with his adult son, Justin, who had cerebral palsy, both perished in the fires. Hajime White, Mitchell's daughter, says officials told her that her father's body was found by his son's bed. “He was not going to leave his son behind. No matter what,” she told the Washington Post. “It's very hard. It's like a ton of bricks just fell on me.”

CNN also reported on the death of former Australian child star Rory Callum Sykes, who perished on January 8 during the Palisades Fire at the family's 17-acre Mount Malibu TV Studios estate. His mother Shelley Sykes wrote on X that she had tried to put out the cinders on her property's roof using a hose but was unsuccessful. “He said, ‘mom leave me’ and no mom can leave their kid. And I've got a broken arm, I couldn't lift him, I couldn't move him,” Sykes told Australia's 10 News First. According to CNN, “(Sykes), 32, was born blind with cerebral palsy and had become famous for his speeches on overcoming disability. He was the co-founder of Happy Charity, which according to its site offers, ‘Hope, Happiness & Health to those that are Hurting.’”

Impact on US Insurance Rates

The effects of disasters like the fires in California can be realized across the United States. The New York Times found at least 18 states where insurers are raising rates and reducing the writing or renewing of insurance due to climate-driven extreme weather-related events.” In fact, while the nation's greatest amount of catastrophic

weather anomalies are seemingly concentrated in coastal states particularly California, Florida, Louisiana, and Texas, a July 2024 New York Times article reports that insurers are charging some customers in the middle of the country and sectors of the Southeast, far more than other homeowners with similar degrees of risk exposure, and have allocated their premium rates at higher levels relative to the value of their homes.

The New York Times reported on a study conducted by the National Bureau of Economic Research (NBER) that shows higher premiums being charged to homeowners in states where state officials are more liable to placate insurance carrier's request for rate increases, as compared to states like California, where officials require greater evidence and data to back up premium hikes in order to maintain affordable rates.

NBER's findings conclude that parts of the lower Midwest, the South, and Appalachia disproportionately pay more as a share of their relative property value. Meanwhile the Northeast and West pay far lower premiums using a similar guideline. To underscore the disparity, The New York Times points to Enid, Oklahoma, with a population of 50,000, as having one of the highest insurance rates in the nation relative to home values, despite not being in a region with high exposure to weather-related risk and damage.

To add to the complicated state of insurance nationwide, 2024 saw a hyperactive hurricane season that spawned destructive back-to-back named hurricanes in the fall, causing atypical areas of the U.S. to bear the brunt of severe climate disasters. Communities established in places like the foothills of the Blue Ridge Mountains in Northwest North Carolina, were hit by Hurricane Helene on September 27 causing a tragic degree of human casualties.

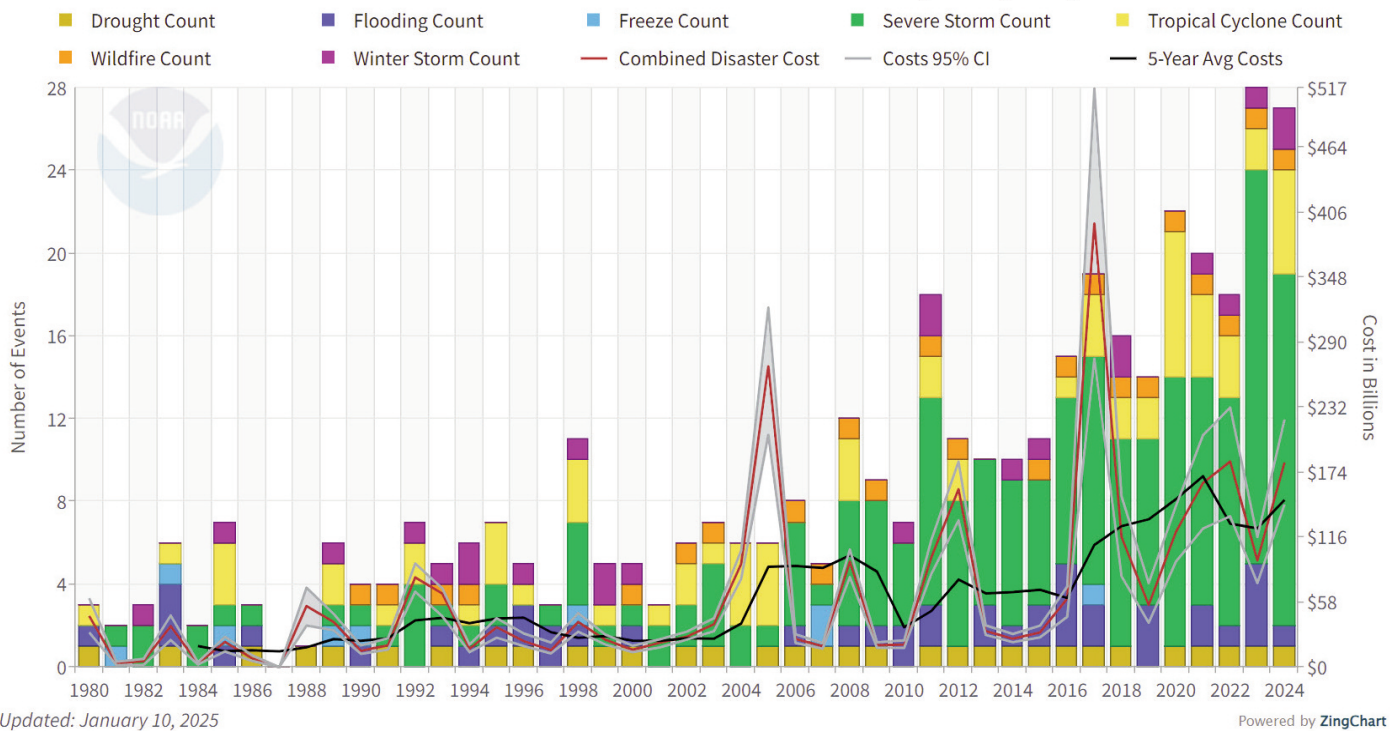
Hurricanes in the South East US

Hurricane Helene made landfall in Florida on September 26 as a category 4 before traveling a destructive path to North Carolina's Appalachian Mountains where it struck as a tropical storm and wreaked havoc to life and property.

Cagney Guest, a long time Transylvania County, NC resident, described the event that wiped out towns like Swannanoa and destroyed pockets of town centers, like the art district in Asheville, as inconceivable and devastating. “Hurricanes are not really something that we worry very much about,” he observed. “In the past. We definitely have had a lot of rain from them, and they have caused flooding. We're in a very rainy place. It's considered a temperate rainforest.”

The elevated mountainside villages and towns in the area are accustomed to receiving plenty of rainfall. Ancient geological forces created this pristine and

United States Billion-Dollar Disaster Events 1980-2024 (CPI-Adjusted)



diverse biosphere of lavish natural beauty and wonder that was unprepared on September 27 for the cresting of its many tributaries that feed the French Broad River, which flows north from its headwaters in Rosman, North Carolina, through Asheville, and then into Tennessee where it joins other major rivers before emptying into the Gulf of Mexico.

Guest, whose property sits on an escarpment near Rosman, explains his house and land dodged the worst of Hurricane Helene's fury precisely because of the 2,500 feet elevation of his little valley situated on top of a mountain. Guest surmises that in this region of many tributaries, being situated at the top of a mountain allowed him to go relatively unscathed compared to the inhabitants of the network of valleys in nearby Swannanoa, Bat Cave, and Chimney Rock, which were completely washed away.

He notes a distinct amplification of severe climate patterns affecting his part of the world. "Well, I mean, like everywhere else, it's escalating, right? Whatever particular weather pattern you have is changing." He continues, "And I remember distinctly when I was a kid, there was a shift—probably when I was about a teenager, somewhere in the late '90s—that the old timers at the store would be talking about the weather. And they would say, 'Oh, you think that was a rainstorm? You should have seen it in 1973.' They would always talk about there having been crazier weather than this. Then there was a certain shift where they began to say that they had never seen it like this before. That's the way that it's been year after year."

In mid-November 2024, over six weeks after Helene ravaged Western North Carolina, the town of Asheville had its water supply restored, the final death toll surpassed 100, and communities struggled to rebuild in the wake of the mass exodus of service workers who lost the bustling districts filled with art galleries, restaurants and cafes.

As reported by local news affiliate ABC 11, "Although life is slowly returning to normal in Asheville, the effects of the storm are long-lasting. And tourism, which historically has formed a crucial part of the city's economy, remains a fraction of pre-storm levels. Local businesses in Asheville and Buncombe County are expected to see a loss of \$585 million in visitor spending during the first quarter of 2025." The total amount of destruction from Helene is estimated to be \$250 billion, with the majority of the cost not covered by insurance since few homeowners in affected areas have flood insurance.

Those residents who are insured are preparing for insurers to raise premiums to defray the insurer's bottom line. It is too soon to determine the impact on residents' ability to rebuild, and they are understandably worried. There is also severe uncertainty for those who are uninsured who must turn to FEMA programs for assistance.

Guest stated, "I have heard rumors that, in general, homeowners insurance is going to go up by as much as 50 %. I don't want to spread misinformation, but that's what I've heard. And that's based on the amount of claims that, I'm sure, they are having to pay out. I guess

that's not unreasonable, or at least it doesn't come out of nowhere. But it's a big shame because I think that people are tired of paying more.”

In the wake of such disasters, it is reasonable for residents to contemplate leaving. Guest said, “My fiancé and I have done a lot of talking and thinking about that. You know that climate change and the weather that comes with it are very real when it hits here because here is an oasis. To have had something that devastating illustrates that I'm not exempt.”

Pondering the concept of how to regain a sense of safety post Helene from one of the most catastrophic floods in U.S. history, Guest remarks, “Our little chunk of mountains are, I believe, the second oldest on Earth, and particularly the little Blue Ridge/Smokey Mountains down here where I have been above sea level since Pangea. Imagine the ancient continents moving around and sometimes dunking under the ocean? But this particular area has always been above the sea. And so, we have incredible biodiversity because it's literally a primordial land, and to have had that happen here, I can't stress enough that I'd felt exempt from the direct effects of this crazy weather. And that has been disabused.”

Less than 2 weeks after Helene, Hurricane Milton roared into southwest Florida on October 9th as a category 3 storm with winds of up to 120 mph, causing many to evacuate. Although spared a direct hit from Hurricane Milton, the Tampa coastline endured massive damage and flooding. Tampa resident Lily Milan was one of the many area residents who chose to evacuate. After receiving tornado warnings, Milan and her family, including pets, made the tense escape to her parents' home, 200 miles away in Hollywood, FL.

Milan recalls, “I remember when I moved to Florida back in '88. I don't ever remember there being tornados. I've always thought tornadoes were like a Kansas thing. I've never thought about tornadoes before, and it just so happens that, during these hurricanes, we're that getting now. I believe it was, like, 103 tornadoes in the area because of Milton. And it was crazy. There were people that, before Milton even hit, their houses had been blown away by the tornadoes.”

Days prior to landfall, around the clock weather modeling kept residents informed, causing Tampa to become a ghost town. Milan remembers the moment the decision was made to evacuate, “The amount of anxiety that I got just knowing that a Category 5 was going to hit, and you were not sure where. The uncertainty that anywhere between here and there within that cone, it's going to hit—and at a category five. That, in itself, was enough for me to say ‘I don't want to stay here. I need to go. I don't want to stay anywhere near this cone.’”

Parts of Tampa Bay were still dealing with the storm surge damage and loss it incurred from Helene, but it

was much smaller in comparison to the catastrophe in NC. Having to deal with yet another, greater storm, a category 5 barreling more directly towards their area kept residents on edge.

As Milan was fleeing, she contemplated the risk of staying in her community. “When that was happening, that was something I was telling my husband on the drive towards my mom's house in South Florida. The amount of anxiety and worry, the dogs, the animals, the house. I don't want to deal with this anymore. And I can't even imagine being affected directly. I think that was definitely when my mind sent me over to where I wanted to say, ‘I don't want to live here anymore.’ But where can we go? Because it's getting worse.”

Modeling and Insurance Rate Fears

In recent years, as climate modeling has predicted an increasing intensification of severity in storms generated in the Atlantic basin, insurance companies have imposed dramatic rate adjustments for residents of Florida. Milan reports that last year she noticed an alarming spike in cost of homeowners insurance. “Last year, my premiums doubled,” she says. “In May, when my insurance was renewing, I realized that the price was outrageous. And that's when I reached out to my agent and asked if she could please find another company or better rate. She basically said, ‘You are looking at one of the better rates that are out there.’ So I reached out to a group of my friends and realized that everyone was paying around that same rate, maybe even more.”

Learning about new insurance requirements that lower rates, Milan set about clearing brush and trees from around her home and installing a new roof. “In the past, usually when you put in a new roof, it was good for many years. That's not the case anymore. Now they are asking that you renew your roof every 15 years versus every 30 years. And My roof is 10 years old. So that was one of the reasons they doubled my premiums. I had to get insurance inspectors to do four different types of inspections. And once those things were certified, I sent those in to my insurance company. Because of that, I was able to reduce my premiums back to, maybe, slightly more than what it was before, but not double. So that helped a lot, and that was because of all the policy changes and everything that's been happening in Florida. A lot of insurance companies have pulled out.

Hurricane Milton caused 33 lives lost and an estimated \$50 billion in damage and costs to insurers. Consumers fear what's to come in the already strained insurance market. According to a September 2024 Bank Rate article, in recent years Florida has lost over 30 insurance companies, and most recently, AAA, Farmers and Progressive announced a reduction in coverage. As of May 2024, there are also 11 Florida home insurance companies in liquidation.⁶ Bank Rate reports that rate increases have been felt since 1992 when Hurricane Andrew



devastated southern Florida. Along with natural disasters, a high rate of insurance fraud have led to rate increases in Florida, while Californians rate increases are partially ascribed to state regulations that have artificially depressed rates relative to risk.

Reached by ABILITY Magazine for comment on the state of Florida homeowner's insurance, Michael Shea Jr., Executive Vice President, Acrisure Social Services Division, explains that the multi-billion dollar re-insurance fund created 24 months ago by Florida Governor Ron Desantis to curb the precarious market was meant to enable insurers to obtain re-insurance (insurance for insurance companies when claims spike) at a time when doing so is difficult.

Shea explains, "Florida technically doesn't really have any restrictions on pricing like California. They do have to get their rates approved a lot of times by the state of Florida, they're an 'admitted' market. So, they have to get their rates approved, but there's really no cap potentially on that. If the insurance company doesn't like the rate approval, they don't have to, obviously, do business in the state. So, they can decide not to provide coverage."

Asked to compare the national state of insurance in relation to climate change, Shea commented, "I think Florida is a really hard state right now for property insurance. Also, other states right now, like Louisiana. Louisiana rates are some of the highest in the country right now. Texas has actually gotten a lot more expensive due to the fact that it had all those hailstorms. California has issues with fire. So, I think every state is having issues due to weather. Is it global warming? Is it weather pattern change? It's having an effect on the insurance market. There's no doubt about it."

Shea is cautious regarding Florida residents' concerns about looming rate increases after 2024's turbulent hurricane season. "I think it's hard to guess that right now," he says. "I think the bigger issue here is actually the flood insurance program. I mean, we just had a huge flood event in Florida due to Hurricane Helene and even Milton. So, I think you're going to have pressure on the NFIP, the National Flood Insurance Program. I think you're going to have some challenges there. It's going to be interesting to see on the homeowner's side."

Climate change's impact differs in its effects across the

U.S. The U.S. Environmental Protection Agency predicts climate-driven change will result in winners and losers. In contrast to the economic impact of climate change EPA states, “earlier springs and milder winter weather can prolong growing seasons in many regions, increasing crop yields and revenues.” Yet, the American Farm Bureau Federation shows the resulting harm to farmers from extreme weather of \$23 billion in loss of crops, which does not include lost livestock and infrastructure.⁷ With an increase of extreme weather events like wildfires, floods, mudslides, intensification of storms, and prolonged droughts, a warming planet spells a perilous future for all.

At the start of each hurricane season, residents like Lily Milan who live in effected areas prepare for evacuation with important documents like birth certificates, the deed to her house, and medical records. Yet the thought of moving to a more temperate, less risky, area of the country for safety is unthinkable. “I wouldn't leave my parents behind. I wouldn't leave my sister behind. What am I going to do alone in another state? So, no, that's not even an option for me.”

In the meantime, when Cagney Guest reflects on the idea of leaving the area called home by his family for generations, he arrives at the same conclusion. “Although I'm definitely not the first to stand on these wonderful lands, there are those that came before me for sure. I have been here for quite a while. Or the family has. This still remains the high ground. I don't have much in life, not really from a privileged background. But what I do have is my connection to this wonderful spot that, as other places become more eminently and directly impacted, I assumed that this would continue to be the last place that would still be comfortable, even if not habitable. But with something like this coming through and seeing literally 20, 30 times the devastation I've ever seen in my whole life. It robs you of that feeling. But no, I wouldn't leave for a million bucks.”

Several mountain communities ravaged by Helene are rebuilding, however, Guest wistfully mourns the transformation. “We have a local author from the 1920s and '30s, the name of Thomas Wolf, among his books is one called “You Can't Go Home Again.” And the sentiment's about how once you go away for long enough, when you return, your parents are no longer your parents. They're an elderly couple. Everything is changed. Everything is different, and so home doesn't exist anymore.

Guest observed the economic impact on surrounding communities, “A lot of that is what's going on in Asheville. There's an exodus. I've heard of people who work in service industries that have collapsed and closed down. I've worked in restaurants, and you're paycheck to paycheck. The places they worked are closed indefinitely, and there's no nest egg to lean on. What constituted the culture of the area in Asheville is physically leaving in a lot of cases or has been washed away.

It will definitely rebuild. It remains in a beautiful giant valley in a beautiful part of the world, but there's a lot of intangible things about it that got washed away and that are gone forever. Too many people's lives changed too drastically for it to come back the same.

The increasing frequency and intensity of climate-driven disasters like the Central Texas floods, California wildfires, Hurricane Helene and more are fundamentally reshaping the insurance landscape. As traditional risk models have become outdated and National Oceanic Atmospheric Administration face cuts in both budget and services, residents nationwide face skyrocketing premiums, reduced coverage, and the daunting prospect of an “uninsurable” future. This growing crisis highlights the urgent need for adaptive policies and proactive measures to protect vulnerable communities and ensure the long-term viability of essential safety nets against the escalating impacts of a warming planet.

■ ABILITY

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Should I Buy an EV?

As electric vehicles (EVs) become more mainstream, many drivers are deciding whether now is the right time to make the switch. EVs offer more than a new way to drive. To some, they represent a shift in values, one that's tied to health and environmental responsibility. To others, EVs represent the demand for innovation and the advancement of cutting-edge technology. Understanding both the benefits and limitations is key to making choices that reflect how we live, where we live, and what kind of future we want to build.

Are EV Owners Happy With Ownership?

Recent surveys indicate yes. In an early 2025 survey of 6,164 EV and Hybrid gas/EV owners, JD Power found that 92% of EV owners are likely or very likely to purchase another EV and 12% are considering returning to combustion (ie. gas) powered engines. Interestingly, owners of mass produced EVs had fewer issues than premium, more expensive EVs. Consumers reported public charging as still a challenge, but owners find public charging availability is improving.

EV Owner Satisfaction Improves but Regulatory, Incentive Uncertainties Create Challenges, J.D. Power Finds

Plug in America, a US nonprofit dedicated to clean energy, found similar results in their 2025 survey of 6,000 respondents, with over 5,300 being EV drivers. 92% were likely to purchase an EV for their next vehicle. Concerns about the scarcity of charging station dropped after ownership with most owners reporting fast charging stations that are 5 miles or less from their home. 2025 Plug in America EV Driver Survey





To Buy or not to Buy?

With growing environmental concerns, uncertain fuel costs, expiring incentives and evolving technology, EVs offer compelling benefits—but they also come with trade-offs.

Pros of Owning an EV

Zero Tailpipe Emissions: EVs produce no exhaust, helping reduce air pollution and carbon emissions.

Lower Fuel and Maintenance Costs: EVs are cheaper to operate since electricity costs less than gasoline and fewer moving parts mean fewer repairs.

Smooth, Quiet Driving Experience: Most EVs deliver instant torque and a whisper-quiet ride, making driving both responsive and relaxing.

Access to Carpool Lanes: In many states, EV drivers can use HOV (high occupancy vehicle) lanes even when traveling alone, saving time during commutes.

Federal and State Incentives: Tax credits and rebates can significantly lower the cost of buying a new or used electric vehicle. Federal tax incentives are expiring on September 30th.

Home Charging Convenience: With a home charging setup, you can refill your battery overnight and avoid frequent stops at the pump.

Innovative Tech Features: EVs often include cutting-edge infotainment systems, autopilot options, cloud/satellite connectivity and over-the-air updates.

Power House: EVs with the required equipment can power household appliances or other life necessities

when there are unexpected power outages.

Job Charger: For those who spend their workdays on the go or on a job site, EV's with the required equipment can keep electronics and battery-operated tools fully charged. Many EVs can be used as Wi-Fi hotspots for laptops and other devices.

Eyes all around: Some EV's capture the driver's surroundings in video form and can help with parking, automatic stopping, and lane changes. Some also have cameras inside the car to monitor security and driver attentiveness.

Cons of Owning an EV

Charging Infrastructure Gaps: Public charging stations aren't yet as widespread as gas stations, especially in rural or underserved areas.

Higher Upfront Costs: EVs typically have higher sticker prices than comparable gas vehicles, though incentives can help offset this.

Longer Charging Times: Even the fastest charging stations take more time than filling a tank of gas, which can affect long-distance travel.

More Road Trip Planning: Traveling long distances can be challenging and will take more planning with distance and locating EV charging stations along the way.

Battery Degradation Over Time: Over time, all batteries gradually lose charge capacity. Older EVs may show reduced range or slower charging speeds. Batteries can be costly to replace, depending on available warranties.

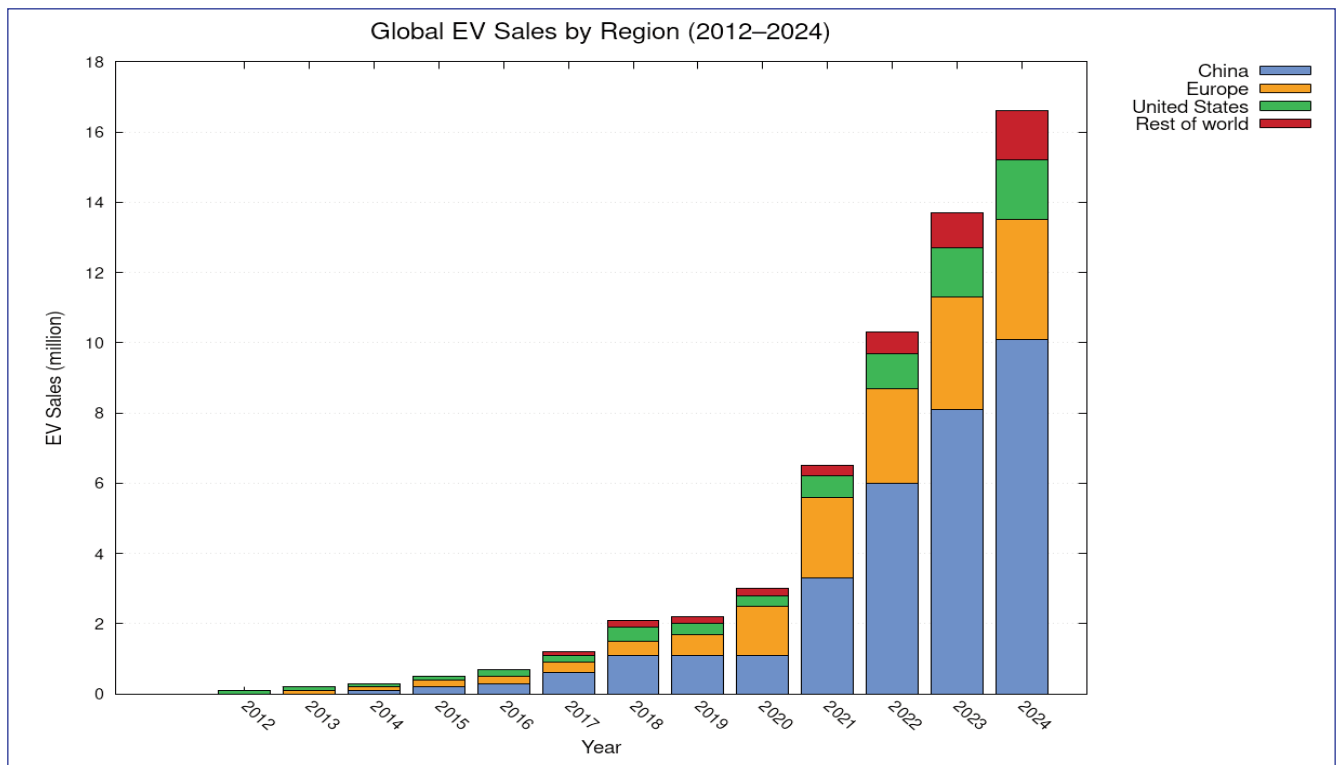
Reduced Efficiency in Extreme Weather: Cold or hot climates can decrease battery performance and range, requiring more frequent charging.

Limited Towing Capacity: EVs built to tow heavy loads tend to have a lower capacity than their gas-powered counterparts.

Faster Tech Obsolescence: Rapid innovation means newer EV models may quickly outshine older ones, affecting resale value and buyer confidence.

With the number of cameras in EVs—some EVs more than others—you may be concerned about privacy, location tracking and the amount of surveillance video recorded both inside and outside the vehicle. Some cameras are integrated with safety systems and can be dangerous to deactivate.

Some US States Charge Additional Registration Fees: To offset gasoline taxes at the pump, many states charge additional annual registration fees. Check with your state's department of motor vehicles for fees.



If you're considering an EV in the US, here are a few things to keep in mind:

Charging Access: Home charging is ideal. If you live in an apartment or rely on public stations, check local infrastructure before buying.

Driving Habits: Daily commutes under 200 miles are well-suited for most EVs. Long road trips may require planning around charging stops.

Model Options: EVs come in sedans, SUVs, and trucks. Popular models include the Tesla Model Y, Hyundai Ioniq 5, and Chevrolet Bolt.

Used EVs: These can be a budget-friendly option, but check battery health and range. Some older models have limited mileage and slower charging.

Federal Tax Credits: These credits have played a major role in making EVs more affordable, but recent legislation has cut the benefit. For a very limited time, buyers can receive:

- Up to \$7,500 tax incentive for new EVs
- Up to \$4,000 tax incentive for used EVs (if priced under \$25,000)
- These incentives are set to expire on September 30, 2025, following recent legislation. That means:
- You must take delivery of your EV by that date to qualify.

- After September, no federal tax credits will be available for new or used EVs.
- A surge in EV purchases is expected before the deadline, so inventory may be limited.

If you're on the fence, now may be the best time to buy—before incentives disappear.

State EV Incentives: Check with your individual state to find out about current incentives. Incentives can range from the ability to drive in HOV lanes at any time to thousands in rebates or tax credits. These incentives can be dependent on limited funding and can be put on hold on short notice. So, it's important to get current information from your state.

The transition to EVs is reshaping how people move through the world. Cleaner air, quieter neighborhoods, and fewer trips to the gas pump signal progress—but not everyone is included in that journey equally. Renters, rural communities, and individuals living with disabilities may face barriers to access, from charging infrastructure to upfront costs. Mobility enhancements are becoming more readily available for EVs and charging stations are subject to ADA accessibility requirements. Innovation is accelerating, and the road toward sustainability is becoming more inclusive. EVs aren't perfect, but they're evolving fast. If you value sustainability, lower operating costs, and a quieter ride—and you can charge conveniently—an EV might be the right move for you. ■ **ABILITY**





JAMES

IAN

Throughout history, music has served as a means of cultural expression, storytelling and an avenue for emotional expression and healing. Music can also serve as a platform for advocacy and awareness for marginalized communities. James Ian had this in mind when he co-wrote the award-winning song “SPACES”, a melodic testament to disability awareness and inclusion.

ABILITY Magazine's Jennifer Woodall met with James Ian in a virtual interview to discuss “SPACES”, performing at the White House, what disability pride means to him and how we can all advocate for disability awareness and inclusion.

Jennifer Woodall: Hello James, can you give us a little bit of background of yourself and how you became involved in the performing arts?

James Ian: Sure. So, I really loved music from a very, very young age and my parents noticed that. My dad's a musician as well. I love to sing, really, then they were like, “Well, would you want to learn how to play piano?” I did. That was the start of my journey. I took piano lessons, and then I also really fell in love with television, and I wanted to be an actor. So then a few years later, my mom was like, “Hey, would you want to take acting classes and things of that nature?” So I found an agent, and I was taking acting classes, and then I landed a role on a TV show and then several commercials. The artistic side of me was always there, and my parents, thankfully, really, really nurtured that. As far back as I can remember, I always loved music, acting, in any way of creative expression.

Woodall: You got to collaborate on an award-winning song called “SPACES”. Can you give me a rundown of what the song is about and the message that it's conveying?

Ian: Often, because of ableism in society, we're not really given the chance to show who we are. People don't really consider us. People often will look away from us if they see someone in a wheelchair. We get denied access in many, many ways, and so the song is really about showing the beauty within the SMA (spinal muscular atrophy) community and the larger disability community. Also,



James at the Adult Skills Center's Fall Music Festival

when I was younger, I did not see any representation of disability in media growing up, and if I did, it was really, really negative, so the song is also not only to highlight and show the beauty within the community and our talents, but that we have these very fulfilling lives, and that we're doing the things we want. We love people. We have people who love us. It's also like a look back in a love letter to our younger selves saying that despite ableism and all the negativity that we encounter regarding access and things of that nature, we will go on to lead the lives that we want. We will go on to achieve our dreams because one thing in the disability community, the SMA community, we're very resilient and we persevere, and that's not really a choice that we have. We pretty much have to do that because of ableism. I think "SPACES" is definitely sending that message.

Woodall: Great. So, you were given the opportunity to perform "SPACES" at the White House as part of an

event to celebrate Disability Pride Month. Tell me about that experience.

Ian: That was one of the most incredible experiences I've been able to enjoy. Very grateful for that. I grew up in the D.C. area. I grew up in Maryland, but I went to college and law school at Georgetown. Georgetown is right in the heart of D.C. and so that is pretty much the political epicenter of the world. When I was in school and doing all those things, that was not lost on me—that I was in this very remarkable city, in this political capital. We would see motorcades drive by with the President or you would see Congress people, senators. We had professors on my campus that were very prominent political figures. I was always in all of that, and that felt like celebrity to me as well, so being able to go home and perform at the White House, which is the most powerful—arguably—political institution in the United States, to have that upbringing, to have grown up in the backdrop

of that, it just felt very, very surreal. It felt like a huge, huge honor to do that, because I have considered a political career before. I still sometimes consider that. Just to do it at that venue, I was pretty much at a loss for words, but it was great. The performance, I thought, went well, and it was just—I think in the moment as I was singing—I definitely had those thoughts of going through my head of like, “This is a big deal.” It was just beautiful. It was so, so meaningful due to my upbringing and my ambitions and my law school. It was phenomenal.

Woodall: What was it like to prepare for that performance? Was it a little bit different than your regular stage performance preparations?

Ian: Oh, that’s a great question. So, in terms of preparation, it wasn’t any different. I pretty much treat every gig, every show as it being very, very important. I want to perform well and give the audience a great show no matter what the show is. But because it was the White House, like I said, I have all these very strong, positive feelings about it, and the lead up to playing at the White House, all my friends that are in the disabled community and very prominent disabled figures, they were so excited for me, and they were like, “I can’t believe this is happening. This is so, so fantastic.” I didn’t want to let people down. I definitely put a level of importance on it. My thought process was just like—I added a level of seriousness to it and being like, “Don’t mess up.” essentially. I prepped the same way, but I just did not want to mess up or let anyone down because I felt like the community also knew the importance of this, and I wanted to represent the community well. And then you’re at the White House, and who wants to make a mistake at the White House?

Woodall: So this opportunity was during Disability Pride Month, and when we talk about disability pride in general, it can be a polarizing topic for a lot of people. I’d love to hear what disability pride means to you.

Ian: Yes, and thank you for bringing that up, Jennifer. People have mixed feelings about it, and people land on either end of the spectrum or somewhere in between. But disability—I don’t want to trivialize it because everyone’s experience is different. I have my days where if I’m feeling really run down or really fatigued or exhausted, I get very, very frustrated. I get angry, and it’s not a pleasant feeling. I am like, “Why does my body not do what I tell it to do?” It can be very, very hard. On the other side for me, and a lot of folks—disabled people too, the barriers that we face, we don’t attribute that to actually being whatever our medical diagnosis is with a disability. We attribute it to inaccessibility within society. That’s why that creates a lot of difficulty, too. The frustration can bubble up from that. So for me, I am personally proud to be a part of the SMA community. I’m personally proud to be a part of the disabled community because I have

fantastic, wonderful folks in that community who are just good people, number one, and then many of them are doing really, really great things to create a more accessible world and to highlight disability visibility. That’s my mission as well, so for Disability Pride Month, for me, it’s a time I do feel very proud, and I almost feel like it’s amplified disability visibility, because there is a month that’s dedicated to it. I feel like we are getting more non-disabled eyes on folks with disabilities. Organizations, corporations, what have you, they’re taking notice a little bit more in July. So I want to put out a lot of content and be very active because I feel like we can do greater good because it’s like our efforts are maximized because there is this focus on the disability community. That’s what it means to me. Like I said, no one asks for their medical conditions or whatever it is, but if there’s a community that you have to be thrown into, this community is great and beautiful. I’m happy to be doing this work alongside some really incredible people that are disabled.

Woodall: What do you think that members of the disability community can do, and really just anybody in general, to increase disability inclusion within the entertainment industry?

Ian: That’s a great question, and thank you for that. As a disabled person, I think it’s a little tricky in some ways because I’m an actor, a musician, and so my disabled peers who are actors and things, we always talk about when we do face barriers on sets or in casting or whatever it might be, there is a fear of speaking up and advocating for yourself because then you don’t want to get blacklisted. You don’t want the casting folks or the production or whoever it is to say, “Oh, this person is problematic because they’re asking for a ramp into the trailer.” or “they’re asking for a ramp on set” or “they need ASL” or whatever it might be, and those are basic human rights, we should be advocating for that, but like I said, people are afraid because it is so hard to book roles because the stats are horrible. The percentage of people who are actually disabled and actually get cast in a disabled role, it’s like 1% to 3%, so I understand that. But I would say if you don’t have that fear and you are comfortable doing that, I would say speak up for yourself and advocate and really fight for your rights, because I think over time, going forward, that will make it easier for other disabled people to feel empowered, to advocate for themselves. I think it will also help to create standards with disabled talent and say, “Here’s what we need. We’ve worked with disabled actors before. We need these sorts of things.” So I think that’s one thing that disabled people can do in that space. I think also, too, disabled people can just follow their dreams and really be who they are and really go out for the things that they want, because I think we are told not to do that, and we are told that we can’t. Our value is not shown to us in the media. I think if you want to be an actor, you want to be a musician, you want to be a model, really go out there and really give it your best



James at the Lincoln Center for their Big Umbrella Day

effort to do that. Once more disabled people are in these roles, we are going to raise the profile of disability visibility. We are going to do it accurately. We are going to do it authentically. The more people that do that, it sets the standard and it sets the tone. Then we will get to a point where one day it's no longer acceptable to hire a person that's not disabled and play in a disabled role. I think just being yourself, being authentic, following your dreams, and really speaking up and just being true to who you are, that's how the visibility is raised because I'm not going about my day in a fake way. I do everything in my life as the real me as I would do it authentically. That's what people want, that is the representation, that is the visibility, and we just exist as we are.

For the side of allies and non-disabled folks, I think I always talk about people opening up the doors for putting disabled people in positions of power—in productions, in media, whatever it is—so that they can make decisions based on their lives and experiences and really

include disability in those ways. If you have disabled decision makers, I think that's a huge positive thing to make that to happen. I think allies and non-disabled people, too, can just also really do more to be proactive in learning about the disability community, so then they start to think about “How can we represent disabled people? What roles can we do? How can we include disabled people in storytelling from the outset and really build that in?” So they can start being proactive in terms of not only the representation and putting us in positions to tell our stories and be highlighted, but then also they can start to think about what kinds of things will help with access on this production or this performance when they're doing this musical show or whatever, and really start thinking about those types of things like having a disabled singer perform at the Super Bowl or whatever. It needs to be very, very proactive and forward-thinking, and we're not there. A lot of this stuff is a reaction to a reaction to disability. “Oh, they need this and that.” and it's like we need to get to that proactive space, then once that happens, more disabled voices can also jump in and

ability

Entertainment

disABILITY Talent in Front and Behind the Camera



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steer the ship and then really, really advance things.

Woodall: On the subject of advice, if there is someone that identifies as having a disability that's wanting to break into the entertainment industry and may not know where to start, maybe feeling apprehensive about it, do you have any advice for someone who's wanting to get started?

Ian: Yeah, to be honest, go to the disabled community. That has been a huge, huge benefit. As time has gone on, I have formed relationships with more disabled creators and artists here in LA and beyond. That community is really, really cool. I have had opportunities pop up just from my disabled peers doing this, but there's a great network here, and luckily this year, I've been really active in that space because there have been a lot of events surrounding some of the work that I've done and whatnot. I'm encountering these people over and over again and in building the relationships, you hear about more opportunities. It's just really cool. The community does really lift each other up, and they'll think of you because there are not only disabled actors, we have disabled writers, we have directors, we have disabled producers—and so my friends are like, “Oh, yeah, I'm doing this project. I'm thinking of you for this.” or “Hey, I know someone.” so I would start really there, form friendships with disabled people that are doing what you

want to do. Then I would also say, too, to really, really take it seriously and train, take your classes on whatever you're doing. I take classes in everything that I do weekly because I want to be the best that I can. It's a really tough industry. It's a really tough industry without being disabled. It's really, really, really, really, really tough being disabled. I think you need all the tools that you can, and then I would also say, too, try to find managers and agents that will represent you. It doesn't have to be an agency that specializes in disabled talent, there are those out there, but I think that really also accelerates things for you and it gets you in doors that otherwise you'd not be able to enter. Those are the really three big things. I would say start with the community first and then create your own stuff, create your own content, find other folks that you can do work with cheaply or for zero budget, and collaborate with them because it really now is a content creator's market. I hear everyone talk about that. All the studio folks are like, “We're finding people making their own stuff on YouTube,” so you really have to do that. I would say those are the big things. It's a constantly changing landscape. It's changed a lot since I've entered it. I mean, I entered it as a kid, but even since adulthood, it's changed a ton in the last five years. You really do need that community support to help you navigate.

Woodall: So, this question I like to ask to the musicians



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that I interview, who is your dream collaboration? If you could collaborate with any musician, band, group, whatever, who's your dream to do that?

Ian: That's such a good one. I'm going to say I'm going to say Beyoncé. I think that would be a super cool duet. That'd be awesome.

Woodall: Yeah, for sure. I think Beyoncé is amazing.

Ian: I really loved her Cowboy Carter album. She does pretty much whatever genre she jumps into. It's really good. I love that album. She is very versatile. She's a powerhouse. She's got to be my big collab right now.

Woodall: Is there anything else that you would like to talk about that we haven't heard?

Ian: Just that SMA Awareness Month is in August. SMA Awareness Month comes right after Disability Pride Month, and so I'm very proud, as I mentioned, to have that. I think SMA Awareness Month is really, really cool because it's all a focused effort to really talk about SMA and highlight people living with it. It's a really fun, exciting time personally, and we're putting out a lot of content and doing lots of social media posts and all those things. I just wanted to highlight that. It was really cool to do the White House performance

leading into SMA Awareness Month. I did a TV interview in DC the day after my White House performance, which was on July 30th, 2024. I got to talk about SMA Awareness Month, so it's like a double whammy. We get Disability Pride in July and SMA Awareness Month in August, then we have National Disability Employment Awareness Month in October, so I feel like a lot of disabled creatives get really busy between those few months from July to October. I would love to see that busyness and those opportunities expand throughout the full year. I think I just want to make the comment that I love these months exist because they do call attention to our SMA community and our disability community, but I would like to see that go beyond and see disability celebrated all throughout the year and those opportunities become more and more with time. I just want to say thanks to Genentech for sponsoring these really cool projects—"SPACES", Most Likely Not To—I would not have performed at the White House if it was not for Genentech and "SPACES". I just want to call that out and say thank you because I feel like they really try to help raise the profile and visibility of folks living with SMA, which there's not a lot of organizations are doing that. It's a really, really beautiful thing, and it's very much appreciated. ■ **ABILITY**

[instagram.com/jamesianmusic](https://www.instagram.com/jamesianmusic)





Blind Ambition and Beyond

Gerrard Gosens is an internationally recognized adventurer, Paralympian, Everest climber, chocolatier, and Order of Australia Medal recipient. His latest adventure tackles open water swimming. His goal is to complete one of open water swimming's greatest challenges: swim the 20 Bridges New York City circumnavigation and cross the English Channel, all within a single calendar month. It's a feat never before achieved by a blind swimmer. Embodying the spirit of teamwork, Gosens navigates the journey with the steadfast support of filmmaker/project manager, Anthony "Gordo" Gordon, and seasoned swim guides—Philip Edwards, Joanna Smallacombe, Nick Barclay and Hayden Armstrong.

ABILITY Magazine's Gina Velasquez met with the team in downtown New York City as they embarked on the first leg of their journey. Velasquez followed their progress remotely, receiving regular updates and emails from Anthony Gordon, who documented each stage of their experience for the documentary "Blind Ambition." Gosens and his team shared their different perspectives of the journey, their teamwork in open water and the challenges they faced along the way, as they strived to push the boundaries of human potential. The team also shared their drive to encourage others with disabilities to "give it a go", in hopes that their journey will show, with the right support, even the most daunting challenges can be met head-on.

Gina Velasquez: Is this your first time in New York City?

Gerrard Gosens: Yeah, it is. It was a long-time goal to get to New York. I've had the opportunities of potentially competing in the New York Marathon some years ago, but that got waylaid by some other projects that came on board. But there's always been that fascination for me as a guide dog user of how people who are blind to low vision get around New York.

For example, when you watch a television series that is based in New York, you never hear the audio tactile lights. We always have a challenge when a dog's walking in the snow. When does it know that a road starts and it stops from the foot pavement? When a person's using a white cane, particularly in the snow, how they use that to identify when they're doing shoring with a white cane. All those things fascinate me. So here I am. And now is a chance to frame myself in the deep end and see what it's all like.

Velasquez: What sparked the idea for doing these back-to-back open water marathon swims?

Gosens: It wasn't something that I grew up thinking, "I'm going to do the 20 Bridges Ocean swim and I'm going to do the English Channel." It's always been

about the opportunities for me. The 20 Bridges swim was an opportunity that became available and there was a slot. And a slot came up to swim the English Channel in July.

Back-to-back from the 20 Bridges swim over to English Channel is a big challenge in its own way, but I think I've got the team. We've done the preparation, both mentally and physically, over the past couple of years, so we're ready to go. Looking forward to the chance to swim around Manhattan Island.

I think what is unique is that I've never seen Manhattan Island. I never will see Manhattan Island. I've never seen the Australian flag. I've never seen my Green and Gold tracksuit. I'll never see the other side of the English Channel. But they're not things I need to see. It's that sense of belief in the journey and achieving that particular project. So, I don't need to see the end to achieve the end.

Velasquez: Do you have any light perception?

Gosens: No, I'm totally blind. I have prosthetics, so I have no vision whatsoever. For me, it's me not knowing what Manhattan looks like. Sure, it's somewhat disappointing. But, as I said to my team, it's that traveling around on the inside of Manhattan Island and getting to experience all that it has to offer through its various ingredients of people and culture. It's like, for example, being a chocolatier, which I am. I can swim around the outside of Manhattan Island, feel the outside, but also experience the inside by walking around Manhattan Island.

Velasquez: It's a vibe. From neighborhood to neighborhood, there's just a different feel, different vibes. The bars are different; the smells are different. Have you ever attempted either of these swims?

Gosens: No. This will be a world's first. It's never been a totally blind person swim around Manhattan Island. When I swim across the English Channel, there's never been a totally blind person actually complete the swim across the English Channel.

Velasquez: It's never been attempted?

Gosens: It has been attempted but never been successful. The New York swim has never been attempted at all, ever before. The English Channel, yes, once before. And that was by me, last year. And I was three kilometers short.

Velasquez: What happened?

Gosens: Mother Nature took a turn for the worse and through everything she had at me with weather conditions, and it wasn't safe to continue. But the weather patterns across the channel can change dramatically, very quickly.

Velasquez: You've also climbed Mount Everest. Now you're doing open water swimming. How did you make these switches through all these elite sports?

Gosens: Running for me was always, I suppose, my trade. I began running at a very early age, and competed at Paralympic Games. It was obviously the goal to represent my country. Then, I went from running to triathlons. I actually got into triathlons because one of my guide runners ran me into a pothole, and I had to take a week off running for a bit. I jumped in the pool and was doing some swimming.

One of the persons who was swimming beside me said, "Oh, have you ever done a triathlon?" I said, "No, I never done a triathlon because I actually hated swimming because you go up and down, up and back." Why would you go up and back when you can run from point A to point B? I said, "I'll do a triathlon with you."

And I went on and competed for Australia at some very small championships and the Commonwealth Games. Then I sort of retired at the Commonwealth Games in Australia, and a person said to me, "There's never been a totally blind person swim the English Channel." And I thought, "Well, let's give it a go."

Velasquez: You were like, I'll do it.

Gosens: That's what everyone says. I'm always a "yes" person. When I did Everest or "Dancing with the Stars," it was always about, "yes."

Velasquez: Everest though. How do you just decide I'm going to climb Everest?

Gosens: Well, that was about an opportunity. I was working at a function and a person said to me, "Would you like to either do one of two particular expeditions?" One of them was Papua New Guinea, the Kokoda Trail. It was either that or Everest Base Camp. And I thought, "Well, sure. Let's go to Everest Base Camp." I went to Everest Base Camp and came back with the knowledge and reconnaissance of what to do to get to the top of Everest. I put together a team, and onwards we went.

Velasquez: And then you summited? When?

Gosens: 2005. So, for me, it's building that team around you and knowing that, in any journey, both mentally and physically, there's going to be some crevasse along the way. And then, those smallest of challenges can be, in actual fact, the biggest. But as you say, in New York, it could be crossing the street because there's no audio tactile lights. The smallest of things can make big changes in your life. For me, it's about those opportunities.

Velasquez: About training, and we'll bring your team in as well. Can you tell us what training looks like for open

water swimming, both in and out of the pool?

Gosens: Yeah, in the pool, it's multiple kilometers every day. So, I'm in a pool at 3:00 AM in the morning, and train there for a few hours. And then, it's off to work as in my businesses in Brisbane, Chocolate Moments. And then obviously training in the afternoon, whether that be strength or running. Weekends are the longer swims, both on Saturday and Sunday. So, that could be an open water swim on a Sunday, or it could be a 10 km swim in the pool. It's day in, day out.

I have the background of endurance. I've done ultra marathons in Australia. We have Cairns to Brisbane, which is a 2000 km run or about 1200 miles. I've done that five times. Coming into swimming was more about the opportunity and about building a team of great supporters and swim guides. And here we are.

Once this is over, I'll move on, because of my background of climbing, to the 2028 Los Angeles Paralympics Games. Indoor climbing is now a Paralympic sport. One of those is my classification, being totally blind. I'll just leave swimming to the side and purely focus on climbing.

Velasquez: So, you cycle between these three types of elite sports?

Gosens: No, I think it's about the opportunity. Again, no one ever said to me, "You will swim." It was just about that particular opportunity. And look, you only live once. And it's about saying "yes." It hasn't always been a success. There's been plenty of failure along the way. But it's about picking yourself up and taking that next step on, which is really the success behind all of it.

Velasquez: And when did you start the open water swimming?

Gosens: I've been in it for four years now. So, I swim in Great Keppel Island in Australia, which is like a 20-odd kilometer swim. And then we've done a few other 20-kilometer swims. And then, the preparation for English Channel last year. And I did another 20-kilometer swim earlier this year. So, the distance isn't necessarily the worry around Manhattan Island. It's the currents.

Velasquez: Your team was telling me that you're not really swimming against any river currents. I thought that you might, but I understand the East River and Hudson go in opposite directions.



River swimming in darkness with empire state skyline in background

Gosens: Yeah, there are some points where we have to get to before a certain time. Otherwise, the tides will change. But no. Whereas the English Channel, if you imagine across the channel, there are four individual divisions. So, you almost are swimming the S shape across the English Channel. So outside right and then back to left.

Velasquez: In an S shape? And that's because of the current?

Gosens: Yes. And if you're not swimming fast enough, then that's where you'll fail.

Velasquez: Can you talk about the logistics of an open water swim. How do you manage nutrition, hydration?

Gosens: Every half an hour when we swap over guides, I'm not allowed to touch the boat or the kayak, they'll toss me a bottle on a piece of rope, and I'll just drink from that or eat from that. Then off we go. But you only take a few seconds to do it, whether it be just hydra-



Gerrard being helped onto the boat after the swim by Jo and Nick

tions, whether it be a gel or other small stuff that's easy to (eat).

Velasquez: How do you figure out navigation?

Gosens: We have a tether that goes between myself and my swim guides. It's a short piece of elastic cord. It goes off at the actual knee. That way, obviously, you can complete your stroke. That piece of tether provides a whole communication, whether it's slack or whether that's tight. That will give me the direction, whether it's any left or right. But once you get in sync with that person, and that's where training with these guys for quite some time comes in. You're well aware where their body is in the water as well.

Velasquez: And they take turns?

Gosens: Every half an hour, they swap over. I've actually chosen some guys that will be taken by the sharks before me. So, they're actually more attractive than me. That's why the shark will go for them first.

(laughter)

Velasquez: I didn't want to say anything, but there's been about seven shark sightings off the New York City

beaches this summer.

Gosens: Well, I have three guides.

Velasquez: There are seven sharks though. But how do you prepare for encounters with sea creatures?

Gosens: I push these guys in the way.

Velasquez: I see. Very smart.

Gosens: We encounter plenty of jellyfish. And in Australia, there's probably more severe jellyfish than what's here.

Velasquez: Are you wearing a wetsuit then?

Gosens: No, there's no wetsuit. It's just a swim cap, togs, and goggles.

Velasquez: Isn't the water freezing cold still around New York?

Gosens: No, it's actually quite warmish here. It's the English Channel, which is right now seeing about 16.7 (62 degrees Fahrenheit).

Velasquez: And you won't wear a wetsuit in the English Channel?

Gosens: No, not for either.

Velasquez: How do you acclimate then to the cold water?

Gosens: We've done some cold-water training back in Australia. We've done it for the last little while. You start to question your sexuality by the end of it.

Velasquez: (laughter) Did I hear that right?

Gosens: Yes. It's cold water. It's bloody cold water.

(laughter)

Velasquez: Is there a reason it's a night swim in New York?

Gosens: No, it's a choice. To me, it doesn't matter to me whether it's night or day. And I think it's a great atmosphere. It's a good chance for these guys to experience what Manhattan is like at night. And it's obviously avoiding the sun. So that's probably a bonus as well.

Velasquez: How long do you think the New York City 20 Bridges swim will take?

Gosens: I suppose nine or 10 hours.

Velasquez: Is that a record? Are you trying to break a timing record?

Gosens: No, there's no record. As I don't claim to be a swimmer. I just claim to be an adventurer who is out there to give it a go with Nick and Phil and Jo.

Velasquez: So, the record is the back-to-back 20 Bridges and English Channel swims.

Gosens: Yes. That's a record. But as I said, there's never been a totally blind person swim around New York. I hope that through this particular pursuit and through the swim tether, my goal is for kids, who are coming through who are blind or who have low vision, have a chance to understand that there are people like Jo, Phil, Hayden, and Nick who are swim guides. Perhaps at places like Coney Island or what have you, those swim guides can become available to take people like yourself or young kids out for a swim in the ocean and to do a One, two, three, four, five kilometers swim.

Velasquez: How long have you had this team, this particular team?

Gosens: For a few years now. They've all been long-standing team members, back in Australia training on a weekly basis. That's why it isn't me crossing the line.

It's the entire team. As it is in producing a magazine, as it is producing anything at all. It's not the one journalist; it's about the entire team.

Velasquez: Then what will you be doing in the interim between the 20 Bridges and the English Channel? Will you be training or resting?

Gosens: We'll go and obviously train and recover. And then get over to the UK on the 18th and then do some water acclimatization in the cold water. We'll have a few days there to get used to the water.

Velasquez: Can you speak more about your goals afterwards, the Paralympics?

Gosens: Yeah, the 2028 Los Angeles Games. That's a journey to have the next three years to get stuck into and build my team around getting up a wall, and driving people up the wall. Look, it'd be a great chance to, I suppose, end the career in Los Angeles.

Velasquez: Did you say end your career?

Gosens: As in from a Paralympic perspective. So, the great thing about climbing is it's not about your age. It's about technique and ability. If I was a sprinter, I'd have no chance. Whereas a climber, it's just about that technique off the actual wall, technique and strength. Like 2032, I'm probably a bit past it. The 2032 Games are actually in Brisbane, my country, as in my state where I live. So, looking forward to that opportunity, as in to play a part in that somehow.

Velasquez: And you're going to be in the '28 games?

Gosens: Yes, that's the goal. I'm in the Australian squad right now, but the goal is to be in the 2028 Games.

Velasquez: Do you have a message you'd like for people to take away from your feat?

Gosens: I think it's about the opportunities, about the challenges. While there are challenges in open water swimming, I think with people like my swim guides, it gives young kids coming through the chance to be in future events, like open water swimming at the Paralympic Games.

And then it's the chance for people to just simply do sport and recreation. While we've come a long way with technology, I think there's a hell of a long way to go with sport and recreation, the support of it, the recognition of it, the funding of it, and also the development of it.

As I said, it takes a team. If I go for run, I'll have a guide runner beside me. Or if I go for a swim, it's having those guides. Nick will tell you—He's a good example. —The first swim they think, "Oh, I'll be hesitant."



Gerrard Celebrating with arms raised on boat with team

Then after it, it just becomes a natural thing. They even forget on there.

But swimming for me is about opportunity and climbing is also about the opportunity for young kids coming through. There's still a long way to go with employment and sports and recreation. In Australia, for example, you're looking at maybe 55% of people who are blind, or have low vision, who don't have a job. But they want a job. It's the same as for access to sport. I still see some really disheartening places where you go to a school, and the only sport and recreation is where the teacher takes them for a walk around the block. This is 2025. We should be way further than that.

Velasquez: What advice would you give to other disabled kids or people out there who want to join the sport?

Gosens: It's about building that team, about not being scared to take the first step. The first step is always the hardest, and also jumping in at times. And as it is here, jumping in the deep end of Manhattan is taking that plunge. It's about taking on the sport that you have a passion for and then thinking, Okay, what are the opportunities? If I can't ride a bike on my own? Okay, let's get a tandem bike. If I want to go for a run around the park, I will find a guide runner, ask a friend, go to a local athletics club. If I want to go for a swim, go down to see a life-saving club. There's always an opportunity, but at times we fear the unknown.

When you fear failure, embrace it because that's the next step on the way to success.

Anthony Gordon, Film Maker and Project Manager

Velasquez: Tell me about following Gerrard's journey.

Gordon: I've known Gerrard for a number of years, and then he convinced me to tell his story. I wasn't really interested in the story because swimming is not the most interesting sport. He mentioned that it was about the team and his guide swimmers and the tethered side of the thing. I've made documentaries my entire life with famous sportsmen and women, but it's about what they do. Not many people can ever aspire to be a number one tennis player, a number one surfer, a number one cricket player. But everyone can aspire to be a supporter. The last film we made was about the team. It wasn't about Gerrard. Therefore, we were inspiring other people to support other people.

Velasquez: What's the name of that film?

Gordon: That was called "Changing Channels". It was his first attempt at the channel. Then when that didn't eventuate, he said, "Well, what should we do?" I said, "What do you want to do?" He said, "How badly do you want to hurt?" He said, "Well, let's try and do something that no one's done twice." Here we are, 12 months later, sitting in New York.

Velasquez: This one is called "Blind Ambition"?

Gordon: "Blind Ambition," yeah. It's a bit of a cliché film, but Gerrard was actually an extra in a film years ago called "Blind Ambition," which was an athletics film. And this is called "Blind Ambition." It's a little bit

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different because I haven't been able to do the lead up because he asked me to manage the project for him. It's hard to do both. I reckon the easiest part of this thing is just getting in the water and bloody swimming, to be honest.

Velasquez: But it still takes a lot of energy, charisma, drive to put this together for him so that he can focus on his swim and the team can focus on what they're doing.

Gordon: It's interesting because you're creating a film for a guy that can never see it, but then he sees through his ears. How I create this has been really unique because a lot of people that can't see have been watching the previous film; they know all about it. You spend more time on the sound than on the vision. But it's given me another unique perspective to actually be his eyes and how he does things. It's really interesting. It's actually made me a better filmmaker because I'm seeing with different senses now, and that's been the rewarding side.

Velasquez: Was it hard to get all the permissions? I was asking the team, and they said that you have stories, at least about the English Channel.

Gordon: When the English Channel wasn't completed last year, there were a lot of human errors in play. The problem is the boat captains and the organization them-

selves just couldn't be bothered. At the end of the day, most of the boat captains are all fishermen. The crazy thing is half of it's an international wire transfer. The rest is cash in a paper bag.

Velasquez: Really? Paper bag?

Gordon: Yeah, it's a fact. So, we eventually paid both with cash and a brown paper bag. And when Gerrard wasn't successful, no one seemed to care. And we tried to get more involved. Gerrard gave them a two-page submission as to how he would better things, not just for people with an ability issue, but with fully able-bodied people.

And in the CSA (Channel Swimming Association) minutes, they documented their response, which was that the recommendation that you've given us, Gerrard, we would apply if we were transporting nuclear waste across the channel. That's just not right.

We started to explore the possibilities of "Do you need an association?" There are three associations, two large ones and a small one. There's a monopoly of boat captains. I went all the way up to the commandant that ran the French naval base. I said, "Where's the legality in this?"

What I found out is the only reason why the associations

exist is because they've been mandated from a 1946 post-war immigration law that prescribed that to go across the channel. It had to be done as a specific crossing, and they had to do it for safety.

Therefore, if anyone could provide the safety documents, anyone should be able to do it, and the channel association should give it permission. I thought, let's just do that anyway, and they wouldn't give us permission. So, it is categorically a probable corrupt organization that is prejudiced against people with disabilities. It's a non-ethical process. People's dreams are being quashed because of their prejudice.

The harder you work, the luckier you get. All of a sudden, a slot opened up. We spoke to Captain Eddie Spelling, and he said, "Right, let's do this." He gets it. He understands.— Finally, after 22 billion emails, we found a guy that said "Let's give it a crack."— Then I had to say to Gerrard, "Right, now you got to back it up." He's got one job right now—to swim.

Velasquez: And it was easier to get New York City permits or permission.

Gordon: The guys in New York are fantastic. It's a pity that more New Yorkers don't understand the swim. The water quality isn't as bad as people say. I filmed it back in 2012. I mean, you might glow in the dark for a few days after you get out. (laughs) The Harlem River is probably the worst part. East River has got the currents flowing. And same with the Hudson.

Velasquez: I would have thought the East River would be pretty bad.

Gordon: Yeah, but that gets a strong current though around Mill Rock. So, it moves. And also, we're doing it at night. So, they're not going to see what they're swimming in anyway, let's face it. And the good thing is with that level of water quality, you're not going to have sharks.

(laughter)

Velasquez: The sharks will be glowing in the dark. You'll see them a mile away.

Gordon: And I'm good with that. Gerrard had done a lot of swims and done his miles. He had to qualify for it. You can't just apply and get in. For this one, you've got to have done the distance, you've got to do a certain pace. Before the English Channel, you've got to have done certain swims. You have to basically swim for 6 hours in 14° water, which is 57° Fahrenheit, which Gerrard did do to qualify. But look, Gerrard's resilient. He's probably one of the most headstrong humans I've met.

Velasquez: Is there a reason why it's a night swim?

Gordon: Yeah, because he wanted it to be difficult for his guide swimmers.

(laughter)

Velasquez: Is it harder to swim at night?

Gordon: Yeah, they can't see anything. He can't see, so he doesn't mind.

Velasquez: Wait, so who really made that decision?

Gordon: Gerrard.

Velasquez: I thought you did.

Gordon: No, I just thought it'd be cool because I filmed it in the daylight once. I don't want to do that again. I sit in a boat for nine hours and look at Manhattan. Let me tell you, the back end of (his) arm, there's nothing pretty, right? There might be some cool graffiti.

When he said he wanted to do a night one, I was like, "Yeah, let's do that." I'd much rather go around at nighttime than in daytime. I'm at my best through the night anyway. I like to see a lot more suffering. I like to see them struggle a bit.

(laughs)

Velasquez: Is it really that much harder? I mean, I thought they go by sight and follow the boat.

Gordon: Yeah, but you still got to see it. When you're on a water level and there's this drop in waves, you can't see over there. Also, when they're that elite and they're that good swimmers, you can make it look easier. I don't want that in the film. I want it to look hard.

Velasquez: How long is the 20 Bridges swim expected to take?

Gordon: The swim begins at 8:00 PM. We should finish, hopefully by 5:00 AM in the morning. That's nine hours if there's good current. You need a good current. It's got to wash all the bodies out to sea.

(laughs)

Velasquez: Hopefully the sharks will get to them first, so you don't bump into them.

Gordon: I mean, Sharks really like that flavor.

(laughs)

Philip Edwards, Swim Guide

Velasquez: What is your impression of the New York City leg and the entire enterprise?



Gerrard and Nick on a sandy rocky beach entering the English Channel

Edwards: I'm very excited about the New York City leg. I've been with Gerrard from the start and went to Dover with him last year on our attempt of the English Channel. But the New York leg, for me this year, was so exciting because I've never been to the States before. I visited through LA on my way to the UK a few years ago, but that was it. So, this is a very exciting trip for me. Actually, Gerrard and Jo have never been to New York either. So, it's very exciting for the three of us. It's a beautiful city, big city, busy city.

Swimming around Manhattan is a challenge not because of the currents. The currents and everything should hopefully be in our favor. But just little things like people tell you that the quality of the water isn't fantastic. We had a webinar a few weeks ago that the swimming association put on for everybody who was coming to New York to swim. They suggested things like wearing ear plugs, and they even suggested certain antibiotics that you should bring with you in case you get sick after swimming. So, it's a worry.

Velasquez: In the East River, I think for sure.

Edwards: We actually tried to go for a swim the other day. I don't know where we were, but it was from Bayonne. We were basically looking across to where there's

lots of container ships and things like that. And there was a little beach there. And we thought we'll go for a swim in here. I got to about knee deep, and I was quite a long way out. It was thick mud. I was going down about ankle deep in mud, and I didn't like that. They're yelling at me, "Oh, lie down!" "Do some breast stroke." Anyway, I laid down, put my hand on the bottom, and cut my finger and thumb. And as I stood up-

Velasquez: Cut your finger on what? Dead body?

Edwards: No, it was just a sharp shell or something like that. But then A crab bit me on the heel. So, I was out of there. I was just like, we'll find a swimming pool somewhere.

Velasquez: A crab bit you. Probably thought you were dead.

Edwards: It was literally on the back of the ankle. And yeah, I was out. It was a little clip. But no, I'm still excited about the swim. We've got four experienced swimmers. Hayden has been with Gerrard for a long time doing triathlons. Jo and I have been with him for about the same time, swimming on the Gold Coast in Australia. Nick's been in and around. He didn't come with us last year, but he's been part of the team for a

long time. He was probably close to being an Olympic swimmer in Australia in his day as a youngster. He's probably our superstar swimmer. But being part of this team—It's amazing.

Velasquez: You all found each other at an association?

Edwards: It was a series of coincidences. A friend of mine, Marty, who we all know, was doing some training in the pool where Gerrard swims. Anyway, Marty was swimming up and down. When he got out, he said, "Is that guy blind or something? Because he kept swimming into me." And I said, "Actually, he is." Marty felt so bad. So, he went over, introduced himself and said, "I've been swimming on the Gold Coast with some guys in this open water club. Do you want to come down sometime?" That's how it happened.

Marty brings him down to the Coast, introduces him to the squad, And then Gerrard met different people from the team along the way. Jo and another lady that swims with us regularly, Rosie. They started bringing him down on a regular occasion from Brisbane to the Gold Coast, and it went from there.

I actually swam across the channel in '22. When Gerrard found out about it, he said to me one day, "What do I need to do?" I said, "I could put you in touch with the right people." And he said, "Do it." So, I gave him all the details. And that went from there.

Velasquez: That was about four years ago?

Edwards: Yeah. So, it's been a long journey, and we've had our ups and downs, but this is the "big two", especially now because we didn't make it last year. There's still that little bit of maybe in the back of your mind. Can we do it? I think doing the New York swim will hopefully be the push that we get around, and then that will give us a little bit of extra confidence to push us over the line on the channel. That's what I'm looking forward to, standing up on the beach with Gerrard in France. They say, "stand on the beach, raise your hands." As soon as the horn on the boat sounds, that's it, you're finished. That's what I did. And it's an amazing feeling.

Velasquez: And how long is the English Channel expected to take?

Edwards: At our pace, I think probably 14 hours plus. There's been some swims lately across the channel that have taken up to 19 hours. I think last year when we pulled out, he'd done over 14 hours at the time.

Velasquez: That's nonstop.

Edwards: Yeah, absolutely. Only stopping briefly to eat. It is a long time. When I swam in 2022, it took me 13 and a half hours. That's a long day. A long day in the water.

Velasquez: How do you and Gerrard manage fatigue?

Edwards: He manages it very well. He's one of these people who's like a machine. He just keeps going.

Joanna Smallacombe, Swim Guide

Velasquez: As a swim guide, how do you help Gerrard establish pace, a swim line, navigation?

Smallacombe: It depends how far we're swimming and whether we need to pace ourselves. But generally, we just try and keep tension on the tether. That's communication between him and us. We judge his speed and we'll go. We position ourselves slightly in front of him so we can guide and navigate if we need to turn around obstacles. In the ocean, we're constantly looking out for waves. There are some quite big waves, big breaks on the Gold Coast. We have to be aware of incoming rogue waves, and the sandbanks change, so we might think we're behind the breakers, but then there might be a sandbank further out. We're constantly looking ahead. So, if we're a little bit in front, then we can make sure we keep that tension on the tether and predict what's coming up, be able to hop and move.

Velasquez: Is keeping the pace and finding the right line harder to do in the channel?

Smallacombe: It's hard when you don't have a point of view. Say, normally when we're swimming on the Gold Coast, it's sky rises and there's things you can pick to aim for and where you always look up to site to make sure you're on track. But in the channel, because we don't have a point of view, we can't see the other side. It's just sea. That's why we keep the boat on our right. That's quite important to have the boat there so we can look up and keep in line with the boat.

Velasquez: You follow the boat. That makes sense.

Smallacombe: But yeah, as for pace, we go at his pace. In the channel, when you're doing a 40 plus kilometer swim, it won't be as quick as when you're doing a short swim. And we, as guides, will be quite fresh each time we swim because we're only doing a half hour to an hour at a time, and we get a rest in between. So, it's just Gerrard maintaining that pace, and our job is to swim at that pace and keep the tension on the rope and look out for any...

Velasquez: Sharks?

Smallacombe: Then we put Gerrard in the way.

Velasquez: (laughs) Honestly, what do you do, though?

Smallacombe: Well, luckily, we haven't actually encountered that yet, but we take precautions. When we're swimming in open water, we don't swim at dawn and dusk. That's shark feeding time. We went through a



Gerrard fitting Gina with the tether

period where there were lots of baitfish, bait balls (small fish swarm) around, and that's a good indication there could be sharks lurking around. In terms of what we would do if we saw one. The best thing is just stay calm. We have seen them. It's a rarity, but they are there, and we do see them. But I don't mind hearing those stories. People see them because they would have seen us a long time before. So, they're not feeding, and they don't generally care. It's only if they're hungry or curious. And if you're splashing around, they would come and probably get a bit more curious. So that's our tactic. You just try to stay calm.

Velasquez: Do you have a message for people who want to become guide swimmers?

Smallacombe: Being a guide swimmer is very rewarding. I was actually hesitant to start with because, for me, the ocean was my escape. It was like my meditation. It was my time where whatever is happening in the week,

I get down to the ocean on the weekend and spend an hour in there and everything was okay in the world again. When someone initially mentioned being a guide, at first, I was very hesitant because I thought, "That'll take up my time in the ocean," because I'd only be able to get down to the Gold Coast one day a week.

But then I thought about it, and being in open water is just a whole unique experience. It's not just about the site and what you can see. It's about the feel of the waves and the currents and the feel of the water on your skin. But I'd love to be able to help someone else experience that who can't by themselves. Being able to give someone the opportunity to go and swim in open water in the ocean and experience that, it's pretty unique. And it's very rewarding and it's fun.

We have a fun team and go out there and have fun during our swims. I'd say anyone that's a keen swimmer

and confident in the ocean and thinks it's something they could do, then definitely give it a go. I mean, it's not just sight impaired people that need a guide. Even just people lacking confidence in the ocean might want someone tethered to them to swim along beside them, or whether there's blind groups or deaf groups that you might be able to link up with. We're definitely trying to encourage that.

Velasquez: Maybe he'll start a movement.

Smallacombe: That's what we're actually trying to build up, a network of guide swimmers. I know there's running groups that have guides available. So, something similar to that. We'd love to work and create a network of guides. It's something on the cards that we're working on.

Nick Barclay, Swim Guide

Velasquez: Can you talk about your perspective as a team member in this challenge?

Barclay: We didn't know whether he'd actually get another crack at the channel because getting channel slots is hard, particularly within a year. If you plan two or three years out, you can get them.

Originally, Phil said, "Hey, Gerrard's going to do the 20 Bridges." I'm married to a New Yorker, and I lived here for 10 years. So, I said, "I'm there. I don't care when it is, I'm coming." And then, in organizing the 20 Bridges, the English Channel started to come into focus. Gordo (Anthony Gordon) was just absolutely hell-bent on saying, "Look, if I can get the right time, he can do both back to back." Again, full credit to Gordo. He was just a dog with a bone. He just did not let it go. He made this happen. It's going to be epic. We're so excited.

Velasquez: And only four people have completed the NYC 20 Bridges?

Barclay: No, many hundreds of people have completed it. I think the four you're referring to is four people who've done both the 20 Bridges and English Channel within a calendar month. I think there's between 100 and 200 swimmers who do the 20 Bridges during the summer months. But then most of them will get out of the water and go to bed for the next two weeks. Gerrard will probably have a short sleep, and then he'll be like, I'm ready to do something else. And then, we go to England, and he'll swim the English Channel.

Velasquez: So, the record is the back-to-back swims within a calendar month.

Barclay: Yeah. There was some research done, and I think Gordo said there's been three or four other humans who have swum both those swims within a calendar month or within several weeks of each other. But certainly, none of them have been partially or totally blind.

Velasquez: I think it's interesting that all the communication is based on that tension on the tether. So, there's no speaking?

Barclay: We can. If we need to communicate more meaningfully, then he'll stop me, I'll stop him. But most of the time it's through the tether. I think I'm developing more of a feel now of the communication back to me. Most of the time it was Gerrard getting communication from me to him saying, "Hey, let's go this direction, that direction". But as we've gone on, I'm starting to feel that communication back.

Just the other day, Gerrard said to me, "We don't want to let the line go slack." Because then he doesn't know what's going on. He knows we're still connected, but it's just making sure that that healthy tension is there. But I'm not pulling him through the water. I'm guiding him. I mean, I liken us to guide dogs. We're not there to pull him along. We're there to make sure that he is pointed in the right direction.

Velasquez: It's very much the same for a guide person. Same concept. How long is the tether?

Barclay: The tether is about, keep or take, two and a half - three feet. So, we're very close to each other, but there's enough room for him, and both of us, to move our arms and complete our strokes comfortably. And you do get buffeted around a bit. So, he'll run into me, I'll run into him. And then sometimes the tether will stretch a little bit. But he can feel that the tether is being stretched because the current is pushing us apart. It's not because I'm saying, "Hey, G, we're going to the right or we're going to the left." You get to feel the right kinds of tension and what it means.

Velasquez: So, that's what all the training and teamwork is about, to get to know those things about each other. I'm sure it's a lot about trust as well.

Barclay: Gerrard has swum tethered with quite a few people, and he's only going to ask the people onto his team that he feels a connection with. He's the one who makes that decision—I want to swim with Phil or Jo or Nick, and maybe not with others. Obviously, he's the ultimate decision maker on that.

Velasquez: Is there anything else you'd like to share about guide swimming?

Barclay: Gerrard explained the tether that we use and the method of communication. I heard Jo speaking about the level of concentration that we have to have while swimming with him because it's actually a different swim. And it's a new one for me, for all of us, because normally swimming is very individual.

I was a very serious competitive swimmer when I was younger. It is the ultimate individual sport, even if

you're in a relay because you're always alone in the water. You're not tied to somebody. But when you're tethered to someone whose life you are responsible for, it brings a different perspective. It's more enjoyable because you're not swimming with your friend; you're swimming for them and with them.

When the conditions are good and you get very much into the zone, you build up a rhythm and you lose yourself because you really don't need to concentrate that much. But as a guide swimmer, you've got to keep your wits about you. There's not much that we can run into out there, but the odd wave that comes on us, we need to be ready to pull Gerrard in the right direction or be ready for the sandbank 100 meters further up. And there's the occasion where Gerrard will feel that tug from us, a more urgent tug saying, "Let's get over to this side quickly because there's something serious coming." So, we do need to keep our wits about us. It's very different swimming, but it's amazing. It adds just a different dimension to the sport that I love.

Swim Tether – Gosens's Invention

Velasquez: Can you tell me more about your swim tether? I didn't realize you invented it.

Gosens: There are obviously no waves (in NYC), but we have some fairly significant waves off the Gold Coast in Australia. So, when we're going out or even coming in through the waves, we have to have something that has some strength about it. So, the actual rope or the actual tether that goes around your body is a lightweight climbing rope that is rated very high. The actual rubber or the actual elastic piece that you see between myself and my swim guide, I've worked with its tension over time. So, for example, if you walk into a sports store and you go to the resistance band area, there's different sizes and different levels of resistance. And over time, I found the particular resistance band that communicates the best.

You can have some that are just too thick, no give. And you can have some that are too floppy and absolutely no communication. It's almost like a piece of spring. So, for the actual tether, we've gone through different designs of different materials that went around the body. And this one doesn't mark the person, as it doesn't create an issue of irritation. It's smooth, it's like silk. Whereas we've used some materials that were rougher, but perhaps a fraction more lightweight. This doesn't really absorb water, so it's not going to stick to the body.

I started to use these when I was competing in triathlons. If you're ever in a triathlon swim, there are quite a large number of athletes, and everyone's fighting. It's like a falling pool of water where everyone's fighting to get to lead. And often at times we have people swimming between us. So, I had to find something that wasn't going to be pulled down if a person tried to swim in between myself and my swim guide. So that's

why the tether goes around the waist, goes down the thigh and around the leg. So it's more of protection. Secondly, when you're running from the beach to the cycle area, you had to have something that was lightweight, easy to unzip. And that way you can either unzip and hold the person's elbow and run very quickly to the triathlon changeover.

Velasquez: Do you intend to market it or patent it?

Gosens: I sell it in Australia. I sell it to athletes. So, the Australian Power Community and Triathlon Australia use my swim tether for Australian athletes. And I sell it to athletes who are either doing swimming, doing triathlons or, recreationally, who simply want to go out and have a swim.

I'm not there to push. It is it's more of a service. I see it as really important for kids who are blind to low vision to have a chance to participate in swimming at whatever age, whether it be very young to people who perhaps are losing their vision.

The great thing about the swim tether is it's not just for people who are blind or have low vision. It can be used for a person who actually can't swim. They might fear the water. Being attached to a swim guide will give them the confidence to go out through the waves and then go for a swim. So, for example, the ocean in Australia where there's some large waves, there's a chance for a person to be attached to another person, and they know they're safe. So, it's not just for people who are blind and low vision. It works with able-bodied people who just lack confidence or skill. And thirdly, it can also be used by a coach in their preparation with the athlete. They can set times and distances and be alongside the athlete as well.

After the NYC 20 Bridges Swim

Velasquez: Okay, well, let's start with the swim. Congratulations.

Gosens: Thank you. It was certainly an interesting swim, since it was in many different parts. The first couple of hours were a bit choppy due to weather, and also ferries. Then the next portion, a lot of it was relatively smooth, but there were also the currents going through the Harlem River where you had to fight into the river as well as the depth of the water. Sometimes we were hitting a few rocks. Once we got to the Hudson, there was a bit of a push behind us. Then there was a bit of colder water, or as we say in Australia, less than warm. Towards the finish, it was nine hours, eight minutes and 47 seconds.

Velasquez: How did it feel when you knew you were done, when you finished it?

Gosens: Well, All the way there we were counting down



Gina with team in NY Cafe

the hours to go. And my body was in somewhat of a flow. There were some parts where we pushed hard. I can lift my arms really well, so that's a good sign. Body's recovered. I'm fairly good at recovering because of my history of endurance events.

As I said to the team when we finished the race, that was a halftime event. We're now enjoying the spoils of the halftime entertainment, and now it's moving on to what we call in Australia the premiership quarter, where you really have to dig in. This is the quarter that really counts. Right?

Velasquez: It was exciting to get the email from Anthony that you completed the swim.

Gosens: Most definitely. The swim around Manhattan Island provides a lot of confidence because it's a lot further than what the English Channel is. But the English Channel is a very different beast in its complexity. It's the challenge of the tides, the currents and the water temperature is a lot colder. So, there are significant impacts on the body with those two realms. So, it's a step down in distance, but perhaps a double step in its complexities and the challenges of the English Channel.

In excess of seven and a half thousand people have

climbed Mount Everest, whereas in the English Channel, it's probably around about 2500. And you have to appreciate that the first crossing of the English Channel was done in 1853. So, it's 100 years longer than what Everest has been climbed upon. So, it can show us the challenges, the complexities of crossing, and not because it's distant, because of its cold and its currents.

Velasquez: I think you guys are going to do very well.

Gosens: We have a great team. It's an awesome team, and great teams make the dream work. So, It's about that team pulling together. And then they've all played very different parts.

And look, I think for people in the US this is a great chance, now, to really lift open water swimming and to realize that while we did it in the dark, there are some great opportunities for people in the day. So, give it a crack. Maybe even have the first blind and low vision relay team, a team of four or five people, and let's really pick it up in the US. ■ **ABILITY**

gerrardgosens.com.au
anthonygordon.com.au



Paula Poundstone

Paula Poundstone has never fit neatly into a box—and that’s precisely what makes her so compelling. With a career that bridges stand-up comedy, radio, voice acting, and activism, she’s carved out a place as one of America’s most authentic and quick-thinking comedic voices. Whether riffing on stage or bantering with fellow panelists on NPR’s *Wait Wait... Don’t Tell Me!*, Poundstone’s humor is rooted in curiosity, compassion, and an unmistakable edge of irreverence.

ABILITY Magazine’s Chet Cooper and Jennifer Woodall met with Poundstone in a virtual interview where she reflects on her early comedic influences, her dynamic with live audiences, and the delicate dance between improv and prepared material. She opens up about her experience voicing characters in *Inside Out* and the challenges of remote auditions in today’s entertainment landscape. The interview also touches on more personal ground—her journey with OCD, her admiration for Robin Williams, and even a solo protest march in Santa Monica. True to form, Poundstone balances the funny with the heartfelt, delivering an honest look at the complexities behind the comedy.

Jennifer Woodall: I saw your academic references on your website, and it seems that as early as kindergarten, you were cracking jokes. Was there a definitive moment in your life when you decided that you wanted to pursue comedy as a career?

Paula Poundstone: I wanted to be from the time I was very young. Probably, honestly, because of Mrs. Bump my kindergarten teacher. Also, we had a neighbor that used to say to me, “Oh, you’re a comedian.” when I was really little, and I didn’t even know what the word meant. I wasn’t familiar with stand-up when I was young. I wanted to be Carol Burnett or Lucille Ball or Lily Tomlin or Gilda Radner. Honestly, when I was real little—maybe even a young adult—I didn’t even know that Johnny Carson was reading off cards. So, I was pretty naive about what stand-up was.

Woodall: Great. You’re on tour now, right?

Poundstone: I’m always on tour.

Woodall: I was looking at your schedule, and it seems pretty grueling to me. You’re traveling everywhere. Can



Paula Pong tag

you talk about what it's like being on tour?

Poundstone: I mean, It's the good news and the bad news. I love my job. Standing in front of an audience, telling one's little jokes, laughing with people is so much fun. The travel part, it's a little not always great, but lucky to be able to do it. Since COVID hit, there's not as many flights as there used to be, and when I'm traveling, I need to have a plan B. What would I do if the flight that I'm on is delayed or canceled? So, I need to travel at a time when if one didn't work, I could get to another. Therefore, since COVID, I do a lot of flying overnight. For at least half a week, I'm a bit of a zombie, except for when I go on stage. It's the weirdest thing. I feel like my teeth know how to do my job, so no matter how tired I am, I go do that. That's really the only hard part. Outside of that, it's really a dream job.

Woodall: You've been a panelist on Wait Wait...Don't Tell Me! for over 20 years now. I know that they're both comedy-based, but can you talk about what the difference is between being a panelist on a show and then doing a stand-up show?

Poundstone: Oh, it's a world of difference. For one thing is that I am working with other people on Wait Wait...Don't Tell Me! For those who aren't familiar, it's a weekly news quiz/comedy show made by NPR on public radio stations on the weekend. I'm not on every week, but on the weeks that I'm on, I sit on a panel of three people. There's a host named Peter Sagal and an

announcement scorekeeper named Bill Kurtis, and they have different little games that they play. Sometimes it involves somebody who calls in, and we answer questions about the week's news. The panelists, of which I am one, we are not scripted. We answer the questions and make jokes just off the top of our heads. That part is great. It plays to perhaps a strength of mine, which is they pitch me something and I swing at it. Sometimes, by the way, I miss, and every now and then I get a piece of it. That works great for me. Of course, doing stand-up, it's just me standing on stage, telling my little jokes, talking directly to the audience. That is one big difference, is that when I do stand-up, I can talk directly to individuals in the audience. Wait Wait...Don't Tell Me! has a live audience, usually, but that live audience is watching us make the radio show, so you don't talk directly to them, except for during the breaks. They're both fun.

Chet Cooper: In your stand-up, then, if I heard you correctly, you're doing improv with the with your crowd?

Poundstone: Yeah, I don't call it improv. I'm having conversations. In fact, it's very similar to when we have a conversation, or if you have a conversation with a stranger, or even with a friend you bump into on the street. There's a certain structure to it. "How are you?" "I'm fine." Whereas most of us probably don't really feel fine, but that's how you begin. Then you might talk about things that are current, that are happening right around you, or somebody may ask you to tell them something that you've told before. There's a certain structure to it just because we're human beings and we have a form of communicating. My point is, every conversation that you have, no one says, "Oh, I had an improvised conversation with my neighbor today." Some people are like, "Oh, how do you do that?" I go, "We do it all the time." Everybody does it.

Cooper: I think the difference is people are expecting you to come back with something that's witty and funny. That's the difference in just pure communications. I was involved in National Lampoon for a little while, and a lot of the writers would try to do stand-up, and they were great at writing, but they were awful at stand-up. They tried to rehearse the materials, but they couldn't communicate with the audience. I'm sure you're aware of what I'm talking about with a certain stand-up, how you just practice what you practice, but they're not comfortable with that off-the-wall interchange with humans.

Poundstone: Honestly, the difference is you have to learn to do stand-up comedy. You could be the most brilliant writer in the world, but if you don't take the time to learn to do it, which requires some bombing. If I consider myself a brilliant writer and I work for National Lampoon, and I've had great success there, it might be really hard to go out and eat in front of a crowd because I thought of myself as such a brilliant

writer, and now it somehow appears that I'm not. But that's not true. It's that you haven't learned this form of delivering what you're writing, and that just takes time. I was going to say it's easier to do when you're younger, but that is not a science-based statement. I don't know that it's easier to do. I just feel like when I was a kid, somehow, I can get kicked around a little bit better than I can now.

Cooper: You knew Robin Williams?

Poundstone: Yes.

Cooper: I was talking to Jay Leno once, and we were talking about stand-up, and I mentioned Robin Williams, and I said something like how much he just adlibs and what he does. He said, "No, he's just got a bigger bag of material to pull from." Is that your view? That even people like Robin Williams that seem to be just spontaneous have rehearsed some of the humor at some point in time?

Poundstone: I don't know the answer to that. I know that in some way that I do. There are times, for example, if I'm talking to an audience member, I generally do the time on where they're from and what they do for a living. If I ask them what they do for a living and they say "I'm a nurse," I might ask them a couple of questions about their job. Then more often than not, I would get to the point of saying, "Look, when my kids were in the hospital, the nurse always came in and thopped the machine when a beeper went off." And then I would talk to them about that. I've had that conversation and made jokes about the nurse thopping the thing beeping many, many times—I guess I would call it a piece of material—and if it's germane to the moment, that's when I pull it out of the bag. There are some conversations that I have with audience members where everything that gets said is unique just to that night in that conversation, maybe because the circumstances that the person is telling me about themselves, I just don't have anything about. Or also, I don't always remember what I've said before, and I like it that way. My point is, I move in and out of things that are pieces of material and things that I just thought of there in the moment and will never be said again. I think Robin probably did the same thing. Honestly, I never asked him about it, but it makes sense to me that that's probably what he did. Otherwise, he couldn't have made his stand-up specials, because I can guarantee you that what he couldn't do—because no one could do it—is stand on stage and think up in that moment everything they're saying. So, my guess is it was all a lasagna. It was a little bit of this, layer of that, layer of that, and part of Robin's brilliance—and he was brilliant—was also the energy with which he did it. I always tell people, anybody my age or older doing stand-up owes Robin Williams a debt of gratitude because he almost single-handedly reinvigorated audience interest in stand-up comedy. The way he did it was with that frenetic ener-

gy. I mean, there were obviously stand-up comics since we came out of the caves, or maybe since before we came out of the caves, but Robin really made people excited to hear stand up again. Also, he showed up in every club. Robin could be working a 3,000-seat amphitheater in Cincinnati, and somewhere after that show, he would show up at Uncle Fannie's Yuck House and play to 50 people. He just loved to perform. He was a bit of a stimulation junkie, and what happened, therefore, was during that really big explosion of the comedy club thing in the '80s, people would go to comedy clubs hoping they might see Robin Williams. And guess what? A lot of times they did.

Cooper: Back to Wait Wait...Don't Tell Me!, can you remember a question that you stumbled on, that you knew the answer, but you said something that you still today think of as, "How the heck did I answer it like that?"

Poundstone: Oh, I can't remember specifically, but trust me, I've answered a lot of things wrong. In fact, there's a guy named Linh Pham who keeps the stats on Wait Wait...Don't Tell Me!. It's just something he started doing on his own. He's a fan of the show, and he makes a little entry into a journal. He'd make an entry about every episode of Wait Wait...Don't Tell Me!. and so, he kept track of how many wins someone had. I believe I'm still in first place for most losses. It's funny. I was doing the show a couple of weeks ago in Orlando—usually, the show is headquartered in Chicago, but about once a month, they'll go to a different city and perform in front of the audience there—so we were in Orlando, and a scholar called in to do the Listener Limerick Challenge. Now, the guy who writes these limericks is so damn brilliant. He writes a limerick, and there's a blank left in each. The limerick is about a current events news story. It could be a news of the weird story, or it could be a more mainstream known story, but the last line where there's a blank, the word is going to rhyme with two other words in the limerick, because that's how limericks are written. Therefore, there's multiple clues. It's pretty hard to get it wrong. The audience in the theater is listening along, and they generally know the answer by the time Bill reads the limerick because, again, it's pretty hard to get it wrong. I can't tell you how many times I've been there as a panelist, and particularly this recent time in Orlando, where the poor listener could not get the answer, and to everybody else, it seems so obvious. Everybody started to laugh like it's funny that the guy is struggling, but the thing is, when you call in to a show or when you're on the spot and you're being asked in front of a lot of people—we have like 5 million listeners—people choke. That's exactly what happens. It happens to me, too, especially in the lightning round where you're supposed to go fast, and I'm not good at going fast. What's funny is most of the time, I listen to the questions asked of the other panelists, and almost 100% of the time, I know all their answer, but when it's my turn, I choke. Not

always, but often. I used to just keep in my back pocket two answers. For the longest time, I would tell myself, “Okay, no matter what happens, no matter what I think, if I’m struggling, unless I have the answer, unless I know for sure, I should just say Trump or lemurs down their pants.” There’s a lot of news of the weird on, Wait Wait...Don’t Tell Me! and sometimes, honestly, I’m proud that I don’t know those answers. There’s tons of smuggling stories. Who knew? Who knew so many people smuggled? And smuggled in really weird stuff, and often down their pants, coming through the TSA. It’s funny, with all those stories, I never once have seen somebody pulled aside by the TSA. Never once. And I travel a lot. But they’ll be pulled aside because they have lemurs in their pants. Who would do that? And what lemur would agree to it?

Woodall: Maybe Wait Wait...Don’t Tell Me! is starting to get the word out so people are being more cautious and putting them in other parts of their clothing.

Poundstone: Yeah, you’re exactly right. They could be getting a heads up. Maybe they’re complicit. Maybe they’re getting a kickback from from illicit lemur sales.

Woodall: Do they ever cut bits out for time from Wait Wait...Don’t Tell Me!?

Poundstone: Oh, Yes.

Woodall: Do you have a favorite one that got cut?

Poundstone: Oh, even if I listened, I wouldn’t probably know what thing got cut because I just have a terrible memory. So generally speaking, once it’s out of my mouth, it’s gone. When I listen to the show, it all makes sense to me. I’m like, “Yeah, that’s how it happened,” but indeed, they do edit for time. Peter always mocks me because I talk a lot. When I do a stand-up show that’s just me, it’s about two hours, and by the way, that’s an effort to keep it under two hours. So, Peter’s always telling me that on the shows that I’m not on, the tapings are much shorter, so I’m convinced that they have a computer program that automatically cuts when it hears my voice. Because trust me, there’s lots less of me on every show that was broadcast than was during the live show.

Cooper: The poundstone filter.

Poundstone: Yeah, everyone should have one. If my kids find out about it, they’re getting that.

Woodall: If it’s recorded in front of a studio audience, then the audience is privy to extra Poundstone content.

Poundstone: They are. The studio audience is often privy to extra everybody content because there’s stuff that they just wouldn’t air on NPR. We can’t sully the name of a really important service. I think most of us

try to honor that to begin with, but there are times where we’ll say stuff and we’ll look at the audience and go, “Okay, this will not be on the show,” and then we’ll say whatever it is we feel like saying. By the way, NPR is an important service because it’s a trusted news source, and even recently, it’s up on the chopping block. It’s been up on the chopping block so many times over the years, but now with Musk, it’s really up on the chopping block. So, they had a hearing about it the other day, and they have statistics—in a world that is so divided—they have really good percentages of people who say they trust both NPR and PBS. In a world where we don’t all believe the same things at all at the same time, I think that’s pretty impressive. And having a strong news source right now is so important. So good for them, and I’m also glad they let us make our little jokes. It always unnerves me when people say to me, “I listen to Wait Wait...Don’t Tell Me! to get my news.” Anytime anybody says that to me, I go, “Oh, don’t do that. Listen to Wait Wait...Don’t Tell Me! because it’s funny. If we bring up a news story, as we do, that sparks your interest just by golly, look it up!” We are not a news program per se, and especially now at this critical time, you need to be getting your news from really solid news sources.

Woodall: If they aren’t getting news from anywhere else, they’re going to think the world is just chock full of people with different things down their pants.

Poundstone: Yes, exactly. It’s just not the right format. I mean, I’ve learned a lot from doing Wait Wait...Don’t Tell Me!, but it’s usually odd little factoids and not necessarily big things. I feel strongly that it is an entertainment program and that people need to get their news, at least from a more massive news source. I mean, even when we bring up real subjects, nobody’s lying, but there’s not a deep well there when we’re talking about it. We’re just making jokes. Sometimes we’re making jokes because if you didn’t laugh, you’d cry. Other times we’re making jokes about something that’s real, like someone smuggling lemurs down their pants that isn’t really important. Again, I often take great pride in not knowing the answers to those ones.

Woodall: Throughout your career, you’ve done different voice acting gigs as well, with the most recent one being in Inside Out, and Inside Out 2 I’m curious to know how the recording process has changed since you started.

Poundstone: Oh, first Inside Out, I went to Pixar to record, and did it in a booth. My partner Bobby Moynihan and I both played little characters called Forgetters. As people will remember about Inside Out, it’s a story that features characters in a girl’s brain. Both movies are very timely, funny and they’re broadly science-based. The characters are playing emotions, but they’re also talking about things that happen within the brain, like how the memory works. They may have simplified



Paula on *Wait Wait...Don't Tell Me!*

it a little bit, but Bobby and I we are blue collar workers within this kid's brain that do the forgetting. We decide which memories to throw away—which is ironic given how much I struggle with memory problems. When I recorded, Bobby was in a booth, I was in a booth, we had headphones on, we could hear each other—I think that's the way it's been done for a long time—but for *Inside Out 2*, I recorded not at Pixar, but at a studio here somewhere in LA, and the director was back at Pixar. He was on a screen, and we use the services of the recording studio here, which I assume is different than how they would have done it a long time ago. The thing that has really changed, and there's good news and bad news to it, is the audition process. I do a lot of auditioning for voice stuff, and they send you what's called the sides, which are a couple of pages of the script that they're having you audition with, so it's not the whole script, it's just a couple of pages, and they send you a written description of the character. If it's for an animated thing, if they have it, they might send you the picture of how that character is being animated, and then you record by yourself. I mean, I just do it on my silly, stupid flat phone, and there's no one reading lines with you, so you're not responding to anything. I find it such an awful way to do it, and then you send that in. Not only that, but even if you're auditioning for a movie or a television show with real people, not an animated one, they still have you do it at home now. And the same thing—no one is reading lines with you. You're just saying the lines, but my house is not a studio. I am not a camera person. I can't create a set. I don't have lighting in my house. It's just so stupid. The good news is that I'm not driving around Burbank trying to find a parking space and trying to go into a cast-

ing office somewhere that I had never been before and get lost. That part I don't mind. But how anybody makes that audition work is well beyond me. I feel like I need to have a crew come in and help me audition.

Woodall: When you don't have the energy exchange of being able to feed off of another person, that seems like it would be really hard.

Poundstone: It is really hard. The truth is, auditioning sucks. Casting agents—and I don't know if they all have an agreement to do it this I would assume so—casting agents are notorious for when they read with you, when they're doing the other people's lines that you're interacting with, they don't put a lot of punch behind it. It is bland, but at least it's something. Otherwise, you're Sybil. I mean, you're pretending that you heard something. I don't know, I find it weird. It's not a way that works for me. However, again, I do enjoy not having to park.

Woodall: Yeah, that's a big plus. I would like that part, too.

Poundstone: I did some news thing not too long ago promoting the show that I was doing, and I had to go somewhere in Los Angeles. I go into a parking garage, and I was trying to be prompt, a lot of traffic, all those things, but I get into this parking garage, and I was a little bit tight for time, not late, but a little bit tight for time. So, I park my car, and I make my way to the studio, and I realized when I've finished doing the interview and I change clothes and head back to my car that I totally forgot to make note of where I parked. It was



so awful. I spent an hour walking around, and it's the parking garage kind where there's different angles of different floors, and you're not quite sure what floor you're on. I finally figured out that I could push the clicker and make the car beep, but here's the problem, it's very echoey in a car garage, and I couldn't tell what direction the beep was coming from. So, it made it worse, not better. So not parking is really a happy part of my day. If I get to the end of the day and I go, "I didn't have to park at all today," that is a win.

Cooper: Paula, do you think you have ADHD?

Poundstone: It's not out of the question. I mean, not that I'm familiar with. I have OCD. I do have letters. What I was told when I was diagnosed years ago was that everyone has OCD, it's only diagnosed based on the degree to which it interrupts your life, and the point at which it was interrupting my life was pretty paralyzing sometimes. The way it works with me—and I don't think they know nearly enough about it to begin with—but the way it works with me is a little bit like cicadas. It'll go away for a long time, and then it just comes out again. I mean, in the case of the cicadas, I guess we know why they go underground and then come out. In the case of OCD, I don't really know what makes it resurface and what makes it stay at bay. I just try to creep around quietly, hoping I don't wake it.

Cooper: When it does appear, how does it manifest?

Poundstone: A couple of things. One is that I tend to find a person that I become so enamored of that I can only think of the world through what I perceive to be

that person's opinion—that'll slow you down, let me tell you—and all I can think about is that person and wanting their approval and what they would think of what I'm doing. When I was young and didn't know that that's what was happening, I just thought it was a perfectly natural thing at the time. I suppose it is natural, but it's not healthy. When I was young and I would be stuck with that, I would constantly be in contact with the person because I didn't know. I just thought that I liked them. It really has nothing to do with liking. It has to do with OCD. It also made packing really hard for some odd reason. I did go through a little period of time where I was given some medication for it. At the time, I was still drinking, and it said on the medication bottle something like: "be cautious drinking." I always say to people, "I was being so cautious," but I was still drinking, and this medication and alcohol interact—there was something good about it, and it'll take you a second to figure out why—but the medication and the alcohol interacted, and what it did was exacerbate the OCD. There was about a week where I had to either walk backwards or like a knight in chess, and if I was walking at all, I had to be close to a wall. It's weird stuff, really weird stuff. What's good about it is that before, the OCD was just a nagging thing that would happen to me. When this happened, it was like, "Oh, my God! That's what it is." Whereas before, I wasn't really sure. Maybe it was, maybe it wasn't. Now I'm like, "Oh, no, that's what it is!" It really highlighted the areas in my life where it was OCD and not just personal choice. Once I understood what was OCD and what was not just personal choice, it actually was really freeing because then I can bow to this or not bow to it, but I know what it is.

Cooper: When you said packing, you meant when you take all your trips?

Poundstone: Yeah, it's a big part of my life. Every now and then my suitcase breaks down and I have to get a new one. I'm telling you, it's like moving to a new home. You have a system. You just develop a system. They don't make the suitcases the way they used to make them. Now I'm like, "No, but I need a pouch there." I have to have my old pouch system.

Cooper: So if your OCD happens again, do you take meds or you just wait it through?

Poundstone: I haven't been in that situation in a long, long time, thank goodness. I mean, not to that degree, anyways. I don't think I would ever take that particular medication again unless, as I said, it is like cicadas where it goes underground and then it resurfaces. I suppose if it resurfaces to a debilitating degree, I might take that medication again. I quit drinking a thousand years ago, so that's not any longer an issue. I'm not exactly sorry for that incident, though, because I feel like it really was an eye opener in that I could understand it in a way I couldn't have otherwise. I don't think anybody could have explained it to me, because that's the other thing about OCD is it's very eclectic. I don't think we all have the same symptoms. Some may, but when it strikes, I don't think it's the same for everybody.

Cooper: Yeah. I spoke with Howie Mandel and definitely different symptoms for him.

Poundstone: Yeah. That's part of the reason why *Inside Out*, those two movies are so goddamn great because the brain is just plain weird. We know so little about it and so little about sleep. I'm sure the two things are very closely related. And I have a schedule that I'm sure will be one of the things that does me in because—what do they call it? Sleep hygiene, a regulated sleep schedule is really important to a healthy brain. I have to get to my jobs.

Cooper: There are studies that indicate different people have different sleep patterns that work for them.

Poundstone: Oh, that's good. I hope Cory Booker doesn't have a backlash because he was up for 24 hours. I mean, the truth is we've all been up for 24 hours at one time or the other, but 24 hours talking intelligently...

Cooper: ...and not drinking water. Yeah. He was dehydrated on top of that.

Poundstone: Oh, wow. I didn't even think about that. You know what's most impressive about it? I mean, I thought it was great that he broke Strom Thurmond's silly ass record, but what's most impressive about it was what he was saying. He was saying that we're in

trouble and that this isn't normal and that we're talking about our democracy. And as he said towards the end, that of the materials that he used to speak, it was mined from both Democrats and Republicans. So, he wasn't saying stuff that was somehow "out there," and good for him. It's time for courage. Now people need to take that inspiration and get out in the streets. I marched by myself in Santa Monica with a sign that said, "Stand up to Trump" on one side, and on the other side, it said "Stop the cuts, tax the rich." I walked for two hours during rush hour traffic, up and back to the 405 entrance—which I'm sure you've heard of the famous 405. It's busy. Who knows if it does any good, but we need to at least attempt to stop what's going on here. I have a very close family member who is disabled and cannot survive without Medicaid and Social Security. I know that we are not the only family for whom that is the case, and so it's hair on fire time.

Cooper: Do you have any pictures of you doing that solo protest?

Poundstone: I don't because I only have two hands.

Cooper: Yeah, I know. I was wondering, maybe somebody came up and took one.

Poundstone: No, no. I walked by a handful of pedestrians, but I left the house at about 5:15. I got home at around 7:15, so it was mostly cars. I got what I believe to have been supportive honks. I got the handful of people going to the trouble of rolling down their window to flip me off.

Cooper: I'm sorry about that. I didn't mean it. (laughs)

Poundstone: Oh, no. Oh, was that you?

Woodall: They're just saying you're number one.

Poundstone: Yeah, that's what it was. I think it's funny. I don't see that well, if people are flipping me off from in their car—I got bad news for you. I got no idea what you're doing. Maybe the people who bothered rolling down their windows to do it understood that I have some visual limitations.

Cooper: Switching subjects a little bit, what charities do you support?

Poundstone: Lots. Right now, I think it's important to back the ACLU. I give money to Habitat for Humanity, which I've also done a couple of builds with and is so damn much fun. It's a great organization. The way they structure it for the people for whom they're building the houses is that those people have to participate in building the house for a certain amount of hours or percentage of time or during the build. But what's amazing, the first time I ever did it, I took my daughter with me, and she was pretty damn good at it, but they have all these



volunteers, and they divide up into teams working on different parts of the build, depending on how far along the project is—this is building houses, what I'm talking about—and there's a foreman for each of the teams. I asked this one foreman that I was working with, and I had a thousand questions in terms how to do what I was doing, and this person had all the answers. They were like, “No, you want to do it like this.” “No, it works better like this.” “Okay, and then this is going to go here.” And I said, “Well, how did you learn to do this?” and she said, “Oh, I've been volunteering for years.” So, people have actually learned how to build houses by volunteering for all those hours at Habitat for Humanity. It's just great.

Cooper: Through ABILITY House we partner with

Habitat for Humanity to build homes for families that have disabilities and we access volunteers with disabilities to build the homes. The first house we built was in Birmingham, Alabama in 1999.

Poundstone: That's amazing. Someone that I love that is disabled, and I have taken them a couple of times to adaptive sports things, and one of the things that I'm struck by—and I feel this when I've watched the Paralympics as well—is that you're watching people who are athletes all the time. You have to be an athlete to get in and out of a wheelchair. You have to be an athlete. You're an athlete all the time, now do athletics that are structured in a different way. The first time we went, we went to wheelchair basketball, and this person is not in a wheelchair—they have cerebral palsy, but they don't have to be in a wheelchair. You have to sit in the wheelchair to play wheelchair basketball, but you do not have to be wheelchair bound, which I never understood before. So, she's trying to figure out the wheelchair thing, and the first time she got in the chair she was practicing shooting baskets. The majority of the other people that were playing that day were indeed wheelchair bound, perhaps not all, but most, and she was a first-timer, and the others had been there for a while. I say to her, “I tell you what, I'll rebound for you.” I step out on the court and she shoots a couple of baskets, and at one point, the ball bounces off my fingers and jams two of my fingers. I'm hopping around in pain and I have to sit down. Then eventually, the game starts. Now she's in this game, and there's all these people. There were kids that had unfathomable disabilities out there with huge smiles on their faces, playing wheelchair basketball. There were adults, and the same thing, all these guys with no legs, playing wheelchair basketball. One of the guys falls entirely out of his wheelchair and has to be

put back in. Do you know, I was the only injury of the day?

Cooper: Did they wheel you out?

Poundstone: Oh, my God. I thought they were going to have to. It really hurts when you jam your fingers. I had a friend years ago that was a member of the first US women's Olympic basketball team, and her fingers looked like tree roots. They went in every direction from years of jamming her fingers playing basketball. But anyways, it was just such a thing to see all these people playing. ■ **ABILITY**

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Joshua TOWERY

We may not realize it, but we encounter design with nearly everything we interact with. Our favorite coffee mug, our mattress, the packages that hold our food have all gone through a rigorous design process—but what about the apps we use? The websites we interact with to navigate banking? Healthcare? Voting? This article you're reading right now? All of these have gone through a design process as well that is known as UX/UI or User Experience/User Interface. When it comes to a navigable product like a website or an app, the layers of design go deeper than appearance to cover the realm of accessibility and inclusion.

ABILITY Magazine's Gina Velasquez and Jennifer Woodall joined UX/UI designer Joshua Towery to speak about navigating the design world with colorblindness, how UX design makes tech accessible, and the drive for an inclusive design industry.

Jennifer Woodall: Can you tell us a little bit about yourself and what led you to become an artist and UX designer?

Joshua Towery: Sure. So the art has been since I was a

child thing. I've always drawn, and so this is something I've always done. I guess, professionally, it led into UX design because I started off as just a designer when the Internet started. I started in print, so to bring it back, this was back when you had to draw something, scan it, turn into a vector image, and then you had a logo. If you could draw, then that was all the better for you as a freelancer. I did logo work for a long time. Then that just evolved as the whole nature of things evolved, and it turned into internet sites and doing design for that, and then learning how to program from the people I worked around. I saw that developing wasn't too hard to do. I took the whole gamut of doing that plus designing. Over the years, it was 3D animation, it was video work, it was everything that was creative to turn something into something better for these people, and so UX design is just something that I've always done, really. It's just it turned into an actual title a few years back. It's always been about the experience, right? So that's the good part, is it turned into a very high paying particular thing. It's an encompassed procedure to do the whole thing, but that's what I've always done.

Woodall: What is your artistic process like from idea to



final product? I'd like to hear about your professional work and the paintings you do.

Towery: Sure. Well, starting with the artwork, there really is no process except just staring at the canvas and something will happen, so that's the idea. I don't really do paintings of something. I don't really do portraits and try to nail down something like that. There's a lot of realism in what I'm going to do, but I don't really do reference stuff. I like to do a lot of very, very realistic things, but you have to be able to see it and then put it on a canvas or draw it. That's easy for me to do, so that's where it starts. Then just experimenting with a lot of different lighting, a lot of different color interaction, and then something cool will happen. People can interpret it after the fact all they want as to what it means. I've learned that it really doesn't matter if I try to make something that means something because it won't mean anything the same way when it's really even done.

There's a lot of shared-line stuff and a lot of experimental stuff happening that maybe people don't even realize, but it's a challenge to just do these little experiments, and that's basically what it is. It's easy to do something that's a reference piece. If I want to do a painting of a painting, that's not hard to do, or just do a portrait of somebody's face, that's not really that hard to do. Anybody can pretty much do that. It's not really that fun for me to do necessarily that, but it's realistic as it needs to be along the way. Same thing with professional stuff. People need something that on a UX level that makes you feel something and needs to feel a lot different than the competitor stuff. If you can get something in Figma—I do a lot of Figma stuff, which is wonderful, that's the tool that we all use—but doing a prototype in Figma, knowing that you can execute it out as a developer, knowing how to execute in a CSS way and all of these things, you're not trying to perform something or put something in front of everybody that really can't be done. I put something that's a lot different because there is the same experimental stuff happening. It's experimenting with stuff with color, with layering, with font-sizing, with padding and spacing, and all these normal properties of something, but you just got to do it a little different. If you don't do it the standard way, then people respond a lot better. If it's upper management or if it's other developers, they're like, “Oh, it looks amazing. It feels like this.” that's the whole idea. As long as you make them feel something but execute it, that's the real thing. You're not working in Illustrator anymore for just prints. You're not doing stuff in Photoshop anymore to be able to hand it out to somebody, and it's their problem to make it into a website. Now you can actually combine the two and you know you can actually make it happen. If you know Material Kit, if you know how to use Bootstrap, and you are familiar with these things, then you can anything. So that's what we're doing these days.

Woodall: Okay. For our readers that might not be familiar with the design world, can you explain Figma?

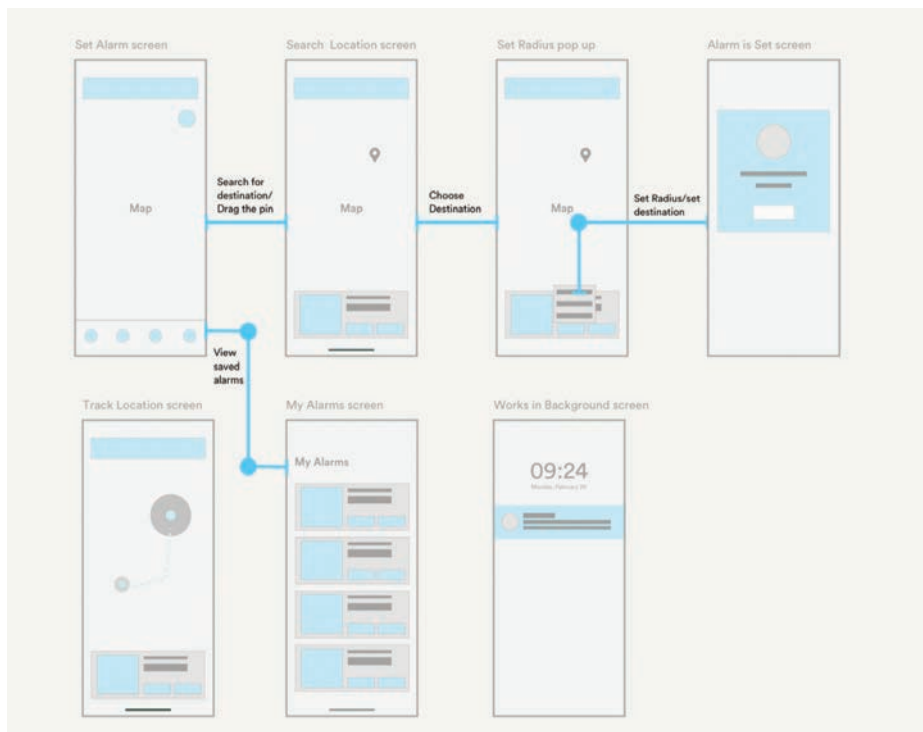
Towery: Sure. Figma is that branch between people that don't code, and they're not designers, they're not developers, but they need to see a prototype of something that's clickable. That's all they want to do is when I click this, it does this. When I want to hit a drop-down, it shows me a drop-down. When I want to hit a link, it goes to a new screen. Those are all Figma screens within Figma. But if you know how to prototype, then you can make them go and interact with each other, as if it's already coded, and then you hand it off to a development team, and then you make it into an actual application. That's the nature of Figma. It's a wonderful tool. Maybe Figma will read this and I'll get something.

Woodall: (Laughs) Yeah! So as a visual artist, outside of your design work, do you have a favorite subject matter or theme that you tend to gravitate towards that you like to paint?

Towery: I guess the theme would be experimenting with lines of other things. So, there's a lot of shared-line things happening. I didn't know about Dali growing up that much, but it seems to be a lot of that stuff because it doesn't really make sense, but it's just experimenting on a piece of paper. That's basically the only style that I have—just surrealism, I guess, if it has to be categorized, and that's with the color as well. Sometimes I'll go and I'll paint, and it has nothing to do with referencing what color it really is. It is a feeling. It's just an experiment on itself.

Woodall: How do you decide which color palette that you want to work with?

Towery: Good question. Well, these days, I'm doing stuff for independent or individual states, so I'm working on some application work for Texas, Iowa, and West Virginia. Let's just say a couple of the list ones. Those are some color palettes in themselves because of the state seals, so that's a particular way we make a materials kit based on themes. It's not like we have to do everything in CSS, where every different div or every different item on the screen has to have a CSS property. It's inherent with a light and a dark theme, so there's ways to group these things. Through the application, it will have a particular look and feel. That's how we decided for the most part. We have a light version and a dark version. That's a standard thing you have to do. You have your mobile, your desktop, you have all the imaging stuff, but the color palette, it usually stems from if they have some brand guidelines—if the company or the individual thing you're going to develop should have some style guide. If it doesn't have a style guide, then maybe one should be made, and that's where you go from there. So, there's a color palette that's either based on the product itself or we just go ahead and make some stuff in Figma and we give it a new look and feel. There's a lot of blues. Different shades of blues seem to be the winner—orange and blue, I like using those intertwined so it makes a good feel with some



But for a little while, it was a little stressful.

Woodall: What advice do you have for other artists with colorblindness that are wanting to enter the design sector, but may be hesitant about it?

Towery: Just to be upfront about it, but also know how to work within the referenced realm of Hex colors. You need to reference things anyways. You shouldn't be going off the cusp about new colors all the time. I can make this shade, and that's it. You have to standardize yourself. There are libraries that need to be used because the developers are going to use these libraries, too. So that's your first step—understand that you're in a company, that you're no longer doing freelance stuff

green thrown in. People still love drop shadows—drop shadows will never die. I don't like to use a drop shadow on everything, but let's say just material kit cards, by nature, they have a drop shadow. That's just a very not elevated one, and everything has to have a really light stroke around it in rounded corners. So that's a standard thing. It's going to be 100 years before that particular style goes away, but that's the way it goes for some people, for some clients, and for some websites. That's the way you have to do it. There's colors and there's styles, but those are basically the things that I would start with.

Woodall: Can you talk about your experience navigating the creative industry with colorblindness?

Towery: Sure. Well, in print, it was a different time. I didn't have Hex color charts to reference at all, really, because there were none. At that point, it really wasn't developed. As somebody who's color blind, it was very risky for me to do anything in a print setting because my prints did not turn out like I thought they would, and there were some clients that were like, "Why do you keep printing it green?" or "Why do you keep printing it purple?" I'm like, "Oh, man, it's the printer." So small contract stuff, but I screwed up some stuff that really made people think, "You don't know this." I was like, "You're going to fire me or you're not going to pay me if I tell you I'm colorblind now." But I was going to do it, it's just that I needed some a reference. I made my own references along the way. I have my own color charts, and that was a risky thing. The people that I work with now, they really like the fact that I am so that we can make sure they're covering that angle, too. So, a lot of ADA compliance that I'm doing, that's one of them that they're now starting to take serious in a certain way. It's fun now. It's not a bad thing anymore. So that's good.

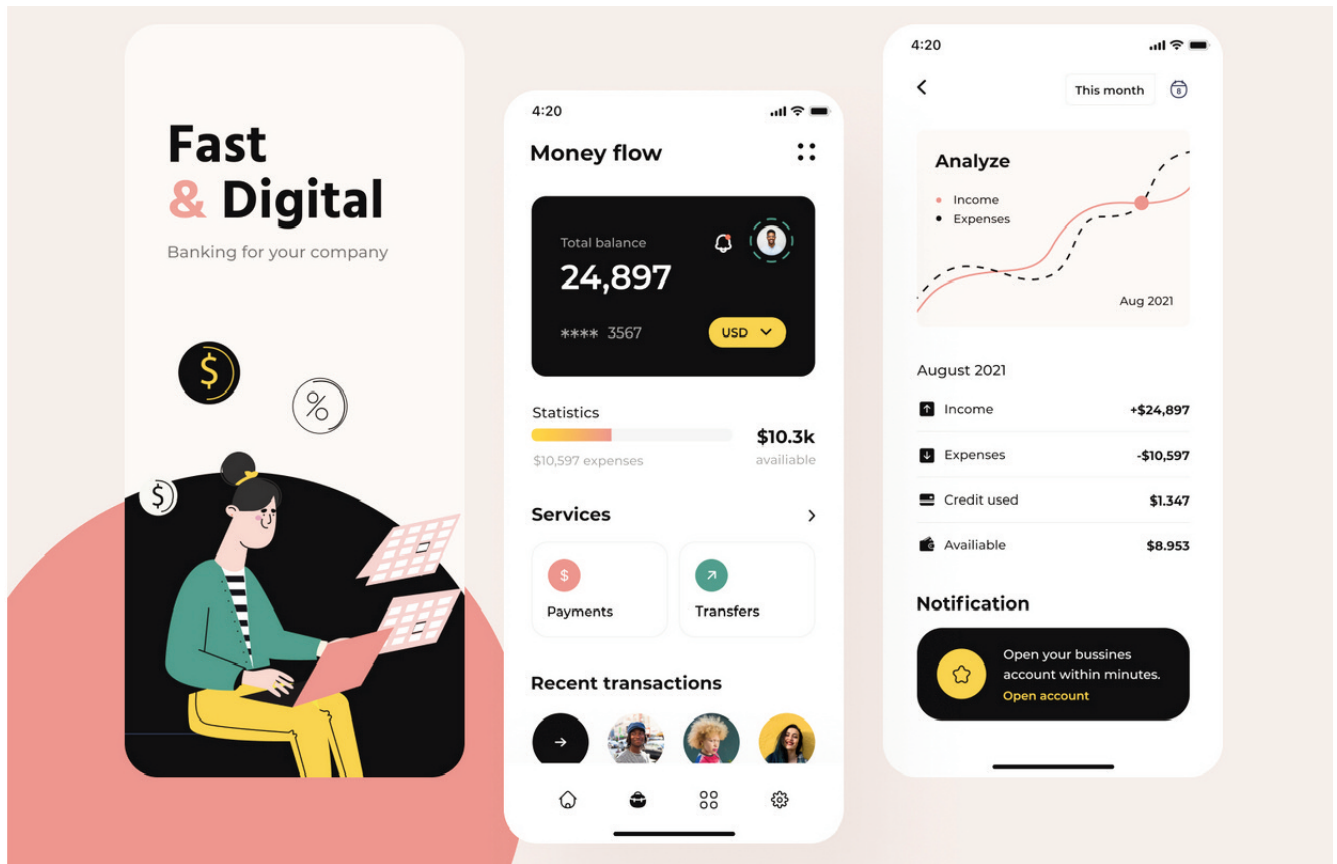
and that you have to be able to use your resources. You've got to use your resources. There's a material library for everything. There are internal libraries in companies. Find out what they already use. If they don't have anything, then build it for them. Then have your own palette that you're going to reference. It'll make you all the more useful at the company. It'll embed you even further. Typically, they don't have anything like that, and they don't even know why they don't, because it wasn't that big of a deal. Well, it's not that big of a deal, but if you're a colorblind person, don't worry about that part, just use your resources that are out there and just reference those things just like you're supposed to do.

Gina Velasquez: I'm very interested to know how color blindness impact your everyday life.

Towery: Well, the first thing that comes to mind are traffic lights. At a distance, I don't know what it's on. That's the pain in the ass part. I don't know if it's red, yellow. The green, if it's not a really bright green at the bottom, then I don't know it's green, and I have to be able to see the whole object before I can know if it's at the bottom or the top of the brightness. Then getting up closer, I couldn't tell if it's red or I guess it's orange in the middle, but whichever one is on that way.

Velasquez: It's yellow in the middle.

Towery: Okay. Well, there, so it's yellow in the middle. It's orange to me, and the bottom one is just a really lite green, apparently a white. See, it's white to me. So if it's a brand new one of those, it's like a white, an orange, and a really bright fire truck red. It's location more than anything. Different signs that are like that, definitely. I



have to use a little bit more common sense on stuff than relying on what color it is—I have to read the thing or I have to judge it in a different way.

Velasquez: That's true. And drive slower.

Towery: And I drive slower, right. You have to be careful. Oh, yeah. I'm a slow driver when it comes to that for sure.

Velasquez: Did you notice a lot of differences when you were growing up, too? Was it also difficult when you were younger?

Towery: No. When I was growing up, my mother discovered it when I was 11 or 12 or something when she finally asked me why I colored all these people green on my paintings and drawings. I was like, "I really don't," and she did a test where it's the ink blot thing, and then we found that I was color blind. It was a later in life thing more than anything, but I didn't give it too much attention. I didn't think much about it growing up until it turned into a professional situation. That's when I was like "This really sucks." and that this was something I had to actually work around. That was only in the print days. Now in the web stuff, it's a big relief because we're no longer looking at two different situations—what it seems like on my monitor, it's going to look like that on their monitor, too, and I can verify these things with a simple piece of code. So that was a big, big change.

Velasquez: You said you produce web content that's ADA compliant. I'm completely blind, so my user experience is very different. I don't rely on color. I rely on sounds. I do remember when I had some vision and mostly what I recall in terms of user experience and where I was looking for a better way to experience web pages. As part of your ADA compliance, do you ever look at those things for people who have to enlarge things, and if the page is very busy, if there are a lot of colors, things that are distracting you from the information you're trying to get to, is there something that is part of the rules of ADA compliance in terms of web design?

Towery: Yes. It's now to a degree where things are not overlapping. We don't have anything that's—how do I say—moving in the background or anything like that to divert attention. I do make my templates up to 200%. We do the bootstrapping thing, so as long as it's up to 200%—

Velasquez: Excuse me, what is bootstrapping?

Towery: Bootstrap is a CSS file and a JavaScript file together that's calling three different classes of the same object so that on a mobile version of something, it looks like it's supposed to on the mobile version. Then the desktop is spread out and it scales itself. It's a scaling of things, but you have a JavaScript file that handles the switching for you. You make one file on the coding side, and then you change CSS classes along the way.

That's where some of those issues come from if they're not bootstrapped and ready for this situation. When I got hired, that was one of the first things that I brought in to play was that we needed to take advantage of the bootstrap situation, but it's also very much because of the ADA compliancy. All of the things that I do for the company is based on that, and it's also based on not trying to get too cute on the overlapping of things and all of these animations that don't need to be there. It's also making sure that everything's tab indexed correctly. Everything is absolutely readable as it should be. We have objects that are not scrolling when other objects inside of that object need to scroll. If you have a bunch of tabs that are inside of a particular container, we need to just scroll that particular tabs container, not the entire screen, so a lot of that stuff was just not done because it wasn't called upon to do it. When I got hired, that was definitely my main thing—to bring that to attention and then be completely okay with our screen readers. So that was another effort in itself. But yes, that's my job is to do those things, and I'm definitely doing them.

Velasquez: Yeah. It's difficult to navigate some pages if there's just too much going on and it's hard to figure out the flow of information and get to where you want to go.

Towery: Yeah. That's what we've done with the applications that I have. It's for voting situations, and it's on the state level. I don't want to name the company, but it's on a state level where we're doing voting situations. Also, I got to log in as a county user. I want to see voter stuff. I want to see stuff in my county for how much the election has spent this year. I want to do all these things. It's a lot of graphs, but it's a ton of data, and it's a ton of navigable data, and there's probably 150 screens that you could end up going through on this particular application. It needs to be there for a public use as well. That's why it needs to get ADA compliant in a hurry and why the developers are now going to understand that when they release something that they call done, they're going to have to check for this stuff. They can't just put something out that's going to be uncompliant just because they say it's done on development side. This is a new thing. Developers on this particular team are very high level, but because of me, they're having to introduce one last check on their stuff before they put it into a build, and that's being compliant. There are tools to run inside a visual studio that will make sure that if they're putting something out there that is not going to meet our requirements, it'll tell them even how to fix it. There's really no excuse these days for people to make stuff that's not compliant. That's just the bottom line.

Velasquez: Do you have visually impaired people on hand to test your products?

Towery: Not on hand. I brought it up many, many times. I'm like, "I can do these tests all I want, but I'm not going to give you the full report without some actual use cases." So, yeah, that's what I brought up. It's not for the

election itself. It's actually to handle state-level money and candidate information and all these different things, so it's not that we're doing the presidential stuff. It's more like on a local level because it's extremely data-driven. When we're going to go live for these particular states, it's been brought up that either the state gives us a third party or we have internal people, but somebody needs to give it that full check before we release it for sure. And everybody's aware of that. I can tell you that. It's what I advocate for, and it has nothing to do with the colorblindness. It has everything to do with me having seizures. It has everything to do with the fact that I understand what it can be like, but there's a whole another arena for folks that want to use this. There's different ways to put it to the managers and be like, "We need to captivate all of our audience." But my own seizures put me in that particular club. Up until a couple of months ago, I was having seizures maybe every week, and the company was working with it, but I was waking up and I had no idea who I was. I didn't even know I had a job. I have my wife, and we've changed things. I'm in the club of different things to advocate for, and they know that.

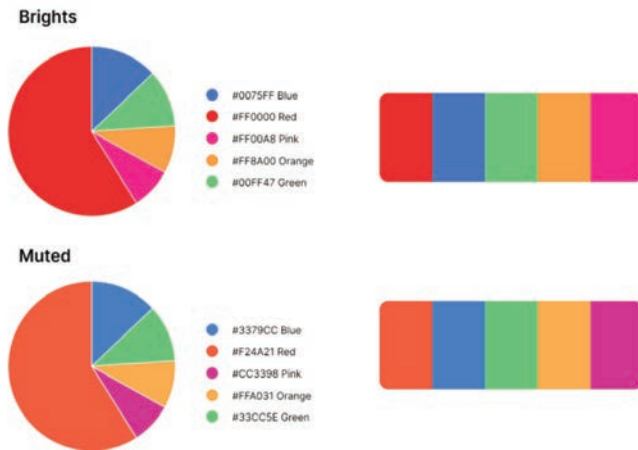
Woodall: So you have developed these color guides for accessibility for color blindness. Can you go in a little bit about that and what that is and how you utilize it?

Towery: Sure. It's there for our own referencing to use on different teams. When I made that, it was right when I got started doing the civic or the company style guide for themselves. So making their color palette, and there's a colorblind version to where they can see what it's going to look like and if we need to adjust the template and stuff, they had it for reference. How do I say? It's being used when it needs to be used. It's there as a reference more than something that we're using. It's there for print, mainly, so if we're going to be printing off user manuals or anything that's instructing these poll workers to do things and all that stuff, which is a lot of print stuff, then that's where we have them come into play, mainly.

Woodall: Okay. And to go a little bit into the screen reader side of things, I'm curious about how you determine the language that's read when certain buttons are highlighted by the screen reader. Who comes up with the descriptions of these things?

Towery: Got you. If it's an image, that's where the description comes in. That's from the product team. When a screen is developed and then put out into the application, it goes through a build process. That build process puts a lot of extra code on these screens. I don't know why, but the developers told me that's just part of the process. Sometimes if there's an ID there, but nothing's in the property value, then there's just a blank ID value. It will fill in certain things for us. We've had to work around that the verbiage that is put there comes from the product team, and they're written inside of the

Color Safe Palette Red-Green Color Blindness



user stories, which comes from meetings with Texas and Iowa and these people. They're the ones who are putting labels on buttons if it needs to be something different. But the development process, it puts its own ID with whatever the property value is, and that's what it reads out. By default, it's going to just read what's already there. Using a default spring reader like just JAWS or anything else that we've been using for testing, it's worked so far. When it comes to the image descriptions and stuff, that comes from the product team, and there's a QA person on that team, and they're the ones that give us some pretty good verbiage for the stuff. It's placeholder until that happens, but that seems to be the only part that doesn't get taken care of in the build process, but everything else is okay, and everything else is tabbing like it's supposed to, and it stops reading when it's supposed to. It's not something I manually have to do, and I think it's because we're not in an HTML setting. We're inside of C# with Visual Studio and a lot of different stuff that's building these screens. There are so many microservices that are pulled in, there's all these different screens that are being built by these other microservices and stuff, so it's not a static page by any means. I think when you're doing an application versus a website, there's different outcomes. This seems to be one of the good ones is that it reads itself quite well.

Woodall: Okay. Thank you for the insight on that. I was always curious about how that gets decided and worked into the page.

Towery: I mean, it's decided upon by me that it's okay to do, and that was the first thing that I did is I just started letting Microsoft's narrator read stuff, and it did pretty okay. Then when we got into the nitty of what it's doing, then we can do that with CSS as well. There's a lot of different ways to get a description on stuff, but the idea was, is it even tabbing correctly? Because there's ways to get the whole navigation and get it right to the first line. There's a lot of different ways to navigate through the screen, but it was starting everybody from the top left, no matter what you were doing, so it had to read everything. Then finally, you got to the stuff, it was like, "but, but,

but," and it would just read everything until you knew what to do because there was no other way to do it. The arrow keys didn't do anything. There were no shortcut keys. There was nothing. We're talking about a team of 25 developers that really don't care about this stuff, but they need to. When the functionality works, they move on to a different user story. Right now, since I've been there for over a year, they understand that's not the end of the road and that they need to put something out that's not going to screw up the whole accessibility thing, and they need to keep us accessible. It means a lot. Now they understand. It makes them feel much better to know that they're making something that isn't going to have to be recoded, too. We told them they don't want to have to go backwards. They need to make sure it's there.

Velasquez: I can relate to everything you just said.

Towery: Well, I'm doing it for you and for all these folks that have to do this shit. The least we could do is make it a better experience. I mean, it's the whole UX part of what I'm doing, and this is a voting situation. This is a government site situation. It should be really good anyways, because they're supposed to have that standard of stuff. We're making sure.

Velasquez: Were you one of the first people screaming in the desert for something like this?

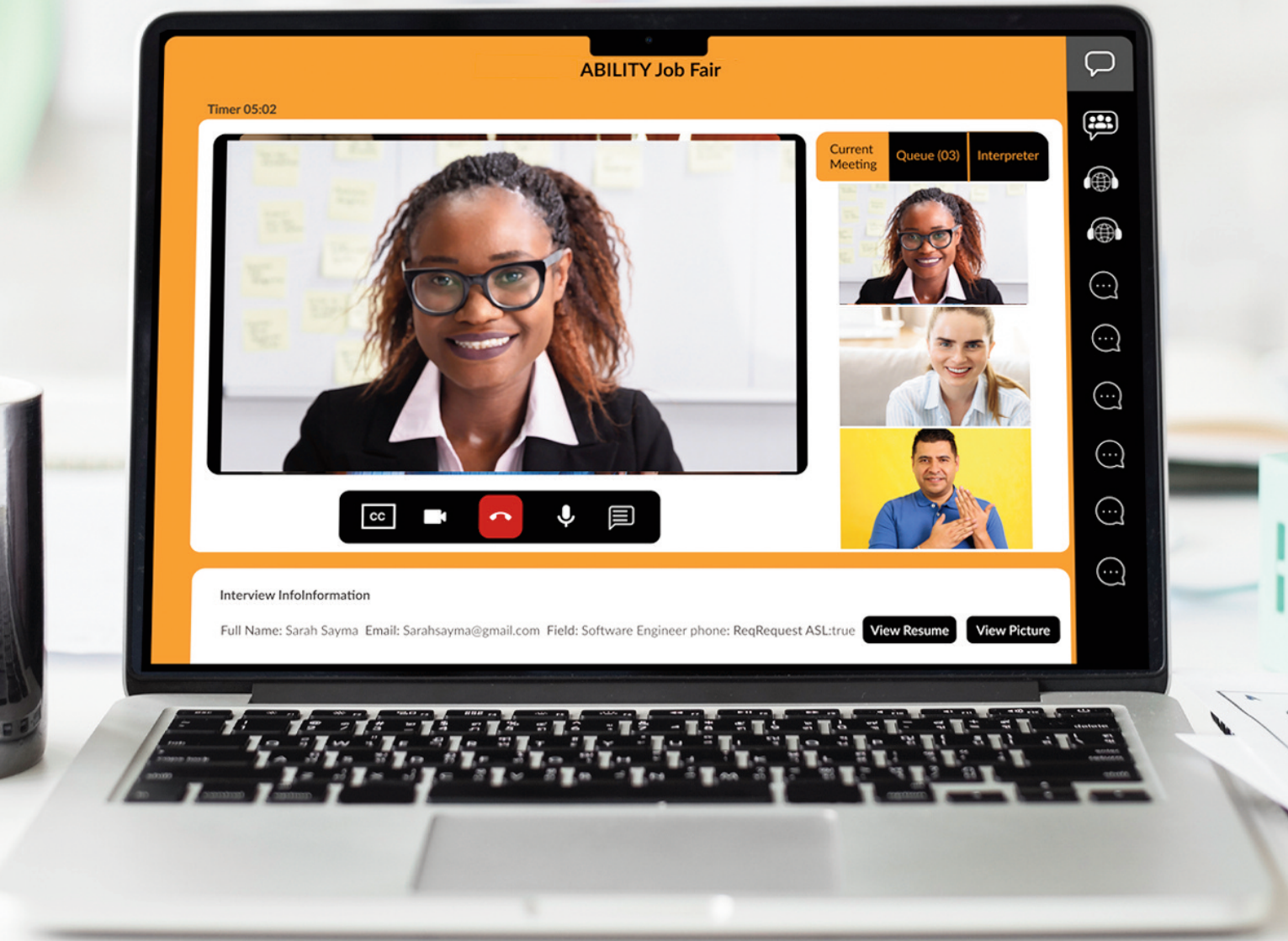
Towery: Yes, for sure. I think as part of my interview, I brought that up. As a designer, you can do things however many ways you want it to and impress this and put drop shadows on this, and I told them, "I'm an ADA-driven designer, meaning that's going to drive our choices, and we can make things still wonderful. It can be an amazing experience and wonderful design, but let's make sure that it's that compliant, and that drives our choices here." so they needed somebody on board that was an ADA person. Once I told them that, then I think that's what got me the job. It's because I screamed it at the interview, and now I'm the advocate for everybody, and that's just part of it. I'm on every team, and that's part of what I'm on the team for, is when they start bringing that stuff up, I'm telling a lot of people, "This is the way we do it now." ■ ABILITY

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The Canary Code



by

Ludmilla
PRASLOVA

Earning the title of Director of Intercultural Relations by age 25, Ludmilla Praslova, PhD is well versed in the corporate world. Being told point-blank that as a woman, she would never advance past that title made her well versed in discrimination. It also sparked a desire in her to do more—to change corporate culture. Earning a doctorate degree in Industrial-Organizational Psychology gave her a platform for change, and her new book *Canary Code* addresses exactly how we can be inclusive on the organizational level.

ABILITY Magazine's Jennifer Woodall joined Praslova during a virtual interview to discuss her inspirations behind *Canary Code*, what an inclusive workplace looks like for everyone, and how diverse and valuable neurodivergent employees can be.

Jennifer Woodall: Hello Ludmilla, what inspired you to write the *Canary Code*, and what impact do you hope it will have on workplaces worldwide?

Ludmilla Praslova: Well, one big influence is just the horrendous unemployment rates for neurodivergent people. In the US, the estimate is for autistic people with college degrees, it's up to 85% [unemployment], which really does not need to be happening, and about 30% to 40% for all neurodivergent people. There are countries who do a little bit better, like Germany and Australia, but even there it still could be better. Unemployment rates are definitely something that can be quite devastating on the individual level for neurodivergent people, and it's definitely not good for society to have groups of people included to that degree. That's really the pain point that I wanted to address. But of course, there's also my own journey and experience with the lack of inclusion and specifically intersectional



Ludmilla Praslova

inclusion. I would work somewhere and it would be wonderful on the big culture level, but completely oblivious that you need to respect gender, or someone will be talking about gender, gender, gender, but completely exclude disability. There's also this intersectionality piece that was very important to me in addition to addressing specifically workplaces and the lack of inclusion of neurodivergent people.

Woodall: Can you elaborate on the significance of neurodiversity and its role in fostering innovation and productivity within organizations?

Praslova: Sure. By definition, neurodivergent people think differently from the average. Our thinking styles could be much more visual or much more systemizing. There's a full range, but we tend to be on those margins where the creativity comes from. Creativity also comes from different perspectives. Sometimes people focus on just the singular genius. Yes, I do use examples like that in my book. For example, I talk about Nikola Tesla and how he literally changed the world by his creativity, but it's not just a singular genius that gives this boost of creativity and innovation to your company. It's also just the richness of perspectives overall that supports innovation. If you only hire that average person that thinks within this traditional corporate box, you're not going to have the richness of perspectives. That is something that would really make your organization innovative and just even aware of how quickly the world is changing.

Woodall: Can you share a compelling example of a company that has successfully embraced the principles outlined in the Canary Code and the transformative effects it had on its culture and productivity?

Praslova: Well, the book is actually based on multiple case studies. There are some companies that have been

doing this type of work for quite a while. One example is Ultronauts, which is a tech company. They've been practicing flexibility—for example, work from home—way before anyone else. When the pandemic hit, no problem. They were already remote and fully flexible. They're also transparent, and they are posting all the minutes of all the meetings. Ultronauts was designed initially for employment of autistic people. They are majority neurodivergent, but they're also attracting all kinds of talent and all kinds of communities that are traditionally marginalized because of their systems and how they are arranged. Another company I absolutely love is a little bit different, and that is a hotel chain in India called Lemon Tree. They decided to hire people others consider unhireable. They started deaf people. Then they expanded to all kinds of people, like survivors of acid attacks, but I specifically looked into their practices for people with Down syndrome. They tailored jobs for what they can do instead of thinking, “Oh, okay, so those people just can't do anything. We're not going to hire them,” they created jobs at which people with Down syndrome excelled, and the company is also thriving. There are many organizations that do amazing things. Now I've heard some universities and colleges are actually using my book structure and the way I present information to revamp their courses. That's an unusual use of what I was doing in my book. Taking the form rather than the principles, but that's cool, too.

Woodall: Yeah. That's really cool, though, that it's being adopted into universities. Have you heard of a company called Ability 101?

Praslova: I think so, but I'm not super familiar with them.

Woodall: They sound like the first company you mentioned. We host a career fair called ABILITY Job Fair and they participated. They're a tech company that just has a sole focus on hiring neurodivergent people.

Praslova: There are several really good tech companies that do this. The problem is we need to expand it beyond tech, so that's a whole other conversation.

Woodall: Yeah. My cousin has autism, and she's a brilliant artist. She's amazing at art. She hates technology. What I noticed is a lot of the focus on neurodivergent positions are within the tech industry, but she hates it. She's like, “I don't like technology. I want to draw.” Making room in other professions to have the same draw for neurodiversity would be amazing to see.

Praslova: That's one of my pet peeves because whenever people ask what jobs are good for autistic people—any kinds of jobs this particular person is suited for because of their individual set of talents.

Woodall: In your experience, what are some common

misconceptions surrounding neurodiversity, and how can we overcome them to promote greater understanding and acceptance?

Praslova: That's one of them. That neurodivergent people seek a particular range of jobs. If you're dyslexic, somehow, you're supposed to be creative. Well, some are and some aren't. Or if you're an ADHDer, are you supposed to thrive in an ER environment. Well, some do and some don't. Trying to see people based on whatever label and just making assumptions about what job they're going to enjoy. There are people who are ADHDers and they love tech, and there's literally any talent they want, any kind of job. Then in a more general way, it's the extremes of focusing on either all limitations and there are no abilities. So whatever label there is, whether it's dyslexic or autistic or any other neurodivergent label, people are like "Okay. So then you can't do anything?" and the complete denial of abilities. On the other hand, we have this idea, "Oh, so autistic people, they have super powers," or "People with ADHD, they have super powers," and the complete denial of struggle that comes with it. Sometimes it comes from looking at the more privileged autistic and ADHDers and whatever neurodivergent people who are able to self-accommodate because they can afford it. They are able to say, "Well, I got those superpowers.", but a lot of people have so many struggles. People are saying, "Oh, we're going to hire autistic people because they're going to do twice the work of the average person." I mean, that was literally the argument that's been presented over and over and over by some companies, Hire autistic people because they do twice the work of the average person. No. Autistic people have done twice the work of the average person, and I have done that too, but that comes from not taking breaks and physically working until you're physically sick, so making this into a superpower and a hiring argument is a significant problem.

Woodall: I can definitely see that, especially when you get into the hyper focus, where you just forget to eat and you don't really drink or anything like that.

Praslova: That's how I work. It works, but it doesn't mean that I should be forced to work like that 24/7 and be expected to do it.

Woodall: When corporations are operating on a bottom line standpoint, they look at that person, they go, "Oh, wow, that's incredible." But It's not fair, like you're saying, for that to be expected to happen.

Praslova: And then they're just going to pile more and more jobs on you. So that's literally what happens, and if you're not careful, and if you're just an autistic person who is trying to please people because you've been bullied your entire life and because you don't really see hidden agendas, then you are going to be forced into years and years and years of overwork until it destroys you.

Woodall: How do you envision the future of work evolving as organizations increasingly prioritize neuroinclusion and intersectional belonging?

Praslova: Well, the whole idea of the Canary Code is that all neurodivergent people are canaries in the coal mine. They're more sensitive to whatever is toxic and not good for any human in organizations, so really making organizations more neuroinclusive and ensuring intersectional belonging—including those who are on the margins and those who are most affected by toxic environments, bullying, the lack of transparency—is something that's good for everyone. It's really making organizations more human-centric and less toxic for everyone, because when canaries can breathe freely and be creative, so does everyone. It also doesn't mean more progress. I'm not talking about bringing more programs for every label. We actually want just fewer barriers, not saying, "Okay, so how do we help autistic people or people with PTSD, to get over that barrier that really shouldn't be there to begin with?" Let's get rid of those barriers. There are many unfair barriers in organizations, and just make them more just and less toxic for everybody.

Woodall: Some companies when they hear the word 'accommodation' or have someone coming in that needs certain accommodations, they would just rather not deal with that. Do you have any recommendations on how someone coming into the workforce that is neurodivergent might be able to navigate that conversation?

Praslova: It really happens everywhere in every industry. People just think that, "Oh, someone is imposing on how I do things," or they automatically think this is going to be expensive, even though most accommodations are not expensive at all. If you're talking about the vast majority, let's say, of autistic people, working from home, flexible work or hybrid with a significant proportion of working from home, sometimes is really the only thing that people need. Or clear communication. Instead of just mumbling something on the run, talk and make it clear, or better yet, put it in writing. Make all the instructions and rules clear and put them in writing, and they just keep using it. You do it once, and you don't have to keep running into the same problems of people asking for clearer instructions. A lot of this is really something that will improve organizations. More flexibility is going to be appreciated by everyone, and clearer communication and sticking to the rules not making things up every time you do something. That is to improve clarity for everyone. Let's say someone does need a unique accommodation, very often it's just different software. Software that helps dyslexic people, for example, has now gotten pretty cheap, so what's the big deal? It used to be that text to speech, speech to text were rare and expensive. Now, it's basically everywhere. So again, what's the big deal? Obviously, it depends. There are some people who have multiple co-



thing to do with your actual job performance. If you are a cook or an accountant or a majority of other occupations, the ability to verbally sell yourself has very little to do with your actual job performance, and sometimes it has the inverted relation to your actual job performance. Why not ensure fairness in hiring by giving people mini job tests specific to what they need to do—and I'm not talking about those two, three weeks camps because that's a lot of unpaid labor—I'm talking like 30 minute snippets of specific qualifications of what you need to do. I'm a university professor. To get a university professor job, you need to teach a class. That makes perfect sense because

existing issues that might require a little bit more of accommodation. We did an article on long COVID, for example. There are some things that might be a combination of multiple accommodations. But still, you get a talented person who can do the job, and there is a particular tweak that you can make that is going to bring this unique perspective and bring a unique experience to your organization. We used to throw around the \$500 number. Now they say it's actually even cheaper than that. It's under \$300 because I think a lot of software went down in price. Even things like, "Oh my gosh, a special desk for someone who uses a wheelchair." Well, apparently they say if you just put a bricks under the regular desk, that lifts it up exactly at the height that's needed. We actually had a demonstration and people came and showed how easy it is, and that's literally what they did. So, sometimes you need a brick or 2x4, which is, again, not going to break your bank. Sometimes people just imagine something that's really not true. Just get rid of those assumptions and just look into it. It might be a lot simpler and easier than you think.

Woodall: Your book discusses the concept of organizational justice as a core principle of the Canary Code. What steps can organizations take to ensure fairness and equity for neurodivergent employees?

Praslova: Again, we're not even necessarily talking just fairness for neurodivergent people. When we ensure fairness for neurodivergent people, we ensure fairness for everyone. We don't want a back door that's just for neurodivergent people. Let's take hiring. Fairness in hiring. Right now, we're really not doing very good job with hiring neurodivergent people. We're not doing that a great job with hiring in general. Most people now, regardless of whether they are accountants or food prep or whatever, get hired through interviews. Okay, so if you are a salesperson, a face-to-face salesperson, maybe the ability to verbally sell yourself has some-

that's what we actually do. Why in so many occupations, people think that just talking to someone is going to replace the actual ability to show whether you can do something doesn't make any sense. Or the resume, or how much experience you've had with something. Maybe you didn't have official experience, but you can do the thing. If we had people demonstrate their skills, that will ensure really a lot more fairness in hiring for everyone. When we do this, which is the use of a valid instruments, which is a lot of the principles of the Canary Code, we actually not just get rid of discriminatory biases that interviews are riddled with, but we make better hires because we use more valid assessment of someone's ability to do the job because we're asking them to do the actual snippet of the job. It's going to be better for organization and it's going to be fairer to every job applicant.

The same thing for performance evaluation. A lot of it is, "Okay, how often do I see you and do I like your smile?" The same thing, promotion. Remove bias, use clear criteria that are known to people that are clearly job-related. Stick to those criteria for everyone, and that, again, will just ensure more fairness in the organization in general. Right now, neurodivergent people do tend to be hit by those aspects of unfairness more than others because the system was designed for neurotypicals, but it doesn't make this system fair in general. It's more unfair to neurodivergent people, but it's not really fair to neurotypicals either because there are cultural differences, there are gender differences that also get caught in those biases when we don't stick to criteria and do whatever in our interviews. So, removing bias and then creating checks and balances and ability to double-check high-stakes decisions, will go a long way in fairness for everyone.

Woodall: Yeah, that's such a great point about the inter-

view process and how it pertains to the job type. I'm a huge fan of a working interview just because, like you're saying, you get to show your skills and you're relying on this piece of paper that's like, look what I can do.

Praslova: It's much more realistic for everyone.

Woodall: So as someone who has navigated both academia and corporate environments, what advice would you offer to organizations seeking to foster a more inclusive culture? We covered this a little bit, but you can you go more in detail about it?

Praslova: Right. We obviously can start in many different places, but there's a reason participation is the first principle in the Canary Code. I would start with participation and ask your people specifically about their pain points. It could be, "Nobody understands how do you get promoted in this place." Or it could be "The office spaces are considered horribly and are giving people migraines." Or it could be something else. Your people are the ones that are going to tell you what the pain point is and why there is, for example, turnover among neurodivergent people or pregnant people or whatever. Start there, fix that pain point thing. Then whenever you want to do any other inclusive work and take any other steps, you're going to get a lot more support for whatever else you're going to do. You can start implementing systems and taking down more barriers. I am a big fan of just finding out this biggest pain point that's really hurting your people now, taking care of it, and then going from there. Then you can ask me, of course, and I'll be happy to come and consult with you, but it's really your people who are going to tell you what their pain points are.

Woodall: Yeah. No, that's a great point, too. For our job board packages that we have for companies, we do consultations, like a one hour consultation thing, where we basically teach them how they can be in accommodating workplace. But part of that is teaching them, talk to the people in your workplace that have the disabilities. Ask them what they need for accommodation because everybody's different, again, touching back on that. And open communication is going to be the first step of success, for sure.

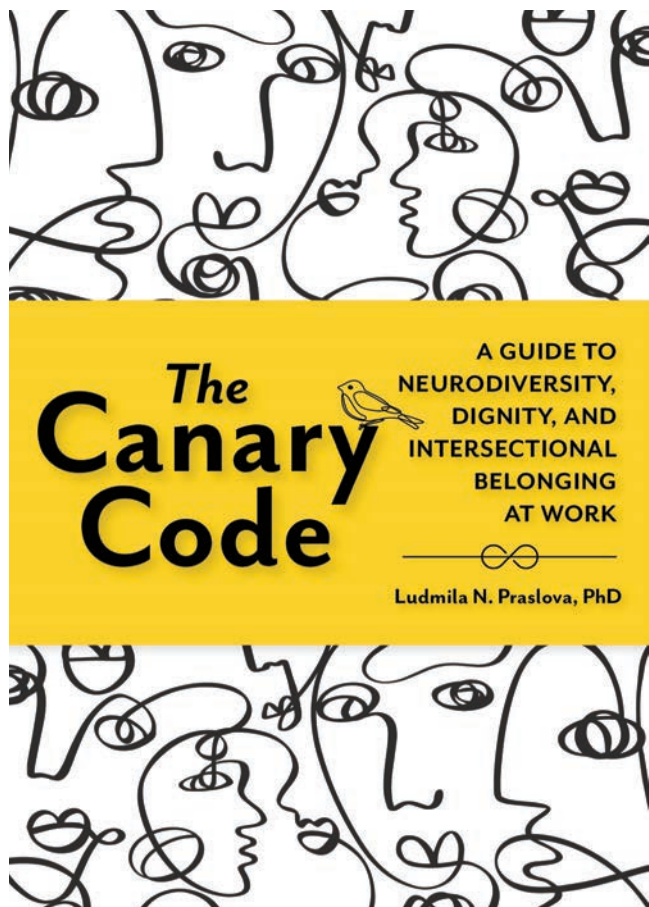
Woodall: In what ways do you see technology playing a role in facilitating neuroinclusion within workplaces? In addition, what potential changes do we need to address?

Praslova: Well, that's an interesting question because sometimes people say, "Oh, yeah, technology is going to save us." or "Technology is going to ruin us." Obviously, technology is a tool that can be used for good means or for bad means. For example, I already mentioned some tech that can improve accessibility. It could be anything from screen readers to text to speech

to whatever else, the organizational software that takes the load off executive function, little robots that help people reach things that they can't reach physically. But people are also saying, "Oh, the robots are going to make everything possible," or "ChatGPT is going to solve all the neuroinclusion problems." That's not going to happen. It's not going to replace good leadership. It's not going to replace just sound decision making within the organizations that is done by ethical and caring humans. It's ultimately humans who make decisions about hiring and performance management and whether or not to provide someone accommodations. That's really the crux of it. Technology can only go so far and not putting an app on somebody's phone that's going to bug them every 20 minutes, telling them to relax is not going to help people, especially it's going to annoy some people to no end.

So just saying, "Oh, yeah, there's an app for that." I think people are getting to the point where it's like, "No, no more apps." There definitely is a tension that some people are uneasy and stressed and just experience a lot of techno stress, both from having to learn things all the time and the future anxiety. Again, that takes us to human ethical decision making. If people are using tech as a threat because they like their employees scared and they think that a good employee is a scared and anxious employee, and they're telling people, "Oh, well, you better behave and suck off or I'm going to replace you with whatever," that's a human behaving unethically. That's not really a tech problem. It's how people are using it. If we are really not thinking on the societal level about what's the appropriate use of tech and what's not appropriate use of use of tech, we can really create society that is even more anxious than it is now. We do know that mental health is not going very well. There is a potential both for tech overwhelm and tech anxiety to really mess up human psyche. Obviously, neurodivergent people who are already more prone to anxiety might be even more impacted by that. That, again, is a matter of ethical human leadership, because what people are saying, "Oh, you're going to be replaced by a robot." or "You're going to be replaced by someone who knows how to use technology." actually, no. You're going to be replaced if someone in a place of influence decides that human value versus monetary value equation always needs to be solved in favor of short term monetary value. I do think, in the long term, it's just not going to work because if you get rid of all the employees, we're going to be buying stuff. Short term people making decisions that are really hurting people, that is something that needs to be addressed or humanity is going to end up in a huge crisis. So, It's a humanity question. Tools and human ethics are just more important than ever because tools are powerful and how we use them, it just needs to be an ethical decision.

Woodall: What actionable steps can individuals take to advocate for neurodiversity and promote inclusive



practices within their own organizations?

Praslova: Yeah, so my entire concluding chapter is about it. One point to remember is that you really can lead from anywhere. Yes, CEOs have power and the boards have the leverage that the average person doesn't, and they can change organizational policies and make things more fair through that. But there's a lot that an everyday person can do just by being an example. For example, I don't have to be a big boss to ask during the meeting if everyone had a chance to contribute, or just say, "If it's a virtual meeting, do we really all have to be on video? I don't have a big problem with it, but I read this article that's for some people that creates anxiety. Why don't we let people do whatever works for them?" and "How about we allow some brainwriting in addition to verbal brainstorming? Because I read this article and it says that you actually get more ideas and better quality ideas, and it also gets introverts and people who are less comfortable speaking to participate." You can do those daily things and be an example. That can actually lead to pretty significant change.

Also building alliances. Building alliances with other people who might come from a different group, but they will benefit from the same changes. For example, all kinds of people benefit from flexibility, from working parents to students. If we're just making it an issue of one group, we're less likely to accomplish an inclu-

sive change versus when we're saying this is good for all kinds of people. So, advocating for changes that are good for neuroinclusion, but are also just generally good for pretty much all employees. Just again, thinking about everyday communication. How do you structure your emails or how do you use a combination of spoken and written communication to reach as many people as possible? Sometimes doing those things is really the best example. We can talk about people in specific position then. People in human resources can arrange training, can check for whether procedures make sense, and check what they do against neuroinclusion audit, and make suggestions for how to train leaders to support neuroinclusion in the workplace. There are people who have more leverage within an organization, whether it's HR or training and development or line managers or CEOs and board members. I actually have a huge table that gives specific ideas for each of those groups in specific places, like from HR to CEOs, but most of us are not CEOs, and we still can make a difference. So that's something that I think is very important to remember.

Woodall: Do you see any room for something that's maybe a branch of the HR Department of a company that might be related to disability and neurodivergent support?

Praslova: Some bigger companies have them. Unfortunately, some of them are also getting rid of them, but it could be under a disability office. There are also some organizations that have accessibility offices, which is definitely helpful. As far as neuroinclusion, a lot of education will be needed because very often people are pretty stretched, and it's one person who is in charge of disability everything and they might be usually trained on the more visible things or more traditional understanding of disability, like you need screen readers and you need a ramp, but with so many different psychological level needs and neurodivergent needs, there may need to be training because people sometimes really do have a hard time understanding how someone who are both autistic and has a dyslexic needs to communicate. Learning a little bit more about various non-apparent differences might be helpful for those offices. Organizations that have those offices, that support those offices, that give them voice in decision making, can definitely go much further in creating inclusive environments.

Woodall: If someone who is neurodiverse is coming into the workforce for the first time, and they may be scared or apprehensive because of their experiences with bullying and things of that nature, do you have any recommendations on when they're navigating the workplace for the first time?

Praslova: Yes. Transitions are always complicated. Learning a new place is definitely not easy for anyone. When we come into a new place, sometimes it is a mat-

ter of just learning, surveying the lay of the land, and finding that sometimes you just need one ally. If you just find one person who is accepting—who you can talk to—it can be very helpful. But they also might be wondering whether or not they want to disclose. That's another huge question. Actually, I did a big article on disclosure. I have this idea that you might want to have at least two people that are supportive of you. In this particular case, if you are any kind of different or need help, because then it creates even a small network is better than one person. So, trying to maybe find two people or maybe three people or maybe a group that can be supportive is really helpful. Also, don't be afraid to ask what ERGs (employee resource group) do you have? You don't necessarily have to ask, "Okay, so do you have an ERG for autistics or dyslexics?" but you could say, "What kind of ERGs do you have in general?" If you don't want to self-identify, you just say, "I just want to check them out." or clubs, clubs or events.

That might be one way to just ask questions without completely self-identifying, or just asking, "So what do we do here? Have we done anything for ADHD month or autism month or anything like that?" and find out who was involved and who leads those things. That might be one way, again, to find people that might be more similar to you and find people that you might be more comfortable with. All organizations are different, and some organizations will easily give you this information. They say, "Oh, yeah, we have disability ERG." and "We have autism ERG, and we have all kinds of things." Another organization could give you a blank stare, which this absence of information is also information that tells you quite a bit of the current state of your organization that might influence your expectations or how you might want to go about it. Anybody is going to be learning the lay of the land of their organization. It might be a little bit more of a mine field for neurodivergent people. We might need to ask certain questions, but there are ways to ask them without disclosing what you don't want to disclose.

You could just say, "Okay, so who is into what cause here?" That might tell you "Oh, so there are other neurodiversity advocates here." Or, you could just ask for a calendar of specific events that you have this month or that month. If the organization has any diversity person, that might be a pretty safe place to start asking these questions. Even if they don't do anything for neurodiversity or disability yet—again, that's information—maybe that person will say, "Oh, maybe we should." Maybe that's how you might end up getting involved or meeting other people with similar interests. Sometimes, trying to figure out what structures are there that could be supportive of this particular diversity is a helpful first step, and working with what is there. You obviously need to know that those things exist. Relying on just your workplace may not be enough, but joining something like a group. There's so many now online groups for neurodivergent people in the workplace. I have a

LinkedIn group, and there's all kinds of groups where you can ask those questions in a non-threatening environment that you won't ask of your colleagues, but you can ask just someone with more work experience, and that can be really invaluable. There are online groups where you can just ask those questions without having to out yourself in the workplace if you're not ready to out yourself.

Woodall: Do you know of any college programs that are accommodating to neurodivergent people?

Praslova: Well, there are entire colleges that are specifically for neurodivergent people. So Beacon College in Florida, or Landmark—somewhere in New England I think—are entire colleges based around neuroinclusive learning. Then there are many, many universities where most of them have in some shape or form, neuroinclusion programs, but there are some larger ones. I mean, like Stanford, they have all kinds of things. You could like the particular university because you like their chemistry program, but you can also inquire whether they have considered neuroinclusion and what they do.

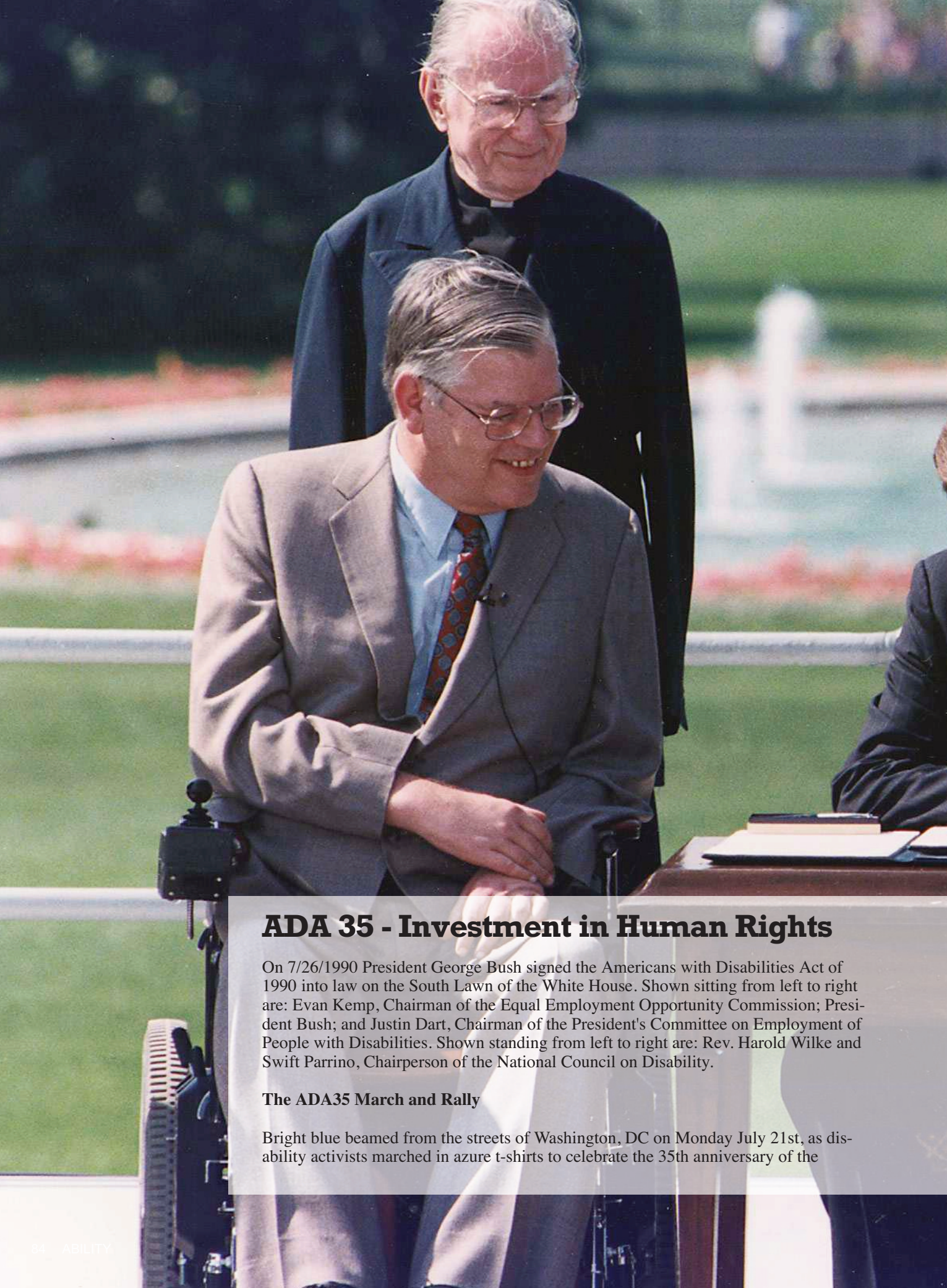
Woodall: Is there anything else that you'd like to cover?

Praslova: Just that everyone is in their own place, and sometimes the society just tries to put neurodivergent people into our boxes. One of the reasons I wrote my book is to blow those boxes apart a little bit and to show the diversity within neurodiversity. There are many different ways to be neurodivergent, and that includes leadership. Very often society tells us, "No, neurodivergent people can't be leaders." but there are many ways that people can exercise leadership, including through thought leadership and through writing. I just think sometimes neurodivergent people have faced so many barriers. It's hard to see the possibilities, and really, I think just finding someone who may be similar to you, but not to other neurodivergent people and be inspired by their example is really helpful. That's why I put so many personal stories from different people, from different types of neurodivergent, just to give people something to see, "Okay, so those are the struggles that we experience in the workplace, but then there are also opportunities." I talk about leadership by people with Tourette. I talk about leadership by people who had brain surgery and to recovered from that. Really, neurodivergent people can do all kinds of things, and we don't have to do it in ways that society tells us to do it.

Woodall: Well, thank you so much for taking the time to talk to me today.

Praslova: Well, fantastic. And again, the more your divergent voices we have out there, the better. Have a good rest of your day. ■ ABILITY

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ADA 35 - Investment in Human Rights

On 7/26/1990 President George Bush signed the Americans with Disabilities Act of 1990 into law on the South Lawn of the White House. Shown sitting from left to right are: Evan Kemp, Chairman of the Equal Employment Opportunity Commission; President Bush; and Justin Dart, Chairman of the President's Committee on Employment of People with Disabilities. Shown standing from left to right are: Rev. Harold Wilke and Swift Parrino, Chairperson of the National Council on Disability.

The ADA35 March and Rally

Bright blue beamed from the streets of Washington, DC on Monday July 21st, as disability activists marched in azure t-shirts to celebrate the 35th anniversary of the



Americans with Disabilities Act (ADA). As a landmark civil rights law, the ADA was passed to prohibit discrimination against people with disabilities and ensure equal access to employment, education, transportation, telecommunications and public spaces.

Beginning at the Grand Hyatt Washington hotel, two long rows of protesters marched and wheeled, side-by-side, hugging the sidewalk, quickly evolved into passionate chants and a full crowd that covered Pennsylvania Ave NW. The U.S. Capitol stood in perfect view ahead, and the energy honored that of the 1990 Capitol Crawl, a turning point in the passage of the ADA when 60 disabled people of all ages left their wheelchairs and mobility aids behind to crawl up the steps of the U.S. Capitol.

The march and rally, organized by the National Council on Independent Living (NCIL)



and the American Association of People with Disabilities (AAPD), spoke to a broader theme—“Our Lives, Our Homes, Our Communities.” The theme resonated on stage with speeches from various disability advocates, including the political voices of Illinois Congressman Danny Davis, California Congresswoman Lateefah Simon and Senator Bernie Sanders.

Throughout the march to the Capitol, signs pointed to the severity of recent threats on disability rights. Phrases like “Disabled Not Disposable” and “Real Inclusion Requires Real Investment,” emblazoned signs that were hoisted above the sea of blue ADA35 t-shirts.

Joining the crowd at the Capitol, Congressman Danny Davis spoke, “It’s good to be here with the National Council for Independent Living, and it’s always good to be here with people who are representing themselves to make sure that individuals with disabilities or with challenges get the attention, respect, and services you deserve.”

Fiery enthusiasm grew with the heat of the thick DC air throughout the day. Each speaker built on the urgency of the speech before. Congresswoman Lateefah Simon

passionately proclaimed, “I will tell you this, there is nothing, nothing we can’t do in this moment that won’t end us in the road to justice, end us up on the road to equity. Center ourselves in every single thing we do. There is no environmental justice without the voices of disabled people. There is no education justice without centering the voice of disabled people. There is no peace movement without centering the voice of disabled people.”

Senator Bernie Sanders—his presence unanticipated by the crowd—exclaimed fervently, “The ADA is not just a piece of legislation. It is, in fact, a value statement about what our country stands for. And it’s a very simple and profound statement. It says, in America, people with disabilities deserve to live the way they choose. It’s not a very radical statement, but a very important statement. It says very clearly that discrimination based on disability is wrong and will not be tolerated. It says that people with disabilities must have the same rights and freedoms and opportunities as everybody else.”

The ADA35 celebration was a passionate day of standing up for disability rights in response to the new administration’s shift in priorities. It was an opportunity



for renewed commitment of people, of all abilities, to defend nondiscrimination, accessibility and justice. There was a mix of excitement and purpose. Jenny Sichel, NCIL Director of Operations reflected, “I am probably most excited about the disability community coming together for the march this year and just the unity that we have with the partnerships with all the organizations going on this year and really bringing together our people and our allies.

Advocates and allies alike find this year’s march particularly vital. NCIL Executive Director Theo Braddy affirmed, “It’s needed. We need to be visible. But more than anything else, the community needs to see that we exist. And we contribute. And we participate. And we march. And we do all the things that everybody else does, especially in this time when we’re facing so many devastating cuts and things that are affecting our day-to-day life. That’s what we’re marching for, our homes, our community. And we’re going to continue to do that, to let everybody know that we exist.”

Shifting from celebration to concern, Braddy warned, “Well, this is the thing about disability. It does not discriminate. Eventually, it affects us all. We’re all going to

age into limitations, but we still want to participate. We still want to be respected. We still want to contribute. And the ADA has allowed us to do that. And so, we just can’t— Jenny and everybody here—just can’t stand by and let that law be rescinded, to be changed. And that’s what now is trying to be accomplished. The administration is trying to pull back some of the requirements of the ADA. We can’t do that. We can’t go back.”

Disability advocates have raised concerns about recent Trump administration policies that may undermine ADA protections. In July, the “One Big Beautiful Bill” (OBBB) Act was signed into law, reducing federal funding and tightening eligibility for Medicaid, SNAP, and Medicare—programs vital to low-income and disabled Americans.

Since January 2025, executive orders have directed federal agencies to scale back Diversity, Equity, Inclusion, and Accessibility (DEIA) efforts. The Department of Justice also rescinded several longstanding guidance documents—some dating back to the early years of the ADA. These documents had historically provided practical interpretations and compliance advice for businesses, public entities, and individuals with disabilities.



Their removal raises broader concerns about federal support for civil rights enforcement and public understanding of accessibility obligations.

Eve Hill, former Deputy Assistant Attorney General of the U.S. Department of Justice, Civil Rights Division, explained that major layoffs from departments that fight discrimination, such as the DOJ Civil Rights Division and the Department of Education's Offices for Civil Rights (OCR), leave ADA nondiscrimination laws less enforced and people with disabilities, therefore, less defended.

Efforts to roll back disability rights continue, some even prompted by requests from the private sector. In a letter from the American Council on Education (ACE) to Russell Vaught, Director of the Office of Management and Budget (OMB), ACE takes aim at website accessibility. The letter qualifies undoing a previously established rule, "Nondiscrimination on the Basis of Disability; Accessibility of Web Information and Services of State

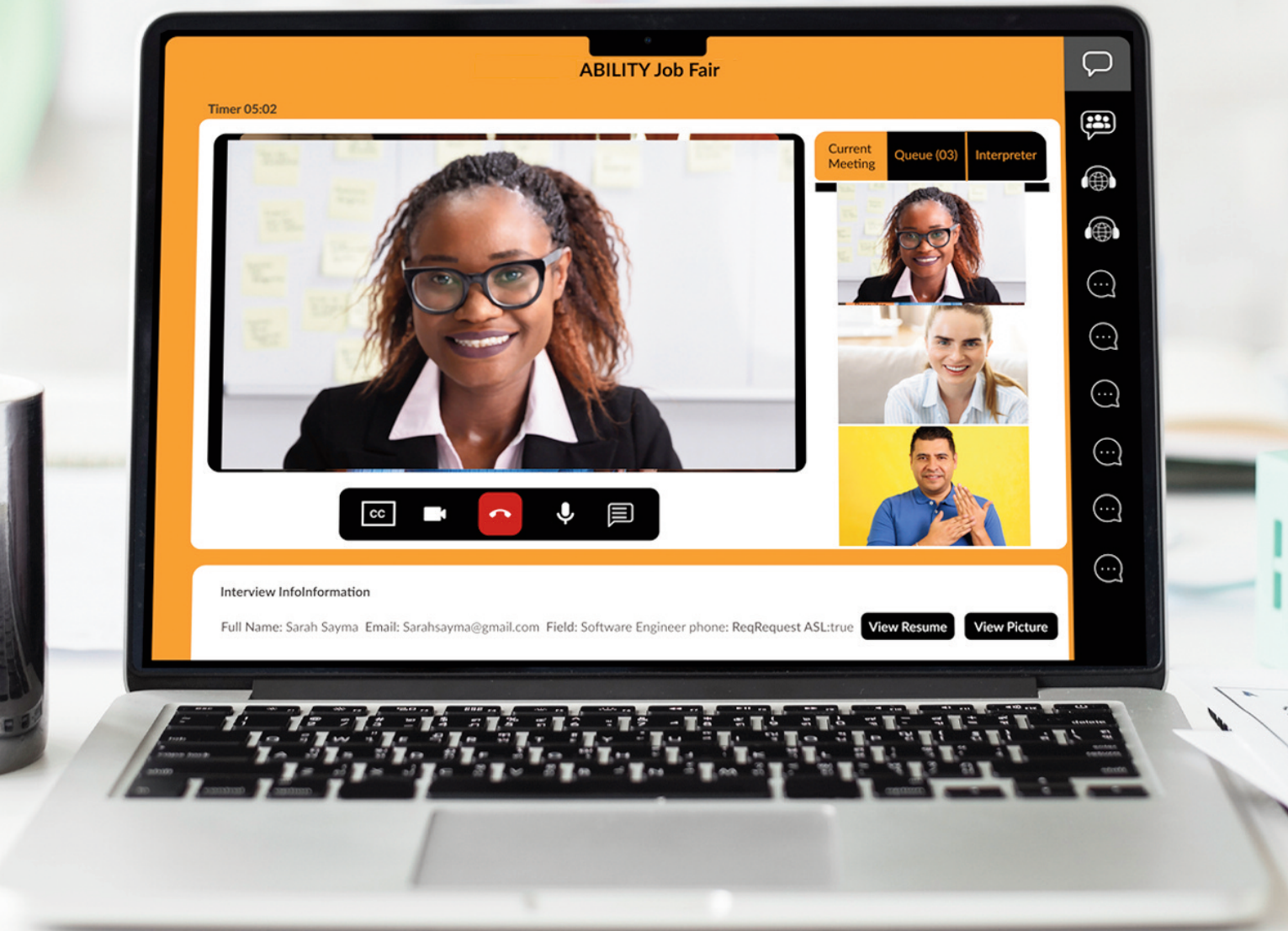
and Local Government Agencies," by claiming the cost to implement the rule is "burdensome."

Clear example of that effort is The Department of Energy's recently published direct final rule (DFR) to remove regulations that require government funded facilities to be accessible to people with disabilities in their construction. The rule, "Rescinding New Construction Requirements Related to Nondiscrimination in Federally Assisted Programs or Activities", claims that the cost for private entities to make their buildings accessible is "unnecessary and unduly burdensome."

"Unduly burdensome" refers to a clause in the ADA that aims to protect private entities in the case they are not financially capable of making their facilities accessible. However, use of the phrase as a tool to rescind government requirements for accessibility, exploits a loophole in the ADA and, arguably, exhibits a choice to deprioritize people with disabilities, accessibility and nondiscrimination.



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Initially intended to go into effect July 15th, this new rule garnered an unprecedented amount of backlash. During the rule's public comment period, over 20,000 disability rights advocates and allies voiced their objections. The rule was put on hold until September 12, 2025. The Acting Chair of The National Council of Disability, David Shawn Kennemer, issued a letter to the Department of Energy, requesting a consultation before DOE's rule takes effect.

In response to the latest attempts to weaken ADA policies, NCIL's Braddy stated "Although ADA statutes remain in force, these administrative actions erode the infrastructure that supports enforcement, interpretation, education and funding. Without clear guidance, active enforcement, DEIA (Diversity, Equity, Inclusion, and Accessibility) supports, or independent oversight, disabled individuals may face new barriers accessing public spaces, employment, healthcare, education and government services."

Decades of advocacy for the ADA have established nondiscrimination and disability rights as fundamental legal principles, but those hard-won gains are now being undermined. The consistent thread across efforts to weaken the ADA is a policy agenda driven by the Trump administration's commitment to reducing tax

burdens, especially for high-income earners, even at the expense of civil rights enforcement.

Bernie Sanders emphasized, "A nation is judged, not by how many nuclear weapons it has or by how many billionaires it has. It is judged by how it responds to the needs of the most vulnerable in our society."

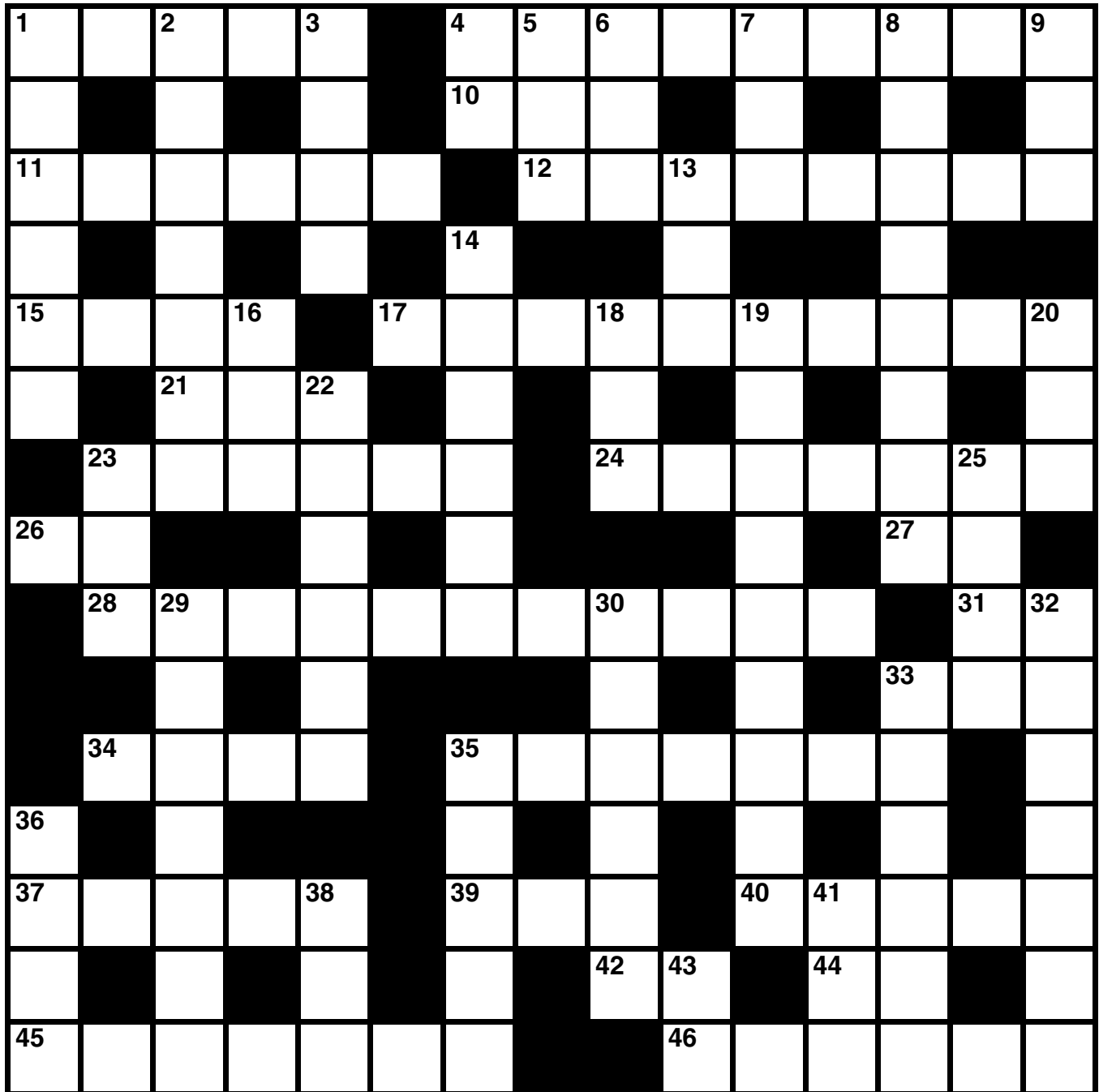
Disability rights are enshrined in the U.S. Constitution and reinforced through decades of legal precedent, including the Americans with Disabilities Act. The ADA35 March and Rally underscored a critical truth: There is much more work to be done. Advocacy remains a relentless struggle—one that disabled Americans have long been forced to shoulder. Regardless of political leadership or shifting legislative priorities, this community and its allies persist in defending the civil rights to which they are lawfully entitled. ■ **ABILITY**

ncd.gov/letters/2025-06-11-ncd-letter-to-doe-regarding-dfr-on-construction-requirements/

federalregister.gov/documents/2024/04/24/2024-07758/nondiscrimination-on-the-basis-of-disability-accessibility-of-web-information-and-services-of-state

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ACROSS

- Netflix reality series launched by Nyle DiMarco- model, actor and filmmaker as well as a constant advocate for the deaf community, 2 words
- Global platform which establishes a go-to resource for accessibility information founded by Maayan Ziv
- Firm's top dog, abbr.
- NFL sports video game brand
- Thrilling
- Catches
- Having a very good grasp of situations
- Place down
- Site of an iconic endurance sports car race, now a venue for adaptive motorcycle racing, 2 words
- Excites, 2 words
- Augusta's state, abbr.
- Famous poet initials
- Blind player in the USA Blind Soccer Men's National Team: he trains blind kids to play soccer, 3 words
- While
- Toward the back of a boat
- Comedy drama film starring Emilia Jones as Ruby Rossi, the child of deaf adults
- Comical
- Founder of Switchify who created a customizable smart phone interface with adaptive switches, Owen _____
- "I'm impressed!"
- Para Olympic category
- Not available, abbr.
- Extra wide shoe fitting
- He lost both his hands during military service, later won an Oscar for "The Best Years of Our Lives"- Harold _____
- The first male deaf actor to win an Academy Award and a BAFTA Award, Tony _____ for his performance in "CODA"

DOWN

- Medical expert on autism, 2 words
- Oscar-nominated documentary short on the Maryland School for the Deaf
- Global taxi service
- Temperature control, for short
- Middling mark
- Deaf Cheyenne woman who received acclaim for her role in the Disney+ series "Hawkeye", Alaqua _____
- Jet ____: fun watercraft that can be made adaptive for aquatic thrills
- Making the most racket
- Hairpiece
- Billiard ball shooter
- Was aware of
- "I am ____": movie centered on the main character who has an intellectual disability
- Starbucks offering: de _____
- Global leader in complex rehab technology
- Medium like perception
- Long Haul Paul's motorbike brand
- Zodiac sign
- Milit. branch, abbr.
- "The Three ____"- comedy team that were famous for several decades
- Disabled actress who plays a confident student on HBO's "The Sex Lives of College Girls", _____ Spencer
- The King's problem in "The King's Speech"
- Sees it the same way
- Heavenly being
- Actor Epps of "House" fame
- New Years _____
- Doggy doc.
- Anchorage's state, abbr.

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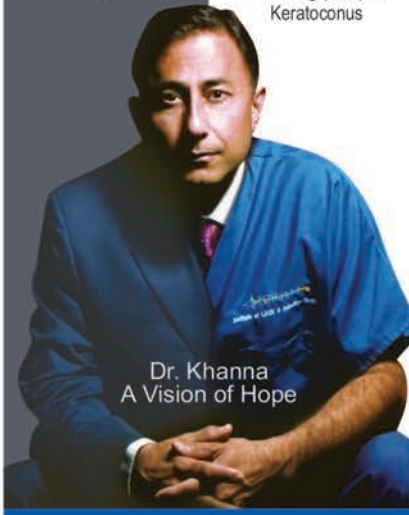
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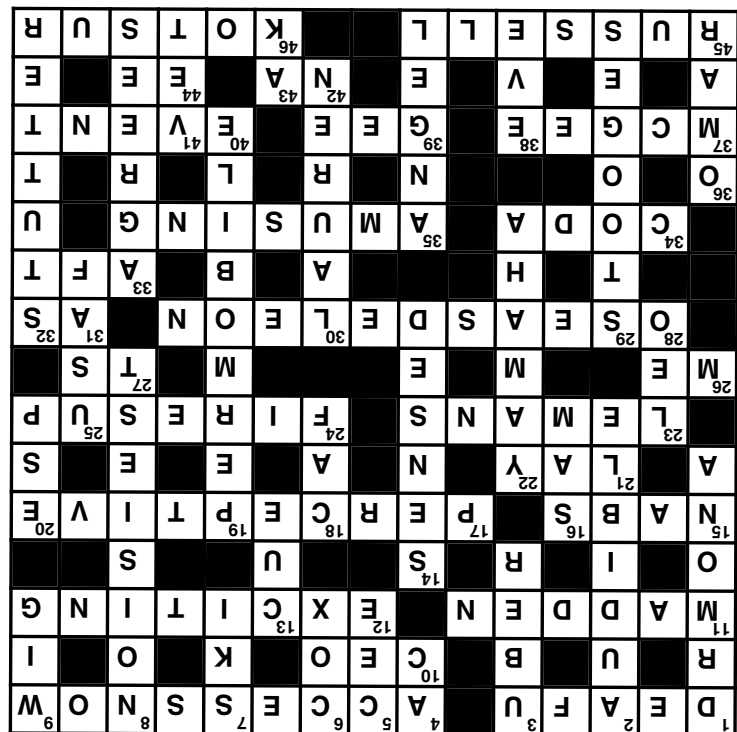
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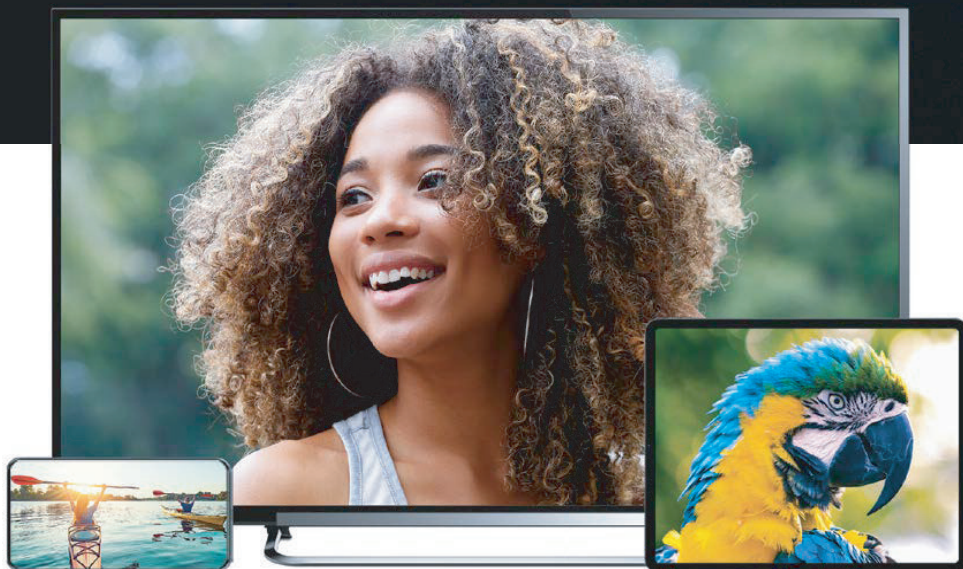
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\$161.8B Market value of stock*

*Based on sales, profits, assets, and market value as of March 31, 2021.

Diversity and inclusion

At Wells Fargo, we believe that diversity and inclusion is key to being one of the world's great companies. We strive to build and sustain a diverse and inclusive culture for all Wells Fargo team members – one where they feel valued and respected for who they are as well as for the skills and experiences they bring to our company.

What other people are saying about us:

- **DiversityInc** magazine has ranked Wells Fargo No. 7 on the list of the 2021 Top Companies for People with Disabilities. **DiversityInc** also ranked Wells Fargo No. 25 on the Top 50 Companies for Diversity, No. 17 on the list of Top Companies for Employee Resource Groups, and named among the Top Companies for LGBT employees.
- For the tenth consecutive year, readers of **CAREERS & the disABLED** magazine recognized Wells Fargo as one of 2021's Top 50 Employers of people with disabilities.
- **Equal Opportunity** magazine ranks Wells Fargo No. 15 on the 30th Annual Top 50 Employers 2021 list.

Accommodations and accessibility assistance for team members and job seekers:
wellsfargojobs.com/accessibility

Accessibility at Wells Fargo: wellsfargo.com/about/diversity/accessibility

Relevant military experience is considered for veterans and transitioning service men and women.

All qualified applicants will receive consideration for employment without regard to race, color, religion, sex, sexual orientation, gender identity, national origin, disability, or status as a protected veteran.

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Wells Fargo helps strengthen communities through:

Diversity & Inclusion:

Ensure all people feel respected and have equal access to resources and opportunities to succeed.

Economic Empowerment:

Strengthen financial self-sufficiency and economic opportunities in underserved communities.

Sustainability:

Accelerate a just transition to a low-carbon economy.



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Oct. 17-19, 2025

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Dec. 5-7, 2025

Los Angeles

March 27-29, 2026

New York Metro

May 1-3, 2026

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June 12-14, 2026

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