Mark Masselli (00:04)
The online news outlet stat has just named our guest to its 2025 status list. Calling her one of healthcare leaders whose work over the past year has made headlines.

Megan Morris (00:16)
There was A survey a few years ago, a national survey of physicians asking 'em various questions about caring for folks with disabilities, and they had some pretty shocking findings. one is, it was less than 50% of physicians reported, strongly welcoming people with disabilities into their practice.

Margaret Flinter (00:40)
Megan Morris holds a PhD from the University of Washington and is an associate professor at New York University's Langone Grossman School of Medicine.

Megan (00:49)
We have long argued, and it is becoming the gold standard that collecting disability status, information, you collect it directly from the patient. This is not necessarily a clinician assessment to determine their disability status. It is part of the demographics. it's part of their, you know, you ask what language do you speak, and do you have a disability?

Margaret (01:15)
This is Conversations on Healthcare.

Mark (01:28)
Dr. Morris, welcome to Conversations on Healthcare.

Megan (01:32)
Thank you. Happy to be here.

Mark (01:34)
Well, that's great. And you're the founder and director of the Disability Equity Collaborative, which is focused on advancing equitable care for patients with disabilities through practice, policy and research. I wonder if you could share a little more with our listeners about your work.

Megan (01:49)
Approximately 27% of the US population lives with a disability, and research shows that people with disabilities, all types of disabilities experience pretty significant disparities in health and healthcare outcomes, and healthcare organizations are actually required to provide all patients with disability healthcare accommodations. Well, a few years ago I was doing research on the topic of disability healthcare disparities, and found that there many healthcare organizations weren't providing patients with disabilities accommodations. And there were a variety of reasons why, but one key reason was that many health systems had, hired someone to be in charge of their disability initiatives at their organization. so their, their projects and their programs, but these individuals felt alone. they were typically the only ones in their organizations doing this work. And so I said, well, why don't we all just get you, you get you together. And so, that was the early days of what is now the Disability Equity Collaborative. And so our sort of flagship group, our collaborative, group, within the Disability Equity Collaborative is we have about 50 health systems from across the country who meet together regularly, a couple times a month, and share with each other, what they're working on, and share advice with each other to asking, you know, how are you doing x, y, z? Yesterday we had a conversation about service animals and what policies do you have at your organization? And what happens when someone comes in with a service animal and they're going to your oncology unit? What do you do with that? 'Cause, you know, due to challenges with infectious, infection control.

Mark (03:52)
I wonder, for, just for people who are listening, when you talk about health systems, are you talking about hospital-based health systems primarily?

Megan (04:00)
Primarily hospital-based health systems, but we also do have, independent hospitals and as well as independent, primary care clinics involved in our collaborative.

Margaret (04:12)
Great. Well, it's hard to believe to me, but it's been 35 years since the United States enacted the Americans with Disabilities Act. It's been called a major milestone and an accomplishment, but I think, many people assume that the challenges that the people who come together are speaking about, maybe are more rare than they actually are, or they're more easily rectified than they are. So when you come together, what's the refrain of, what people identify as this is missing and we have to fix this? What are the things that bubble up to the top of what people feel still needs to be rectified?

Megan (04:50)
Well, unfortunately, there's lots of things that still need to be rectified. I'll, I'll highlight a few of them. One is, yes, we have the Americans with Disabilities Act. That was passed in 1990, but actually before that we had the Rehab Act in 1973. So, it's actually been more than 50 years. And that was the first law that did require healthcare organizations to provide accessible care to patients with disabilities. Most recently, last year, department of Health and Human Services released the new standards, or new rules for, part of the Rehab Act is called 5 0 4, and specifically it calls out, which is really important, accessible diagnostic equipment. So, research has showed in surveys that, in surveys of primary care clinics, approximately 10% of the clinics have equipment available to examine someone who's in a wheelchair on an A table. There's also research that women with disabilities, particularly, for example, using wheelchairs, they have very low rates of mammography and pap smears, in part do the lack of accessible diagnostic equipment. So there's a new rule that goes into effect next year actually, that at least 10% of a facility's, medical diagnostic equipment, or at least one, has to be accessible to people with disabilities. So physical accessibility, including our diagnostic equipment, is a really important factor in, in improving and providing accessible care to folks with disabilities. Effective communication is another area. So we have found, that, again, healthcare teams are typically not trained and don't necessarily have the, the skills or the tools to effectively communicate with their patients with hearing loss, with speech or language disabilities such as developmental disabilities or strokes. So that's another area. We also have a challenge with, frankly, attitudes and beliefs about people with disability, and assumptions about the quality of life of people with disabilities and, and, and frankly, their value. And so there was a survey a few years ago, a national survey of physicians asking 'em various questions about caring for folks with disabilities. And they had some pretty shocking findings. One is, it was less than 50% of physicians reported, strongly welcoming people with disabilities into their practice. And when you delve into that and try to understand why are, why are these clinicians not wanting to, or feeling like they are welcoming, again, patients with disabilities is they feel like they don't have, again, the training or their resources, to provide accessible care. And so that, really translates into a negative attitude. And, and patients can feel that, as well, we, patients with Disabilities report having very, huge difficulty finding providers who are willing to see them. And again, I think that's a consequence of these issues.

Mark (08:24)
You know, I wanna go back to your first answer where you described that there, I think it was 27% of Americans are living with a disability. Maybe talk a little more about that. That's certainly a big number. I think for people listening. They might, may not have been aware of that. Maybe shine a little more light on that, statistic.

Megan (08:44)
Yeah. So there's always this question of who, who is, who is disabled, who do, who do we, include? And there's, there's a mentally, various definitions, but the, we generally consider people with disabilities are those who have, physical disabilities, cognitive disabilities, and that can be from, a developmental disability, something that originated in childhood or later in life. Such as, Alzheimer's and dementias, also communication related disabilities. Again, if someone had a stroke and has difficulty speaking or someone with a stutter, would be considered as someone with a disability. It also includes people who are blind and low vision, and those with hearing loss. And, those are the major categories. We also talk about individuals who have difficulty with, daily tests such as drape, bathing and dressing, as well as doing errands. And we know that, as we all age, the, the rates of disability goes up. So, some have said that, hopefully we are all lucky that we, become disabled because there are such high rates of, again, particular hearing loss and vision loss in, our, our older populations.

Margaret (10:10)
I wanna go back to those new rules. The tables that are accommodating the speech, the different kinds of equipment. Are you concerned, that in the environment that we're in now, where there's so much going on with healthcare facilities and federal regulation that there'll be a backing off on enforcement? Tell, tell us where you think we are kind of in the country at this moment. A lot of legislation out there moving the ball forward, but are you concerned that it's gonna continue to have that momentum?

Megan (10:41)
Again, we have this, this collaborative, this learning collaborative of health systems, and we meet every two weeks and every two weeks since January I've been saying, okay, how are things going? Yeah. And honestly, folks are saying, we're going strong. Our health system, our, our hospital, our clinic is, is recognizing that people with disabilities are an important population, and are in our organization. And that they are a population that has these gaps in quality of care. And so for us to improve the quality of care to all our patients, we need to make sure we're including folks with disabilities. What we're also seeing is that separate from the federal government, is that our accreditation organizations like the Joint Commission, so the Joint Commission a few years ago released a new health equity, certification. And in, to be able to qualify for that certification, you have to be documenting patient's disability status. And that's a really important foundational step in any healthcare organization, clinic, hospital, et cetera. Because how do you one track the quality of care you're providing your patients unless you know who has a disability? And two, how do you provide accommodations to your patients unless you are asking them, Hey, do you have a disability? Do you have any accommodation needs? So we're seeing, again, accreditation organizations like the Joint Commission as well as the, NCQA National Committee on Quality Assurance. They oversee accreditation of health plans as well as some other healthcare entities. They are working on putting, getting, putting together some requirements as well for both of, their health equity certificate, and just their general, quality measures as well.

Margaret (12:46)
That's great to Hear. Good.

Mark (12:48)
Yeah. You know, you've written very passionately about how disability does not discriminate, and yet how black and Hispanic adults with disabilities experience greater disability in access to healthcare than black and Hispanic, adults without disabilities. Tell us a little bit about how you conducted this research and how the entire healthcare sector, can overcome it and, do we need to do better training or what's the, formula for success here to address this issue?

Megan (13:22)
Yes. So we've done research both, so at a high level where we're doing, looking at national survey data, looking at healthcare experiences and, and health outcomes. So yes, we did a study looking at intersectionality of race and ethnicity and disability, and we do yes, find, greater disparities in those who are live at the intersection of, racial ethnic minority communities as well as disability. We also do the, the more, at the patient level. So we do a lot of qualitative work. So we currently actually have a study looking at, again, that experience of, of individuals from minoritized racial and ethnic minoritized communities, their experiences, as people with disabilities as well. And that is, you know, actually goes to the, to the previous question around how in the current climate, how are organizations perceiving, their programs and their initiatives towards providing accessible care to folks with disabilities? I think organizations are also recognizing that there's much higher rates of disability in certain, again, racial ethnic minority communities. So by focusing on and making sure we're being inclusive, a disability, we're gonna rise, rise the tide of, different other, you know, other minoritized populations as well.

Margaret (15:00)
You know, I, wanna tie that back to what we were saying about the documentation in the, electronic health record, as something the Joint Commission and others would be looking at. And it, it seems to me, and I think you've had a focus on this, how do, how do practices, you wrote a, you wrote a guide, right, to how to practices document disability, and I'm, I'm wondering beyond the, you know, checking the boxes and just writing things down electronically speaking, has AI been brought to bear on this in terms of helping get a more comprehensive electronic health record or prompting providers or listening to the patient and being able to, comment and maybe have a more robust documentation, the disability, what, what's out there beyond just getting it in the electronic health record that you think is really going to advance care for people?

Megan (15:53)
Yes, great question. So first off, with documenting disability status. So we have long argued, and it is becoming the gold standard that collecting disability status, information, you collect it directly from the patient. This is not necessarily a clinician assessment to determine their disability status. It is part of the demographics. It's part of their, you know, you ask what language do you speak, and do you have a disability? 'Cause they both need accommodations during that visit. And we, there's actually a requirement that is going to go into effect, next January, January, 2026, requiring all electronic health records in the United States to have a standardized

disability data elements. And that comes from the, office for the National Coordinator for Health Information Technology. So the federal agency o that oversees guidelines for, electronic health records. So we, we continue to advance that work, to figure out how, and we're working with EHR vendors to, build out the tools, within the software to, collect information, but also automate some of the accommodations. So for example, if you come in and you say, yes, I am, I am low vision and I need my patient materials in large print, then the, system will automatically print all of their after visit summaries in large print, and a staff member doesn't have to go in and, you know, manually change the settings, for that to happen. So, so again, lots of innovations in that space in terms of, I think we are still really early, and we're still figuring out, there's mentally not very many researchers in this area. And so there's much work to be done, and not enough, hands to do the work. But one piece that I've always, that has been a little bit of a concern of mine is around bias. And we know in, in race and ethnicity, disparities literature that, bias in the electronic health record, has been documented. And so it is, we, it's just that has not been explored in disability. How are our healthcare teams documenting writing about disability and how might that be affecting our AI models, as we start to build them?

Mark (18:46)
Great observation. You know, I wanna ask a couple of questions about telehealth. Last year, the FCC, the Federal Communications Commission required that video conferencing platforms had to ensure that they're accessible to people with disabilities. And I'm wondering what you're hearing about these efforts and do they work? And also just the general question post covid, lots of opportunity to do telehealth seems to be embedded in our healthcare system. How impactful has that been, with the community?

Megan (19:18)
Telehealth has been, a mixed bag mentally for some folks. It's been excellent, individuals who, where transportation is quite difficult. We, yeah, getting to the doctor's office is, is difficult. So telehealth has allowed for, on the alternative, so it has increased access, so absolutely. But it has created some barriers, particular for certain populations, for example, with, our population who is deaf, or, has hearing loss, looking at the accessibility, and the different features, accessibility features in telehealth such as closed captioning as well as we, we have lots of conversations, particularly at the beginning of the pandemic, if you have a sign language interpreter. There, the box of the sign language interpreter is quite small. And so how does someone, actually see, see their hands to be able to, to, to, you know, follow along with the interpreters. So there again, the, we continue to make improvements, but there's still, there's still challenges.

Margaret (20:41)
Lots to work on. But Megan, you've written that your research and advocacy have been deeply informed by personal and professional experiences with ableism in the healthcare setting. And part of this, involved a close relative, your Uncle David, you know, personal stories are so powerful, in this work. Can you share some of that with us?

Megan (21:03)
So I could probably spend the rest of the day, sharing stories both my, again, personal stories and then stories from the disability community. Very quickly, I'll tell a story about my, my uncle. My uncle, David lived with a developmental disability, which also conclude, included pretty significant epilepsy, and he would have seizures, and unfortunately he would fall frequently with his seizures and end up with injuries and end up in the hospital. So in one of those times, he, he again ended up with a brain injury, and he was unable to breathe on his own. And so they had placed a, tracheostomy, he had a trach in, and I was out of town at the time. I came and went to the hospital to visit, and this was about three days after his injury. And I walked into the room and I was shocked to see David's hands were in soft restraints eye to either side of the bed, and he didn't have a, the nurse call button anywhere near him. And so I waited for a little bit, expecting for someone to come in really quickly of they wouldn't have left him like this, right. But after 30 minutes, no one came. So I went to the nurses' station, and I said, oh, can you tell me why his hands are restrained? And she looked at me confused and said, well, he has a developmental disability. He's dangerous. He's dangerous to himself and, and to others. And mind you, right before this hospitalization, David was an active member of his community. He attended bible study at his church. He was involved in Sunday school. He was in, you know, again, very involved in the community, no history of violence at all. And then I asked, well, can, can, why doesn't he have access to the nurse call light? And she said, well, again, he has a developmental disability, he has no communication skills. So I went back into the room with the nurse, and I said, okay, David, put your left hand, put your thumb up for yes, your right hand, put your thumb up for no. And then I asked him a series of yes, no questions, including who the, the date, who the president was in current affairs, and he was a hundred percent correct with all of my questions. So he had been in that bed for days, and no one had given him an, any way to communicate, let anyone know he was in pain, how he was feeling, both physically and emotionally. No one was explaining

anything to him. He was a prisoner in his bed. And it was, again, really because the team won one, oftentimes there, there, the training, on how to engage someone with a disability, it's just not there, or what tools he could have used if they had just given him a whiteboard, and a pen. He would've been able to, to write out his questions or give answers and, and no one had thought to, to give him those tools.

Mark (24:26)
Well, we're so sorry for the experience that he had. But instructive, I think to our listeners, and something that many of our listeners probably can relate to, you know, nearly two years ago, the National Institute of Health formally included people with disabilities as a population with health disparities. A great decision. And it was expected to lead to increased funding and research opportunities. Give us your assessment of how things look at this time.

Megan (24:55)
Immediately after that, that announcement, NIH did release a, a call for grants on ableism. And so I believe it was, it was either eight or 10, grants were funded on addressing ableism, both in society and in healthcare. So that is great. We… admittedly right now things are questionable. While the NIH is a great funder of research, one of, another institute that has historically funded research on disability and rehabilitation is called NIDILRR, The National Institute of Disability, Independent Living and Rehabilitation Research, and NIDILRR lives within the Administration for Community Living, and that was recently dissolved. And so we're not sure the state of, of NIDILRR and all of that funding, and again, may have been, historically the funders of research in this area. So hopefully, NIH takes this on. There are, there have been proposals for, to create, within NIH, a National Institute on Disability. And so we, we do hope, disability, again, continues to be funded. Disability is something that crosses both sides of the aisle. Disability affects us all and, we, we all have someone in our, in our family, we all have neighbors, friends with disabilities. And so we, we hope that, again, recognition that people with disabilities have been, unfortunately sort of ignored historically in thinking about, again, quality of care, quality of health, that we can come together and continue to, have this focus on, improving outcomes for folks with disabilities.

Margaret (27:01)
Well, that's great. And, you know, maybe, my last, question, we're very engaged in primary care and building best practices for primary care. As you look around that room of your colleagues that come together, the research that's been done, what's your recommendation for primary care systems, either primary care practices or large primary care systems for how to maybe launch the same kind of focus, on these issues as we have over the years mm-hmm. On anything from, diversity, equity and inclusion or chronic illness management, cultural sensitivity. Tell us what you've seen work in terms of effective structures that people put in place to get this important work moving forward.

Megan (27:44)
Yes, and actually most of my research has been in, in primary care. Primary care is near and dear to my heart. So first off again, so section 1557 of the Affordable Care Act is a section around, non-discrimination. But it says that if you have, if your organization has 15 or more employees, you are actually required to have someone to be in charge of all accessibility initiative. So you need to make sure, that you have someone who is trained and has dedicated t to actually devote to making sure your, your clinic is accessible to asking do you have a disability? Integrating it into your workflow processes, from your intake forms to the MA asking when someone gets roomed, and then asking what accommodation needs do you have today? We actually tested a, we just finished a study in primary care. We enrolled over 650 patients with communication related disabilities, and we implemented a tool where they would, in their primary care clinic, indicate what are the top three strategies they would want their healthcare team members to use with them. They brought that tool with them into their appointment, shared it with their, their team, and we found that this improved patients' feeling of being respected and being included in conversations about their healthcare. So just, again, it wasn't rocket science, not magic, it's just asking, how can I best communicate with you? How can I make sure that we are meeting our needs today?

Mark (29:29)
Well, thank you, Dr. Morris, for joining us today and for the important work that you're doing. And thanks to our audience for being here. Just a reminder to be sure to subscribe to our videos on YouTube and find us on Facebook and X. You can also share your thoughts and comments about this program. Take care and be well. Thank you again so much for taking time with us today, Dr. Morris.

Megan (29:50)
Thank you for having me.

Margaret (29:54)