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ADA NATIONAL NETWORK

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State of the Science Conference on the ADA ‑ AM SESSION ONLY

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>> KURT JOHNSON: I think apparently there is a slow‑down on the orange line and some complicating factors, but we have a full schedule so we'll get going.

I'm Kurt Johnson, and I'm the principal investigator on the ADA knowledge translation center ‑‑

>> Audio recording for this meeting has begun.

>> KURT JOHNSON: So welcome to the State of the Science Conference for the Americans with Disabilities Act Network. We're right on the tail of the 25th anniversary of the ADA. And for those of you who don't know the ADA National Network includes ten regional ADA centers, most of whom are represented here. And are ADA knowledge translation centers. The ADA network is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. And the director is right here who is going to say a few words to it.

One of the things that we're excited about today is that over the last few years, 4 1/2 years, we've been able to create together with the network and the KT center a unified collection data center and begin making inferences about ADA implementation and trying to get an understanding of the process by which systems change happens.

Mark Harniss will talk a little bit more about that later.

We're delighted to have a number of federal partners including folks from DOJ and the Access Board and from NCIL and a number of other advocates and people working in the area of accessibility and ADA.

I want to give a brief overview of the program since we made some changes. So we'll start with an overview for ‑‑ welcome from John Tschida who is the director of NIDILRR, and then Barry Taylor is going to talk. We're switching out ‑‑ Joy Hammel has a doctoral defense she needs to do by Skype this morning so she needs to be finished earlier. So we're swapping out Sarah parker and Joy Hammel and we're going to push the break ‑‑ first break so that joy can go immediately after Barry and that will keep things on schedule. We'll just proceed with that. The schedule is really packed. You will have lunch on your own.

With that, I want to give a shoutout to our NIDILRR project officers, (saying names). Shelly leads the ADA network as project officer for many of them and really this conference is their vision of bringing together the science and way to highlight some of the research, not just by us but by others. And I want to let you know in advance that although we'll be having presentations on research that was done by members of the ADA Network, many of them have been able to leverage NIDILRR funding and get funding from other sources to amplify the effect of the original funding which we want to highlight.

With that, let me introduce John. Oh, wait, wait. Housekeeping. Housekeeping. We're Webcasting this. And so if you're in the room, please be respectful of our Webcast participants and always use a microphone to speak and we'll have runners to bring a microphone to you.

If you are connecting to the Webcast on the phone, please mute your phone lines using the star/number/hash tag. Remember to Webcast participants, log out in the morning session and log in the afternoon.

Captions are available in the front of the room. And if you need ‑‑ and those are also available on the Webcast. If you need assistance on the Webcast, you can contact the northwest ADA center at 425‑774‑4446 or Adobe Connect or with any of us in the room or Kathe Matrone who is our concierge, sorta.

Okay. So with that, let me pass this off to John.

>> JOHN TSCHIDA: Good morning, everyone. Sounds like the microphone is working just fine. Welcome to our folks who are participating via the Web as well as those of you in the room. On behalf of the National Institute on Disability, Independent Living, and Rehabilitation Research, thank you all for coming. I also want to thank our coordinating agency, the ADA Knowledge Translation Center for pulling this State of the Science conference together.

As Kurt said, we are funders of the ADA National Network. I want to embellish on that a little bit by saying we are not just funders but we are strong supporters of the ADA National Network. I have been in this position a little over two years now and I have been asked by a number of folks: Is there still a need for the ADA National Network? It's been 25 years. Do we need to continue to be making these investments? And the short answer to that question, preaching to the choir here, is yes, of course. Have things changed over time? Has society evolved dramatically? Of course, it has. Have opportunities for individuals with disabilities increased dramatically? Of course, they have. That's the good news.

There's still ongoing need for technical assistance. There's still an ongoing need for training. I think it looks different than it did 25 years ago, and it will look different 25 years from now. But we will continue to have individuals with disability who is are born and need to understand their rights and responsibilities. We will continue to have a need to educate businesses, governments at every level, multiple constituencies, community‑based organization, non‑profits, all of those who are in the room today. It takes all of us and all of our different stakeholder groups and constituencies to ensure that the ADA is living up to its promise on behalf and for and with individuals with disabilities. So we are excited as a funding agency to continue that focus.

There is a third prong and that is research that we see as critically necessary as well, understanding what the impact of the ADA has been and continues to be on things like employment, community participation, how can we engage businesses and H.R. representatives and professionals in a meaningful way to fulfill the promise of the ADA. These are just a few important questions, and they are important research questions, and they will all be addressed today as a part of your agenda.

We know the Americans with Disabilities Act isn't perfect, nor is it a magic bullet. But we need to understand what its effects have been, both intended and not and that will also be a part of today's agenda.

So as Kurt said, today is pretty packed. I will close by again thanking you for attending. For those via Webinar, thank you for your participation. And to the ADA Knowledge Translation Center for coordinating, I look forward to a productive and enlightening day. Thank you.

(applause).

>> Go ahead.

>> Audio recording for this meeting have begun.

>> How many people do we have on the Webcast?

>> 25 right now. And those are sites. We expect multiple people at sites.

Thank you, John. And, Barry, come on up.

Let me introduce Barry Taylor he is the vice president for civil rights and systematic litigation at Equip for Equality. He has overseen many individuals and systemic disability and discrimination cases including successful ADA suits against the national board of medical examiners, the Chicago Police Department, the Chicago transit authority. He's co‑counsel in five ADA class actions including lead counsel on behalf of people with disabilities who are seeking community services. Prior to coming to Equip for Equality, Barry was the aids project attorney in the lambda legal to advance civil rights of people living with H.I.V./AIDS. He is a graduate from the College of Law. He will talk on the Americans with Disabilities Act with the law research reveals about trends and unanticipated application of the law.

And one of the reasons, just a side note, that we were eager to have Barry here as one of my staff members, Becky attended an ADA symposium where Barry spoke and came back lauding him and said you got to get him to talk.

And then we can ‑‑

>> BARRY TAYLOR: Good morning, everyone.

>> Good morning.

>> BARRY TAYLOR: Can you hear okay? Great.

So thanks very much for welcoming me here. I appreciate the kind introduction. I know a lot of you in the audience, some great familiar faces and folks that I don't know. But I know a lot of you are very well‑versed on the ADA. What I hope to do today is what Kurt asked me to do, talk about has the legal research shown with respect to how the ADA has evolved and what are some of the trends that have developed and what are some of the unexpected applications of the ADA that we didn't really anticipate back in 1990. I think when you have anniversary like the 25th anniversary, it gives you a chance to really look back and think about sort of where we've been and how did we get here, and then maybe that gives us the framework for moving forward.

Okay. So I'm pressing the arrow and nothing is moving. Is there more to it than that?

>> You have to press this arrow.

>> BARRY TAYLOR: Okay, thanks.

I think I said all that.

What I have done is I have identified eight different cases for us to talk about and I'm happy to answer questions as we go along as well as talk about other cases that people are interested in discussing that we don't get to ‑‑ or didn't identify initially. And so the first case we're going to talk about is ‑‑ not to start on a negative note, one of the worst cases ever for the ADA. Many people know the Sutton versus the United Airlines case. I think it is useful to talk about it a little bit because it really did impact dramatically how we tried to enforce the ADA for many years, really from the initial implications of the ADA all the way up to 2008 when the ADA Amendments Act was passed.

The reason why this was a surprise for folks is that when the ADA was passed, people thought, we've got a pretty broad definition of "disability," right? Physical and mental impairment that substantially limits one or more of the major life activities. People also regarded it as having a record of an impairment or being regarded as a such impairment. That was adopted from the Rehab Act H there was very little litigation about challenging the definition of disability when it was under Section 504 litigation. And we even had a Supreme Court case the Arline case which talked about the definition of disability needs to be interpreted very broadly. I think if you had asked folks back in 1990 when they were passing this, do you anticipate this is going to be a problem? I think ‑‑ I can't imagine anything who said they thought it would be a problem. So why did it change? Why did things go differently?

There's probably a lot of theories out there. I would be interested if people had other thoughts. Had you a different base. All of a sudden you had five employers who employed private attorneys whose goal is to get rid of the cases as quickly as they can, what better way to get rid of a case than to say, well, whether they have been treated differently or not is irrelevant because they don't have a disability. That's really what they did.

And while Sutton wasn't the first case, it was really the first case that the Supreme Court looked at on the definition of "disability" that really got this whole thing rolling in the wrong direction. And so people probably remember that Sutton was the case involving the two twin women who wanted to be airline pilots for united airlines, global airline pilots. And they happened to use glasses to address their vision. Without class these could see 2400 but with glass these could see 20/20. United had a rule you needed to see 20/20 without your glasses so if you broke your glasses, you could land the plane. So they say you couldn't be a pilot because of your visual impairment. They sued under the ADA.

United then just said you are not covered by the ADA. You didn't see well enough to be a global airline pilot but you see too well to be covered by the ADA. A little irony there. What this really drove us to was our mitigating measures considered whether determining whether somebody is substantially limited in a life activity or not.

The lower courts had all said, all but one, had said ten out of the 11 had said, no, you don't look at mitigating measures to determine whether somebody is covered by a disability ‑‑ by the ADA, you only look at that when you are determining whether they are qualified under the ADA. But the Supreme Court disagreed with that and said the effects of corrective measures are to be determined whether somebody is substantially limited in a major life activity. And this had a huge impact. The Supreme Court did not limit this case to people wearing glasses as a mitigating measure. It could be any mitigating measures. It could be hearing aids, prosthetic devices, medications that people use so it had major implications. Hundreds of ADA cases were dismissed because the plaintiffs were deemed not able to show that they were substantially limited when the mitigating measures were taken into account. It put the plaintiffs in a catch 22. You had to choose being covered by the law or the manifestations of your disability. What a terrible choice.

To add insult to injury, we had some great regulations and guidance from EEOC and DOJ that the Supreme Court disregarded saying that, well, Congress didn't really technically give EEOC and DOJ the right to interpret the definition of "disability." It's not part of title I or title II or title III, it's in this part beforehand they didn't designate anybody. So we're not going to look at their interpretation of the definition of "disability." Even though there was clear guidance from EEOC and DOJ that mitigating measures should not be taken into account when e when determining whether somebody is substantially limited, the court disregarded that.

As if that wasn't bad enough for people with disabilities, things got worse three years later with Toyota versus Williams. You might remember that case was involving the woman who has carpal tunnel syndrome who worked in a factory, Toyota factory. And they had a requirement that had you to rotate to different stations and do different work. She could do some of them but the ones that required her to have her arm over her hand exacerbated her carpal tunnel. She asked for accommodations that didn't require her to have her arms overhead. She was ultimately terminated and filed suit saying she should have been given that accommodation.

And she claimed that she was substantially limited in a major life activity of performing manual tasks. And this made it all the way up to the Supreme Court and there was deposition testimony she had where she said, well, you know ‑‑ where she described how difficult it was to do certain manual tasks at work. She also talked about how she could brush her teeth and she could dress herself and take care of her children.

And so the court said, well, you know, it doesn't appear that she really is substantially limited in a major life activity of performing manual tasks, and she can do the tasks that are central to most people's daily lives. And they talked about all the things she said in her deposition. She was found not to have a disability.

But the thing that was more damaging about this case, I think, other than sort of the underlying facts which were obviously bad for Ms. Williams is what they said afterwards which is the definition of disability is to be interpreted strictly to create a demanding standard. Interpreted strictly to create a demanding standard. What's so terrible about that is that historic little civil rights laws have been interpreted broadly to effectuate their purpose.

We now saw disability was having a different hurdle than any other civil rights law out there. You don't spend time of having an African American bringing a race discrimination clays or that you are a woman for a gender discrimination case. But all of a sudden there was this huge barrier, this huge hurdle that people with disabilities were now being asked to get over and it was becoming increasingly difficult with the more that the Supreme Court said.

And this was ‑‑ as those of you who lived through this ‑‑ I got to do this, sorry ‑‑ will remember this was really devastating.

For some reason ‑‑ I'm usually good at this kind of thing. It's just not... I have bullet points that are supposed to come down.

>> Sorry, folks. We are having a little bit of trouble here.

(Background noise via the Webcast).

>> We are going to try to move you through the slides.

>> BARRY TAYLOR: Great. So as I was starting to say, this really led to just ridiculous implications. The number of cases that were dismissed and I know a lot of you lived through this, I certainly did, was just so disheartening. And people got really, really bummed about the ADA and, wow, this law doesn't really help a lot of people. Look at all these people whose cases are getting dismissed. We don't get to the underlying drippings because we can't prove people have a disability.

If you asked the person on the street sort of who is covered by the ADA, I think a lot of the ones that are listed here, you would think, oh, yeah, a person who has heart disease or depression or asthma or cancer, well, they are covered by the ADA. These are all examples of cases that were dismissed because of the mitigating measure or the strict interpretation we heard under Toyota. And I had a slide before that. Yeah.

And so some of the other ones, intellectual disability, epilepsy, diabetes, multiple spell sclerosis, back injury E pretty much every category you could think of, some of those folks weren't able to go forward with their case. It didn't mean everybody could go forward but it was very, very difficult form folks, especially if they used a mitigating measure. We all know that this story has a happy ending. And that Congress came to the rescue and said, okay, enough is enough, courts. You got it wrong. There was a real hesitancy of Congress, I think, to look at this because you are opening up a civil rights law, hoe knows what will happen. Ultimately things got so bad Congress said they had to do something. They passed the ADA Amendments Act in 2008. It's really clear on the changes here.

First of all, it says Supreme Court, you got it wrong. Sutton is wrong. Toyota is wrong. So there's no ambiguity about that. And they also said really what we want is your primary focus to be on whether the covered entity violated the law or not. And we're not going to be spending a lot of time and a lot of evidence and a lot of money trying to prove that the person has a disability. That should not require much time at all.

And they also said Supreme Court, another thing you got wrong, Justice O'Connor who wrote Sutton, we want the EEOC and DOJ to interpret this definition of "disability." That's what we want them to do. The EEOC has stepped up and done that and provided a lot of great information I think. The courts of Globing on to this without any hesitation at all. Whereas before the courts were told not to look at the EEOC and DOJ opinions, now it is central to the opinion we see coming down.

Talking about impairments, it should be easily be found to be substantially limiting. It doesn't mean we now have first disabilities, you still have to put on some evidence. But you will see court after court citing this list. You will see, basically, sort of the lead group and actually a lot of the same impairments, right, that we saw in the previous list are listed here. Deafness, blindness, mobility impairments, intellectual disability, the list goes on and on about one that is should not require a lot of information, evidence for the court to get over that first hurdle.

And while this wasn't necessarily an issue in in Sutton or Toyota, another really important thing the ADA Amendments Act did was address that real concern we had about people who had episodic and condition that is were in remission. Because if you couldn't show you were substantially limited on the day of the adverse action, you usually lost your case, right? And what that failed to take into account is that as we all know disability, it isn't sort of a straight line. If you have a mental illness it comes and goes and things happen. Life happens that affects that. Other types of disability and how you're controlling with your medication and different things. Cancer and all those different kinds of things that are not steady impairments, still people are discriminated against because they have that as part of their identity, right? That made a big difference.

Here we have not only the general rule that's in the ADA Amendments Act itself that impairments that are episodic or in remission are disabilities if they are substantially limiting when active. But we also have this list, this appendix from the EEOC regulations that's very helpful that talks about examples of impairments that can be episodic. And we see a lot of kinds of impairments that were booted before, cancer and a lot of different mental illnesses, those types of things, epilepsy, diabetes, asthma, really helpful.

And then we also saw a ton of litigation about what is even a major life activity. And that litigation really was just all over the place. You go court to court and some courts recognized a major life and then you cross state lines and that court wouldn't recognize something that's a major life. So Congress really helped us out here, too. What they did, while they didn't define "major life," we still don't have a definition, what they did is put examples in the statute itself which is incredibly helpful because in doing so we really have sort of again the major groups ‑‑ major life activities that will come up in most cases in the statute. There is no debating it. Congress has said these are major life activities. There's no basis to litigate anymore. It's really helpful. Those are ones we've seen before but interestingly Congress added three that were not previously in EEOC regulations guidance, reading, bending, and communicating. Congress says this is a big list, but it's not exhaustive. There are going to be other ones that will come up. It doesn't mean you can't raise ones. All those this is comprehensive, it's not exhaustive. EEOC added three a nailed activities, interacting with others, reaching. They are in the regulation, but since Congress said we want the EEOC to interpret that, they will get great deference. Not as great if they are in statute itself but they will get a lot of deference.

Of course, we have those impairments that never really fit very easily into the major life activities list, right? And people are just having the hardest time trying to prove just because it didn't quite fit. And so Congress helped us out there, too, and has now this other group of list of major bodily functions. And these are so broad they pretty much cover everything. So you'll see in this slide on the left side is what's actually in the statute itself and on the right side are some additional ones that the EEOC put in and built in every other bodily function that Congress didn't put in. We had a lot of problems with people with cancer trying to prove what major life you were impaired well. Now they have normal cell growth. That's the definition of cancer. People with H.I.V., really helpful, you no longer have to say I'm substantially limited in a major life of reproduction which a lot of people were having to do. That wasn't necessarily true for a lot of people with H.I.V. That was really a tough one. And now this makes it so much easier.

And then with the EEOC, you'll notice one of the biggest one these ended was musculoskeletal. That is another one that has had some challenges in the courts that now has the EEOC. Again, these lists just like the other lists are not exhaustive, so no negative implications by omission.

So how have the courts embraced the ADA Amendments Act? It really is can a happy ending because for the most part courts have been incredibly compliant now that Congress has given a little bit more clear direction with the ADA Amendments Act. And the Gogos case I have here is great example of tying in a lot of the contests we just talked about. This is from 7th Circuit which is notoriously conservative in it's interpretation of employment discrimination cases in the ADA. It was like a big weight lifted off my shoulders. Now we have a way to get relief for folks that we didn't before. We know longer are stuck on this issue.

The Gogos case involves a gentleman who was pipe welder for 45 years and for about eight years he had high blood pressure. He had controlled it by medication. He had some problems, though, one day where his blood pressure was spiking and he was experiencing some intermittent vision loss. One day he was having a real hard time and he went to his supervisor, I'm really feeling terrible. I'm not seeing well. I need to go to the doctor. His supervisor was fine. Unfortunately, he also had a foreman who was not so fine. And the foreman is like what the heck is wrong with you? I haven't been feeling well lately. I have to go to the doctor. He said if he go, you're fired. He left. He was fired.

He filed under the ADA after the ADA Amendments Act was applicable, right? And the initial district court decision was bad. And they dismissed the case because they said, well, you know, this wasn't something he had very long and seemed like it came and went a lot. So we think they're transitory and we think thee impairments are suspect, like he's committing some kind of crime. (laughter).

So good‑bye, we don't care if you were treated badly in the workplace or not, you don't have a disability. He appealed that to the 7th Circuit and the 7th Circuit actually read the law and applied it correctly which is nice when judges do that. And they found for the plaintiff. This is one of the first appellate court decisions to apply the ADA Amendments Act.

And the analysis goes through a lot of the different contests we just talked about. First, they looked at episodic conditions. They say even if the plaintiff's blood pressure spiked and the vision loss were episodic, they can be disabilities like we talked about as long as they are substantially limiting when they manifest.

But they also said let's look at the EEOC's list of examples of things that can be episodic. So no longer are we avoiding what the EEOC has interpreted, we're going straight to the list. Hypertension was given as a specific example that could be episodic. It's like, check, move on. That's great. And then they talked a little bit more about short‑term impairments. And people will remember there was sort of this rule of thumb if your impairment wasn't more than ‑‑ it was less than six months, you were going to have a real hard time prove you had an ADA disability, remember that?

Well, that's no longer the case. The court went right to the appendix of the EEOC regulations and said the fact that the periods during which episodic impairment is active and substantially limited for major life activity may be brief is no longer relevant. Incredible. Huge.

And he would have lost on this before the ADA Amendments Act. This helps incredibly. And then they went to the major bodily functions because he talked about how his blood pressure affected the major bodily function of the circulatory function. They said, yeah, Congress added these major bodily functions. It's right in the statute. We're going to apply it. No problem there. They easily accepted that new concept.

And then the big bugaboo of Sutton. He was using medication to mitigation his blood pressure. They said we will disregard the ameliorative effects of medication. They went to the EEOC's appendix to the regulations and found language directly on point that talked about medication for hypertension. And they said, you know, we've got a path here. This guy is covered by the law. Let's talk about whether he is being discriminated against or not. He's now covered.

The next case I want to talk about which was sort of a surprise application or you might have been able to predict this when you read the EEOC regulation is the breadth of direct threat. Everybody is probably aware that direct threat is a significant risk of substantial harm and in the statute it says to others that can't be reduced by reasonable accommodation. The challenge was the EEOC regulation had added not only direct threat to others but direct threat to self, okay?

And I don't know if there's anybody in the EEOC or anybody who knows the rationale behind why that was added. I don't know that I have ever heard why. But that's what the regulation says.

And so we had a case that went all the way to the Supreme Court, Chevron versus Echazabal, involved a gentleman who had hepatitis C. He worked in a chemical plant. He wasn't hired not because he was a danger to other people but he was a danger to himself and they thought he was a direct threat to himself and, therefore, they felt they could exclude him.

So we had this question: Do you follow the plain language of the statute, direct threat to others, or do you also add what the EEOC said, that direct threat also includes direct threat to yourself?

And this time unlike in Sutton and Toyota, the Supreme Court was happy to look at the EEOC and give them deference on this situation that narrowed things for people with disabilities.

And they said that direct threat does include threat to self and upheld the EEOC regulations.

Why is this a big deal? The concern to the disability community was: You know what? People are already paternalistic toward people with disabilities to say we'll take care of you or it's not safe for you to do this or that, we will make these decisions for you because you have a disability and you can't make decisions for yourself. Well, people with disabilities don't like that obviously. And that was the concern, is that now employers and courts were going to be telling people with disabilities what was safe for them to do and not to be able to make those choices, those risk assessments for themselves.

And what we've seen is a lot of courts finding that people are threats so themselves when they are not threats to others with that threat can't be reduced by reasonable accommodation.

I have one example that turned out and is a good example of how this played out. Taylor versus Rice. This is why we have Condoleezza Rice's picture there, she was the secretary of state. This is a case involving somebody who wanted to be in the foreign service. He happened to have H.I.V. At the time, the State Department prohibited as a blanket prohibition anybody who had H.I.V. from being a foreign officer, foreign service officer. And the reason was they said, you know what? We are not sure where you are going to be deployed and there are a lot of places you could be deployed that don't have adequate medical care. And you are a threat to yourself if you are deployed to one of those places.

And the trial court relied upon Echazabal and said, yes, this person will be a threat to themselves. But the D.C. circuit reversed and said, wait a second. When we're talking about direct threat, we have to look at reasonable accommodations. Can you reduce the threat whether self or to others using a reasonable accommodation? In fact, the plaintiff here had come up with a couple of ideas that the State Department had rejected. One was well, how you deploy me to countries that have adequate medical care?

(laughter).

There are a lot of countries out there that have adequate medical care, I'll go to those. Or, you know what? As a federal employee, I actually have some medical leave that's available to me and if something happens in a country that doesn't have the medical care I need, I'll go somewhere else and get my medical care. And the D.C. circuit said, those are some good reasonable accommodations that you should have done. And, therefore, they found that the direct threat analysis was incorrect and that he should not have been deny that had position based on direct threat.

That case demonstrates how self can get in play but with reasonable accommodation on top of it, it can be reduced below the level of direct threat. In case you were wondering after this case, the State Department changed their policy and they no longer have this exclusion for people with H.I.V. That's a good result beyond the individual plaintiff.

Another unexpected issue I think that people didn't necessarily predict, at least I don't remember people talking about this as a concern, was the potential conflict between someone seeking to enforce their ADA rights and somebody who is seeking at the same time to get some sort of benefit, particularly Social Security benefits but it could be pension benefits or other disability benefits.

And what we've seen over the years were a lot of cases being dismissed, ADA cases being dismissed, because the person has ‑‑ when they applied for benefits said they were unable to work to get the benefit. Then they had to turn around and said I'm qualified to do the job and there's this concept in the law called judicial estoppel which talks about you can't sort of speak out both sides of your mouth kind of thing and your estopped from making an argument that conflicts with something else you said in court or even said outside of court.

This case made it up to the Supreme Court. This issue made it up to the Supreme Court. The Cleveland versus Policy Management Case. This is one of the earlier cases, 1999. Just general scenario outlines a Social Security beneficiaries asserted an ADA claim after they were fired and the employer argued they are not qualified because of the statement in Social Security that they are unable to work. What the Supreme Court said was good news for people with disabilities this time. They said, you know what? It's possible that you could be unable to work for Social Security purposes and be qualified to do the job for ADA purposes. Those aren't necessarily inconsistent statements. Why not?

Let's say when you were fired you were able to work, and then your condition changed and they were unable to work when you applied for Social Security. Those aren't inconsistent. If you look at the Social Security application, there's nothing about reasonable accommodations on the Social Security application. You can't say I'm unable to work unless I had a reasonable accommodation that my employer denied me. There are a lot of per se disabilities in Social Security. If you have certain impairments, you're automatically there. And so there's really no way to explain why you're available to get Social Security benefits ‑‑ eligible for Social Security benefits ‑‑ (no audio.)

Are the ones who can give an explanation as to why they are inconsistent. And the one that is lose, people who are either unable to give an explanation as to why they're consistent or just failed to provide the evidence. So that's turned out well. But people have to remember to put the evidence on.

And then the last Title 1 concept I want to talk about is the concept around disability harassment. Before we started having cases under the ADA, it wasn't really clear whether the ADA would cover disability harassment. If you look at the statute, there's nothing about disability harassment. It's not in there. So how do you get covered by disability harassment?

Well, what happened was there was a lot of case law developed under Title 7 especially under sexual harassment. It talked about if you alter a term, condition, or privilege of employment by harassing somebody, that can be actionable. The question is: Could we apply that same concept of sexual harassment to disability harassment? And the answer is yes. The Fox case is one of the first ones that came out back in 2001. And in the Fox case the plaintiff sustained a back injury and had light‑duty restrictions. And this was a really bad workplace. The foreman and other employees were incredibly abusive to Fox. The foreman had instructed the employees not to speak to the plaintiff, not to bring the plaintiff supplies. They put the plaintiff at a table that was too low and he ended up reinjuring his back even though he had asked for a higher table. He had been denied all kinds of opportunities to different jobs that would be helpful for somebody with a back impairment.

It was just really terrible. And so he filed under the ADA not claiming anything other than that he was harassed at work, disability harassment, hostile work environment.

So the question was: Is that something that's actionable on the ADA? And the court said yes. And the jury said employer, you got to pay for this. And you'll see that they found that the harassment was severe, pervasive that he experienced and he got significant damages, $200,000 in compensatory damages and also some money for medical expenses and lost overtime.

What this case did was, basically, lay out the factors that you may be familiar with under sex harassment with adding disability to the mix. So you will see the five factors. The first one is the person has to be a qualified individual with a disability. They have to be subjected to unwelcome harassment. The harassment has to be based on the disability. They can't just be harassing you because they don't like you. You have to show a connection to the disability.

The harassment has to be sufficiently severe or pervasive to alter a term, condition, or privilege of employment and there has to be some factual basis to either impute liability for the harassment to the employer, either the employer knew or should have known and then they didn't take appropriate action. And what we found almost uniformly across the country in the courts is the courts say, yes, you can have a cause of action for disability harassment under the ADA. That's really not the fight.

What the fight is is factor number 4: Was the harassment that the person subjected to severe or pervasive? And, you know, I looked at a lot of these cases. There's no rhyme or reason to them. I will read a case and before I know the answer I will think, wow, that is really severe. That is really pervasive. No disability harassment at the end. And then other ones where I'm like, you know, that's pretty bad but not as bad as that other one that rejected harassment. And the court will say they found harassment. So it's very fact‑specific. But even the facts themselves I find sometimes aren't very helpful in predicting what happens. It really varies from court to court. I guess because it's such a factually based inquiry, it's not surprising. These cases are all over the map. I would say the bottom line, yes, there is a cause of action but it's very hard to prove.

Any questions on Title I before I move to Title II?

So Title II, state and local services, I wanted to start with the Olmstead case. You heard in the introduction, we have three ADA class actions under Olmstead that we are working on all under consent decree. So it's more about implementation at this point.

When I was doing the retrospective that Kurt talked about of the ADA last year for the ADA symposium and I talked to a lot of my fellow attorneys about what cases to highlight, the case that almost everyone said you should talk about is Olmstead just because it has such impact on the lives of the disability community.

So I think everybody probably is familiar well this case. This was the case involving two women, duly diagnosed, they were living in a state hospital in Georgia. They wanted to move out. They didn't want to live in the state hospital. And the state agreed, yeah, you are appropriate for the community. You should live in the community. The problem was there wasn't ‑‑ there wasn't any room in the community. There was insufficient community placement options for people, so they had to wait. They said they didn't want to wait. They said under Title II and the integration mandate though have a right to live in the community.

They filed a lawsuit. Two women standing up for their rights. This went all the way up to the Supreme Court and ultimately the Supreme Court said unwarranted institutionalization of people with disabilities is a form of discrimination under the ADA. A lot of people compare this to Brown Versus Board of Education and separate can never be equal.

I want to talk about the trends and the surprise. We talk a lot of cases are limited to facts. Olmstead, I'm happy to say, is one that has gone way beyond its facts. I want to talk about how it has gone beyond its facts. First, you probably know all these already. The factors, you have to show treatment officials find community is appropriate. Person doesn't oppose placement in the community. And the placement can be reasonably accommodated taking into account state resources and needs of other people with disabilities. That third factors, of course, is where we see almost all the litigation.

The one thing that was surprising ‑‑ well, wouldn't say the one thing but one of the biggest things that was new in Justice Ginsburg's opinion ‑‑ she quoted all the DOJ regs and everything like that ‑‑ was this thing about the state can meet its obligations if it has a comprehensive, effectively working plan. I rather the day reading that opinion. That day was crazy, I don't know if people remember, that day the Supreme Court came down with Olmstead and Sutton on the same day. So it was one of those bittersweet days, oh, this is great, oh, this is terrible. And you just didn't know what to think.

But the thing that really jumped out at us when we were reading the opinion was the comprehensive, effectively working plan. How are states going to defend themselves? We are all like: What is that? Where did that come from? It's nowhere in the ADA, of course, or in any of the DOJ regulations. It's something that Justice Ginsburg or one of her clerks came up with. There has been a lot of litigation about what is a "comprehensive, effectively working plan" because it was such a new concept.

And the Frederick L. case from their circuit is the best case out there that has the guideposts on how to determine that.

But what I want to talk about is how Olmstead is going to apply the facts. Olmstead were two women living in a state‑operated facility. Well, there's some states including my State of Illinois puts folks with a disability, they put them in state ops for sure but they also rely on private institutions for housing people with disabilities. And Illinois happens to have the largest number. You will see three of the four cases listed here are all our cases in Illinois. That's why we filed our litigation because that's where folks work.

But the question was, well, wait a second, these aren't state‑operated facilities. These are private facilities. How does the ADA apply there? Are you suing the entity, the private facility? No. You sue the state because the state is putting money into a private facility. And now it seems like, of course,, of course. But at the time, there was some uncertainty. The DAI case in New York and the three in Illinois that were all going after the state with respect to placing people in private facilities. The good news for people with disabilities is across the board, courts have said, of course, Title II applies to people in private facilities that are funded by the state. That's well‑established now.

I think probably the most surprising ‑‑ well, I guess there are two really surprising things, but the first surprising thing that happened as far as the application of Olmstead was applying it to people who weren't in institutions. And, again, this is something we all sort of take for granted now but it was it was a radical concept. One being fisher versus Oklahoma. Steve gold thought of what if people are on the verge of institutionalization if they don't get what they need, are they covered by Title II? Or do you have to be in an institution? The Fisher case presented a compelling set of facts. For some reason Oklahoma said if you live in the community you can have five prescription drugs, that's it. But if you live in a nursing home, there's no limit. Again, I don't know who came up with this. (laughter).

If you were a law professor, this is the kind of thing you would put in your hypothetical or you would put in your law school exam. So Steve and his co‑counsel said, wait a second, if somebody needs six and they are living in the community, they're at risk of institutionalization. Should they have to go into a nursing home to be covered by Title II? He argued no. Being at risk of institutionalization is enough to be covered by Title II, enough to be covered by the Olmstead decision. And the court agreed and said that the integration mandates protection are not limited to those currently institutionalized but by those who stand in peril of segregation because of state policy. And those words are just gold for litigation. And it's been used on a lot of different context.

One of the context we have seen a lot over the years is in budget cuts situations. And, of course, we've seen a lot of that especially during the recession where states were cutting back. And the VL versus Wagner case was a good case of that where California was producing to reduce or term nature in‑home support services for elderly or people with disabilities living in the community. The plaintiffs filed a claim under Title II, a suit under Title II saying if you make these cuts, people will have no other choice, they will have to go into a nursing home. Before they go in a nursing home, court, we want you to issue an injunction and prevent any movement while we litigation if this is a violation of the ADA so people don't have to go into a nursing home. They can maintain what's called a status quo.

And the court agreed. And they granted that preliminary injunction. And we've seen this happen in case after case after case where we have seen these budget cuts happening.

And in Illinois, I didn't put these cases up here, but we've had another situation where you had a lot of kids who are on waiver ‑‑ it is called an indicate at this Beckett waiver for kids who are technologically dependent, in Illinois and in other states these waivers go up until your 21st birthday. And in Illinois, that protection, that in‑home nursing services is reduced dramatically when you move onto the adult waiver and I think the reason behind that is the time when the Katie Beckett waivers were established, most of these kids didn't make it to 21. But as technology has gotten better, they are. They go from receiving significant services to stay in the family home to getting cut by half or 2/3. And we brought a number of these cases using an Olmstead theory saying these kids are at risk of institutionalization once they turn 21. They shouldn't have to move into a nursing home. And we got a new opinion that agreed with that and the state changed its policy.

This whole risk at institutional has been an incredible tool for people living in the community to stay in the community. And then, of course, the biggest surprise, I think or maybe the biggest extension is extending Olmstead beyond housing. At the time Olmstead came down, it applied to people living in the community so many people lived in the community and they lived in an integrated setting but they spent their days in a segregated setting. Making no money or minimum wage. Some folks got together and brought a case out to Oregon. I'm sure you are familiar with it. The Lane cases. Some DOJ folks were part of the intervention in that case. Ultimately it is it was a class action.

The provision does apply to employment services. Terrific.

(Technical difficulty).

And so they sued under Title II and the court said in our first opinion post-trial finding that a government emergency preparedness violated the ADA as well as the Rehab Act, New York has an impressive preparedness plan if you don't have a disability. If you have a disability, you can have problems and they called it benign neglect. They said there was no evacuation from people from high rises. There was unreliable and ineffective communication systems. They said the city was unaware which emergency shelters were accessible. There was no protocol to address the needs of people with disabilities when there are power outages and New York system's relied heavily on inaccessible public transit for evacuation. Instead of ordering a specific remedy, the court directed activities to confer with one another. We got a link there. And then if the parties could not reach a remedy, they could possibly have a second trial. The parties were able to reach an agreement and agreement is quite comprehensive. We got a link at the bottom of the slide. They are required to hire a functional needs coordinator, they am have an advisory panel to provide feedback. They will have a post‑emergency canvassing operation to survey households. After disaster to identify the needs with disabilities, they're going to have at least 60 shelter that is were physically and programmatically accessible and they are creating a high rise evacuation task force to address the needs of people with disabilities that will be implemented in three years. So really significant systemic change. And I think at least on paper, this looks like a model that a lot of other cities should look at when they are thinking about their emergency preparedness plans and how they interface with people with disabilities.

And then the last Title II case I want to talk about was the voting case. Technology for voting has evolved significantly since 1990 when the ADA was passed. But also what else happened since then? We had the 2000 election and the hanging chads, right? (laughter).

Can't forget those. Crazy as this election seems that was pretty crazy, too.

One of the things that came out of that time period was the Help American Vote Act which addressed a lot of issues. It also addressed that was important for our purposes was voting access for people with disabilities and requiring every polling place has an accessible voting machine, one that people can use touch screens to allow for people who need it particularly blind people to vote privately and vote independently. The question is how does this play out under the litigation with the ADA? This was the Help the Americans Vote Act. This wasn't the ADA. This was The Help Americans Vote Act. You had some voters in California that went to vote and the accessible voting machines were either broken or people who were there weren't trained well enough to actually help folks make sure they were working. And so people who were blind were not able to vote privately and not able to vote independently. They were able to vote, somebody helped them out and helped them vote but they couldn't do it privately or independently and they sued under the ADA, Title II.

So the question is: Is that a violation of the ADA? And, of course, the county says, well, where's the violation here? They were not disenfranchised. They were able to vote. There's no violation here. And the court said, yes, there is a violation. It's one of the central features and benefits of voting is voting privately and independently and voters with disabilities should have the same opportunity as voters without disabilities should have. And they're not getting it in California in this county. And relying upon third parties creates an inferior voting experience.

Big stuff. And the concept that they really focused on I think is really key here is the concept of meaningful access. You need to be able to vote independently and privately like everybody else. That's what meaningful access is.

That same concept was applied to a physical voting access case in New York a year later. And these were again in the City of New York where polling places had some sort of accessibility barrier in 80% of polling places in New York City. Huge, right? And New York said the same thing. Look, we have alternatives, they can go to a different polling place or do absentee or have somebody assist them. If they can't get in, we can do curbside voting. Second circuit said that's not meaningful access. That's a violation of the ADA. People should be able to vote privately and independently in their own polling place. And as a result, they were able to get a positive decision in New York as well.

The last case I'm going to talk about is a Title III case and then we can open up to questions people might have. We still have about 20 minutes. And that's the Netflix case. The reason I want to talk about that is that raises another issue of unaccepted application of the ADA and that's the application of the Internet.

In 1990, we weren't on websites. It's hard to believe but it wasn't happening back then. We weren't pulling out that phone plug and finding people's phone numbers and paper menus for takeout and everything like that.

(laughter).

If you look at the ADA, there's nothing about ADA. There's nothing about the Internet. And so the question is: Is website accessibility something that's covered under ADA? It could be under Title II or Title III, potentially under Title I, but for now we are talking about Title III context. This is one of those situations wherever you are in the country, it's going to change what the courts are saying.

So some places say, you know what? You don't need to have any kind of physical nexus. Remember what we were talking about here in Title III is place of public accommodation. Some courts have said place means an actual place. And the early cases weren't Internet cases, they were insurance cases. And people were suing because their insurance, they were capping mental illness and H.I.V. different from other impairments. Remember when that was happening? Probably still is. At the time, those were some of the cases that are challenging the place of public accommodation. The courts said you had to have a physical place. If you didn't get your insurance in a physical office ‑‑ we are talking about physical access, not a problem with the policy. People were saying if there is not a physical nexus, you are not covered. Other places have said no physical nexus is required.

And the leading case is the (saying name) case. You have California and the 9th circuit which had initial cases that talked about the physical nexus and painted themselves into a corner. Remember the Target case when people said the Target's website wasn't accessible. And the judge wanted to say, yes, the website is covered by the ADA. But there was this other precedent that said you had to have the nexus.

What this judge came up with ‑‑ I will read it because it's like when Bill Clinton said "is" doesn't mean "is" or whatever he said that one time. It says ADA applies to the goods and services of a place of public accommodation rather than only the goods and services provided at or in a place of public accommodation. Only a lawyer or judge would come up with something like that. Basically, what the judge ended up saying was, anything that's on the website that is also in the store, that has to be accessible. But if they have stuff on the website that's not in the store, that doesn't have to be accessible. Bizarre, right?

And, really, are you going to have part of your website accessible and part of it not accessible? That's an odd thing. But it was her effort, I think, just to find a way to make that website covered after she had this bad precedent that she couldn't overturn as a district court judge. That's why we have, you know, all the different standards from different courts because people are trying different ways to figure it out.

So the Netflix case was one that was brought out in the East Coast where that car parts case was decided that said you don't need to have a physical nexus. This is a case where Netflix had streamed content that didn't have closed captioning and so people who were deaf, hard of hearing, really couldn't access that content. They sued under Title III under the ADA. Netflix said not a place of public accommodation. DOJ filed a really great of interest. We have a link if you haven't seen it and says Netflix is subject to the ADA even though it has no physical structure. Any said, you know what? We're not done with our regulatory process, but we are still taking the position that the ADA covers websites. And if you look at their briefs and things, DOJ has been very consistent on, I think, on the ADA applying to the Web, even though the regulatory process has not been moving as quickly as all of us had hoped.

And so Netflix filed a motion to dismiss and the court denied that motion relying on the decision that said you don't have to have a physical structure to be covered as a place of public accommodation. And they talked about the 12 categories for public accommodation. Netflix fell into several of them including a service establishment, place of exhibition or entertainment or a rental establishment. And so that gave Netflix what it needed ‑‑ excuse me, gave the plaintiffs what it needed to get past that initial motion to dismiss.

Of course, right after that the case settled so we don't have more in‑depth analysis like a summary judgment motion or a trial but that language is very helpful. And you will see a link to the consent decree that was entered and the press release.

Like I said, very similar case filed in California. Because you have that sort of tricky language out in California, they found that it was not covered by Title III. So, basically, the same two cases and because it was brought in different part of the country, the results are different. And so things are very confusing, I think, in the website world these days.

And I did the slide before DOJ's announcement last week that they were pulling back their proposed rulemaking and seeking additional comment. So that's happened since then. I don't really have much to say about that ‑‑ (laughter) ‑‑ except I hope things get resolved as quickly as possible because there's a lot of confusion out there. And I think clarity would help all of us.

And so that process will continue. We actually did our Webinar in conjunction with Robin Jones on access issues. And we have a link if you want to see a more in‑depth analysis about the cases. We go through those different cases and how they have been interpreted starting with the insurance cases evolving into the website cases.

And you guys have all these resources already so I don't need to do that.

We have 15 minutes still. Are you okay with taking questions?

>> Yes.

>> BARRY TAYLOR: I have other cases I can talk about. But anybody have any questions about any of the cases or issues? Got a hand back there.

>> (inaudible).

>> BARRY TAYLOR: The brief is there as well as the actual presentation and the PowerPoint.

>> (speaker off microphone.)

>> BARRY TAYLOR: I do. I have got to be careful. Oh, sure. Of course. Yeah. I'll repeat the question. So the question was are some of the bad decisions because of bad lawyering or just bad facts that were taken up. I think the Sutton case is terrible facts. You know, it's not sort of the case you want the Supreme Court deciding. First of all, if you look at the Supreme Court, all of them are wearing glasses, right?

(laughter).

Do they want to be considered by the ADA? Probably not. Maybe some of the progressive ones. Serious. It was the wrong case. And I think if that case had been somebody with mental illness or something ‑‑ somebody using a prosthetic device, something that made more sense, I think we might have had a different outcome. I hope we would.

But that adage of bad facts make bad law is certainly one in that case and a lot of other ones. I can't necessarily tell you all of them. But myself and a lot of other colleagues through disability right case work were on the phone saying we, please, don't appeal this case, please don't appeal this case. It's hard because the person is wanting to do the right thing. Sometimes they are doing this without any background in the ADA and they have a client they want to try to help. I think the motives aren't necessarily bad motives but the outcomes are horrendous. So I think that's a ‑‑ I think a great example but one of many as to why we got some bad case law because the ones that went up weren't great.

I thought the Braggat case was a bad case. That was the person that had H.I.V. and she said had a substantially limiting major life of reproduction, and I thought the Supreme Court would never buy that and they did. It's really hard to predict. That was brought by people who really know the ADA. It was brought by GLAD up in Massachusetts and they did great job and got a great result. That was one that I was really holding my breath on, too. So you just never know. But that was a great point.

>> Hi. (saying name).

I have two questions. One is around ‑‑ of course, you did great job and thank you. The ADA notification, you know I have to bring this up, and we now have three laws in Congress that are addressing this and California is one of the states, Florida, Texas. How do you see that moving forward and any ideas about fighting that?

And then my second question is around the intersectionality of disability and all other things, just like ‑‑ I do policy work. I'm not a lawyer. But, of course, know what you guys do. In policy work, we are seeing we are all helping each other out as far as race, religion, sexual orientation which is not a protected class all over the country but, of course, here in D.C. But how do you see that moving forward as a person of color with a disability or LGBT with a disability? Where do you see that going?

>> BARRY TAYLOR: Those are both great points. First thing on the ADA Notification Act, I'm not a policy person but certainly help our policy folks with the arguments that we make. I think everybody's familiar but just in case, that's where you would impose a 90‑day notification before you could bring a Title III case. Right now you don't have to exhaustive administrative remedies you can go right into court on Title III. The best argument is why do you need 90 days? You have had 25 years. That just seems to me to be the most obvious one.

The other thing to point out is that there are no other civil rights laws that require that type of notification. You don't have to ‑‑ if a restaurant is discriminating against African Americans or women or whatever it might be, there's no notification. I just think it's almost like a common sense argument more than anything because what they're going to bring out is ‑‑ and I hate this term more than anything, but I'll say it anyway, those drive‑by lawsuits ‑‑ just horrible ‑‑ and that's what people go for where people are filing these suits, settling them for money and not getting access. That gives the ADA a bad name and backlash. We have got to continue to be vigilant and point out how absurd it is to treat disability different than others.

The intersection between disability and other protected classes I think is a really important issue and it's one that when I was on the legal committee of NDRN, we worked a lot on those issues because there really is so much overlap. And there was ‑‑ what we call around is when there was all the sovereign immunity cases, remember those, Garret and Lane where they were saying you can't bring cases under the ADA for money damages against the state because of the 11th amendment. And that was affecting all of us. And so that was a really great one because we were all fighting the same issue. I think it's a little more challenging when you are fighting issues that don't apply to everybody else.

But, again, you are just sort of raising the boat as much as you can.

As disability lawyers, we have people who come in other protected class and we don't have experience. We want to serve the whole person but at the same time you don't want to ‑‑ first of all, commit malpractice but also don't want to do anything bad for the client when there may be a nuance that's different. I mean, there are a lot of parallels between Title VII and the Age and Discrimination Employment Act but a lot of differences as well that we have to be careful of. We actually had a project that we had proposed and we are hoping will get funded for a woman who is African American, speaks Spanish and has a disability to lead a project to talk about the intersection between those groups and to bring litigation so that we do develop the expertise and can help people who are covered by more than one protected class. But it is a little challenging if you don't have that expertise. It's something philosophically I think is really important but sometimes in practice can be a little challenging.

>> My name is Rosemary C. And I own my own company Accessible Living and I'm a nurse practitioner and I coordinate care for people with disabilities. Talking about the intersectionality of disability, healthcare, and race, the worst outcome, morbidity, mortality in cancer screenings and healthcare is the worse for African Americans with disabilities.

Since this is my wheelhouse, a great manufacture the hospitals in this country are not compliant with 504, the Rehab Act, and the ADA. And this is impacting the quality of life, quality of care and outcomes for people with disabilities. Most doctor's offices are not accessible. And there have been multiple (inaudible) showing poor outcome for people with disabilities, much greater impact for people of color.

Where do we go with this? We can't study it anymore because the statistics are just worse as the population is aging. And hospital and doctor's offices are not being forced to come into compliance. It's up to the individual person by person to litigate this and something we can't litigate ourselves out of.

>> BARRY TAYLOR: I agree with you. I think it's a huge issue. So the question, if I need to repeat it ‑‑ okay.

I think there are a lot of cases where I feel like I bring this case, I'm pecking away at an iceberg, okay? I got the results for my client. That iceberg is till there. So what I think is important is try to think of ways to affect systems and ways to change the broader healthcare provision as opposed to they didn't provide an interpreter for that person. That's important for that person but, you know, in two weeks they might not provide interpreters to somebody else. Plus, there's 80 other issues of that hospital beside the interpreter issue.

So what we've done ‑‑ not to say we have the solution but we and some other attorneys have been working on this issue with a concept of what's called structure negotiations. I don't know if people are familiar with that. There's an attorney out in California, Laney Feingold who is just the best. She really focuses on this whole concept of structure negotiation as an alternative to it litigation. She mostly works for blind folks. And she goes to places that are violating the law and says, you're violating the law. Instead of suing you, I want to work with you to try to change your system so that you are more accessible to people with disabilities. And they literally enter into a negotiation, enter into an agreement, she gets paid her attorney's fees. Her clients get paid some sort of ‑‑ what they would get for damages if they actually filed litigation and they work together and negotiate and provide the expertise that her clients have to make a difference.

And so she started off doing that in accessible ATM cases, so bank accessibility is where she started. But it's now being used as a method in accessible healthcare. We have two cases pending. One we've resolved and one we're negotiating. But one is a major hospital system in Chicago, I mean, huge. And we ‑‑ it took a while but we got the structure negotiation with them. The changes they are making are, again, across the board systemic change. Of course, there will be implementation issues and things like that. But it's just ‑‑ it's a way to get to a system as opposed to, you know, trying to fix one thing at a time because that's really hard.

Now, our case didn't talk about that intersection of people of color in the healthcare system. I am hoping obviously it would help people of color. Because I haven't really heard of sort of an initiative that's focused on people of color initiative. This is an initiative that will help. And DOJ has their initiative on their website that others may know about as well.

>> One more short question.

>> This is actually a comment, so I'm sorry. It's not entirely ‑‑ my name is Charlotte. I'm a trial attorney in the disability rights section of DOJ. And I would strongly encourage everyone here who encounters what they perceive as being barriers to access to communication to any services provided by hospitals or healthcare providers to file complaints with our office.

We are very interested in these issues. To the extent that they bring forth racial discrimination allegations, we have the opportunity to collaborate with other sections in DOJ on those issues. And so please do not hesitate to bring those issues to our attention.

>> BARRY TAYLOR: Thanks for that.

I was alluding to this before. There is a link on their website that shows their past work. I think we're done.

>> KURT JOHNSON: Thank you so much.

(applause).

>> KURT JOHNSON: So now we're going to shift gears and Joy Hammel is going to talk about the collaborative project that was funded for the ADA Network on the Participatory Action Research Consortium. Immediately after Joy, we'll take a break and then resume.

Guys, remember, we're substituting the break so that Joy can do her dissertation defense. In the spirit of keeping doctoral students coming out.

(Whistling).

Here comes the visual cue. We don't have break right now. Sorry. We had to swap out so that Joy can do her dissertation defense.

>> JOY HAMMEL: Thank you, Kurt. And thank you for accommodating a very nervous doctoral student in Chicago who needs to be for her defense right after this so I will be running. Thank you, Kurt, for inviting us here to the ADA KT State of the Science.

The project I will be talking about is the ADA‑PARC project which stands for Americans with Disabilities Act Participatory Action Research Consortium. This is another NIDILRR‑funded project but very complementary to the ADA KT centers here. And we work back and forth with many of the same players.

As you can see from this slide, ADA‑PARC is a very participatory, large Participatory Action Research Consortium. Involves many of the ADA regional centers as players with us as well as a number of universities that are also kicking in to help turn out some of the research that then gets taken back to the ADA centers. A lot of the people who aren't shown here by name are in this audience or on the line with us. So a big thank you to everyone who's participating.

And the other group who is not represented on here is our community advisory boards or CABs. And those are groups that every ADA regional center has developed specifically within their center region to reach out to community stakeholders like policy makers, like transportation authorities, like centers for independent living and other disability groups and to take all the information that I'm going to be showing you and take it back out to the community, share it with them, get their feedback. Is it accessible? Is it working for you? Can you use this information? But also to get feedback from them on what data they might have available at the community level, too, that we could share with the other centers.

So the purpose of the ADA‑PARC is threefold. Primarily it's to collaboratively examine participation disparities that are being experienced by people with disabilities post‑Americans with Disabilities Act and post‑Olmstead. And we say disparities is very much a public health version of disparities that we are looking, at the community and societal levels. Really based on social determinance of help, what's happening here post‑ADA.

We're also doing research to then benchmark those disparities. Give you a scorecard or a way to compare your state to another state or your city to another similar city. And then we're working on how do we take all of that information and action plan with the ADA centers, how to get it back out into the hands of people who could most use it, including potentially people like what Barry was talking about, the legal advocates, the policymakers, and protection and advocacy groups as well.

Specifically we're focusing in on looking at three different types of participation under ADA. And I also have the link here to our website which (saying name) is here from California and he hosts that website for us. That will give you a lot more information on the ADA‑PARC. Also give you accessible versions of all of the maps and things that I'll be showing you today.

So the three areas we're focusing in on are community living. This is Olmstead 101. What's happening in terms of least restrictive access to community living with supports now?

The secondary that we look at is community participation. So getting out of the home and into the community, are you able to live in that integrated setting? Are you able to get access to the supports and services that you need to actually be a member, a citizen of that community? And then our third area is work and economic participation.

Right now in ADA‑PARC, we have chosen to focus in on a number of cities first to pilot all this. These are also where we have our community advisory boards because we wanted to share a lot of information in a lot of different ways with the communities, see what was working, what wasn't working, get their feedback, make it really good. And then we could expand it beyond any city, right? Because the data we're accessing in many cases is nationally available data and it's fairly easy to extend it to other cities. But it's now you show it, that's the problem. It's usually not very accessible to anybody about a researcher, right? That's what we're playing with. And you can see we have over 40 cities right now that were chosen by the ADA centers as representative across their regions that they wanted to try out this analysis with.

We're using three main different kinds of research methodologies here. The first one is GIS mapping. And what you're seeing on this slide is on the left, you see people with disabilities who are living below the poverty line. On the right you see people without disabilities living below the poverty line. If you click on the website, you will get the accessible tables that also give you the same information.

But what this gives us is a way to visualize disparities. And you can see it, if you look between the two graphs right away without even looking at the numbers for a minute, you can right away starkly see the differences in the percentage of individuals who are living in poverty with disabilities versus those without.

When you go to the website, you can click on any of these states and that will take you down to the city level and you can drill down to cities and census track levels to see what's happening there. GIS mapping allows us to do that visual, spacial of disparities. It makes it accessible as well in table format.

The second methodology we are using is called indexes or benchmarking. This is used a lot in the public health research, specifically when you are looking at disparities related to healthcare access which was one of the questions from our last audience member.

What we're doing is using that same technology to now look at disparities related to participation as well. What happens when you do indexing and benchmarking is we take all these different indicaters that are on all different scales, right, and we put them all on the same scale. We give them a score from 0 to 100, just like you would on, say, a test kind of thing. So 100% is the best opportunities. This is the participation promising practice state or city that we want to look at.

0 and below the 50% are the ones that are having some disparities and potentially significant disparities. 50% would be your average with rest of the cities. I think this gives you a score that's much easier to understand than trying to go to a census and make sense of every single factor that's there on a different scale. It's called benchmarking.

And then the third thing we're able to do as well is risk ratios. Another thing that's used in public health disparities research a lot. What this lets us do is compare are people with disabilities more likely to experience a disparity when we compare them to people without disabilities and to what extent.

So a risk ratio would tell you how much more likely are they to have that disparity? And we will get into a few examples of this as we go here.

So let me just take you through just a glimpse. We only have a few minutes. So I'm just going to take you through a couple indicaters and a couple ways how this research plays out. Again, I invite you to come back to the website. I invite you to come over to us in the ADA‑PARC and we have got lots more data and all the indicaters we can share with you.

But let's look at these three areas. So the first one is community living participation. Again, this is that least restrictive access to living in the community versus in an institution. One of the indicaters we look at among many is how much do people with disabilities have access to community living supports? And this is where money speaks loudly. So one of our indicaters is how much are states spending on community living supports such as home and community‑based waivers and other systems to stay in the community versus how much are they spending on institutions or nursing homes? It's a ratio, okay?

The darker the state, the higher the number. That means those states are spending a lot more on community. They have gone over the 50% end of this. And some of these states are at 80 to 90% ‑‑ oh, I'm sorry. I'm blocking the slide. I know, I do a lot of this. (laughter).

So some of these states are ‑‑ Oregon, Washington are up to 80 and 90% of their budgets are now spent on community. What you can see here, though, is some of the states in the lighter colors, lower numbers like my own State of Illinois is struggling. We are trying to get over that 50%. Every time we do it, we go backwards in a time of budget cuts, right? So we're able to track that via this GIS mapping and the accessible tables.

The other thing that's interesting on this is we're just about to update these with the latest statistics for this past year. And so now we can track it over time. So following on what Barry was just talking about, we can now track in Illinois post‑three class action lawsuits does this change? And I do think the latest one is going to show that the percent is spent on community living is going up in my State of Illinois.

What else can we look at under community living? This shows you those benchmark scores I talked about. On a 0 to 100 scale where we put it all on the same scale, which are the best states? Which are the worst states? For a minute, I just gave you a top five. You can actually go and see all of the states and see how they play out.

But we see here a couple things. One is we see three different indicaters that are giving us information on community living. That is the number of people who are getting out via waivers, the money spent on waivers and the number of transition money follow the people. All factors related to community living.

That yellow composite score on the bottom is we have taken all those factors and we've summed it up. So you can see across and, in fact, we have many more factors under community living that are part of the composite, how well are these states doing overall in terms of enabling least restrictive community living or not, okay? So we see those states in this case that are some of the best states, Utah, New Mexico, Arizona, Oregon, Alaska.

And some of the states that are struggling, Rhode Island, Mississippi, Indiana, Alabama, Florida, New Jersey, and North Dakota. Another way to see some of these disparities.

And the last thing we're doing under community living right now is a new initiative in the ADA‑PARC and that is across the ADA regional centers, we're now going back to people with disabilities themselves and we're doing interviews of 300 people with disabilities who have ‑‑ who are moved out of nursing homes and institutions to the community to actually track across all these different areas of participation, community living, community participation, and work and economic, what's happening to them since they transitioned out. So they compare institution versus community but they also track it in the community and say: Which things are working for me? But which things are still an issue for me? How we can compare that individual perspective to the more community and societal ones you see in the map. That's happening right now. And, indeed, we are recruiting for that.

If you have folks that you know of or that can reach out that want to be a part of these national interviews, we are more than happy to accommodate that.

The second area we are looking at is work and economic participation. This is one in this audience I know you are incredibly familiar with. I will breeze through it very quickly and send you to the website if you want more information.

But some of the things we're doing again is we're GIS mapping, we're showing what the disparities are related to employment. So on the left you're seeing people with disabilities. On the right you're seeing people without disabilities. This one you're seeing the percentage of people who are employed in that working range of 18 to 64. Right away you see the stark disparities here between the two.

We start to think about, well, what's causing that? Is it that they are unemployed? When he we do the maps on unemployment and there are other people doing lots of data analyses on these, too, we don't see that big of a difference between people with and without disabilities. Just unemployment isn't the driving force here.

But when we look at not in the labor force anymore, e.g., people are dropping out of the labor force completely, they are no longer searching, no longer trying to get into that workforce, that's really where we see the issues and disparities happening with people with disabilities. When you go to ADA‑PARC, you can click on any of these states and go down to city level information and accessible tables as well.

What happens to those individuals then? We are also tracking what are they living on then? If they are not employed, what's happening to them? One of our key variables is not only cost of living which is another one we're looking at but how many are living below the poverty level. And, again, you're seeing some striking disparities here in terms of people with disabilities living below the poverty level.

We can benchmark this. We can scorecard it, right? So you can actually see it in a 0 to 100 way, exactly how this plays out, too. So, again, here you're seeing some of the factors related to these bad economic issues, right? The percentage of people living below poverty, not in the labor force, and unemployed. And we can sum across those and say which states are having the most issues or are the worst states with these negative things and that would be District of Columbia, Michigan, Kentucky, Mississippi, Florida, North Carolina. And which one are doing party or above the average? Somehow are trying to deal with some of these issues maybe? And that's North Dakota, Wyoming, South Dakota, and Nebraska.

We can then dive down to the city level. Same thing, the benchmarks or the scorecards show us now maybe on a more meaningful level for systems change what's happening in that city. And in some of these, depending on the data we've got, we can go all the way down to a census track so you can actually see it even at certain neighborhood levels here as well and really delve in if you are trying to do some systems change.

Here's one where we do I have a risk ratio for you because I think it's a really quite compelling story alone. And that is the percentage of people with disabilities versus without who are living below the poverty line. Here you see some very compelling statistics, especially in those cities on the right, the cities that have the most disparities, Asheville, San Francisco, St. Petersburg, Seattle, Washington, D.C. We will take Washington, D.C. since we are here's for a minute has a risk ratio of 2.62 which means people with disabilities are 2.6 times more likely or 261% more likely to be living in poverty in Washington, D.C. than people without disabilities.

So, again, this is not new to you, right? But to a community player, this is the kind ‑‑ it's an arsenal, shall we say (chuckles) of data in a lot of different compelling ways that are easy to understand and that you can take together and present as a case.

Our third area is delving into community participation. And for those of you who are in the research world in this one, you know there's far less information available on a national dataset version of this. So we're trying to go sub. We're diving under into the underground network to try to figure out what can we look at here.

One thing that we are looking at and have established a relationship is with the folks who do the Walk Score. The Walk Score was originally developed not disability specific in any way, it was developed for Realtors to be able to market housing in that community, to show what was available to you. And the Walk Score is really misleading, I think. It's not about walking. It's about how far away are basic community participation resources. Are they within a quarter mile of you, right? Or a half mile of you depending on the resource. So it's things like grocery, like pharmacy, like libraries, like transportation, right?

So I think that's as applicable to people with disabilities as to people without. A very interesting indicater for us. It again gives you 0 to 100 scores and you can see how ‑‑ in this case we have cities mapped ‑‑ are scoring in relationship to access to basic community participation resources in that community.

This is one that I can go all the way down to a zip code level or a neighborhood level and actually really get into the specifics in that neighborhood.

The developers of the Walk Score also have something called a transit score right now, that they're in develop with but they are working with researchers to release all this information to us so that we can get access to it. And that's just like the Walk Score but in this case it's very specific to transportation and public transportation. So it's looking at things like how far away is it, how accessible is it, how reliable, how much money is being spent on it, all these kind of variables rolled into one score. So, again, we get a 0 to 100 score where we can go all the way again down to a specific level of a neighborhood and get that information.

Transportation, huge issue, right? We're spending a lot more time delving here in the ADA‑PARC. We are definitely diving in for transportation because that was the number one community advisory board request. They wanted much more information on transportation. So just to give you a couple examples of how we're doing that, this is a GIS map of transportation access. And in specific, this is one is looking at Houston as a metropolitan area. We mapped via the ACS and census data where people with disabilities are living. In the darker colors, that's the one where more people with disabilities are living which actually also if you correlate it has a lower socioeconomic status neighborhood as well often.

On top of that, we can then say where's transportation and do people have access to it in that city. So in Houston, if we just look at their train access for a minute, we've mapped it from the federal transit data that we have access to. And we can see here that only 5% of people with disabilities are getting access to public trains in Houston.

However, it's not that different than people without disabilities here. Houston's not a good train city.

Now we go to Chicago for a minute. And here's my city mapped out here. We find out that there's a very big difference than Washington, D.C ‑‑ sorry, than Houston even though we are both large urban metropolitan cities. We have 31% of people with disabilities are able to get train, public train access within a half a mile of where they live in Chicago. Could be the result of we've had a lot of lawsuits and class action suits in Chicago, a lot of activism specific to transportation that affects that.

We can also look then at buses so in Houston, we can look at how many people are getting access within a quarter mile to a bus because you should be closer to a bus than a train. And we see only 52% of people with disabilities have access to this public line of transportation. But in Chicago, 94%. Okay?

So this data already is being used by our community advisory boards in several of our ADA centers right now that have taken transportation as their number one thing, including the folks in Houston. I'm looking at -- Lex Freiden is now an appointment to the authorities there and they are doing major look at transportation. We also have our compadres in the southeast ‑‑ southwest region here in North Carolina, South Carolina, that are also using this data as we speak to try to effect some systems change and target it in those communities.

The other thing we're doing specific to transportation right now that I invite you to participate in is we are in the midst of a national survey of people with disabilities to actually get that consumer individual standpoint again on transportation access, accessibility, availability, use, and quality. We have a little bit over 1,000 responses to that already, and we're now ‑‑ within the next week, we're putting out our second call to blanket as many people as we possibly can and to up the numbers.

We especially want to increase the numbers in all the cities so we can compare across them, so we can show those transportation maps but then we can also show from a consumer standpoint what's the quality of that transit. What are some of the issues that people in that city are facing? So right now we're in the second round of the transportation survey, and all of you will be getting a lovely email inviting you to widely distribute that. The more people we can get to answer the better for us.

So that just gives you a short glimpse into ADA‑PARC and some of the things that we're trying to do from a knowledge translation standpoint. Where are we headed? Right now we are in the process of updating all those GIS maps and adding those indices and those benchmarks and the risk ratios to the website. That's massive undertaking right now for the latest data.

We're going to be adding more data transportation, including the maps I showed you. They are already out to the ADA centers, but we're going to make them now publicly available for any community. And we're going to add that transportation survey data to it as well.

We're in the midst of these Olmstead interviews. That will then be added to the website as well, that links to those community living findings that we've got. And we're in the process then again of working with our community advisory boards who are now doing some really interesting things. Like, they're having transportation conferences and Webinars and things where they're getting together many players in the community to look at this and act upon these data and these disparities, and we're also now working with the ADA centers to then provide the technical assistance, the training, the promising practices case study that are directly linked. So if they see a map and they see disparities, we can link them right to the ADA center that's tackled that. They can get some information and find out how to do it in their community.

So that just gives you a little bit of an overview of the ADA‑PARC. A special thank you to everybody in the audience who is involved in this project and collaborating and contributing to it. If you have any more information, please go to our website. It's definitely a wealth of different data there. But also contact us if you want access to any of the data that we talked about in your city. We're able to run that.

Any questions from the audience?

>> KURT JOHNSON: Let me add that there's a slightly easier address for the website if you'd like as well which is just adaparc.org.

>> JOY HAMMEL: That's true. (laughter).

In fact, it's the number one Google. I will take that as a good thing.

>> Thank you very much. I'm really looking forward to visiting the website. You've mentioned cities specifically. I was wondering if you have done anything in particular to target information on people in rural areas, or is that something that we could find on the website as well since there's unique problems in those areas.

>> JOY HAMMEL: Yeah. So our first take at it is we needed to have accessory to ACS and census data for a lot of these things. It limits to us places that are at least 50,000. And we do have ‑‑ it depends on your definition of Suburban, urban, and rural. But the way the census in remarks CS would say it under 50,000 would be the rural areas. So if it's under 50,000, I do not have you on here yet, right? Because that's harder data to make clean, let's put it that way.

There's more or less data so it could be skewed. It could be identifiable. That kind of thing. That's what ‑‑ we will be adding more of that. Just note it's a little bit chancier on rural areas for data and how to interpret it.

However, we do have several smaller places that are what I would call very ‑‑ have very rural components to them, kind of thing in it.

We also have rural components in a lot of our bigger metropolitan, like, Cook County has rural aspects on it to pull out on the data. If it's available, we pull it out. Yeah. But you're right, it's definitely a huge issue is, takes a little bit of more finessing and you need to be a little bit open that the data is a little less clean when you go at a smaller level. But it does exist, and you can get some runs on that.

>> Hi. Excellent. Very, very interesting.

I was just wondering, though, the ACS as you know uses a different definition of "disability" than the ADA. So given that this is a knowledge translation, a lot of people will be using this not fully aware perhaps of that rather significant difference in definition. So how do you deal with that?

>> JOY HAMMEL: And it's a really good point. In fact, all these databases use different versions of "disability." It's not between the ADA and ACS, it's between a lot of different sources define "disability" differently. The good news is at least there's the initiative at least on the federal data level have everybody using the same version of "disability" which is different, you're right, than ADA.

The way we address it right now is we tell you on the website exactly what the definition is, okay? So we actually say: Here's the definition according to the ACS.

We can also go into some of the categories. ACS does get at mental and physical disabilities which is a conglomeration of a lot of different things and we can dive you down a little bit but no further than that on this kind of data, right?

So what we're trying to do is find those data sources. And is it, say, Department of Justice or other, you know ‑‑ or to H.U.D., has tea spot data and things like that are more related to the ADA definitions of discrimination, right? Can we also be mapping some of that? Can we also be showing that, right?

So I think you're hitting on a huge KT issue, right? How do you ‑‑ one of our biggest areas this time is how do you even show it in a way isn't this statistical mish‑mash that you can't make sense of unless you are a researcher. That's step one for us, was to even show it with what we do have.

I think step two is how do we cross‑cut, marry the two, how do we inform for ACS even if it exists ‑‑ there is an issue if ACS will exist as a source ‑‑ how can we inform them to adopt more of a civil rights kind of definition of disability than the very strict kind of definitions. They have more classical definitions than they have in here right now. A whole other area of action, right?

I think all we can do is tell what you it is or what it isn't. And we're very clear when you go to the website, here's the definition and we take you right to the site if you want to read more about it. And we say here's the things you can learn from this and here's the things you cannot. So can you extrapolate to ADA? No, you can you see disparities of community living, community participation and work for a whole population? Right. Yes. The problem is the extrapolation, right?

>> KURT JOHNSON: So we're supposed to release you. So thanks so much.

(applause).

Take a 15‑minute break. And we're going to ‑‑ we're speeding things up to get you longer for lunch because I know it's challenging to find something to eat here.

See you back in 15 minutes.

(break).

>> Let me review again.

>> Audio recording for this meeting has begun.

>> (inaudible). After the break, we're going to talk about some research that our group at University of Washington on ADA implementation using the databases and systems that we have been able to put together. And then we're going to (inaudible), I know lunch can be a challenge here and may need some more time to find something to eat. So we'll try and move things up by about 15 minutes to give you some extra time for that.

Then once we're finished with our presentation, then Sarah Parker Harris and Robert Gould are going to talk about some work they have done on reviewing the state of the ADA research, what we think is a really innovative process, methods being able to analyze research. We will try to do 20 minutes here with our stuff and then some question and answer and then switch to Sarah and Rob.

>> MARK HARNISS: Thanks, Kurt. My name is Mark Harniss. And I get to move out from behind the Webcast for a minute. Am I on? Okay.

And try to move into my presenter mode.

I'm co‑director of an ADA knowledge translation center. Kurt is the director in the PI. This presentation is on the question of measuring the ADA implementation as a result of the activities ‑‑ they can't hear me in the back.

>> (speaker off microphone.)

>> MARK HARNISS: Thank you. (laughter).

I was trying to point that out to Joy and now I'm doing it. Is my big head out of the way? All right. I will try not to gesture too much either. Audio is okay in the back? Okay.

I'll just start again. So my name is Mark Harniss. I'm director of the ADA knowledge translation center which Kurt is the ‑‑ co‑director. Kurt is the director and PI.

In this presentation, we want to give related to work that we've been doing in which we have been attempting to measure implementation of the ADA as a result of the activities of the ADA National Network.

Many of you think I are familiar with the ADA National Network, but for those of you who are not and for those of you on the Webcast, the ADA National Network is composed of ten regional ADA centers across the country. It also includes the ADA knowledge translation center and the ADA collaborative research project which you just heard about from Joy. Funded by NIDILRR.

The purpose of the network is to provide ADA training, technical assistance, develop ADA‑related materials and so forth. It's really one ‑‑ I think it's the only federally sponsored national network that provides technical assistance on the ADA in this way. It's unique in the sense that it's not ‑‑ it doesn't have legal implications. People can connect with the national network. They can ask questions. There won't be any legal outcomes of asking those questions. They can ask those questions anonymously. They don't have to reveal who they are. It really is intended to be a support for people to help them to implement the ADA, not to punish them if they're not implementing the ADA.

We do have a website which many of you probably have seen, www.adata.org. And a lot of information and a lot of fact sheets and links to answer there.

So the ADA Knowledge Translation Center which we make up is really unique within the national network in that our goal is not to provide technical assistance directly to people. Our job is to provide technical assistance and support to the regional centers. And so we work with the regional centers to develop evidence‑based fact sheets that are based on consensus and professional best practice.

We implement the scoping and systematic review that Sarah is going to describe. And a number of activities related to trying to translate information about the Americans with Disabilities Act for the people who need to understand it and need to use it.

And so our goal as defined by NIDILRR are really to optimize the efficiency and impact of the ADA National Network's activities, to increase awareness and use of ADA research findings to inform behavior, practices or policies, and to improve understanding of ADA stakeholders' need for and receipt of ADA Network services.

As part of our work ‑‑ one part of our work, we collaborate with the regional centers in an attempt to understand how the services they provide result in greater implementation of the ADA. And we define ADA implementation simply, it occurs when entities or individuals are able to exercise their rights and responsibilities under the ADA. That's what we're trying to understand, to what extent do the services we provide result in an increase of people's ability to exercise their rights and responsibilities.

So we're focused on really two things, assessing to what extent ADA implementation outcomes have been achieved and to try to characterize those outcomes. And then we also attempt to increase understanding of how the ADA National Network services themselves support the ADA implementation or don't.

And we've come at this from a number of different directions. I'll just let you know that this is an ongoing process, a collaborative process with the regions themselves. And as of yet an imperfect process. I don't think we have figured out the right way to do this. But we have three measurement initiatives or approaches that we've attempted. So one thing that has been a lot of work to get in place but now is pretty stable, it's something called the outcome measurement system. I will talk more about what each of these or. The outcome measurement system, it is really more about outputs. It's really the types of services that are provided, what topics that are covered. Is it simple information or complex information? Who is the information provided to and so forth? And I will talk a little bit more about it.

We also have an outcomes survey which is a follow‑up survey we do after the receipt of TA for a subsample of individuals. It's also focused on what are the types of outcomes that are achieved as a result of services.

And then we have something that looks more like a typical research project and that is an interview of technical assistance providers in the regions. And so we've gone and connected pretty extensive interviews with a sample of TA providers, the people in the regions who actually talk to people about the ADA to understand how they do their work. And then the fourth thing we've done is what we call success stories. They are, basically, rich case studies trying to understand why there have been successes in certain areas based on ADA National Network services.

So why do we have multiple approaches? Why are we coming at it from different directions? Attempting to try to understand the parameters of the issue. So the OMS and the outcomes survey really do capture what services are provided and what resulted from those services. That's what we're trying to get at there.

And we can report those quantitatively so we get a sense for numbers of things that are happening. But it doesn't give us a rich sense of the specifics of what's going on in terms of the change process. And so the TA evaluation project and the success stories are an attempt for us to really qualitatively dive into that understanding of ADA implementation. And that gives us rich accounts of process and it helps us understand barriers and facilitators a little bit better.

So let me quickly overview what each of those things are, and then I'm going to provide you a snapshot of some of the data. And I'll give you a big summary overview of what we think we've learned. So the OMS is really a national database and every region collects data on all of the technical assistance and training activities that they conduct. Sometime everybody from the region calls in, somebody from the region captures the information and identifies what happened in that technical assistance interaction.

The same thing is true for training. We also have a section on public awareness. That section is not as well pulled together and it's something we'll be looking at some more. But regions use it in different ways so I won't talk about that today. But training and technical assistance we collect pretty rigorously.

All of those centers direct that data. We provide trainings that helps them how to understand to use the database and we work with them around quality assurance. We generate quarterly reports that goes out to each region and NIDILRR that gives a summary of what was learned.

Since this is a research conference, I will note there are standard operating procedures in place that would allow you to access those data if you wanted to. So you kind of have to go through a little process, the directors approve the use of those data, but these are federally funded data collection. And you could access them.

The out com measurement survey is a little different. This is only for technical assistance. We attempt to get 250 calls every quarter so each region attempts to capture 25 surveys. And this is a purposeful sample. In other words, we just don't randomly go pull these. We actually go in and say, we only want ‑‑ we want interactions that are complex, not simple. We are including both technical assistance to individuals and to entities. And we're really kind of honestly cherry picking a little bit trying to find those where we can see ‑‑ where we expect that there will be some implementation activity. And so ‑‑ but the goal of the survey is really to follow up with people to understand what happened, what kind of implementation happened and to decode that so we code those ‑‑ that qualitative data into five different codes and then we report those back again quarterly.

These are the outcome types we code. So no outcome, that simply means that, in fact, technical assistance was provided, nothing happened. That does certainly occur.

Knowledge outcomes, so technical assistance was provided, people learned something. They understand what they should do but they haven't been able to do anything after it. Decision outcomes which are a little bit rare because they intend to be sort of time sensitive but decision outcomes are when people have decided how they're going to proceed so I'm going to begin administrative procedures or whatever. And then implementation outcomes meaning that something actually changed. It's a broad range of things that could happen that could be a design change, it could be somebody requesting accommodation and they got. It could be as simple as somebody wanted to know how ‑‑ what the bathroom height should be for the counter and they understood it and they implemented it into their designs. So it's a really broad range of things. And this is part of what we ‑‑ in our continued work we need to begin to parse out is how to differentiate those types of implementation. And then sometimes we just don't have stuff data to make the coding decision.

The outcome measurement survey is really intended to demonstrate the intent to which TA services result in implementation. So the types of outcomes ‑‑ we also do capture topics and audiences that are addressed by those outcomes. I think I have kind of talked about this. But it helps us understand the needs of recipients of the National Network technical assistance and it increases our understanding of how technical assistance providers address ADA information.

So what we did is a combination of what the TA was and then the survey follow‑up to get a sense of what happened three to six months after the survey.

That's number two. Number three is the TA evaluation project. That's the research project I told you about. It's really a qualitative evaluation project that's aim at exploring the role of TA providers and it's a follow‑up survey. TA specialists were recruited from all ten regions. Semi-structured interviews. Participants reviewed and refined their interviews and we involved in a qualitative process. I will tell you more about that.

And last thing I will mention are the success stories. They are the complex cases. They are nominated by the National Network, by the regions in the National Network. They say, look, we have this great interaction where we were really successful and so what we do is we follow up ‑‑ and we, basically, engage in investigative journalism with the regions. And we interview people in the regions and we interview the people they worked with and we attempt to understand what happened. What made this a success? Why was it successful? And then we write that up in a plain language journalistic style.

So I'm going to give you a quick snapshot of results. For the OMS, I will show you really quickly some year four data so you can see what that looks like. For outcomes, I will show you recent data. It's the second quarter 2015 when the TA events happened and the surveys were collected over December 2015 and then the TA evaluation project was conducted March to June. And we engaged in validation August to February. And then we have four case summaries that were published 2014 to 2015. Those case summary are online. They are on the www.adata.org website. You can read those. They are labeled as "success stories."

I'm not going to spend a lot of time talking about the OMS because frankly it's really boring and there's not much that you care about. (laughter) ‑‑ that you couldn't easily read somewhere. But I did just want to show you what it would capture. It's important that we understand the kinds of services, kind of activities that the ADA National Network is engaged in. But it's sort of ‑‑ it sets the stage for other kinds of work that we do.

You can see this is just a snapshot of the amount of technical assistance and training that occurs in a year. So not surprisingly, there's a lot more TA because those are individual touchpoints but still significant amount of training events that occur.

If you look at top training types, most of these are presentations. Some are training courses and workshops. And you can see the number of participants on the right‑hand side there. We can also look at training topics, so we can get a sense for the kinds of things that people are requesting in terms of training in year four, Title II, general ADA information were the top two. And then it drops down, Title I, Title III, disability awareness, and facility access kind of group there.

But some other things that you would not ‑‑ that you would expect as well, service animals which has been a super hot topic.

Moving on to technical assistance, I think it's an interesting note that a large majority of the technical assistance is provided to individuals with disabilities and three times as much as the next category and the next category is family members with disabilities. So the people who are accessing technical assistance from the National Network are largely people with disabilities who are trying to access some help about how to implement their rights under the ADA. Businesses come next. Lots of architects and design professionals and quite a bit of state and local government.

If you look at the topics being covered, facility access topped the list in year four with title III, II and I. Reasonable accommodation, service animals and housing. Probably what you would expect.

But we do try to differentiate the type of technical assistance provided. Again imperfect but we try to identify if it's relatively simple information being provided or complex information. The difference there would be somebody who has a question and you're able to send them a fact sheet and that resolves their question versus somebody who has a real complex situation that may require further research, may require bringing in other experts in the regions to help them understand ‑‑ or help you understand how to provide the technical assistance for them.

Moving onto the outcome survey, these are the kinds of reports that we're able to generate implementation outcomes versus knowledge outcomes, versus decision outcomes. Because of the way we select the TAs for call‑back, it's not super surprising that there's a lot of implementation that we're able to report. In this case, you know, probably double the knowledge outcomes. But this is an area where we have, I think, a lot of work to do to continue to understand and to code implementation in a way that's more informative because at this point, all of this ‑‑ this implementation that I noted really cuts across a variety of types of implementation. And so this is an ongoing thing that we need to engage in. It does give us a sense that for the more complex technical assistance events, something is happening three to six months afterwards. So you looked at it no outcome and there are very few no outcomes. People are able to exercise their right to some greater degree after they contact the National Network. Whether that's solely the responsibility of the National Network or that gets them started on to a path, that part we don't know.

But we do at least know that most at least of this sample are able to either understand their rights or to exercise their rights or responsibilities after they connect with the ADA National Network.

We can look at outcomes so entities being architectural firms and those kinds of things. You can see for implementation, we tend to have more entities than individuals but for knowledge, it's kind of half and half. And I don't quite know what to make of that. I would say we probably have a little bit of a bias towards entities when we select the TAs because when we're purposely sampling them, we're looking for TAs that provide ‑‑ potentially provide the ability to have implementation.

But we originally started trying to only collect implementation data on entities. And we quickly realized, as you can tell, that so many people ‑‑ individuals with disabilities are contacting us that we need to include individuals as well.

We can look at the primary role of the contact, at least in that quarter architects were primary with individuals with a disability being second, state/local government agencies third.

And this just gives you a sense for some of the data we are able to collect from the outcome survey. Again, those are quarterly reports. And we will continue working on what "implementation" means in that. We are using the TA provider survey, and this was conducted by Becky Matter who isn't here but she is listening here, she is in South Africa. I think she is on the Webcast. She conducted a series of interviews with technical assistance providers in the region. We were able to get interviews from at least one person in every regional center, up to three in some centers. Generally more women than men. But a nice distribution of experience with some folks having been there only one to five years and other folks having been there greater than 15 years.

And this is just the beginning of a project that I think will be really fruitful. And that is to really delve into the experience and expertise of the technical assistance providers that are in the regional centers to understand how they're providing information, how they capture information and organize it so that when people call in, they're able to give them the information they need in order to support implementation by individuals.

Some of the characteristics much the TA requests that providers say they are experiencing, their comments support one of the findings from OMS. They said one of the most common recipients for TA are people with disabilities. So they support that in their interviews. When asked about common ADA topics, service animals pop to the top this year as you might imagine. Parking is always big. Housing is always big. Employment, of course, is big. Building, design, and transportation.

But I would say those top three, those are the ones I heard a lot about this year and ‑‑ it would be interesting for some of the regional folks to talk. But those keep coming up.

The other thing, however, they say we don't just get questions about the ADA. They are viewed as a support kind of a network for people with disabilities. A lot of people, regardless of whether they have disabilities or not have a hard time differentiating the ADA from other laws. So they get a lot of calls where they have to help people understand what the ADA covers, what it doesn't cover, what laws cover the issue that you're experiencing. Housing obviously is a big one where there's overlap and not complete. So they spent a lot of time helping people parse out where I would go? Is this ADA issue or not?

They did report that requests have become more complex they feel over time. Again, some of these people have been working for over 15 years. And so they are finding that although we do still provide a lot of simple information, they feel that a lot of their requests are becoming quite complex and that they're having to spend more time dealing with these nuanced issues.

And then most people are ‑‑ more people, not most, but more people are getting the simple, easy information online.

In terms of emerging topics, they identified these. The intersection of the ADA with other laws, as I mentioned. So thinking about housing and so forth. They're getting more calls about Web accessibility. They're getting calls about mental health and the ADA increasingly. Public transportation. They're getting called about criminal justice system and the ADA and public education and ADA. And these are the things they represented as kind of increasing in recent years.

The other thing we looked at is how to understand how they address information requests. Because we want to understand how technical assistance providers support implementation of the ADA. So this was pretty variable. And it probably varies based to some extent on experience and training.

But in general, the first step is always to ask the question: How does this issue apply to the ADA? Is this an ADA question? That's almost always where the technical assistance providers start.

And then they help people know what options they have, kind of what next steps might be available and they offer ‑‑ they will for complex issues often offer the option to call someone back if they don't know the answer. It's one of the nice things about the National Network. It's not one of those places where if we don't have the answer, you're done. Often people will call with complex issues and the technical assistance providers will spend a fair bit of time researching those issues and getting back.

The other thing that is important is that ‑‑ and it ties into the regional nature of the ADA National Network is that TA specialists are often providing regional‑specific information, state information, county information and so forth. And so they understand regional regulations and laws. They can refer to local resources, organizations or experts. And they can understand regional case law.

And so this piece is a unique piece I think about the ADA National Network, is this ability to connect to regional resources.

We also ask them why they think people seek technical assistance from the ADA National Network. And one of the reasons is they felt there is really no other option for individualized TA with a real live person who can talk me through this. And that's highly valued. So when you think about implementation, people's ability to understand their rights and implement them, being able to talk to somebody who can actually walk you through that is pretty important.

They also feel there's good consumer service and that's probably not a surprise. The regional centers have been doing this for a long time and they do really good work. High quality, useful, accurate information. They like the strong regional relationships. A lot of the regions say that people have ‑‑ they have frequent callers, frequent flyers, I think that's what they call them. They have people who call back a lot. These are folks ‑‑ sometimes ADA coordinators, people whose job it is to understand stuff, they have people who they call frequently and who value that resource.

They also feel the National Network is the only resource that covers all info related to the ADA. So it's not just the DOJ. It's not just the EEOC. It's not sort of targeted information. It's not just employment. But they actually cover the broad range of the ADA. They report that TA providers are a nice bridge to those federal agencies. So all the reams have connection to the federal agencies. If they don't know how to answer the question, they know who to ask so they can connect on up.

So just a couple quotes from TA specialists. One ‑‑ the first one: You want to bring these large federal laws back home to people because they trust sources that are closer to them. They trust people they know. Again, trying to think about this in the context of implementation, how do you either convince people to engage in their responsibilities understand ADA or to exercise their rights under ADA. Part of that is by this kind of personal connection that people make to TA specialists.

The second one is the types of questions are getting more complex. I believe people with disabilities, HR specialists and others that implement the ADA are more savvy about the ADA. The level of the questions and the complexity has increased as the years have gone by, and people have been educated in many ways through their employer, in their community, with their open HR specialists with their own research on the Web. This is just sort of highlighting simple access to information is not sufficient, that there's a lot of nuances and complexities.

And the ability to actually connect to a person who has a sophisticated understanding of the law can be really important for supporting ADA implementation.

Last one, the success stories. These are the four success stories that we've done so far. These are online. We did one in Hattiesburg, Mississippi. One in Pendleton, Oregon. One in St. Louis. And the Frist center, Tennessee. Thank you. These are all written up online and they are complex cases that really highlight the ‑‑ the one I'm remembering the most ask the St. Louis Arch. Highlighting the process that regions went through in setting up relationships with organizations who are engaged in kind of large‑scale systems change projects. So the St. Louis Arch project is a project where they were renovating that St. Louis Arch complex, big renovation. And the National Network and some of the disability organizations were able to get in at the design stage to ensure that to the extent possible, all of those renovations were going to be accessible.

And I think they had really amazing results that the only thing that I think you can't do is go ‑‑ necessarily go all the way to the top of the arch because that's a historical ‑‑ they weren't able to make some alterations there. But other than that, they had a great success.

So some of the characteristics of the implementation that we see in those success stories: Strong regional relationships. These things happen because there are people in communities who are engaged and who have connections to the people who are making decisions.

There's a clear vision of ADA implementation early on in a project. It's the kind of thing ‑‑ this is again not a surprise. But it's the kind of thing where if you are in at the beginning, then it's just an expectation, right? And so in the St. Louis project, for example, by the time they got halfway into the project, it was the project's architects who were making statements about accessibility. So they had to kind of manage to get those people on board so they were the ones as the advocates and were focusing on implementation.

And then meaningful sustained engagement with community organizations. These are the kind of things the regional centers are able to support.

So this is my last slide. ADA implementation just kind of broadly lessons. I mentioned the first, trusted regional relationships are key.

The second is implementation requires both information and guidance on the ADA but also how the ADA intersects with other laws and that piece can't be discounted. It's a confusing kind of legal world for people and there are lots of pieces they have to put together. We don't have comprehensive policy and comprehensive law.

The last is just information alone is not really sufficient. The recipients need to know how that information applies and they need guidance and support to make that happen.

I guess it's not my last slide. But close. We have a lot of work that we're going to be doing to try to improve the systems that we've started. And that I think is an ongoing ‑‑ but getting implementation is challenging. If you all have ideas about other ways that we might approach it, I think we would be really interested.

>> KURT JOHNSON: Just a couple of acknowledgments. One is in developing the OMS, we worked with Bob Gathers who help develop some of the original measurement outcomes with region 8. And in figuring out how to begin to estimate ADA implementation, we built up ‑‑ worked closely with Glenn who did some demonstration with Robin Jones in region 5. Those were part of the teamwork that was involved.

Any questions for Mark?

Are you on lunch?

>> One obvious characteristic of the network is that it's regional. So I'm wondering if you would speak to any differences in either volume ornate of services delivered regionally.

>> MARK HARNISS: I don't have a specific number in my head about that. Definitely the regions are quite unique. They're unique in their geographic scope. Some of the western regions are huge. Obviously they're also unique in their urban density, so some ‑‑ like the northeast has pretty significant urban density.

We also have, you know, region 9 connects up to the Pacific Islands. Region 2 connects down to Puerto Rico. Those all kind of bring unique challenges and opportunities related to language and culture and so forth in terms of connecting and communicating.

I think the other thing that's true is that the regions ‑‑ there are regional people. My perspective is that the regions into specialize a little bit. Some focus on architectural issues. Region 3 has a strong focus on hospitality and lodging. And so the regions tend to have a strong base in the ADA for technical assistance.

And then to have some specializations that work in synergy, so we have something that is called national projects. And so a region will engage in a project and develop some expertise. And then all of the regions will decide that that's actually important enough to be a national project or it represents something that we should push up.

So if you go to www.adata.org you will see there are national projects. Different regions are running those projects but it's supported by the network in the sense that it's elevated to something that's used by all people in the network so region 3's work on hospitality which in my head, they are the ones who kind of developed that website and developed that project and other regions focus in other areas. Does that kind of get at your question? Yeah.

>> KURT JOHNSON: Do you guys want to come up and ask your question on your way up?

So Sarah Parker Harris and Rob Gould are going to talk briefly about their work. After lunch, we're going to have David Pettinicchio who is going to talk about some of the limitations in ADA implementation and his research on that.

>> Without showing our cards too much, Mark, I just had a question about the idea that ADA information on its own isn't always useful without that TA piece and I think that's something we will talk about, too, that I found interesting.

Do you have a sense of what kind of information is most useful and what makes the information used by the ADA National Network, what they're providing, what's special about that that really leads to success?

>> MARK HARNISS: I have my opinion, but it's just my opinion.I think what helps is that TA providers are able to focus on a specific challenge and connect it to the Americans with Disabilities Act.

I think for a lot of people, they are really interested in here's my situation, what do I do next. They want some support, guidance really related to more specific issues. They are not trying to become experts in ADA. They are trying to move forward in their own lives and TA providers can provide that ongoing interaction that allows you to figure out what are the next steps. That's my take. But be interested to actually hear from a TA provider.

Switching back to Webcast mode.

>> SARAH PARKER HARRIS: Thank you and thanks, Mark. I do think as we're about to talk about, it's going to show a lot of need to start integrating and to further integrate the TA or the data that's been gathered through the TA project with the research. It's funny, some of the gaps you were talking about we have some answers for from the research perspective but not from the experiential perspective.

I'm Sarah Parker Harris and I'm from the University of Illinois and I am joined with my colleague Rob Gould. We will talk about the systematic review project which is part of the ADA KT center and the project also included Robin Jones and Glenn Fujiura.

>> ROB GOULD: What we've been doing for the last five years is really looking across the full gamut of social science research on the ADA to try and put it all in one place and figure out what it means as a whole instead of looking at its individual parts. What really interesting, if you look at the social side of ADA research instead of really just looking more at the legal side is that you actually get a much broader picture. The social research of ADA obviously is much bigger than what we have seen in the case law.

This morning when Barry Taylor was giving his talk ‑‑ he has come to speak at my class that I teach with Robin Jones, one of the things that students are often surprised at is what discrimination actually looks like in practice, that when we really look at the social reach of the ADA, it's actually much wider than what we'd actually think is seen in the case law and literature.

A lot of it has to do with Sutton and the limited cases that we have actually seen pre‑‑ late 1990s, early 2000s. So we actually haven't seen a lot of the more complex situations that we would imagine to fall under the promise of disability civil rights. The reach is extremely far and actually connects to how we look at the very social fabric of our society.

On the screen you have a picture from the 1993 ADA anniversary march. You probably recognize a few people on the screen. We have Mark Abristo, Paul Miller, Judy and Justin, of course, under the banner that reads "injustice anywhere is a threat to justice everywhere." Of course, the ADA has often been overestimated and probably wrongfully saw as a cure‑all framework. We realized the power of the ADA is within the power of the people that implement and use it.

Did I lose the mic? I have some weird reverb going.

The reach of the ADA is extremely broad. When we look at the social science research, we have to look much broader beyond the legislative impact.

>> SARAH PARKER HARRIS: So the overview and purpose of the project, it's a five‑year grant. As we said part of the ADA KT center. It was funded with the goal to increase the use of research findings and to create a descriptive knowledge base of the kinds of evidence in the ADA. The second part of the project that came out unexpectedly was also to develop a process for a mixed method systematic review. One of the challenges that ‑‑ the biggest challenge I would say that we had with this grant ‑‑ sorry, with this project is as Rob mentioned, the ADA research can be found in many, many different places. And it is extraordinarily heterogeneous. From a researcher's perspective, a large part of what we did was to try to figure out how to systematically review the research. We could do this entire presentation just on methodology but that would send you to sleep. So I will just briefly go through the methods, and then we do have some papers and plain language summaries and reports that are listed on the ADA KT website.

It was a three‑step review. We started with a scoping review that mapped the landscape of how the ADA has been studied since 1990 which as you can imagine is huge. The second part was what's called the rapid evidence review. The goal was to refine the priorities. Again, the ADA is so varied and covers so many issues and topics, what are the actually research priorities for the project?

And then also as part of that, we really got into figuring out the methodology process of how you do a systematic review in social science research that captures all the data.

And, then, finally, what we're finishing up right now is a series of systematic reviews which synthesizes the research and answers key questions based on key stakeholder feedback. So we worked with an expert panel that had representatives from business, policy, advocates with disability, researchers. And then we also worked with the ADA network, we worked with representatives and directors from the centers throughout this whole process. We were trying to make sure we had this participatory approach to making sure that what was happening on the ground was being fed back into defining the research priorities and what the research questions were and then looping that back to get feedback, are we on the right track. So it was a constant iterative approach back and forth.

We did what's called a mixed methods of synthesis. We did not do a metaanalysis. You can maybe talk a little bit when you do the chart with the mixed methods metasynthesis because the research is so complex and involves quantitative and qualitative research and the gray literature, the unpublished literature, we needed to develop this new novel approach to synthesizing research.

So we used ‑‑ we adapted and we went rogue a lot of times and then we came back again and tried to figure out a new approach. We systematically created our new methodology with a lot of mistakes. And we did a lot of descriptive mapping and thematic synthesis as well. We brought together the existing research on the ADA that has been published since 1990 and analyzed it.

So the research questions that were informing the project at each stage, these were as I mentioned developed from surveying the expert panel that we worked with and also surveys ADA centers. Some of you may remember the surveys that we sent out. And they refined through discussion with the research team as well.

So in the scoping review, this is a very broad part of the research. It's what English‑language studies have been conducted and/or published from 1990 that studies the ADA. This rapid evidence review focused much more specifically on knowledge, attitudes, perceptions as related to employment. This was identified by the groups we were working with as one of the priority areas, trying to understand what's the research saying about how knowledge, attitudes, and perceptions have been affected in employment.

And then stage 3, which is what we're finalizing now is the systematic reviews. We did one broad question across three different areas. What is the current state of knowledge about the ADA's influence on disclosure which is one of the systematic reviews on health which is a second systematic review actually I'm presenting on tomorrow and then also an attitudinal change cross‑cutting, so not just related to employment but across the whole project.

>> ROB GOULD: So Sarah alluded to the fact why we didn't ‑‑ weren't able to conduct a metaanalysis. Typically when you are looking at a systematic review, you are beginning with a pretty small set of data, looking at a very specific cause‑effect relationship, especially in the medical sciences. Usually you're starting with a group of maybe at the most a couple thousand studies. We actually had to source through 33,000 different records about the ADA's influence during the first year and a half of our project.

Through that we ended up with 980 studies that were related to the ADA which gave us our initial base for looking at the ADA's impact and practice.

From there we worked closely with the various stakeholders to really find out what was most useful. They really wanted to get more specific. They started in the second year really parsing that down, looking at ADA‑specific research. ADA that specifically mentions the statute or an aspect of implementation and its research goals. That brought us down a little bit better and more manageable number, to 460 studies.

From there we wanted to make sure that we were only looking at the most quality data possible. And we used pretty standardized appraisal tool that looked at six measures of reporting across research, making sure that what we included was up to that standard. And that brought us down a little farther to 290 studies that were included for our final systematic reviews.

As Sarah mentioned, this year we're completing three systematic reviews, one related to healthcare, includes 20 records, one related to attitudes with 38 records, and we'll be finishing up this summer one on disclosure with 11 records.

>> SARAH PARKER HARRIS: So part of what was discussed a lot at the beginning of this is what is evidence and where does the evidence come from. Unlike traditional reviews which are often RCTs, randomized controlled trials, we had to figure out what actually is evidence in the first place. The majority came from academic journals that are published, manuscripts in academic journals. And the rest came from the gray literature, reports, dissertations. We scoured through a lot of dissertations and some limited extent books as well.

In terms of the state of evidence broadly of where we're kind of at the most common topics that have been studied over the past 25 years is around employment, not surprisingly. 48% of the research on the ADA is focused on employment. The second‑most study topic is around education but even that is 16% of the research. There's a big dip between employment and even education.

And then we have a whole list of other topics that have kind of been broken down since then. The least topics studied are emergency preparedness and voting but civil engagement by people with disabilities. There's a really huge gap right now in research around emergency preparedness and around civic engagement. I thought it was interesting one of the talks this more than talking about the increase ‑‑ and Barry talked about the increase in court cases around these two specific areas.

So yet another example of how research and practice aren't necessarily aligning. And when we start looking at what are the common issues across all of the research that's been done, there are common themes that come out regardless of the specific topic. Attitudes really keeps coming out. What are the attitudes by people with disabilities about people with disabilities, by employees, about employees in particular? How do you get knowledge? Who has knowledge? What happens when you get nom?

Implementation barriers, compliance which comes into that and then to a lesser extent costs as well because most of the research is unemployment, no surprise that one of the common themes is around what's is going to cost and the myths around that as well.

In terms of who's being studied in the research, the main subgroup is actually ‑‑ and this was a little bit surprising to us even as researchers, very little research across different stakeholder groups which is unfortunate. The majority of the research is actually on people with disabilities or on what we call like the pseudopeople with disabilities. So on psychology 101 students who pretend to have a disability, for example, and let's talk about what happens there.

So there's hardly any research out there in 25 years out of the 33,000 articles that we will looked at that are actually with people with disabilities. Most of the research ‑‑ and, again, it's not surprising because the majority of research is related to employment. But most of the research is with business representatives, so employees are the ones most commonly surveyed and interviews as well.

And then in terms of the methodology, most of the research ‑‑ more than half of the research is quantitative. It's the large‑scale surveys done not actually with people with disabilities but with representatives or people talking about disability. So in terms of the state of the evidence, there's a huge gap in qualitative research. The nerd in me is super excited when I start hearing Mark always talk about what's happening with the TA project because we can take the results from the TA project and merging those with the research results, it would start to give us that actual real picture of what's going on in the ground. I think this is an area that really would require much further work and collaboration.

And we're just going to move to talk about some of the common ‑‑ rather than getting in‑depth into each of the results from each of the studies, we're going to do the 30,000‑foot view and we are happy to get into more detail. And we do have some publications and plain language summaries on this as well.

>> ROB GOULD: So when we start to look at the research across the different systematic reviews, we start to see an interesting track record of what it means across the different titles and areas of implementation. One thing that was really clear from the get go we have growing reports of compliance over the last 25 years. If you're just looking at that basic level of physical access, it seems like we have a very, I call, positive picture. But when you dial in, it gets much more complicated and nuanced.

There's a large body that check about conceived compliance versus actual compliance. Actual compliance most typically have been studied using the ADAGs, the ADA accessibility guidelines. And we note there's a great positive trend of people overstating the compliance efforts when they're asked. So that's kind of an interesting finding right there, that even though we have this growing report of physical compliance, it's not as great as some of the research has pointed to. And it gets more nuanced when we look at the knowledge implementation gaps, too.

We also know that when people are more likely to report compliance, they don't necessarily have the full picture of the ADA. They're not as likely to note that they're embracing the spirits of the law or the understanding of the social goals. But they really don't understand some of the more complicated aspects of the ADA and process. Especially we see research and implementation gaps related to knowledge about how to facilitate things such as program access, accommodation processes, and accompanying more complex support needs especially for hidden disabilities or people with mental illness. We see reports of less understanding of about how to apply the ADA and practice.

Again, kind of an interesting findings when we look to the OMS. When we saw that program access was actually the lowest of the reported outcomes, I thought that was really interesting. We actually see from the research, there seems to be a big knowledge gap there where people don't actually know what that means in practice. So we can kind of start seeing some explanation when we bring the research together.

What does this mean for practice? I think it really shows some important information about how people get their information about their ADA, when knowledge of the ADA has not necessarily meant that we embrace disability rights when it's framed about how to avoid litigation. This really translates into the idea that we need to frame research information in terms of compliance as well as the more spirit of the law, the more complicated aspects, the social goals of the ADA as well as just plain information.

Second key theme that came up across the research was related to organizational change and organizational culture. Loosely what I mean by this is the way people respond to and just policy and practice within their institution. Across the board, when we look at the ADA research, we see that change is often valued when formal accommodations are not necessary. A lot of this finding comes with people with disabilities discussing the disclosure process, when there's already applications in place for individuals to feel comfortable stating their needs and litigation isn't necessary. That's when we often see the most success in ADA implementation through the research.

Similarly, through granting accommodations, oftentimes entities really value when they don't have to go through a formal process and they're able to work out needs and adjustments without using formal litigation. However, there's also some barriers to putting this in practice where equal rights and equal opportunities are often misunderstood as special treatment. A lot of that finding comes from the attitudinal data on the ADA. From the practitioner side, I know a lot of you who work with ADA TA centers, especially I look at service animals is one area where I see this where a lot of times we have a disparate impact where entities might say no animals allowed in their store. This is a classic example of misframing where we see individuals misunderstanding equal treatment as a special right.

In the research, this is more commonly seen in simulations of test scenarios, there has been a lot of research looking at the service animal side or in terms of hiring decisions. This I think is another plug for why we need more data from TA providers and others who are really on the ground looking at the ADA process.

And the big picture that comes out of this is we know that the ADA is a tool. It's not necessarily meant as the end‑all to ensure that civil rights are granted in practice and this is a great quote from Bob Kafka, he said on his radio show, the day the ADA was signed, if we believed that the ADA is the power and we are the recipients of the its strength, rather than we are the power and the ADA is a tool for us to use, fire we may still have a long way to go. From the first day the ADA was signed in practice, we really had this idea that the law is a tool rather than the end solution.

And just to give you a little teaser for our presentation at NARTAC we will talk about the systematic review findings to get more nuanced. I want to talk about a few of the findings specific to different areas.

The first is what we know about attitudes and discrimination. We know that discrimination is not necessarily overt and blatant when we look at ADA discrimination. A lot of times it's actually more hidden. One of the most common ways that people have looked at how discrimination manifests itself in practice is through what's called attribution or disability origin. A lot of times decisions about accommodation or hiring are factored into if an individual blames an entity for their disability. Example might be drunk driving or stigma related to mental illness. There's a wide range of research exploring that in practice that I think is really interesting.

In terms of healthcare, we actually have just a very cursory understanding about what the ADA has actually related to change. The most notable missing is very few experiential data points about a people using the ADA in healthcare settings. There is some great work being done out there to capture that but not necessarily in research form. Some examples is DREDF healthcare stories, the disability invisibility project. We have a long way to go to make sure we are capturing the research side of what's actually happening on the ground.

And the last kind of theme that I've talked a lot about, especially because there's so much research on employment, we know that there's still some serious gaps and a lot of the employment issues are related to attitudes still. The evidence shows that there's no direct relationship between the knowledge of the ADA and likelihood to hire individuals with disabilities, nor is there any evidence that the way an employer gains knowledge about the ADA changes attitudes towards people with disabilities or simply put, just because we have ADA information doesn't necessarily mean we're embracing the message of civil rights and we're getting all of the nuanced facets of the ADA. And I think those are really important to move forward as we think about the next generation of how we are understanding the ADA in practice.

>> SARAH PARKER HARRIS: What we don't know still ‑‑ there's a lot that we don't know. We still have a limited knowledge ‑‑ and this is specific to the research. There's still a limited research of what are the success stories in the research. It's good to see we've got a lot of success stories being gathered, but in terms of actual research studies being done on the success of the ADA and the implementation, we still don't know a lot.

The biggest gap that we have is how people are actually using the ADA. So how we know how people are using the ADA does not come from the research. It comes from the on‑the‑ground reports. It hasn't actually translated back into the research studies about it. So we don't know how people are using the ADA. And a large reason we think for that is there's not a lot of qualitative research out there on the experiences of people with disabilities. If you are actually excluding the one group that would be using the ADA from research studies, then it would seem that we don't know in the end how to understand how people are using the ADA.

So I think from the 25 years, the main take‑home message is we really do need more of that qualitative experiential understanding of how people are using the ADA and then the knowledge translation process related to that. Once you understand your right in the spirit of the law, then how are you using the ADA in terms of that next step?

The challenges, limitations, lessons learned, it's still too soon to see the research, like a substantive amount of research come out about the ADAA. So any amendments related to research is just starting to trickle out into academic journals and articles as well. I think we are starting to see more court cases being brought on that, we will start to see more research come out. At the moment, it's too soon to see.

From a research perspective, it's really difficult as we said in the beginning to assess such varied data. We have had a challenge of actually understanding the evidence, understanding what is evidence, where to get evidence from, how to use the evidence. And this is still essential. We are going to understand kind of the state of the ADA moving forward is to bridge the research with on‑the‑ground lessons.

In terms of next steps, we have immediate next steps related to the project. We will be completing the remaining systematic reviews. We have completed attitudes in the health which we will speak on tomorrow and we are finalizing the disclosure systematic review. And then moving into dissemination and translation of results.

And then in terms of ongoing needs, I think ‑‑ what we have right now is this incredibly large database of research. 33,000 plus articles and everything that's kind of been broken down from there. Further work is needed to expand this to include the ADA Amendments Act because that's kind of the next step in terms of policy and legislation. And then also to consolidate the research with the on‑the‑ground accounts. Like the TA project, for example, that's going on and with more on‑the‑ground interviews, qualitative research definitely needs to be done so that the research data can actually be managed in way that provides a tool for the stakeholders who want to use the research so you can pick up the research brief and say, like, here's the problem that you are getting as a TA person, here's the problem I have on the phone. Here's some research that I can actually show you to make it very simplified.

We are starting to do that with the research. This is definitely an ongoing project.

And then mentioned is the biggest gap is to understand how the ADA is being used. The next steps naturally on that would be to start to collaborate across everybody that's kind of using ADA research both on the ground and from the research perspective.

So I think we'll just end there because you are probably all starving and want lunch. If anyone has any questions...

>> ROB GOULD: This is like in class where you don't dare ask a question.

(laughter).

Thank you very much.

(applause).

>> David is our next keynote speaker in the afternoon. 1:30.

(Lunch break).