UNEDITED TRANSCRIPT

**2019 Jacobus tenBroek Disability Law Symposium**

**“Barriers to Justice: Helping Your Deaf Client Navigate the Legal System”**

Held at:

The National Federation of the Blind

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Members Hall

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8:30 a.m.

Welcome, Introductions, and Opening Remarks

MARK RICCOBONO: Good morning, everybody. Welcome to the 2019 Jacobus tenBroek Disability Law Symposium. Let's play ball! Let's go Yankees. It's great we can all be in the same room even though we know the Brewers will be the next champions.

I am Mark Riccobono, President of the NFB. Thank you for coming to our Jernigan Law Symposium. We are not filled to capacity but pretty darn close here. I think this might be the record setting attendance for the law symposium, so thank you for being here.

We're going to get underway very shortly, but I do want to give some special acknowledgments. This law symposium happens because of a great team of individuals that makes it possible, and that is especially true of our sponsors who help by sponsoring this event and promoting it across the country.

I want to acknowledge our 2019 symposium sponsors starting at the gold level with Brown, Goldstein & Levy; Disability Rights Advocates; Rosen, Bien, Galvan & Grunfeld as well at the gold level.

At the silver level, we have Derby, McGuinness & Goldsmith.

At our bronze level, we have the AARP Foundation Litigation; the Burton Blatt Institute; the Law School Admissions Council -- I think that's a new one, so thank you -- Pearson Incorporated; and also Rosenberg, Martin & Greenberg, LLP; and Whiteford, Taylor & Preston.

At the white cane level, we have the Mid-Atlantic ADA Center.

And finally, our supporters, Goldstein, Borgen, Dardarian & Ho; LaBarre Law Offices; Lainey Feingold; and the Law Offices of John F. Waldo.

[Applause]

Also we have a number of folks who help throughout the year do the planning for this event and talk about the nature of what's happening on the cutting edge of disability rights and who would be an excellent presenter here at this symposium. They scour the land looking for interesting topics that have not been explored, and this is our symposium steering committee, which has now for many years been chaired by Lou Ann Blake.

[Applause]

Who undoubtedly is herding people somewhere, so she's not here, but you will see her around, and thank her for her hard work.

Also other members of our steering committee, thank you to Stacie Dubnow, Charles Brown, Matthew Dietz, Robert Dinerstein, and Timothy Elder, David Ferleger, Leslie Francis, and Jasmine Harris.

On page two, Sharon Krevor-Weisbaum, Scott LaBarre, Anil Lewis, and Michael Perlin. Thank you very much to our steering committee.

We have a packed day and a half ahead, and one of the wonderful things about this is it gives us a space to bring all of you together, to dive in to some topics. And as valuable as our connecting is, the thoughtful presentations that have marked this symposium from the very beginning, presentations that have often gone on to spur collaborations, innovative legal cases, and new thought patterns about disability rights. And that is exactly the model that Dr. Jacobus tenBroek operated in, sometimes from his living room in Berkeley, and other times from places where he had the opportunity to gather together those who were interested in using their hearts and their minds to advance disability rights along with him.

In that spirit, we have again to chair our law symposium a gentleman who has chaired every one to date, and he has poured more of his heart and mind into disability rights over the last 30 years than most. He continues to serve as the director of legal policy here at the NFB. Here to chair our law symposium is Dr. Marc Maurer.

[Applause]

MARC MAURER: Thank you very much, Mr. President.

I think these things have been going on now since 2008. This is my memory, anyway, and I believe it's correct in the historical documents.

The first one -- I was remarking to Michael Bien a little bit ago. The first one, we had many fewer people. We are running out of chairs here, so use your chair carefully there. Make sure you get all the use out of it you can.

But the first one, I was very, very nervous. Because Daniel Goldstein had talked me in to it, and he said, you know, you're dealing with blindness all the time and it's a good thing to deal with blindness, but you don't have the broad range of what we've got to do in this work. We've got to get the community of interest to be more broadly represented. And he said, you've got to have a group here that deals with all disabilities.

We said, okay, we'll try it.

But I thought, how much community of interest does it mean? And how can we talk to each other when we're all trying to get our own share, and is there enough share to go around?

So I was nervous.

It turned out that we have such a broad community of interest that it's astonishing how much more we do with each other than we do separately.

So it is a joy for me to come to these symposia. It's a joy for me to welcome you. It's a joy to recognize friends I've come to know and cherish that I wouldn't have had without these gatherings. And it's a joy to know that there are brains gathered here who are going to make such significant differences in the opportunities for all of us to have freedom, equality, opportunity that never existed without us.

So I am delighted to be back, and I hope that all of you have as much fun with this as I expect that I shall have in the next day and a half. And I want to urge you to remember that we put on this agenda what we believe is important at the moment, and the most important that we can find at the moment. And if you should find that we left something out, be sure to bring it up to the committee so that we can make it a part of next year's agenda. Remind all of us that there are things to think about that we haven't thought about already.

With that in mind, I should tell you that I'm working with the American Bar Association. I'm on the Commission of Disability Rights. I mentioned to them that there should be a private right of action in the ABA space which there used to be and we got a law adopted that we thought was going to take care of it and for about two seconds it did, and then the Supreme Court told us, no, that Congress didn't do it right.

Consequently, we don't have this private right of action and we've been trying to get a resolution passed through the American Bar Association that says we ought to have it. Of course the ABA folks are dramatically against this and have been trying to talk us out of it.

Any of you who have an interest in pursuing the matter, we have a chance to talk with all the ABA folks, and if you'll let Patricia Miller know that you want to be involved, then I will put a committee together and we'll do something about that.

I have announcements that I've been urged to make before we get to the first panel. I know it's cutting into the first panel's time, and I apologize. If, Maria, you would come, that would be great.

We have in the National Federation of the Blind come to be a place where we recycle things like bottles and cans and paper and so forth, and apparently we have a place for you to put them. So please help out.

We have changed some of the locations of the workshops. They are not as have been specified in the earlier documents, but if you look in the directions that you have in your packet, the changes that have been made are shown and you can find the right place if you follow that.

Ruth Colker, who was supposed to be facilitating a workshop, called to say that she's not able to be here. Those of you who signed up for the workshop she was going to be leading, please attend any of the others.

Now I think I have the announcements out of the way.

8:40 a.m.

"Discrimination against Homeless People with Disabilities"

MARC MAURER: Today we begin -- I want to know if we have a person here by the name of Maria Foscarinis. If so, I need you up front.

LOU ANN BLAKE: We're contacting her, Dr. Maurer. She's not here yet.

MARC MAURER: Thanks, Lou Ann.

Okay. We start with "Discrimination against Homeless People with Disabilities." How much to say about that?

Two people are scheduled for this. We hope we find both of them. But we have one, and we're going to talk about what can be done to address the question of discrimination against people who have not just one but a number of disadvantages, homelessness being one of them, disability being one. And ordinarily, with homelessness, there is also poverty. If you put all that together, it is a challenge.

I would ordinarily not take much time to introduce our panel members, because the idea is that we get a chance to talk about the topic, and so I leave to you the opportunity to read about the people making presentations, very fine people, lots of friends of mine and some I hope will become friends soon.

The person we will hear from first this morning is an attorney at Mental Hygiene Legal Service. Here is Naomi Weinstein.

[Applause]

NAOMI WEINSTEIN: Good morning, everybody. I'm very honored to be speaking about these important issues.

So my name is Naomi Weinstein. I work for an agency called Mental Hygiene Legal Service. We are a state agency in New York divided into the different appellate division departments. We represent people with psychiatric, mental disabilities who are in psychiatric facilities for issues of medication or trying to get released from the hospital.

We also represent persons who are facing guardianships. We represent them if they do not want a guardian. Sometimes we act in an investigatory role.

We also represent sex offenders facing civil commitment, and we also do work with intellectual and developmental disabilities who are living in facilities licensed by the state of New York.

So my copanelist is going to speak more about broadly homelessness and what we mean by that, the intersection of homelessness and disability, barriers to services, and also the criminalization of homelessness and litigation that her organization is working on.

My topic is a little bit more narrow. I'm going to be primarily focusing on people with mental disabilities, because that's primarily what my work focuses on, but I really think that this issue of continuity of care is not just limited to people with mental disabilities; it's something really that everyone faces. The issue of poverty, homelessness. I work primarily in the Bronx and I would say the number one issue our clients face is finding affordable housing, finding housing that will accommodate their disabilities.

And oftentimes what we see in our practice is that supportive housing that is designated for people with mental disabilities are quick sometimes to kick those people out once problematic issues arise. And when the person is hospitalized, they then try to dictate that person's care. For example, we see the residents telling the doctors, well, we'll only take this person back if they're on this medication, or we'll only take this person back if they're on mandated outpatient treatment.

It's very difficult, because, again, it's hard to find housing. So I think it's just an extra layer of discrimination that people face.

So I would also -- it's a little bit tangential to what I'll be working on, but there is also a jump to guardianship when someone is facing eviction, and I think in general there has to be a better way to support people to make sure that their housing accommodates them and to make sure that if things change and they're living in a walk up and they suddenly need a first floor apartment, that somehow those accommodations are met, that people aren't kicked off of their section eight benefits because they forget to renew their benefits.

So what do I mean by continuity of care?

So by continuity of care, I mean the issue of making sure that there is continuity of control over your medical decisions, continuity of the social environment, continuity of attachment, continuity of service and program content.

One big issue that we see, that I've seen in our work, and I think it's a global issue, that there's a lot of this cycle between people in the community, to the hospital, to sometimes jail, to community, to hospital. And between those shuttles, people lose housing. They lose benefits. They're incarcerated and lose benefits. There are a lot of detrimental things that can happen in that shuttle between the various places.

In between them, if somebody goes on and off medication, sometimes they're trying a completely new medication or they're saying I'll take this one and not that one and the doctor is saying, no, no, try this.

So what I'm trying to talk about in my part of the presentation is what is the current state of affairs. Using some case examples that I've had. What are the legal arguments that support continuity of care. And what are the legal issues that can complicate continuity of care.

Finally, I'll discuss strategies to hopefully improve continuity of care.

So I'll start a little bit about the sort of current state of affairs. We know mental illness affects about 44 million people in the United States. One in four people suffer from mental disability, statistics say. We also know that jails have unfortunately become de facto mental health institutions, and that is a real problem because there can be a lack of training. They're not really properly equipped to handle people with mental disabilities, and they're not necessarily making accommodations for people or making sure that they are screened so that there is an understanding about behavior. It's not just about not following the rules and being obstinate or difficult; it's about suffering from an illness that requires compassion and treatment. And some of our clients are really criminalized for homelessness, trespassing, minor issues, minor assaults, but they get stuck in the system.

I think deinstitutionalism is often wrongly blamed for that. I don't think this issue is because we no longer keep people in state hospitals for years on end without review. I think the issue is we don't have the appropriate community support to help these people stay in the community, are have the support they need, so that they aren't repeatedly hospitalized, so that they aren't criminalized for trespassing or minor issues.

So I think another issue is there is a privatization of medical care. And so there is a push by medical insurance to limit length of stays. I thought that was interesting. Recently I started doing acute care hospital, and I was surprised to learn that insurers sometimes can drive life of stay, what medication is covered, which can hinder a psychiatrist's ability to treat these people.

And there's another issue that has happened since deinstitutionalization besides the lack of community support. There's also something that's been termed transinstitutionalization, where it's just moving one person from another setting. So again, it can be the jail setting or it can be adult homes that are not proper, that are not giving people the freedom and the dignity that they deserve.

So I have a briefcase example that can show sort of the breakdown of what happens and why it's so frustrating. I had a client I'll call Billy. He was institutionalized in a long-term state hospital. While on the unit, he assaulted a staff member and was given a desk appearance ticket, which is a lower level. You're not sent to central booking. Usually if you're in the community, you just go to the police department.

He was arraigned and brought to the state trial court, and he acted out in court. So even though he was in the hospital and brought by hospital staff and would have been returned to the hospital, the judge remanded him to jail. So he was sent to Rikers, where he was not provided the right psychiatric medication, stopped taking medication, and began to deteriorate.

During that time he was then waiting an evaluation to determine whether he was competent to stand trial.

Eventually he was transferred to a psychiatric ward where he was treated for his mental illness, and over the course of several months he was evaluated twice to determine whether he was competent to stand trial. It was a misdemeanor charge, so in New York if you're found to be incompetent to stand trial and it's a misdemeanor, the charges are often dropped and you're sent to a hospital for evaluation. That's what happened in Billy's case, but the irony is that he was in jail for far longer than he would have been if he had just pled guilty. It was tough because it was a complete basically startover of his care once he returned to the state institutionalization. And the unfortunate part is there was a big gap about when this incident occurred, when he was arraigned, he started to actually improve and was about to be discharged, and then because of the stress of court, because of everything that happened, you know, he really had to start at square one when he returned to the hospital.

Now things have changed, we are happy to report, and we do have more liaisons so if one of our clients is sent to Rikers, we are able to contact them and give them a heads up so that hopefully they will receive treatment. There is now a New York City law that says you have to do mental health screening for every person who enters the jail system. So there are improvements.

But this case is not an outlier. It shows why continuity of care is so important and how it can really disrupt someone's lives. And again, the issue, in his case, he didn't have housing. He had an application for housing, but once you're discharged to a jail, you lose your spot, your place, and you have to start all over. We see that a lot in the long-term state hospital. Just yesterday my colleague had a case where really the hospital was only keeping him to find housing, but if the person doesn't agree to stay and they don't meet criteria, there's no legal reason to keep someone against their will. When you are homeless and have a mental disability, it's just another barrier, another hindrance.

So some of the arguments that support continuity of care is I would say of course the Americans with Disabilities Act, and of course Olmstead, the landmark case. I'm sure everybody knows that the Supreme Court held unjustified isolation is discrimination based on disability and that the ADA requires the state to provide community-based treatment. The Supreme Court has also said that this extends to prison inmates. What the Supreme Court has not decided is whether this applies to arrests themselves. Lower courts have been split about whether the ADA does apply to arrests.

And I would say there's a lot of research out there that supports why continuity of care is important, how it leads to better outcomes, how it leads to less hospitalizations, and gives people more determination of their rights and their outcomes.

And also I would argue that it's supported by the U.N. Convention for the Rights of Persons with Disabilities. That always talks about the right to healthcare, the right to be free from discrimination. And though unfortunately the U.S. has not ratified or signed the CRPD, which is another issue, I think there are ways that it can be incorporated into legal practice for people who are attorneys out there, and it's important to remember that the tenets of the convention, that there's an inherent right to dignity, that there's freedom from torture or cruel inhumane treatment, freedom from exploitation, violence, and abuse, that all parties should have access to justice and treatments and free and affordable healthcare and programs and that health services should require early identification, intervention as appropriate, and services designed to minimize and prevent further disabilities.

Really to encourage people to have the most freedom and support their decisions, not to impose decisions on them, but to give them the ability to live their lives independently with support if needed.

There are some legal issues that complicate the continuity of care, and ironically I had a case in court yesterday where it was under the guise of continuity of care, and I did tell the other side, I'm talking about continuity of care. But there is a way to effectuate continuity of care that does not infringe on person's rights.

I feel very strongly that continuity of care should never override individual rights, especially the right to medical privacy and the right to refuse treatment. So in the context of yesterday's case, without getting into the minutia and boring everybody, this was an application by a long-term state hospital seeking to transfer a patient to have another hospital where he's going to be transferred, administered specifically hemodialysis. Our argument was, there's a proper way to do this and you haven't done it properly. It should be his treating doctors, the ones actually going to be administering the treatment, who should be making that determination if you're going to override his ability to refuse this treatment.

So despite what the other side was saying, I was not arguing against continuity, because the hospital presented it as a continuity of care issue, but I think there is a proper way to do that doesn't infringe on person's individual rights. You know, HIPAA governs whether covered entities like hospitals or medical facilities can dispose PHI. Of course you have the right to waive that.

I think in terms of medical care and emergency care certainly, doctors can have access to your medical information. As I had touched upon before, insurance can also dictate what's available and what's not, so that can be a hindrance.

And in New York there's a psychiatric services and clinical knowledge enhancement system, a database that covers only people who are under Medicaid and allows doctors to quickly search information such as history of outpatient, inpatient services, what medications they're prescribed and what labs were performed. I think there's some issues with that because it only covers people with Medicaid and not people with private insurance. There's no sort of waiver that people sign into to allow this information to be readily available, and I know in particular our agency has a problem because we don't have access to it even though doctors testify to it and it's contained in their record.

Another thing I wanted to touch upon is just briefly is advanced psychiatric directives, which can be used to address the issue of continuity of care. It can help people determine, much like healthcare proxy, well, a little bit different because it's not just -- it's a little bit more specific. But it can specify both who should make treatment decisions, what specific treatment can be administered, including psychiatric medication, in the event of incapacity. In theory it should follow the person, but they are allowed to revoke it. And it can have therapeutic value because people are able to determine their own care.

There are potentially problems with it, if, for example, a doctor wouldn't honor it or if someone were to change their minds while in a hospital and the hospital determined that they're not capacitated, could it be used to challenge that issue in court.

But I think in an ideal world, these directives could be used to help this issue of continuity of care.

So some strategies to -- still on time. So some strategies to help address the issue of continuity of care. Just want to talk briefly about therapeutic jurisprudence, the idea that there's a therapeutic value in the way that the law is applied, that it's important to give everyone voice and validation. And certainly we see that in our work, that the core process itself can often have a therapeutic value in that it gives our clients a voice. The courts are very respectful and give all of our clients a chance to say the reasons for why they want to be released or why they don't want to take the medication. You know, it's a focus on procedural justice, restorative justice, and I think that maybe people don't always use the term "therapeutic jurisprudence," but I think if you talk to lawyers in this area of work, they utilize the principles of therapeutic jurisprudence in their practice in terms of making sure that their clients' voices are heard, that their wishes are known.

Another way that possibly could improve outcomes is diversion, which could be through mental health courts, if you are subject to criminal proceedings. It could be diversion in the sense of being screened when you're arrested. Again, it's about identifying early on to hopefully help people not get stuck in the loop of jail, prison, community. And I think the major thing, especially when it comes to homelessness, is improving community services and access to housing, to make sure that people are not kicked out because they have one minor incident. You know, to make sure that if people are in shelters, that they are still receiving care and support, that their services are connected, and that it's not like starting anew every time you see a new doctor.

Again, I think while a lot of my talk has been focused on persons with mental disabilities, I really think that this happens to everybody. You know, it shouldn't be so hard to switch medical providers. If you have an emergency and you see a new doctor, it shouldn't be like reinventing the wheel or facing discrimination because the doctors just assume you don't have the capacity to make this decision.

So again, I think that there needs to be a real movement I think to look at this cycle and how can we break it and look at the issue of homelessness and how can we support people in the community better, how can we help people live independently, how can we make sure that they maintain their dignity, that they maintain their rights.

So I don't want to infringe too much because I know... But I think we're going to reserve questions to the end, but I'm certainly open to questions later. If you see me, grab me.

Thank you.

[Applause]

MARC MAURER: Thank you, Naomi.

We now have the founder and executive director of the National Law Center on Homelessness and Poverty. Once again a very extensive biographical writeup is available. You may look at that. We won't take time to go over it.

Here is Maria Foscarinis.

[Applause]

MARIA FOSCARINIS: Thank you very much. I appreciate it.

And thank you, Naomi, and thank you all for hosting this wonderful event and symposium. I'm so happy to be here.

I had a bit of a harrowing trip coming up from Washington, D.C., this morning, but I am here and I am happy to follow Naomi to kind of step back a little bit and broaden the lens. We've heard about some of the very specific and important aspects of being homeless and also mentally disabled or disabled generally.

I want to step back and talk a little bit about homelessness in general. I'll give you a little bit of a two-minute national overview, and then talk a little bit about some of the current trends today and discrimination faced by homeless people, especially what we call the criminalization of homelessness. Some important advocacy that we and others are doing, including some key court decisions. And hopefully we'll end by talking about our campaign and invite you to join us in that campaign.

So first little introduction, the National Law Center on Homelessness and Poverty, which I founded 30 years ago, our mission is to use the power of the law to end and prevent homelessness in the United States. We feel that homelessness, for homelessness to exist in a country with the wealth that ours has is intolerable and it's a human rights violation that must and can be ended and prevented.

That's our mission, and the law can be a very powerful tool towards that mission. That's what we do.

Our vision is for an end to homelessness, that housing is a right, that everybody should have, that it is not something that is a privilege.

So I guess I would like to start with a question. It's often said homelessness has always been with us. How many people in the room, can I get a show of hands, do you think homelessness has always been with us?

Okay. So a lot of people think this. Not all, I'm glad to see.

So homelessness, in fact, at least in its current form, in its mass form, has not always been with us. Homelessness first became a mass -- and I'm talking about modern day homelessness. This country has had periods of mass homelessness, for example, during the Great Depression, but I'm talking about current modern day homelessness really started in the 1980s.

Before then, it existed but it was pretty limited in terms of the population affected and the parts of the country affected. There were skid rows, there were people often known as hobos, but it was not a mass phenomenon like it is today.

It really started in the early '80s. One of the primary drivers was the cuts imposed by then President Reagan. And housing in particular suffered extreme cuts. So the federal government used to fund significant numbers of affordable housing for poor people, low income housing. Just to give you a sense, in 1978 the number was over 300,000 new units each year of low income housing. And then three years later, by 1982, that number was down to 3,000 per year. So this is a massive cut that has not gotten a lot of attention. It was a massive cut, and it came on the heels of loss of inexpensive housing in the private market. So you may be familiar with the term SRO, single room occupancy housing, which is a form of inexpensive housing often used by disabled people. There was a loss of over a million units in the 1970s alone.

So these two trends together resulted in the loss of a tremendous resource that kept poor people housed.

It's a loss that continues to this day. It has not been made up.

Other cuts to social welfare programs, notably cuts -- not just cuts, but making it more difficult to get benefits. This was particularly the case with SSI and SSDI, which are especially important for people who are poor and disabled in some way. And this was litigated, but it remains extremely difficult to get these benefits to the point that many homeless people are eligible for these benefits and few actually receive them.

So these are trends that started then but continue to this day. And basically they come down to lack of affordable housing and lack of adequate income to pay for it. You know, factor in to that the minimum wage, which has not kept up with the cost of living, and factor into that also payments under SSI or SSDI, which are not adequate, not sufficient to pay for housing. So there's a huge gap between income and housing, and that is the primary driver of modern day homelessness.

That is how it started, and those continue to be the primary drivers.

Right now federal funding for low income housing is so inadequate that only one in four of poor people, people who are poor enough to be eligible for federal low income housing assistance, actually receives it. So one in four. That means that three in four are out of luck and they're on waiting lists that are years long in many cities around the country. Private market, gentrification affects housing. You can see tremendous development in cities around the country that is displacing people and not providing housing for people who are poor or sometimes even for people who are middle income.

So these are the drivers. Right now, what is the landscape of homelessness? Right now, depending on who you ask, between 1.5 and over 7 million people are homeless each year in this country. It depends on who you ask because there are different definitions and different ways of counting the population. So HUD, the Department of Housing and Urban Development, takes a very narrow definition of homelessness. The Department of Education has a broader definition. And the counting methods are flawed.

But the bottom line is it depends on whether you consider people to be homeless if they're just people who are in a shelter or living on the street or in another public place, or if you also take into account people who are doubled up with friends and family because they have been evicted and cannot afford their own place. People who are doubled up do that out of necessity. So that's why there is a variation in the numbers, but the numbers regardless are too large. By many accounts, they are growing. More people are becoming homeless. More people are unstably housed, and that's because of the continuation of these trends that I talked about.

Now, what about disability? I mentioned this as part of the driving cause, the cuts in disability benefits. There's an intersection between homelessness and disability in many ways. Disabled people are disproportionately represented among the homeless population. People with disabilities make up 16% of the overall population but over 40% of homeless people. So that's a big gap. This is not limited to this. This kind of overrepresentation also applies to other groups of people. Like there's an overrepresentation of people of color in the homeless population. African-Americans make up 12% of the overall population and 40% of the homeless population. So there's a lot of disproportionality in who becomes homeless, and that's not surprising. There's disproportionality in the poverty population, but it's even more so in the homeless population, and it's because of who these causal factors, these trends, impact the most.

So what are the resources that are available? A lot of people think, well, you know, sure, we have homelessness, but there are shelters for everybody. And people who are not in shelters just choose not to go there.

Well, in fact, this is not the case. There's not even -- first of all, we don't consider that shelters are a solution to homelessness. A shelter at best is a temporary stop gap. The solution is housing, permanent, affordable housing. But even if we talk about shelter, is there enough shelter? Well, no, there is not. No matter how you count the homeless population, even if you look at HUD's counts, which are very grossly underestimated, there's not enough shelter space for the homeless population.

As a result, 45% of people who are homeless are unsheltered. That means people are living on the streets, they're living in parks, they're living under bridges, in abandoned building, in caves in rural areas, on subways in urban areas. All kinds of public places.

And the numbers of people who are unsheltered are growing, even according to HUD's counts they're growing. According to other measures, they are growing. So couple of years ago, my organization produced a report looking at tent cities across the country. Tent cities, when we talk about tent cities or sometimes we call them homeless encampments, we're talking about groups of people who are unsheltered who are living together outside, forming communities, living outside.

We found that -- we did a look over ten years, using a proxy measure, and found an increase of over 1300% over ten years in reported encampments of homeless people across the country. So that is huge, and that is probably also an underestimate.

Again, a significant intersection with disability, because people who are disabled are not only more likely to be homeless; they're also more likely to be unsheltered. So a huge intersection with people disproportionately represented among the unsheltered homeless population.

And once people are unsheltered, when they're living in public spaces, that can have very deleterious health effects. Whatever health problems someone has can get worse. It is hard to treat somebody who is living in public. It is hard to maintain medication regimen or to get access, reliable access to medical care, or even hold on to basic items like medication or medical documentation.

So health crisis, disability status, can create the risk of homelessness, but it can also exacerbate it once it happens.

So what can we do? It's not that nothing has been done. I should say that before I go further. You know, in the early '80s during the Reagan era, we worked towards getting the federal government to respond as this national crisis emerged. I was part of that effort. It was a big advocacy movement that involved a lot of different groups and a lot of different pieces and strategies. The result was that in 1987 Congress enacted the first and still only major federal legislation addressing homelessness, the McKinney-Vento Homeless Assistance Act, are focusing primarily on emergency relief. So much of the funding was for and is still for emergency shelter and other forms of emergency aid.

However, over the years we have worked to strengthen the act, to increase funding for it, and we've also worked to get other mainstream social welfare programs to amend their statutes in order to address the problem of homelessness. And we've had success on all those fronts but not enough success to solve the problem. And this act was never intended to be the solution to homelessness; it was intended to be a first emergency step. And the real solution is increasing the commitment to affordable housing and that is something that remains on our agenda and remains an unfulfilled promise.

That means we're in the situation now where we have some emergency relief, not enough, and certainly not enough in the way of permanent solutions to stop the influx of people who are becoming homeless.

So we've got this growing number of people who are unsheltered around the country, and we also have this trend in the past decade plus of cities responding to the influx, to the presence, to the public presence of people on their streets by not only by not providing resources, but by criminalizing their public presence. So by criminalization, I mean passing laws, and these are usually city laws, that make it illegal, that make it a crime to sleep in public, to sit down in a public place, to rest in public, to ask others for help in public, to eat in public. There are all manner of permutations of these laws, and my organization has documented this extensively. We have national reports that look at the same 187 cities for over ten years, so we have national data and trends about these laws and we've documented significant increases over the past decade plus.

One of the most compelling or telling increases has been in the number of laws that make it illegal to sleep in your car. Those laws increased 143% in the past decade. So that tells us something about people who are losing their homes, moving into their cars, and cities responding by making it a crime to do so.

Why are cities doing this? Well, cities are feeling under tremendous pressure to do something about the fact that there are so many desperately poor people living in their downtowns, in their midst. They're also under pressure from businesses and city residents. So what they do is a kind of quick fix, passing a law to make it illegal. Problem solved, right? Problem with people sleeping in public, in your downtown, well, just make it illegal.

Problem with that is it doesn't solve the problem. People have to be somewhere, and they tend to then just move somewhere else. It's obviously also inhumane. People who are caught up in what are called sweeps often lose their possessions, they lose things that are vital to them. They can lose their birth certificate and other vital documentation. They can lose their medications. Things that they need to live, to survive, also things that they need if they are trying to get out of homelessness. You need an I.D. You need documentation of who you are.

It makes it harder for people to get out of homelessness in other ways too. For example, getting a job, getting into housing, even getting public benefits becomes much harder if you also have a criminal conviction or an arrest record in addition to being homeless.

So this is the type of cycle that Naomi talked about, about people cycling through the criminal justice system because they are homeless. And it's a particularly egregious example of this because they're basically being punished simply because they have no home, simply because they have no place to live.

The theme of the conference is stigma. Well, stigma has something to do with this. Why is this allowed to happen? Well, public attitudes about who homeless people are -- couple of minutes. Okay.

So stigma has something to do with this and allows it to happen. What are we doing? I've got to wrap up, so let me cut to the chase. Part of what we're doing is we have a campaign called Housing, Not Handcuffs. We believe that housing is the solution, not criminalization, and we're pursuing this in various ways. We just had a big court victory in the ninth circuit where we got a great court decision that said that it is unconstitutional to punish someone because they are homeless. It's unconstitutional to impose a sleeping ban when there is no alternative in that particular case. But the ruling has big significance. Ninth circuit covers nine states. We're using this now to say to cities, look, you can't arrest your way out of homelessness; let's work together to help you develop some more constructive solutions that are based in housing, which actually does end homelessness.

In this campaign, we're inviting other organizations to endorse it, to join us. We have a listserv that's very active. We have a lawyers' group made up of lawyers who are litigating these kind of cases. And we have an annual event that we put on that brings everybody together. And you can find out about the campaign and endorse it by going to our website nlchp.org, and the campaign also has a separate website, housingnothandcuffs.org. We have over 800 endorsements and we would love to have you all endorse. We are bringing together law enforcement to support us because there are many people in law enforcement who are starting to realize that deploying the police, to arrest people simply because they're so poor they are homeless doesn't make sense. And it's also poor use of their resources and a very expensive, in fact more expensive, than solving the problem by providing housing.

So that is our campaign. There are other pieces to it, but I think I'm out of time. We have some federal advocacy going. We have human rights advocacy going before human rights bodies. But I think I've given you the critical pieces and would love to hear your questions if we have time for them.

[Applause]

MARC MAURER: Okay. We have a roving microphone. If you wish to ask a question, please state your name first. We have 11 minutes. Let's see if there are some questions in the audience before we get to my 20 questions.

Tell me who you are.

And Naomi and Maria, if you'll take the microphones on the tables.

>> Leslie Francis.

Thank you very much. This was great. To what extent -- neither one of you mentioned opioid issues and drug issues. One of the problems with federal housing policy is the question of whether or not you can get access to subsidies if you've got any kind of drug conviction history or if you're a legal user of marijuana in some states.

I wonder if you could comment on the extent to which those issues have played into the problems that you see.

MARC MAURER: Which you of would like to address this?

MARIA FOSCARINIS: So the opioid crisis is significant. I am glad you brought that point up. And certainly also the restrictions on people who have a drug history in public housing, and these are important drivers for part of the homeless population now.

But I didn't mention this not because it's not important. It's just that it comes -- I see this as coming within the overarching issue of lack of resources. There are not enough resources for housing, period, for anyone. And there's not enough resources to respond to the opioid crisis.

It's not an issue that my organization has worked on specifically, and not because it's not important, but because there are a lot of important issues and we have only so much capacity.

If you have something more to say, I'm happy to hear it.

NAOMI WEINSTEIN: I think that adds another barrier, another layer of possible discrimination, another barrier to housing. We do see a lot of people who do use substances.

What's very common, at least in the Bronx, is synthetic marijuana. And that can create a lot of issues. There just isn't as much programming. What I anecdotally noticed in my work in the last ten years is that there's just not as much programming or support for the mental health and substance abuse programming. It used to be, for example, with mandated outpatient treatment, it used to be that you would go if you had these issues, there were programs that you could go to that were available, and we just don't see it anymore.

It's certainly an important issue that our organization doesn't directly work on, but we see it.

>> Hi, this is Claudia with the national ACLU disability rights program.

I'm wondering how the campaign against homelessness, how your campaign uses the principles of the ADA and disability rights in your work, and if you use ADA claims in your litigation strategy. Thanks.

MARIA FOSCARINIS: Great question, and something I just didn't get to. But yes. We are working with Disability Rights Advocates, and we recently filed a lawsuit in San Diego with California disability rights, where we did -- and this was challenging a city ordinance that made it illegal to live in your recreational vehicle. And many of our plaintiffs are people who are disabled and for whom shelters are not an option because of accessibility. People who still have their RVs. It's certainly not ideal, but it is an option. They were being ticketed, they were being fined, their vehicles were being impounded.

So we got together with Disability Rights California and filed litigation. One of our claims was under the ADA, yes, and the Rehabilitation Act.

We won on our motion for preliminary injunction, but the court did not address the disability claims but just our constitutional claims.

>> So this is Victoria. As we all know, you didn't expand on the intersection of disability and how disproportionately impacts LGBT people and people of color. I'm wondering how you can expand on that and that intersection with disability for the benefit of the audience.

NAOMI WEINSTEIN: I can respond to that.

So yes, you're right, there is an intersection there, and there's lots of intersections with homelessness and other issues. And this is one of them.

The place that we have specifically focused is on homeless youth, where about 40% of homeless youth are members of the LGBTQ community, and that is a huge percentage and a huge issue. There is discrimination there. We do put out legal information focusing on homeless youth. We just published two big state reviews to on that issue.

The broader issue of the intersection with the homeless population at large is not something we've looked at specifically, but certainly that is an intersection that's important.

MARC MAURER: So here's what bothers me about this. I wasn't going to do this, but anyway...

The trend is that the homelessness is on the rise. The story is that the workplace is becoming smaller, that is to say we have full employment today, which is an astonishing thing to me except that there are a lot of people not looking for work who could get it.

And then there is the story that the jobs that are out there are going away, they're going to be automated, and they'll be gone.

If you put all those trends together, homelessness will be endemic and it will be enormous in the very near future.

What to do about that?

MARIA FOSCARINIS: Is that a question for us?

[Laughter]

MARC MAURER: That's what I was hoping you would tell me.

MARIA FOSCARINIS: I guess I would say a couple of things. I think what you're describing is the income piece, which is one of the key drivers of homelessness, that inadequate incomes. We might be at full employment, supposedly. There is the question of people who are just simply not counted, which is critical. So those figures may be suspect.

But there's also the question of what kind of employment. I mean, people working service jobs, people working at minimum wage, there's data that shows that if you're working a minimum wage job, there's no place in the country where you can afford housing based on federal affordability guidelines which say you're only supposed to be paying 40% of income for housing. Many people are paying 50 and even 80% of their incomes for housing, which puts them at imminent risk for homelessness.

So what do we do?

This is not unique to homelessness. This is about fighting for a living wage. It's about fighting for housing to be a right, that everybody has and not something that is dependent on federal, state, or local budgets each year and that is subject to cuts.

So this is part of making this more about human rights, that everybody has essential human rights. That's why we are applying a human right lens to our work and working towards the human right to housing.

I believe that this is possible. You know, we've just witnessed how the conversation about healthcare has moved in the direction of people talking now about healthcare as a right and not a privilege.

I think we can have that same conversation. This is something we've been pushing for a long time. But it is starting to bubble up. Housing is also a right.

If we look at human rights laws, there are other things that are rights, like the right to earn a basic standard of living.

So I think we have to make common cause and push for this different way of viewing these issues.

NAOMI WEINSTEIN: I think the start is also recognizing that this is a problem. Certainly the cutting of state and local benefits, I know that causes a lot of our clients to lose housing for our clients who aren't able to work. I think that, again, I would say it all comes back to community support and housing and awareness. And I think that there is going to be a boiling point where this problem really can't be ignored anymore, especially in someplace like New York City that's so expensive. You talked about doubling up. That's so common for clients that we deal with across the spectrum, including guardianship, people at risk of eviction. It's just not sustainable.

MARC MAURER: Maria and Naomi, I appreciate very much your coming. I hope you can stay a while, and I hope that there will be an opportunity for those who have many questions -- I have some more but I'll hold them -- can talk to you maybe at lunch or sometime in the breaks.

It is a problem that -- I remember talking to a man from a major corporation and he said the disabled, they're like the poor, they're with us always.

And this annoyed me enormously.

I said, you are saying this is unmanageable and I do not believe it! So I gave him a piece of my mind. And I don't know, it made me feel better anyway.

Some of the people who were with me at the time said it was a good thing to have done.

Be that as it may, this has to have a solution. We start with the proposition that you can do something about it. That's what this symposium is about. So please stick around and answer questions if you can find people who would still like to know more about what you know.

Thank you very much for being with us.

[Applause]

9:45 a.m.

"Disparate Treatment under the Law of Mental and Physical Disabilities"

MARC MAURER: Even though we haven't done everything we could on that topic, we're going to move to the next one: "Disparate Treatment under the Law of Mental and Physical Disabilities."

We have to present to us two people today. The first -- Ira, you know you're next. Come ahead.

Ira Burnim is director of the Judge David L. Bazelon Center for Mental Health. He's been there for a long time. He's been a friend to this effort that we're doing on disability.

And I believe you're going to begin, yes? You are starting, aren't you, Ira?

IRA BURNIM: Yes.

MARC MAURER: Here is Ira Burnim.

[Applause]

IRA BURNIM: Good morning. I want to begin by thanking you for the opportunity to speak here today. It's really an honor and a privilege to be a part of the gathering of so many thoughtful and effective advocates, people who care so deeply about disability rights.

This symposium is devoted in large part to looking at the relationship of public attitudes and disability law. It's a big topic, and we'll spend a lot of time today admiring it.

I find very concerning the state of that relationship today when it comes to people with psychiatric disabilities, whom I fear are increasingly portrayed as both dangerous and scary.

I'm usually optimistic. I've been doing civil rights and disability work for a long time, and I can see that a lot has changed for the better. The growing strength of the disability rights movement, the enactment of the ADA, Supreme Court decisions in cases like Olmstead, Lane, and Endrew, among others.

But I am very concerned about the challenges going forward, which I think are quite formidable.

Our political culture is less progressive and less inclusive than it has been in a very long while. The judiciary is getting more conservative. Democratic nominees have been, in my experience, a fairly mixed bag. We've had some not great experiences recently with judges appointed by President Obama. The days of Presidents appointing to the bench individuals steeped in civil rights may be over, and President Trump is placing judges on the bench who are quite hostile to civil rights and to inclusion.

In my experience, the media, when it comes to reporting on mental health, seems interested mainly in sensationalism, listens to very few voices, and does little work to understand the facts. The takeaway from today's coverage is that we need to be wary of people with psychiatric disabilities. Their decision making is deeply impaired, they become violent, you and your children are at risk.

Reported stories on the mental health system tend in my experience to be ignorant about the basics of proven approaches for meeting the needs of people with psych disabilities. And a little bit to my -- I don't know if it's amazement or chagrin -- they seem to be unaware that states already have legal tools for involuntarily institutionalizing individuals and laws on the books that allow courts to direct people who are deteriorating severely to take medication. Maybe half of the calls I get from TV and newspaper reporters are for people doing stories whose primary theme is that somehow our nation has very weak forced treatment laws and that it is vitally important that we increase the amount of forced treatment in this country, which of course is completely the wrong solution.

The media, and seemingly the public as well, believe the problem with our nation's mental health policy is too many rights, too few beds. That is, beds in care facilities, otherwise known as institutions. Sadly, the theme of too few beds is often heard from other advocacy communities as well.

But the problem is not too few beds or certainly too many rights. I believe something quite different instead. The voices and the preferences of people with psychiatric disabilities should be central to our nation's mental health policy, but they are not. The contributions and capabilities of people with psych disabilities should be understood and appreciated, but they are not. People with psych disabilities are like other people. They can and do live lives like those of people without disabilities. No one should be judged or stereotyped by who they are at their worst moments, but that is all too often how people with psych disabilities are seen. We think we know all about them and their needs, from seeing them at their very worst.

I'll take a little time to tell you about my first client, who had a psych disability. Actually, it was my second client of when I was in law school. Mrs. B. She was a public housing tenant. She assaulted her then ex-husband. She terrorized her neighbors, or at least that was the report. She allegedly exposed herself. And she was unsurprisingly being evicted from her public housing.

When I went to the clerk's office and mentioned her name -- this is actually true -- the staff in unison said, "Well, we know Mrs. B. We know her well." They then told me stories of her various exploits.

She got my number, claiming it was an emergency, called my apartment frequently. She was the subject of an ethics paper I wrote in law school because she would repeatedly fire me on those calls, and then we would continue talking. Which raised ethical concerns.

She was entitled to a lot of due process in Massachusetts, it turns out, and that resulted in her eventually the Cambridge housing authority arranging a tenant swap. This is literally true. The Boston housing authority agreed to place her in an apartment if the Cambridge housing authority would take one of Boston's problem tenants.

The case was closed.

I saw Mrs. B a year or two later at a demonstration, of all places. I don't remember what she or I were demonstrating about in Boston. But she was fine. She was, in fact, lovely. She was very appreciative of the work I had done for her. And I don't really know what happened in the year or so between the time that I represented her and I met her at that demonstration. But I can truthfully say that when I was a student representing her, I never expected to see her the way I saw her a year and a half later.

And shame on me. I think that is a recurrent experience that we have and something that we need to guard against.

Instead of what is today our national policy, instead we should offer people with psych disabilities supports that will allow them to follow their dreams and be part of the American dream. For those of you who are lawyers and mavens of the ADA, that was my reasonable modification analysis. We should give people the support that would allow them to follow their dreams. That's the reasonable modification we need to make in our nation's mental health policy.

I don't mean to be Pollyannaish here. People do become psychotic. People can understand and experience the world in ways that are quite bizarre. And people make choices that place them and others at risk.

But I would also note that people with psych disabilities are not the only people who sometimes have a tenuous understanding of the people who then surround them or who make bad choices. Political and economic elites sometimes do. Trump's base surely does. Sometimes family and friends do. But they tend not to be punished or devalued in ways that people with psych disabilities are when they engage in such conduct.

People with psych disabilities whose crime is being poor or homeless, who are disruptive in a 7-11 or downtown business district, who commit minor drug offenses, who don't show up for relatively meaningless appointments with their probation officers, they get locked up in institutions and in jail.

People who get us into thoughtless wars bring down the banking system or pollute the earth rarely suffer such consequences.

At the Bazelon Center, in our community, we fight in numerous ways the ways people with psych disabilities face discrimination, such as paternalism. There's discrimination in the workplace. Until recently, federal law directed school districts to provide students with disabilities some educational benefit instead of an actual education. People with psych disabilities fare badly in the justice system. They may be killed at rates as high as or exceed that of police killings of people of color. And for the same offense, people with psych disabilities are more likely to be incarcerated than people without psych disabilities.

Discrimination is reflected in our nation's appetite for institutions. Nursing homes, boarding care homes, shelters, hospitals, etc.

Now, what might we do to change the public attitudes that are driving policy and that are stalling the development of more positive law? I don't really have any great ideas. I have a few. And I'm very interested in yours and I hope we'll have some time at the end of our remarks to hear your ideas.

I want to briefly talk about three approaches. The first is one I have heard often discussed I think in decades ago. It's really the strategy of coming out. It's the strategy that was employed by the LGBT community. That is, people with psych disabilities who are successful in their careers, who are neighbors, who are family members, would come out on a grand scale and show the public that their ideas about people with psych disabilities are just wrong. It's a strategy that I think could be effective in combating fears and stereotypes of people with psych disabilities, but there are some obvious challenges. One is the tendency for people with psych disabilities who come out to be seen as exceptions, not representative, and people's response is, well, these individuals aren't really ill or they're ill in a different way than people with psych disabilities that I'm talking about.

It may be that a thoughtful campaign can overcome this. I'm not sure.

In addition to the tendency for people who come out to be seen as exceptional, the other challenge is that it's hard to come out. I would say as a lawyer, I tend to counsel people not to do so unless they absolutely must. And that's because there are pretty severe consequences. I was going to tell you the story about family member who I counseled who had some psych issues while serving in the Peace Corps, but in the interest of time, I won't. But essentially I remember myself saying how important it was for him not to let the Corps know he was experiencing psych problems and arranging for him to take a vacation, come to the U.S., get treated, return without the Peace Corps knowing what had happened to him or anything about his psych disability being in the Peace Corps records.

So maybe if the campaign of people with psych disabilities coming out changes, I would be interested in your views. A different political strategy that advocates have viewed, there are different constituencies being represented. But nonetheless, I think there's opportunities for finding common ground that offers a different picture of people with psych disabilities than is painted by our current politics. A common ground that focuses on investments and services and housing that would help people thrive.

I also think that the most influential membership organization devoted to mental health policy may be the key to this strategy. I think some common ground needs to be reached on forced treatment with NAMI, and I think it could be possible to get them to recognize that there are more important or at least equally important priorities than expanding for treatment. And that's really I think what's happening in the organization today. I think NAMI is really recognizing that to some extent its earlier focus on forced treatment was a mistake, in part because it paints such a harmful and damaging picture of people with mental illness. And if you lead with that in public policy, you obviously are helping to create and sustain really negative public images of people with mental illness.

I think it would take some compromise on the part of organizations like mine to reach some understanding or common ground, and it may also be time for the more progressive elements of our community to join rather than to eschew organizations like NAMI and work within them for culture change.

The continuing controversy for forced treatment has setback efforts for the needs for more positive and supportive investments.

The third strategy I'll mention is one that's really directed to ourselves and to the theme of this conference, which is thinking about how we might shape or be responsible for particular attitudes concerning people with disabilities and people with psych disabilities in particular.

In our work at the Bazelon Center, we try to emphasize the capabilities and the potential of people with psych disabilities. But it's also true, and we confront it every day, that people with psych disabilities are exploited, abused, and mistreated. But I think sometimes we talk about these experiences in ways that fuel the public's negative perceptions. It may be useful to describe an exploitation as very concerning but also exceptional events, which I think they are. And also people being steered into settings that promote dependence, which shrinks rather than expands them as humans. That people with psych disabilities, especially when deprived of the opportunity to thrive, who are put into institutions, are devalued. That places them at risk. I think we too frequently communicate that victims are impaired and they need protection. I think we need to improve our messaging and the service of changing public attitudes and political possibilities.

On a related note, I've been giving some thought to the narrative about the disproportionate arrest and incarceration of people with psych disabilities, an issue on which I've been working a lot in recent months. That narrative hinges on the claims that people are in jail due to their mental illness. Think about that message. It's repeated time and again by many people, including often myself. We may need to emphasize instead that people with psych disabilities are disproportionately represented in jail because they are disproportionately poor and homeless because they have committed drug offenses, not because of their psych condition, or that they are victims of various practices associated with mass incarceration as opposed to emphasizing that they're there solely because of a psych condition.

I haven't given a lot of thought to that, but I think it is an area we may need to pursue different messaging about the issue.

So those are some ideas I have, not necessarily good ones, about how we might change the dialogue. I'm very interested in hearing yours.

Thank you.

[Applause]

MARC MAURER: The next person to present is the person who is partner of the law office of Lycette Nelson. As it happens, it is Lycette Nelson. So here she is.

[Applause]

LYCETTE NELSON: Good morning. Thank you.

My comments today will be related to the issue of disparate treatment and intersectionality and discrimination starting from a general comment issued by the committee on the rights of persons with disabilities last year that clarified some aspects of what the Convention on the Rights of Persons with Disabilities demands of the states' parties who are parties to it.

Within this comment, the committee referred over and over again to the need for states that are parties to the convention to address multiple and intersectional discrimination and to make sure that their laws provide remedies for such discrimination.

So I'm going to start from that, just by way of background. The committee is the enforcer of the CRPD, and they issue general comments on a wide range of issues related to the convention. As I said, mostly to clarify issues that have arisen in country reports, reviews, and issues that they see states' parties not fully addressing in their laws and policies.

This is general comment number six, which is sort of surprising that this is the sixth one that they have issued and not an earlier one because it's so crucial to the whole crux of the convention and its models of equality.

So I want to review a little bit what those models are in the convention and then address more of the issue of intersectional and multiple discrimination.

So the 2018 general comment six on the committee of the rights of persons with disabilities seeks to clarify the responsibilities of states' parties regarding nondiscrimination and equality. In clarifying the equality principles of the CRPD, it calls attention to the intersectional aspects of discrimination and the need for intersectional approaches to combating disability discrimination.

The general comment outlines the evolution of equality principles from formal equality to substantive equality to inclusive equality. The formal equality seeks to combat direct discrimination, which is what we generally call disparate treatment in U.S. law, by treating persons of a similar situation similarly. It may help to get negative stereotyping and prejudices but it cannot offer solutions for the, quote, dilemma of difference, as it does not consider and embrace differences among human beings.

The substantive equality seeks to address structural and indirect discrimination and takes into account power relations, that difference entails ignoring and acknowledging difference to achieve equality.

Inclusive equality, which is the model that the CRPD is really aiming for, includes numerous other dimensions, what the committee calls a redistributive dimension, so redistributing benefits and rights, recognition dimension, participative dimension, and accommodative dimension.

So that's the model that the convention is trying to move to, and in order to do that, the states' parties to the convention are supposed to adapt policies and laws and practices that do that.

Within the convention itself, there are two articles that specifically address multiple or intersectional discrimination. Article six and article seven, one about discrimination against women with disabilities, and the other discrimination against children with disabilities. So already within the convention, those two aspects are highlighted. And again, the committee has called attention to those over and over again, saying that the states' parties have to pay particular attention to those intersecting issues and to address them in their laws.

In the general comment, though, they go beyond that and actually say that those two articles should be seen as illustrative and not exhaustive. It was never their intention to say that the intersecting issues with disabilities are gender and age, that those are just examples and that the number of intersecting issues are unlimited, really.

Anyway, the committee on the rights of persons with disabilities in general comment six expands on and emphasizes the importance of recognizing and providing remedies for intersectional discrimination. "Many national laws and policies perpetuate the disclusion of persons with disabilities and violence. They often lack intersectional discrimination or discrimination by association, fail to acknowledge that the denial of reasonable accommodation constitutes discrimination, and lack effective mechanisms of legal redress." The committee goes on to indicate what it means by intersectional discrimination. It says, "Discrimination can be based on a single characteristic such as disability or gender, or on multiple or intersecting characteristics. Intersectional discrimination occurs when a person with a disability or associated disability suffers discrimination on any form on the basis of disability combined with color, sex, language, religion, ethnic, gender, or other status."

Intersectional discrimination can appear as direct or indirect, denial or harassment. They use the example of a woman who is denied access to general health related information for her disability due to inaccessibility. While that would be discrimination against anybody with a disability, they say that denial to a blind woman access to family planning services restricts her rights based on the intersection of her gender and disability.

They go on to define multiple discrimination as a situation where a person can experience discrimination on two or more grounds which can be compounded or aggravated. Whereas intersectional discrimination refers to a situation where several grounds operate and interact with each other at the same time in such a way that they are inseparable and thereby expose relevant individuals to unique types of disadvantage and discrimination.

And I mean, I'm going to focus more on the intersectional aspect than the multiple aspect because I think the multiple discrimination in some ways doesn't change the analysis of the discrimination. I mean, it's really saying you can be discriminated against because you're disabled and because you're from a specific race and those two things can happen independently and you may have evidence independently of each of them happening. But the intersection of them causes other forms of discrimination that are harder to address, and that's really what I want to tease out in the rest of this.

Finally, in section seven on implementation at the national level, the committee states that one of the steps states' parties should take is to adopt measures to include inclusive equality for persons with disabilities who experience intersectional discrimination such as women, girls, children, older persons, and indigenous persons with disabilities.

So in the U.S., this idea of intersectionality and discrimination arose mostly out of the work of Kimberly Crenshaw, who was looking at this in relation to black women. And after Crenshaw's work, there have been a lot of analyses of how that issue, race and gender together, can be litigated and what the obstacles to that are.

Often, I mean, certainly in early cases related to this, the issue facing courts and facing litigants was that in traditional discrimination law, particularly regarding disparate treatment claims, what you're looking at is how the person was put at a disadvantage relative to somebody who doesn't have that characteristic in a comparable situation. So you need some kind of comparator to establish the claim and if you are claiming multiple forms of discrimination, you would have to multiply those, but sometimes they cancel each other out. So if you say I was not given the job that a white woman got but there was also a black man who got the job and the black woman didn't, then you would have to look at both of those for comparison.

More recent analyses of this have stated regarding intersectionality and discrimination, Crenshaw's focus was taken up by political science as an instrument of categorizing social disadvantage. However, the theory has been criticized as being of little relevance to law. Since law is a blunt sword, it depends on a finite number of categories in order to be not overly limiting.

That's one of the limitations on intersectionality and actually addressing claims of intersectional discrimination legally is that laws have to be limited in the number of grounds they specify as grounds for discrimination, and within those then the definitions of those grounds are limiting and then obviously court's interpretations of them are limiting the means of proof necessary to prove different forms of discrimination. All of those make this like broad sociological idea of seeing discrimination as relationship of power in which people are disadvantaged in multiple ways difficult to actually bring to courts and have courts acknowledge them and give remedies for them.

So I want to look a little bit at some of the ways this has been done successfully. There are some good examples internationally of courts that have recognized this and then also look at some laws that maybe offer some hope of overcoming some of the barriers to this kind of litigation.

So one of the examples where courts have given good decisions in this area is in Canada. The Supreme Court of Canada has issued several decisions in which they recognize intersectional discrimination. In one case, which is called Law versus Canada, the court found that there was no reason why a discrimination claim positing an intersection of grounds cannot be understood as analogous to or a synthesis of the grounds that are listed.

So that is specifically recognizing that the intersection of a number of different categories can be recognized just as well as any one ground.

But the court also found in some ways this is even broader in terms of how you view discrimination and getting away from the idea that the characteristic of the individual is what's at issue. What we want to get to is what is at issue is the disadvantage projected on people who are claiming discrimination by society. And discrimination is on society and views of characteristics and in intersectionality how those characteristics combine to create new forms of disadvantage and discrimination.

So the Canada Supreme Court says disadvantage arises by the way in which society treats particular individuals rather than from any characteristic inherent to the individual. Already that's getting to moving away from individual characteristics to look at how society views people and not anything in particular to them.

I want to look a little bit at cases from the European court of rights, because when in my past life I worked in Europe and did quite a bit of litigation in the European court of human rights, and it's hard to bring discrimination -- it's hard to have the court recognize discrimination because you have to find a violation of a substantive right. And then they'll look at that sometimes but often not through the lens of discrimination if that's claimed as well, but it doesn't arise as a separate right. It's always connected to some other right in the convention. So you have to show that there was an underlying violation.

And often what they'll do, I mean, when I was working in a place called mental disability advocacy center, we brought cases about guardianship in Europe that was discriminatory because it was completely status base. We would argue those as violation to right to privacy and discrimination. If they found violation of the right to privacy, they would just say, okay, we have found this person's rights were violated and they will provide compensation for that, and they will often say we don't think it's necessary to address the discrimination issue, which obviously is very frustrating. But they do sometimes go there. In fact, in one case where they did find intersecting discrimination was the case of an African-American woman abused by the police, a prostitute, and in that case they did find that she was mistreated and discriminated against both on the basis of her gender and her African origin.

So I want to address one case that didn't find intersection of discrimination and raised a lot of issues about how to litigate cases where there could be intersectional discrimination and the choices that the people bringing the claims make that excludes that.

There's a case called DH in the Czech Republic which was about Roma children who were being very disproportionately placed in segregated schools in the Czech Republic. Schools for children with disabilities. And the court found that that was discrimination against Roma children, but they left it, the decision came out seeming to validate segregating children with disabilities in segregated schools because rather than trying to address the broad issue of placement in segregated schools as a discrimination issue, you know, it was only brought related to the Roma children. So the decision not only was limited, but also almost seemed to create a new ground for exclusion of children with disabilities because there was no mention of the fact that that was discrimination as well.

That could have been a really nice claim of intersectional discrimination and forced the court to address that.

I think that raises one of the issues of why intersection cases may not be brought as frequently as they could be, because, you know, often organizations have a particular mission and so, you know, nobody wants to risk weakening their own claim by broadening it or expanding it to include other groups. So I think that's something that needs to be addressed in terms of how we think about intersectional discrimination.

The previous panel I think was a great example. Homelessness is an issue that clearly calls for an analysis that is intersectional of how and why people become homeless and what the issues are that need to be addressed.

I wanted to look a bit, one of the ways to look at backup discrimination is what grounds the laws specify for who was protected. Most anti-discrimination laws have the classic categories of gender, race, religion, possibly disability, depending on when they are from, and that's become restrictive in looking at intersectional issues because. Courts won't go beyond the grounds that are in the laws because they have no way to; they can't address types of discrimination that are not outlawed.

So one way to move forward with this issue I think is to expand the list of grounds, but that obviously has problems because it's infinite. You could go on forever adding new grounds.

One way this has been dealt with is just to say, like in the European convention for the people of human rights, it names several grounds which are kind of the classic ones, and then says "other status." Disability has come in, sexual identity, under that.

So that's why leaving it open-ended but kind of allowing it to the courts to determine what gets added within that. But another way of doing this, I want to cite an example from French law, is to just add grounds. I mean, I think one of the ways to get to the issue of social disadvantage and not just personal characteristics is to include grounds that are specifically related to social positioning rather than where seen as personal characteristics.

I want to read this list of what is now prohibited under French law.

Sorry. Before I read this, one thing that kind of characterizes French law in terms of discrimination is that France specifically doesn't recognize race as a category, and so under French law, you can gather data related to race. And so the law now includes a lot of references that perceive traits which, you know, again, is a way of getting away from the inherent characteristic of the person because it's really about how you look at people. So the French equality body has done studies about discrimination and housing, and the reference they use is not the person's race but being seen as belonging to immigrant group or being seen as belonging to a Muslim religion. So it takes the focus very much off of the person and puts it on the discriminator.

Okay. Sorry. This is a list of grounds specifically prohibited in national law. Sex, pregnancy, gender identity, belonging, whether real or supposed, ethnic, origin, race, physical appearance, last name, family situation, union activities, political and philosophical opinions, age, health, disability, genetic characteristics, loss of autonomy, place of residence, capacity to express oneself in a language other than French, economic vulnerability, refusal to be a victim of bullying, banking residents, which is a weird one. I guess it means if you live in one of the French territories and you're being discriminated against in terms of credit, that's what that refers to.

So I mean, what I find interesting about this list in terms of intersectionality, not only are there many grounds, which give you much more opportunity to find intersections, but many of them specifically refer to an economic situation. But also, I mean, for disability discrimination, this category "loss of autonomy" has all kinds of implications in terms of combining with disability. And I think the way that they are phrased, it's more like the drafters of the law looked at how people are discriminated against more than who the people are.

So it's really expanding the possibilities of what you can claim as discriminatory treatment.

This is in a report that's from a European committee of experts that reviews national laws and European Union law, and the writers say this new category of loss of autonomy has not been challenged in any way in court, so it hasn't really been determined how it could be used or for what, but they say this is obviously available to people with disabilities as a category now.

And the other thing is many of these categories are not defined in the law. So the French courts have to kind of look at how the disability -- I'm sorry, how the discrimination is related to the ground from the point of view from the discriminator, rather than the person.

Okay. So I am going to wrap up. I think one way that we might move forward with this in the U.S., because obviously within federal law there are a lot of limitations. The grounds are not very numerous. And there is probably less flexibility in terms of what the courts can do. But looking at this list from France, what I went to next after that was to look at the list of grounds prohibited in state laws and especially within state human rights laws, and often they are very multiple. Maybe not as expansive as the French one, but they often do include certainly discrimination and housing laws often include source of income or source of payment for the housing, which immediately goes to an economic issue.

So I think that's one place to look to start doing more intersectional work around disability as it relates to other types of discrimination.

I think another thing is just how disability activists and disability rights groups can do coalition building with other groups to try to find cases that would be intersectional and that can get in that way.

So I will conclude there, and look forward to more discussion on this. Thank you.

[Applause]

MARC MAURER: Okay. And thank you very much.

The question that you raised, Ira, I am going to take questions from the floor, but let me say this to you: Universities have a group of people who have the job of protecting the university against being sued by anyone. And they go by various names. Sometimes it's a board, sometimes a committee. But if you're going to do research, then you have to get this board to review your plan and approve it. And they have categories of human beings, and I've discovered in my work with universities that the disabled are a fragile group. And consequently apparently I'm a fragile person. And therefore I need more protection than other people, which came to mind when you were talking about people with psychiatric disabilities.

How do I get out of it?

IRA BURNIM: Is that a question?

MARC MAURER: That is a question. I don't want to be a fragile person. How do I get out of it?

IRA BURNIM: Well, I don't have an answer for that, but I can say that there is some tension between the notion of equal treatment, don't treat us differently, we're like everyone else, the same rules apply to us, and don't diminish us or devalue us.

On the other side, sort of the notion, which is also part of the ADA, that special treatment is required, that there's something associated with the disability that requires something special. And I think we've done a lot of good work to say that that thing that is special is really to just kind of change the rules of society which were developed sort of without people with disabilities in mind to give them a fair shake. The notion of reasonable accommodation, reasonable modification.

But there is this strain, and I think it's particularly true when it comes to people with psych disabilities, that individuals are very vulnerable, that they need special protection, that they need folks to look out for them. A kind of paternalism that I think really does -- its intention is very much intentioned with this whole notion of equal treatment and fully capable people. I mean, I don't have much more to say than that.

MARC MAURER: Your question of forced treatment comes dramatically to mind with this concept. There are many people who would like to tell me how to live my life. I hope they get away with it perhaps, but anyway, questions from the floor?

>> Dan Goldstein.

Ira, I appreciate immensely your taking on the question of strategies to address the perception of disability. In the 15 months that I've been retired, I've had a lot of time to think about where we are and why we aren't farther down the road and where the accelerants are and where the barriers are.

And I've come to believe that as long as the popular perception of disability is lesser ability, discrimination gets perceived as common sense, not as discrimination. Unless we can change that perception, we can't win.

So thank you for focusing on that, and I just hope everybody thinks hard about what our strategies can be. When you look at what's happened with other civil rights movements, the understanding of who that group is has been critical to change. And we've got to address that issue for ourselves as well.

MARC MAURER: Did either of you want to answer Dan?

IRA BURNIM: I would have to say thank you.

[Laughter]

MARC MAURER: Dan talked me into these law symposia long ago. I give you full credit for it, Dan. I was very nervous about it.

Any questions? Say your name, if you would.

>> I'm James Fedder at Brown, Goldstein & Levy right now.

Question is in terms of intersectionality. It all sounds great and I agree with everything that was said, but I wonder if we have a more fundamental problem right now, that disability isn't even as part of diversity at this point. We don't track it in legal hiring. It doesn't count toward minority clerkship programs in the legal setting. And there are obviously more profound systemic problems with that.

I wondered to what extent can we talk about intersectionality until we make disability a full blown part of diversity.

MARC MAURER: And of course it's not on the questionnaire to determine the suitability of judges to be appointed.

Anybody want to answer this?

LYCETTE NELSON: Yes, I think obviously that is very necessary before we can really talk about how to intersect it with other categories. Obviously we know in practice it is very intersectional as well, and I think even within disability, one of the things that lends itself well in terms of disability discrimination and intersectional claims is how intersectional it is to start with. But clearly we need the evidence for the discrimination and the categorizing of it in order to make those claims.

Thank you.

MARC MAURER: Okay. Who else is ready to ask a question?

>> Hi. I am Maris, a current law student, and I wanted to ask about statistics tell us that there are very large number of lawyers and law students with psychiatric disabilities. Especially depressive, anxiety, and substance use disabilities. The legal profession and bar examiner criteria for fitness greatly impact the ability for treatment for these lawyers and the ability for lawyers to both come out and practice law.

What are your thoughts on the ability of lawyers with disabilities, especially psychiatric disabilities, to affect the conversation that the legal profession has about mental illness?

IRA BURNIM: That's a great question. I think it is an arena in which the sort of issues I discussed are very relevant.

We've done some work at the Bazelon Center on this area, and brought a complaint to the Department of Justice as you know. You probably know about the findings letter in Louisiana. But essentially the notion is that one's psych history or history of treatment is completely irrelevant. Which it is. You've got a record of performance, and it's either good or bad. And that's what should make the difference.

But in that particular case, the individual who came to us wanted to raise issues before she got admitted to the bar. They were going to impose a conditional admittance.

Because of the stigma associated with mental illness and certainly the history of bars, there's another instance in which I counseled her not to take action. So the theory, our theory, which seemed to work, was just do what they want you to do to become a lawyer, because it's probably better for you to become a lawyer than make a point, which is an unfortunate tradeoff.

And then be a good lawyer for a couple of years. And then we'll challenge the conditional issue, which is what we did. Because then it wasn't sort of theoretical what her performance as a lawyer would be.

I don't have any good answers obviously but it's a tremendous issue. And as you say, it discourages people not only from the coming out strategy, but just from seeking treatment, because you don't want that record in your history. Similar to the family member I spoke about in the Peace Corps. I did not want a government record of mental illness to follow him.

MARC MAURER: Other questions?

>> Yes. I'm Christopher with the Saks Institute at USC.

Ira, I'm hoping you can speak more about NAMI, maybe moving away from forced treatment being one of the things they're advocating for. I understand the issue is family members really want to take care of their family members who may be ill, homeless, may be in crisis, but whereas the individual's autonomy in that is questionable.

I'm seeing at least colloquially that the younger generation is more open and honest about their psychiatric disability or diagnosis. I'm wondering if you've seen that same type thing.

IRA BURNIM: As to the second part of your question, yes. Given my age, I really can't speak much to that understanding or culture.

But I think it's a very promising development, and I think we're kind of seeing younger people be more inclusive kind of across the board.

As to NAMI, my perception is that it's really moved away from forced treatment being its core agenda, and that it is much more interested in kind of investments in services and housing.

There's a little bit within the organization because I think there are older elements, newer elements. I think the trajectory is a good one but that we might want to accelerate it.

I think there's another thing that happens with family groups. If folks are often in very desperate circumstances, in terms of trying to get help for loved ones, part of the political dynamic I think is that sometimes mental health advocates, particularly family groups, they're happy for anything. So in a sense, politically they sometimes are indifferent to whatever initiative is being undertaken, as long as someone is doing something. I don't know how many of you have tracked the Murphy bill, which was federal legislation and was really disgusting. But there was broad support for it. Even though people knew it.

Anyway, I think that's sort of more a show of weakness of the community than its strength, but I think also that weakness gets exploited by interests who want to divide the community and pushing their own agendas like gun control or defeating gun control.

Anyway, enough said about that.

MARC MAURER: Last question.

>> Hi, this is Martie. I don't really have a question. I just wanted to let folks know that the Disability Rights Bar Association does have a working group on the issue of the character and fitness questions on bar applications. So just to kind of tie in to the previous question on that. We're working on the questions, getting rid of those, and also the process of discrimination against folks with mental health conditions who are applying for admission as attorneys.

If anybody would like to join our group, contact me or Aerial and we would be happy to help you.

MARC MAURER: I appreciate your bringing up the issues that are in this panel, Ira and Lycette, and which help determine the future of the rest of this symposium that we will have for the rest of the day and tomorrow morning.

It has been a pleasure to have you. I look forward to the rest of it.

It's time now for the coffee break.

[Applause]

[Break]

11:05 a.m.

"Framing Deaf Special Education in Due Process"

CAROLINE JACKSON: So we're going to go ahead and get started.

TAWNY HOLMES: Hello, everyone. My name is Tawny Holmes Hlibok, and I work with the National Association of the Deaf. I'll repeat my name, Tawny Holmes Hlibok. I work for the National Association of the Deaf.

CAROLINE JACKSON: I am Caroline Jackson, one of the litigators at NAD.

TAWNY HOLMES: I'm happy you were able to join us today to get into our discussion. We'll go ahead and get started with that right now.

Just kind of an overview of what we'll be discussing in our presentation. You can take a look here on the display. Basically we'll get into three areas today. First thing is who are the Deaf students. Secondly, what is the IEP process, what does it look like. And third, we'll discuss the different due processes and going through that.

First of all, who are the Deaf students? They come from a variety of different backgrounds. I'll give you an example. Looking at the statistics there, you can kind of peruse those, if you would like. Can you guys see okay?

I'll go through each of these statistics one by one. We'll talk about birth rates first, as far as Deaf children. For the past 20 years now, we have 1.5 per 1,000 that are Deaf. And then we also have newborn hearing screening rates that have improved to 98%, and they have all 90% gone through that screening process to be able to identify as early as 1-year-old that they are actually deaf or not.

The early intervention service rate is still low. That's typically around 40-60% of families getting the services they need.

About 85% of families select spoken language for their deaf children. A lot of times they don't have sign language services available, so they end up having to just pick one and go with the spoken language services only.

If you move to the right side, you'll see that when entering into kindergarten, 55% of children typically know sign language, but 72% of their parents are not exposed to sign language. They don't. So that makes it a challenge to communicate in the home.

86.4% of children attend public schools. They end up with IEP services when they enter these public schools. And really that is really our landscape as a whole.

It's important for you to know, and research shows information to support this quote. Take a look there. With full language access from birth with no other disabilities, the deaf child experiences all milestones, including those of social and emotion and linguistic, as any other hearing child. Really that's an important consideration, because they have something that they don't have any limitations holding them to having any issues. Really it's the language that ends up being the issue that's holding them back.

So we'll move on to our next slide. The mediated instruction versus direct instruction. Mediated instruction really means using an interpreter in an educational environment. That can be helpful, but sometimes it can be a struggle.

If you notice in the picture to the right of our slide here, we have a little bit of a faux interpreter. That happened a few years ago when Nelson Mandela's memorial service, we had that situation. The guy stood there on the stage and really just made up sign language on the spot during the actual funeral services for Mandela. And this is something that was brought up international, on TV. That person was not certified, wasn't even a qualified interpreter. He didn't even know South African sign language. He raise his hand and volunteered, they put him on the stage next to all of the dignitaries and famous people who were there. That was really a sad situation for Mandela's memorial service.

And really interpreting, the challenges are something we're presented with every day. Children sometimes don't have enough language to express to the interpreter, I don't understand what you mean. They're just sitting there in class and they don't understand what's happening. They are devalued and left in a deficit because of the interpreting situation is not qualified. That's a challenge that we face quite often.

Research has shown that out of the 25,000 interpreters, only around 400 of them actually have certification. 25,000 educational interpreters, only 400 of them have certification.

Now, it's really important for us to make sure that these interpreters exposed to the Deaf children have the appropriate qualifications.

Now, if you're still in the IEP process, you really have to -- let's move on to our second point. Those individuals still involved in the IEP process. Some of the concerns, some of the resources that we need to be taking advantage of.

Move on to our next slide. Here what we're looking for in general is the question. Really there's three basic necessities. One is each year we're going to process a year at a time. And really that is related to the Supreme Court involved with an autistic child who was struggling because the school was providing him with low expectations. Really the court found out that the student was receiving IEPs, but in reality, she wasn't having the opportunity to have higher expectations. But a lot of times they ended up with lower expectations, the same goal repeated over and over again, and it really wasn't providing the appropriate amount of time to meet these standards, to be able to get employment in the future. This was something found during that case.

The second situation with the IEP goals, they need to align with the state curriculum as well, and it needs to be grade and age level appropriate. I have one short story I can mention about that that highlights that point. One parent reached out to me and said they were upset because her deaf son in 8th grade, public school, she was concerned that the school decided to make some adjustments to the classroom setup at that time. They had two different classrooms, one with deaf students and the other for students who were focused more on oral methodology.

The other one was using sign language teaching in that class.

So the school decided to combine both of these classes and put them in one room, and then they were going to be using something called sim-com or simultaneous communication, signing and talking at the same time, to provide instruction. Now, really that doesn't work out. Two languages happening in the class at the same time is really doomed to fail. Think about using French and Greek in the same room. It's impossible. Your brain can't function that way. You end up losing one or the other.

So the mom reached out to me and asked me to be involved in her next IEP meeting. So I was educating the school to let them know that with two languages, (inaudible) maybe sign some of the time, then maybe just switch between the two languages but not having them running simultaneously.

Now, I was involved in the meeting by phone because it was a little bit far away, and I understand deaf services are provided around the country are a challenge. So a lot of times I attend IEP meetings by phone.

So they started off the discussion, and right now we say level of performance that the student is at, they discuss that for a little while, then they move on. Started going through that process, and I'm kind of waiting for my cue to interject to provide my services, but after they went through the discussion of their goals, then they just moved on. So I had to say something, because as I was looking through with a fine tooth comb the IEP, the student in that situation was in 8th grade but his reading and math level goals were in the 3rd grade level. So I was a little bit perplexed by that. I didn't have an opportunity to ask the mom before the meeting, but during the meeting, I went ahead and spoke up. And they were getting ready to wrap up, and I said, I want to make sure the IEP team there, why do the goals not match with grade level?

Really they had nothing else to say. But if he had another severe disability, they should have mentioned that. But he was ADHD, and that was it, so I asked them to explain themselves.

They said, we don't necessarily know why. The mom doesn't sign or communicate well with him since birth. The school has tried sign language with him. And there were some other issues. And my colleague will get into that a little bit later. But for this student, he didn't have any of these other issues. Why would they have 3rd grade level for somebody in the 8th grade?

Really it was just lower expectations established for the student, saying he can't. And I said, hold on now, that's not the truth. Let's go back and look at the research that shows that to be able to access this information, he needs to be on that same level. He needs to have the same milestones that are established for the other hearing students. Now, there are tons of Deaf lawyers in this room. How many? Can you raise your hand? You can see. I see three hands that were up. So obviously we shouldn't have these lower expectations.

So that's something we need to look at when we're talking about goals. They need to match their age and grade level.

If there are some other disabilities, other concerns, we want to take those into consideration, but not if we don't need to.

Some other things what we should not do. It's important to look at the IEP, and sometimes they have the same goals that are just being passed on from year to year. And again, that relates to lower expectations.

Secondly, sometimes we need to have these goals that are so comprehensive but they're really not services that are apropos with this. So you're reading a sentence at a time instead of reading a full paragraph. But there isn't any change in services to provide them with the skills needed to achieve those goals. So you have to have some sort of modified teaching, in-class reading, or something to help them be able to accomplish these goals.

So now there were some other challenges. But what can we do now to help them to be success? The things we need to be looking for when it comes to a Deaf child are what we will focus on. These are four things we're going to discuss. That successful inclusion from the Deaf child's perspective is important. And really that's based upon what I call the information there, you can click on the link there, the information is there to provide the information necessary to help us be able to look at it to help determine the goals.

It's important to communicate with the child in their language. We see that they want to make sure that they have a Deaf identity. There are different factors that play into helping in this process.

There are a lot of different factors involved in that individual. There is one paragraph in the IDEA focusing on Deaf children specifically and the impact to them. So it's important to discuss and consider those factors in each IEP meeting when you're dealing with a Deaf student. Do they want to use interpreters all the time? Sometimes that's not successful. The interpreter could be there so they can interact with their peers. Children often learn more from their peers than they do from the teacher that's in the classroom.

So the second thing that is really a focus is effective communication. And the ADA, the Americans with Disabilities Act, and really IDEA also came as a result of focusing on children need to have effective communication.

The U.S. Department of Education and U.S. Department of Justice both work together to release a document, an FAQ, a guide for different school departments in providing services for Deaf and hard of hearing children. So makes it clear that IDEA has this list of requirements, and ADA has their own list of requirements as well. So those come into effect when talking about laws to implement for Deaf children.

The Rowley standard is really the minimum children can get. The ADA mentions they need 100% equality and accessibility. And that's not a law, but there are guidelines that are there to achieve that goal. And that's based on different court cases that have happened previously. And you can see a list of those at the end of the Power Point. And that's helping us to get a new view of the legal gaining accessibility for Deaf students, the legal rights of Deaf children.

Okay. So the other thing we focus on is milestones, making sure that they're appropriate. By the time the child is 2, they should be speaking in full phrases or sentences. Those are things that can be set as goals.

If we don't have those milestones or they're not able to meet those requirements as quickly as possible, if they're not meeting the milestones, then you need to have an intervention services established so that do they ask the person, do they have the appropriate language access, do they have the technology working. We need to, again, observe the student in the environment to figure out what the issue is as early as possible. We don't want to wait until later on. It's important to catch it as early as you can.

Move on to the next slide.

Here are the more concrete goals and ideas.

It's important for us to during this IEP process that things kind of stay superficial. The goals they mention, the student is going to read one sentence at a time and that's what the goal is. But really the goals should be focusing on language proficiency, being able to express themselves in an effective manner. Is the teacher instructing them clearly. Can they have a complex discussion. It's more than if the person can just or the student can just add 20 vocabulary words. We need more goals than that.

Now, if the child receives an evaluation, it's important to focus on their total language capabilities, not just the standardized testing or their being able to accomplish the scores that are necessary. They accomplish their reading score and we're satisfied with that. No. We're not going to use that as a baseline. They need to be able to express themselves fully.

Also, we have a hearing test that will be done periodically. Now, just because the hearing students, proficiency of hearing may change over time, so it's important for to have instruction evaluation. So you have a room set up for an acoustic --

CAROLINE JACKSON: She said it's important to test their hearing in an environment that mimics the classroom.

TAWNY HOLMES: The reason why that's the case is because during the hearing test, they may go into a booth that's extremely quiet, it's a controlled environment. It looks like they're locked up in a vault. But during the hearing test, when they're now back in their classroom and the kids are running around and making a bunch of noise or people are coughing and talking to each other, how much does that now affect how much they can hear? So we really recommend that the audiologist is involved in an observation and making sure you're doing it in an environment that is similar to the classroom instead of using the booths that they've used in the past.

CAROLINE JACKSON: So I'm going to add to this now. It's not just about the testing in an appropriate environment, but it also is testing what they can understand based on what they're hearing. So it's not just can they recognize sounds, but do they understand the actual verbiage being used, understanding the words being said. Looking for that is what's important. Typically audiogram doesn't measure that portion. So you need to observe what they're actually understanding.

TAWNY HOLMES: That is definitely an important point. Thanks for adding that.

The reason that's important is because a lot of times students may hear higher or lower frequencies. There is a range with that. But listening to specific words or vocal patterns, it kind of depends on the person who is speaking at that time. Can I understand? I may understand this person but not another person. There are so many different things that play into that.

So it's important to know, if the Deaf child is struggling, oh, it's because they're Deaf. It may be they have another disability that's affecting them. Maybe their oratory processing or maybe another disability is having an impact. There are other neurological things that could be impacting. So it's important to observe for those.

Really the point is that there's no excuse for a Deaf child to be held back or have lower goals just because they're Deaf. It may be something else, and we need to check so that we can provide the services that fit that situation.

Next slide. Now we will pass the baton to my colleague.

INTERPRETER: Sorry, I missed your name.

CAROLINE JACKSON: I'm Caroline.

I will be talking about from that point now getting through to the due process hearing and making sure that you are bringing out what needs to be brought out.

Going back to the previous slide for just one moment, I want to look at the top one, top line that says that you want to look at goals that evaluate progress in language and not just reading. And that often is the key to when you're intervening with the child who is Deaf or hard of hearing because the schools are used to testing to see whether a kid is learning what the other kids are learning. Are they learning to read and write and do math? But what is unique about the experience of a child who is Deaf or hard of hearing is that they can be learning not language at all, and that is something that a school district is not used to testing.

So you want to make sure that the goals they're evaluating, the evaluations are testing whether or not they're learning language.

The next slide is about independent educational evaluation. That is something that you the parent has a right to. So you can just request it because you don't like the results that their evaluation accomplished.

Often school districts will give you a list of who you can go to to get your evaluation from. I don't have strong thoughts on that except that the correct evaluation has to be done. So you need to insist that whatever evaluation be done tests this child for language proficiency.

The most important element of that is that the school district has been testing reading and writing for five years and the kid has been doing terribly for five years, and then you initiate due process because they can't read, you can only go back two years. But if the school district has been assessing reading and writing for five years and missing out on language and your language evaluation reveals that the kid is language delayed, that is a different way in which the school has been denying your child a free appropriate public education and you can use that difference to expand the statute of limitations. So in a case recently, we had a kid who had been reading at a first or second grade level for 12 years. So when we finally intervened, to be limited to the last 2 years of that, we would have lost a lot of compensatory education. But because the school had never evaluated an acquisition of language until our evaluator did it, that meant that we were able to persuade the judge of this and we got compensatory language services for the entire 12 years.

So when you're looking for that IEE, you can get a lot out of what hasn't been evaluated by the school district.

And it doesn't have to come in the form of an IEE. Because of your involvement in the case, you can get the school district to evaluate the child's language for the first time, and that's still going to be the first time anybody is finding out that this 18-year-old has the language skills of an 8-year-old and that is your cause of action under the IDEA.

Going to the next slide that says "now it's time for the hearing." Let's talk about how we're going to draw out this and emphasize these kinds of situations in a due process hearing.

The next slide, general case strategies. I would strongly suggest that you reach out to the NAD as early as possible to get our input. Tawny is a phenomenal and incredibly knowledgeable person in these regards. So I was consulting with her from day one in my special education cases.

You also want to make sure that if you're going into the hearing, that all the interpreting needs are met. If you have a student who has a significant language delay because the school hasn't been meeting their needs, then you want to make sure that there are appropriate interpreters for the hearing and that might be in addition to the hearing interpreter who will listen and sign what they hear, an additional interpreter called a certified Deaf interpreter, who will go from what the hearing interpreter is going into a clearer form of ASL that will be more accessible to the student who is attending the hearing.

And then I'm going to go into some strategies of how you show and don't just tell. So the next slide is witnesses and witnesses. And we just have to the right side an image of two people in a courtroom, one showing a document to the other.

You show through your witnesses. Like constant fear when I am taking a Deaf case to any sort of hearing is that my audience, the people deciding my client's fate, don't understand what Deaf people are capable of. And you have a wonderful opportunity when you get to select the witnesses for your hearing. So it is wonderful if the only Deaf person in the room is not your client, who either can or can't read, can do this or can't. If you can bring in a Deaf expert witness, that can be a very powerful example of what Deaf people are capable of.

In a recent due process hearing that I did in Michigan, we led with the Deaf PhD clinical psychologist, and she hasn't done a formal evaluation of our client, but we got her in in part because the rules are more flexible in due process hearings, but also because she is a clinical psychologist. She evaluates people, she evaluates Deaf people's language, so we just had her evaluate our client and then testify to what she had learned.

And that showed to our judge that Deaf people are capable of earning PhDs.

So they can have a role as an expert witness. You can also have as an expert witness or fact witness somebody who is Deaf who has been educating this student, potentially from the community or from the school for the deaf in the area.

Just to name drop for a moment -- sorry. I misunderstood something.

Another way to show don't tell during the hearing is to, as best you can, provide potent contrasts between this student's experience in the classroom and what the school is going to tell the judge happened. So what I had in the hearing was we had a student who had just graduated high school, and we were talking about his experience through the end of his junior year. His senior year, he spent at the Michigan School for the Deaf. Prior to that he had been in a mainstream classroom with spotty access to interpreting services.

So we used the state standards to develop questions that we could ask the student that would draw out what he had missed in his classroom at school. For example, he had taken biology. So we looked at the state standards for biology instruction in high school, and lo and behold they learned about photosynthesis. The judge can understand photosynthesis, and a high school biology student should understand photosynthesis no matter what grade they got in the class.

So in the hearing we asked our client, "What is photosynthesis?"

And he said, "I have no idea."

Well, maybe that's a language thing. Maybe that's a vocabulary thing. So we asked him, "How do plants make food?"

And he had no idea.

And yet he had a passing grade in biology. So that was a way of showing and not just telling that he had learned nothing in school.

And then we contrasted that with the chemistry class that he had taken at the Michigan School for the Deaf. In chemistry you study atoms. So we asked him, "What's an atom?"

"Oh, an atom is the smallest unit of" -- oh, I forget what he said. He explained it better than I did. He knows what an atom is. He knows what water is made of. He could answer the science questions.

So with that contrast, we were able to show not just from the grades he was showing or through some expert evaluation, but by eliciting our client's human experience to provide that contrast between his experience in the environment where he was not receiving an appropriate education and the experience in the environment where he was.

Very useful. You'll see on this slide, in the bottom right corner, one of the elements is to use the common core for soft skills like communication. If you go to corestandards.org, they actually list soft skills like communication and specific goals for this for every year of a child's life. I think they might do high school and with a broad brush, but they do kindergarten, first grade, second grade, third grade. And you can look at these tools and use them as leverage to explain what this student is missing.

One of the goals that students are supposed to learn about speaking and listening when they're in kindergarten is how to take turns in a group conversation. If you have a student who is participating in kindergarten through an interpreter, how is this student supposed to learn how to take turns?

So that's something where you can use those common core standards to show what a child at this age should be learning and then also to advocate for direct access to instruction and direct access to peers that the student needs to actually receive an appropriate education in the classroom.

I realize I haven't been explaining to people what is on the slides. But as part of show don't tell, first we want to set a baseline for what Deaf people look like by using a Deaf expert witness. You're welcome to reach out to the NAD for that.

Using Deaf lawyers, judges, doctors, making sure you show that image of what a Deaf person can be. These are the only appropriate expectations for the student.

And then we also want to set a baseline for what successful learning looks like using state standards for content knowledge and the common core for soft skills like communication.

Going to the next slide, I already covered this, but using questions that show. The first bullet point item is, they can do math problems. Great. But can they do word problems. That's a question that shows for two reasons. One is, it shows whether they can generalize the concept, but also for a student who is probably not learning language on par with their peers, the fact that they can't do the word problems is typically because they don't have the language for it. So that's another way to illustrate that the student is not getting the language services that they need.

The next bullet point is what classes have they taken. Biology? Great. Quiz them on the common concepts. That's the photosynthesis example that I gave.

Next item on the slide is have they been at different schools? What worked or didn't work? That was the contrasting example between the hearing mainstream school and the deaf school.

Second half we have what reading level are they on? Third? How is the school trying to improve that level?

This relates to what's also going to be on the next slide. You also want to look at how they are accommodating the student in the classroom. There's a significant difference between the goals of special education and the goals of the ADA. The point of the ADA is to give somebody just access to what everybody else is saying. So if a person cannot read notes that a doctor is writing to them, you provide the sign language interpreter who can sign that same information.

That's not applicable or not a sufficient accommodation in the IDEA because the goal of the child is to learn to read. So that can accommodate them on a test to make sure they're being tested what they learn as opposed to reading the test, but you have to make sure the school is also doing something to getting that child closer to being able to read the test for themselves.

And what we had in the Michigan case was a student who had been accommodated to the point of not having to do anything himself. So every homework assignment was signed to him and then they had -- or was spoken to him, depending on who they had access to, and then a lengthy conversation to, quote/unquote, make sure he understood but he never did, and then the person who was helping him with his homework would then write the answer for him. And on cross-examination, elicited was that if he didn't understand, she would make it look like he did. He had someone doing homework for him. That was an example of how he was being accommodated to the point where he wasn't doing anything.

A student who is reading so poor they can't read their own homework assignments shows you a lot of intervention designed to help them read. If the interventions aren't working, there need to be evaluations and interventions to figure out what else is going on. That was crucial in that case because there had never been an evaluation to understand why this 15-year-old was reading at a first grade level.

Next on the slide. Can they answer simple questions about their family, their favorite foods and colors, their friends? Again, that can show that illustration between a school where they're getting an appropriate education where they would have access to their peers directly, and a school where they're not being served. The IDEA requires that services address the student's academic and functional needs. So social interaction is a functional need, and if a student can't tell you what their best friend does when they're not around, that is a very strong indication that that kid can't communicate with anybody and doesn't have a real best friend in the way that we understand friendships.

Moving to the next slide. Defenses to confront. Oh, they're just Deaf; that's why they can't learn.

And after that, they should be evaluated for learning disabilities, early language access, access to sign language. The classic situation in these IDEA cases is that the lack of progress is attributed to the disability. But when you start with that Deaf PhD or those examples of Deaf attorneys and Deaf doctors, then the judge realizes that if a kid is just Deaf, there's no reason why they can't be a PhD, so if they're not reading on grade level, something else needs to be evaluated.

Next bullet point. They can hear just fine. But can they understand what they're hearing? The student, the example in Michigan, could hear and understand something like -- sorry. Not understand. He could hear and detect 84% of phonemes with his FM system. So the school district used that to argue that he didn't even need an interpreter. He could understand just fine.

So finally there was conducted a test of auditory processing skills. That test evaluates what is understood of what is heard. And that test showed his memory for sentences was poor after the fourth word. Which means that he can't understand a sentence that's more than four words long.

Also there was a test of could he draw inferences or expand on meanings from what he was hearing. He tested in the first percentile for that. Which means he could not get inferences or implied information from what he was hearing, which showed clearly that though he could detect the sound, he was understanding none of it.

Next bullet point. They didn't even look at the interpreter or want to use the technology. After that, behavior's the answer. Did they already have a language foundation? Know how to use the technology? When you're providing something to a student that actually gives them access to a classroom that they don't have access to without, that kid is going to love that. And so if you have a child who won't even look at their interpreter, that is a very clear sign that the child does not understand the interpreter. And if the school has never assessed this child's ability to understand sign language, then the school has no basis to say that the kid understands the interpreter. And if they didn't evaluate it, that means the school wasn't even trying to do a good job. And that's what we had in the Michigan case, was the school district was blaming the student for not looking at his interpreter.

If the student's sign language skill is fine, that means the interpreter's sign language skill is not, regardless of what credentials they have. They're not signing in a way that the student understands. So we might need a different interpreter or environment for people to modulate their signing to what the student can understand.

What we had in Michigan was a student with such limited access to sign language that he couldn't understand an interpreter no matter how strong the skills were.

Next bullet point. We tried to teach them more but it didn't sink in. Increased time on reading strategies are not the answer when they need language access. So the student we had in Michigan had spent a tremendous amount of time in elementary and middle school getting pull out services on reading and writing. But the problem was language. He didn't have the language foundation for the writing and reading skills. That's another thing to look at in the defenses. That's something you can draw out, are is that they were laser focused on reading and writing English without making sure he understood English to begin with.

And finally, we accommodated them but did they improve? The example of sitting down with this student and spoon feeding him every answer to the homework doesn't teach him anything. It just makes sure it looks like he's learning. You can draw that out at the hearing. What we did was make sure that the special education teacher went into elaborate detail, which they typically will do because they are very proud of what they are doing, she went into elaborate detail about how they were accommodating him on every single assignment.

And then they never actually bothered to teach him anything. So that was very effective to show that the accommodations that he was using enabled him to make progress in the curriculum without learning anything. That was important because it was contrasted with the student's own testimony about how very little he was recalling of anything he supposedly learned in the classroom.

Then the final slide which I've gone to, important other cases. The first case everyone should know by now, KM versus Tustin. A student's rights under the IDEA are district from their rights under the ADA. So even if the student is receiving an appropriate education, they still might not be having effective communication in the classroom under the ADA.

We have go more cases under that. One is DeKalb city Board of Education versus Manifold.

And then Poway versus KC.

Both of those are district court cases where the court understood that distinction between access to the special education services and then the ADA effective communication.

One of the drawbacks of the Tustin case was that the experts had not evaluated the students actually in the school where they were receiving instruction so the court didn't give as much credit to the testimony that the students couldn't understand what was happening in the classroom.

In DeKalb, they had the experts actually observe the student in the classroom, and there they could testify to the student not understanding X, Y, and Z.

Final slide is a thank you.

Any questions?

And also comments, because I know we have a few experienced advocates in the room.

DAVID FERLEGER: Hello. Thank you both. That was really so good. I'm trying to think of the right adjective.

With school districts' IEP for a Deaf student, where would one expect them to have the expertise to know what's on all these slides? Because many school districts I think just don't have it, and special ed teachers, as you mentioned, Caroline, often are graded putting together goals and all kinds of stuff on all those crazy pages of the IEP, but in terms of the expertise within school districts and where one would -- how one would cross examine that alleged expertise, where do you see it? Or where would you actually not see it?

CAROLINE JACKSON: School districts are responsible to get that knowledge. So in the Michigan case, the way the state of Michigan's education system is organized, there is the local school district and there is the intermediate school district. And the intermediate school districts tend to be a collection of all the school districts within a county. And they are charged with having specialized instructors. So the intermediate school district had someone with a credential specifically for teaching Deaf students, and that would be the person who is supposed to be educating the school district on what they're supposed to do and not do. So that's how we can go after that, because that educator is supposed to have the specialized expertise on specifically how to educate Deaf students and what they should be looking for.

DAVID FERLEGER: Do you find that they do?

CAROLINE JACKSON: Not in this case. But optically, it's less sympathetic. Because their only job is to educate the Deaf student, so why couldn't they get it right?

>> Hi, I guess this question is for Caroline. You were talking about evaluations and IEEs. One thing you said they should be testing for is language proficiency. Most evaluation reports that I see standardly they test for IQ as well as achievement in math, reading, and writing. Very have tests of achievement on those.

What type of normative assessments are utilized for language proficiency?

CAROLINE JACKSON: I know there's several. Do you want to explain it?

TAWNY HOLMES: So there are quite a few specific to language and communication evaluation for Deaf and hard of hearing students. For example, there's one called vision communication and sign language checklist, if you will.

The second one is MacArthur-Bates Communication Development Inventory.

One is the Peabody assessment adapted for Deaf children.

Really the psychologists need to have someone experienced with Deaf children. Maybe they can sign or they have that experience. But because you're giving an assessment, you need to be able to see related to being a big D Deaf person. It's something that's completely different. So really that's the big issue.

I really encourage anyone, if you need expertise, please feel free to contact NAD, who can help you get in contact with the right people. Many times I've seen people linked up with psychologists that don't have that experience, and the experience is it doesn't end up working out. And it really will impact the education going forward, so it's important to have an appropriate psychologist.

CAROLINE JACKSON: Just minor supplementation. She said the misinterpretation, she said misdiagnosis stuck with the kid for the rest of their life.

>> What do you do with a smart Deaf student who signs at home, knows sign language, parents know sign language, goes to school, gets basically nothing, doesn't understand the teachers, goes to assemblies and obviously can't hear what's going on? She's getting really good grades. She earns the grades. What she writes is fine and what she reads is fine. But she says, I can't understand what's going on in the classroom.

Does she have any rights?

TAWNY HOLMES: Do you want to answer first?

CAROLINE JACKSON: That's where the ADA comes in. That's why Tustin is so important. Because the right under Tustin is to effective communication. The focus on effective communication, I mean, depending on the jurisdiction, sometimes they lower it to just meaningful access. But it should be full and equal access, and it's the opportunity to access the instruction. So it's knowing what the teacher is saying, not figuring out later.

There's also very good language in the regulations under the ADA that says that to be effective auxiliary services have to assure for timely access to information. So an auxiliary aid or service that only results in somebody finding out after the fact what a teacher said wouldn't satisfy that standard because it's not timely.

TAWNY HOLMES: In addition, the ADA covers not only discrimination in the classroom but also really is any place. This happens in any space. Could be employment area, on a field trip, anything outside the classroom needs to make sure that that child has equal access to communication in all the different situations, regardless of where they are. It's important for ADA to be considered in those situations and advocate for the Deaf student in those situations as well.

Thank you so much for your time. I appreciate you guys being here. We definitely enjoyed it.

[Applause]

12:05 p.m.

Lunch and Keynote Speaker

MARK RICCOBONO: Good afternoon, everybody. Can I please have your attention.

Good afternoon. We've come to the lunch keynote, always a highlight of our law symposium. I know we've had a great morning of discussions, and we still have many more sessions to go.

Last year at the symposium, I had the opportunity to talk with you about not just Dr. tenBroek's legal work, but his work to build movements, which I think are essential to our successful use of the law.

Today we are more effective than ever before because of our active involvement in not just disability rights work from the legal perspective but bringing that back to disability rights movements.

There certainly is a lot more work to be done. Low expectations continue to hold people with disabilities back in so many aspects of life. Websites continue to be developed without including accessibility principles.

And by the way, on the subject of websites, it's worth noting that our progress in web accessibility is actually being held back by lawyers who file lawsuits regarding web accessibility without coordinating with disability rights movements, which actually ends up misrepresenting the broader strategy that we have for making sure that access to digital information is accessible at the time it's created.

Parents with disabilities face real discrimination in almost all aspects of raising their children. I can tell you my lunch was interrupted yesterday by a call from a blind foster mother in the state of Michigan who was at the hospital preparing to pick up the baby that was assigned to be under her foster care, and the doctor said, "There's no way we can release this baby to a blind person. We can't do that."

We got on the phone and took care of it, but -- Valerie Yingling helped with that by the way, so if you see her around...

The media and TV industries still romanticize the otherness of disability, helping to make sure that the general public continues to love us out of competitive employment, out of raising our own children, out of real opportunities to pursue our dreams.

Old structures of support for people with disabilities continue to perpetuate the idea that the disabled or for that matter that disability should not be a concern or should only be a concern when it shows up, that it really shouldn't be a primary value of how we build society.

But of course each and every one of you in this room are working on those problems, and that's because we value not just the law but making sure that we use the law within the context of disability movements.

And we do have a lot of great tools at our disposal now. And the fact that we coordinate these tools is part of what helps us be successful. That we can come together and make real decisions about when to use the law, when to use some other strategy, to advance the causes that people with disabilities so urgently want us to advance.

In coming together in this room, we have an opportunity to explore how we can best leverage this community of practice that we have brought together. Just going around the room listening to the conversations that are happening, you know, that's where the real power is going to come from in the collaborations we create in the future. And I know we have great tools today and we have social media and we have Zoom and we have webinars, but I'm just going to say, I don't think there's anything more powerful to build connections than being in a room with each other. And I think the collaboration that I've observed already happening at this symposium is an example of that.

I hope that each and every one of you take away from this symposium a renewed charge to not just work on disability rights but a charge to take that passion and find ways to get disability to be talked about in the broader conversations of human rights issues. We know that disability is a powerful conversation in this room, but we need it to happen in so many more places. And we should not be afraid to think big in terms of how we are going to make that conversation happen in many more places.

And in that regard, we do have many things that we can celebrate, and one that definitely comes to mind is the fact that because of the work of many in this room, especially our own Scott LaBarre, the United States will soon officially be, in just less than 6 weeks, a party to the Marrakesh Treaty to be able to share accessible books all around the world.

[Applause]

When I say think big, we were told you could never get an international treaty dealing with blindness to happen. And if you could get it to happen, at minimum, it would take 20 years to get it done.

We took 10 years to get it done, and on May 8th the United States will join 82 other countries to be part of this movement that hasn't stopped yet. We're not going to stop until we get all of those countries.

And that brings me to our keynote speaker today. Dr. Harpur is a leading international and comparative disability rights academic. He is a senior lecturer at the TC Beirne School of Law at the University of Queensland, an international distinguished fellow of the Burton Blatt Institute in Syracuse, and has been awarded a 2019 Fulbright Futures scholarship.

Dr. Harpur's recent monograph, "Discrimination Copyright and Equality: Opening the E-Book for the Print-Disabled," analyzes the intersection between the anti-discrimination and copyright laws, building on international and domestic notions of digital equality and rights, including access to information, just one of many important topics that he has given emphasis to exploring and one that certainly is powerful when we consider what we have been able to accomplish related to the Marrakesh Treaty.

But he's not just an academic. He is active on many boards, promoting the rights of persons with disabilities as well as the rights of persons with disabilities to use assistance animals, certainly patterns of equal access and perspectives that are in the true spirit of Jacobus tenBroek, for whom this symposium is named.

So without further ado, I would like to bring you today's lunch keynote speaker. Here is Dr. Paul Harpur.

[Applause]

PAUL HARPUR: Thank you very much for these exceptionally kind words.

I apologize for the accent.

[Laughter]

I would like to say thank you to my fellow federationalists. I am a fully paid up member of the Marrakesh Treaty because it benefits people across the globe. So many things you are doing is having a global impact, and it's amazing to be standing here meeting so many people who I have seen on various lists and spoken with over Skype and Zoom, so thank you.

Now, in this room we all have a vision for disability inclusion. We believe in the right to live in the world, leading the way with participatory justice, the right to be physically present in the world, for public approval, and of course the legal right to be out in the land.

Later, the CRPD, the Convention on the Rights of Persons with Disabilities, included these principles. So I will say our rights are now clearer than ever before.

That doesn't mean that the dream is here yet. We don't live in a society that is without prejudice. With so many issues we've heard today, I sat and thought, what will I talk about? I asked myself, what would interest you?

So what can I say that I can have any authority on? And of course what is interesting?

I had a look at case law and social media, and one challenge that I thought worthy of attention is the erroneous view held by so many in the community that it's not their fault. I hear this again and again. "It's not my fault the building had no accessible lifts or that the guide that told the academic it was fine to post it there wasn't accessible. It's not my fault that the podium isn't wheelchair accessible or doesn't have the capacity for people using screen readers. It's not my fault the software on the HR system doesn't work so a person with a disability can't determine how much leave they have to take. It's not my fault that the ebook is not accessible, which is something I talk a lot about in my book."

So whose fault is it? It's a legal concept of negativity. Of course ADA and the anti-discrimination laws in Australia, fault is the key. You shall not do this. That is incredibly important, but in terms of systematic change, you tell someone not to do it, it's very hard to litigate in the end.

What you really want to do is flip it and look at who can make the change and how.

How do we do that? Well, positive duties are very limited in the U.S. and Australia. So what could I do about it? Beyond feeling exhausted and sleep deprived, in my keynote, I'm going to talk about something I have achieved in my university. UQ is a big university, University of Queensland. The annual budget is 1,300,000,000 U.S. here. We have a lot of supporters. We're ranked 48th in the world and 43rd in terms of law schools. We do a lot of work. So we're big.

So we could be, to get a change in that large institution, which we'll talk about, putting funds behind it I think has been big. It's not just that I want to do this but now the university is supporting me and funding me, which is always the hard part, to reach out.

So I think these fantastic results, some jurisdictions have exceptional proactive and positive duties. You think of the Scandinavian countries and their laws. We don't have that in Australia. You guys have it better.

Let's talk about the legal frame in which we operate in Australia and here around coping. In other words, the right to be in the world. And then I'm going to talk about how I've almost by accident developed this ability of equality and it's in the strategic plan now in the university.

So you know I'm Australian. In some respects in Australia, discrimination rules are superior in regards to direct discrimination. We've never had a Sutton trilogy. The comparative test in Australia is easier to satisfy than here in the U.S. So that's good.

But when it comes to indirect discrimination, the disparate treatment doctrine is so much more superior in the U.S. than how it's being applied in Australia. Why? The coping. What you have to do in Australia to prove the coping component which I'll address in a moment.

Essentially what I could ask is where does the law require those who disable us to remove the barriers that disable us? I'll say that again. Where does the law require those who disable us to remove the barriers that disable us?

Anti-discrimination laws is indirect in Australia. We have obligations, but we limit our approaches by relationships. Employer, employee. And outside those particular relationships, it's very hard to get anything done.

So you turn to the disparate impact doctrine. You may be familiar there's four elements. So the equal treatment element, the unfavorable impact, in other words, what we call in Australia harm, which I'll impugn momentarily. And then it's hard to justify. I think we could spend an hour talking about that, which we won't.

So what the third element, particularly in Australia, is really asking is harm. What level of disadvantage should a person with disabilities have to experience for them to have a legal right or legal redress? This approach accepts that people with disabilities do not have equality. We are not experiencing equality.

So U.S. laws have had its faults. We heard about them today. With the coping tests, you do them pretty well. I'll start with a U.S. case to illustrate just how different we have it. Both involve blind applicants.

The Australian case you may be familiar with. If you read my ebook, there are cases where Daniel Goldstein has been involved. There are heaps of cases in there that we use in Australia. So thank you, because your work touches everyone around the world.

[Applause]

How the bar exam is set. Excellent candidate. A blind lawyer, I've been in high school given a cassette tape and I handed it back and said, no, sir. The Australian technology wasn't great, but you just don't do that. If it's a handwritten document, I get someone to read it.

But anyway, the California association accepted her argument that it wouldn't alter the substance or content of the exam. The National Conference of Bar Examiners for some reason didn't like that approach, and they said the accommodations weren't acceptable.

The ninth circuit agreed and now we don't have such a situation.

Now, entities must provide access and equal opportunity. Australia doesn't have this situation. She could have realistically coped. Australia, we look at coping. Yeah, she could have coped. Wouldn't have been easy, but she could have managed. We don't look at what's equal; it's whether you can cope. It turns the focus really on to whether or not the person with a disability can cope.

A good case is against the University of Sydney. That's not my university, so I can talk about them.

[Laughter]

But it's one of the top three universities. It's a very big and powerful university. It's a fantastic institution.

Now, she was first required to access this university's central readings in a way she couldn't use them properly. So they gave her reading material in a format only provided her half access. So she couldn't use it and it wasn't fit for perfect. It's like given a car without tires. The university gave her an incomplete document in an inappropriate format, and classes had already started.

This student went to court. The court, in assessing whether the University of Sydney had breached the anti-discrimination regime, they considered whether she could have coped, whether she was coping with her disadvantage.

Generally, she did okay. Why? Because she was low vision and not totally blind. And her mother was wonderful and her grandmother, and they scanned stuff. They said that was good enough.

I hoped it was going to be an anomaly, but we've had other judges uphold this. But essentially the approach still remains. If someone can cope with a disadvantage, if you're quite good at coping, then you're probably not going to be actionable.

So the gaze on the individual's capacity to cope I would argue is against the CRPD. And when I advocate outside my employer, I'm quite strong and firm, and I generally gloss over the Australian position and go for what is reflective in the CRPD because advocating for change in your own institution is a bit more challenging. Firstly, I don't really want them to go to their lawyers and get proper advice. Once the lawyers are involved, it's all about risk mitigation. Once you're done that track, you can't get away with a lot. I used to work with an employment lawyer, and that's why I'm an academic and not an employment lawyer.

So what I do. I really wanted something more positive action. So I wrote books about it. And I'm an academic.

In 2011 when I started at University of Queensland, I was in a post doc rat research fellowship, which was great. But I felt really isolated. I sat in my office, I worked, people taught. I didn't teach, so I was isolated from my colleagues. They would welcome me and the library was very supportive. That started my process of the ebook because of the library procurement practices. But initially at this point in 2011 I was isolated. Didn't find any other staff or students with disabilities.

Hindsight, they were there. About 5% of our student population has a disability. Back then it was only 3.8 I think it was. But now we got 6,000 staff full time. Maybe even more. About 55,000 students. So there's a lot of people there. I just couldn't find them.

So we didn't come together. Staff definitely didn't.

So then I had issues about coming up with barriers. They didn't stop me working, but I went across and asked property facilities to fix this. ITS, information technology services, didn't know how to talk to them. I thought, maybe property and facilities. It's also near the library, so I thought maybe it was their issue. This came up again and again. You have all these different bodies and everybody is busy and no one has the impetus to do anything.

So I wouldn't say my issues were properly addressed at all. No one knew how to do it essentially. Like these people were friendly and helpful, but they didn't know within the scope of the organizational structure, they weren't supported to really do anything.

So after a while, I did get sick of this and thought what do I really want. First, I could cope. I couldn't see. I also wanted promotions and full-time employment. Tenure positions aren't supported by your employer. Tomorrow is going to come either way, I thought. But I thought, what do I want tomorrow to look like? Well, I want to be employed and I also want change. So I thought, well, it would be nice to see if I could just talk them into it. Which was the soft approach.

I walked up to the front of the desk of the vice chancellor secretary and said, "Can I talk with the VC?"

She asked what I wanted.

I explained and said I wanted to talk about university's inclusion first.

It turns out we had an exchange of documents on disability inclusion, disability action plan. We had had one since 1999 continually apparently. It was a good document within some extent except there was no one with a disability anywhere near it. And that was possibly one of the reasons because no one recorded staff with disabilities. I didn't take a lot of action to find people.

2015, they're in the process of drafting the new disability action plan. I said, can I just have a group to talk? I wasn't expecting to get much beyond that. And interestingly, they said, well, we'll take that upstairs.

They came back and said, they don't like that idea, but they would like you to actually do something. We'll fund it. Let's put in all the directives of the different operational groups and have people with disabilities actually do something.

I said, that would be pretty good.

[Laughter]

And that was then adopted into the strategic plan. So that was a big change, and we've done a lot of things.

So they saw my interest. It was written in. That put me in a situation of, what do I do? Because there's embedded people already, a lot of activities already going, so I thought, I developed this model which I had never really spoken about because quite frankly I developed it just to get something done, based on leadership and discussion with people, but since it's been working and now the last action plan which was adopted by the university in December last year includes my ideas. Now it has more merit.

So what I came up with, I call it a yes model. Because I like catchy things. Like University of Queensland disability inclusion group. They had written letters of support for us over the time period, but I knew from the outset that wouldn't get us a long way. Just running upstairs every time there's a problem doesn't get us there. One situation where someone didn't think it was their problem and it was. We just got a letter from the boss' boss to say, can you have a look at that please, and it got fixed.

So this model, the yes model. It's not designed for academic rigor, so I apologize if you think it's a bit simplistic. I thought, YES. Y, why? I usually get back responses of thank you. No one even knows what they're doing, so we don't know if it's good or bad. Part of the process is trying to collect data on what's happening. We typically send out emails thanking people for meetings and couple occasions get letters sent by the leadership team, thank you for meeting with the vice chancellor. Thank you. An individual in their position, the library, for example, when you get a letter from the CEO of the company saying well done to the manager, the person thinks they're doing something right. So that's an internal process.

Now, the disability action plan in December recognized and adopted, which is good. Now there's onus on the university for obligations to report on what's happening and seek out and find what's happening and promote it, which is good.

So you're thinking that's all well and good. Yes, you are doing well. Really empowers them to do well. But it doesn't do much to support those who are already doing good. Those who are doing good keep doing good.

To try to get to the next level of another aspect is make it easy. Which is E. Make it easy. We can argue about universal design and it's a great notion, but as you're probably aware, you try to implement any universal design, it's very hard. A good example is our library. We are going to purchase accessible ebooks. Cool. How do we do that, Paul?

There are systems out there. But that's good, but if we're going to explain to the finance people that we're approaching this one and this one and if it gets challenged, what can we use, we still haven't got there, but they've now done enough research that they're happy. And one of the things, when you go to a publisher, the person who tries to buy the product says, we spend 10-15 grand on this a year, but there are some problems with it, can you fix it, this one over here is problematic. So a lot of things have been fixed that way.

People don't have hours to spend researching this, so people come to me. And I try but I don't have hours either.

So one of the things I argue is review of the GOA which in Australia is similar to Ivy League. So we did a review of all the documents. Michael Stein reviewed it, which helped do it in the cloud.

Anyway, I thought the university wouldn't take much notice, but that was attached to the action plan for the vice chancellor and the Senate. They actually looked at it quite heavily.

One of the ideas there was around funding research to help find out what's going on. That's now the action plan 4.6. So support and funding research for disability inclusion and disability action plan, which sounds good but the disability action plan isn't just about students and staff. There's a wider mandate. So we're finding requests now to try to tap in to the money. Got one already around disability tourism and travel, particularly for academics with disabilities, like myself. And students. So that one is already funded. A few other things. That's exciting.

And the other thing, the S is strategic. Because universities all want strategic focus. It's all about money. So some of the things we have tried to get in to get things into the central plans, and other people down the line owned things and now do things on it. A good example, we got the university to pay for a snapshot digital snapshot. They're doing an audit of the university and bunch of problems, bunch of suggests, it's just a snapshot, not comprehensive. So we got that funded and operationalized. Some of the units took it off us, I couldn't do it anyway because I didn't have the resources. I thought that would be nothing but turns out they hired someone full time for the last 6 months so they probably spent 160 grand U.S. on it. So they're taking it pretty seriously. So that's positive, real change. Some impact me, some don't.

So the -- I'm sorry. I said that.

But beyond the students, helping the staff, I'm hopeful this will have a wider impact. How it's going to look is unsure. One of the things I'm here for and going forward is I've been asked, I actually got an email from the VC saying, you're over there, can you talk to people about disabilities, you're at NFB. I ran the speech past him first. They said, NFB is doing a good job, and I told him I would tell them he said that.

So I'm trying to increase conversations, as charged by the boss. And of course there's many people here who have been doing much better than I have down under for a long time. In fact, looking at when they started, I was an undergrad. I don't want to reveal someone's age here, but I'm going to be Fulbright next year with Burton Blatt Institute. So great opportunities there for collaborations.

Now, I think overall, I mean, in the U.S., I didn't think the implementation act would get through. I'm an outsider, but Donald Trump didn't strike me as someone who would be signing that. I don't know how that happened. I could speculate, but I won't offend someone else's President.

[Laughter]

No, seriously, it will have a monumental impact. In Australia, we have reasonable access but there's countries where people don't have resources, they don't have any. We've been restricted with sharing our resources, mournfully. But there is sharing that happens. But this will open up so much. So this momentum is going and it's fantastic.

So why I say there's a lot to do, I think there's so much already done. And I think what illustrated it for me last week was a judge who is blind, applying to become a judge, and the discussion around blind judges. The discussion was around how could the judge be more efficient. That was the content.

That made me reflect. When I was a law student and just starting, people were asking me, how can you study when you're blind?

So it's changed over my career from not whether a blind person could be a law student but how can a person be most efficient as a judge if they are blind.

That's a huge change. And we have come so far. And I think we're going to go so much further. And I think from what I hear today, I'm enthused at what's happening and what's going forward and the projects discussed from the table. So I would like to end on this note, a very positive note, and say we've gotten so far and I think we will go farther. So thank you so much.

[Applause]

Do I stay here?

MARK RICCOBONO: Thank you very much, Dr. Harpur, for that presentation.

Unfortunately, we don't have any time for questions. Lou Ann, who is in charge of the agenda, says it's time for people to move to the other side of the room.

1:30 p.m.

"Disability Rights and Immigrants"

MARC MAURER: All right. Can I have your attention, please? Time to get rolling here.

Any of you who are sitting next to somebody who is talking, just hit them in the head.

This afternoon, we begin with disability rights and immigrants. We have three people to present on this panel on this particular item. The litigation counsel for Disability Rights California, Aaron Fischer, and the pro bono coordinator of Al Otro Lado -- how did I do?

>> Not bad, Dr. Maurer.

MARC MAURER: Katharine Gordon. And Mark Weber, who is the Vincent DePaul professor of law at the DePaul University College of Law.

The subject of immigration is in the news always, especially recently. The subject of disability is rarely. However, there is a significant interaction, and it is an important matter for us to discuss.

We begin with Aaron Fischer.

[Applause]

AARON FISCHER: Good afternoon. Thank you so much for having me. I've heard from a number of people today that immigration is pervading this conference. I think that's great.

I want to start by why I think that is the case. And it's not just because it's in the news so much. I think it's extremely relevant to the work that we all do and the roles that we all have.

So why? Why does it matter? Why should we be talking about it?

The first is obvious: More and more people and more and more people with a range of disabilities are getting entangled in the increasing challenges of our immigration system. That's because the number of people coming into the country is going up. Number of people seeking asylum is going up. We also see more and more people being detained. We see more and more people getting caught up with the barriers to gaining asylum, to remaining in the country. Mark will talk a little bit about the public charge regulation that may be coming.

And these are issues that sort of distinctly impact people with disabilities. I'll talk about that a little bit. But it's not just that there are people in any population that are going to have a range of disabilities, and immigrants are no exception. I think there's actually been an increasing targeting of people with disabilities in the immigration system, the public charge issue that Mark is going to talk about top of the list but that's not the only one.

In 2009, DHS did its own studies and came up with a report with recommendations that said we can do better with our system, and one of the ways to do that is to exercise prosecutorial discretion and who gets detained.

Right now, more than 40,000 people on any given day are in ICE detention. More in customs and border patrol. And many, many youth are in a separate system of detention.

In 2009 there was a push to try to rethink that. Exercise prosecutorial discretion.

By 2011, further clarified in 2014, there were directives from Department of Homeland Security saying that there needs to really be a compelling reason for people with physical and psychiatric disabilities and other sorts of special needs, people who are pregnant or nursing, family members with special needs, to keep this group in detention while their immigration proceedings are going on.

January 2017, probably no surprise here, that guidance was withdrawn. No more prosecutorial discretion. And what we've seen is an increasing number of people with disabilities ending up in detention for weeks, months, and even years.

So that's sort of the backdrop. I'll just give a personal anecdote about how our organization got involved with this issue, the rights and well-being of immigrants with disabilities. In 2017, California, the state legislature, passed a few laws trying to protect the rights of immigrants in the state of California. And one of the directives from the state legislature was for the California Attorney General to go into an immigration detentions facility up and down the state and report back on condition, circumstances of arrest and transfer, access to counsel and those kinds of things.

The Attorney General convened a number of sessions up and down the state of California and invited advocates, people who could be helpful as they worked out what this investigation and report was going to look like.

I went to one of those meetings. My colleagues went to one of those meetings. We were invited because we were investigating Sacramento jail which at the time had about 100 immigration detainees, so they invited me to come.

In the room were about 40 of us, immigration advocates, ACLU, all types of great organizations. At some point I realized I was the only person in the room that came from a disability rights perspective and background.

Coming out of that meeting I was convinced that the Attorney General's staff was going to do an excellent job at their report and there was no way that disability was going to get the attention that it needed. So our organization, Disability Rights California, tried to complement what they were doing with modern investigations.

So quick word about Disability Rights California. Most people know how the P&A systems work. For those who don't, we have a special statutory authority that allows us to go into facilities that house, treat, and serve people with disabilities. That includes hospitals, psychiatric facilities, jails, juvenile facilities, and why can't it include immigration detention as well, we said.

So since that time, in the last two years, we've opened up a number of modern investigations to allow us into these facilities, where we can monitor, bring experts, take photos, talk to people in the facility, talk to staff. We have a pretty wide range of tools to try to figure out what is going on and how people with disabilities are being treated and what the experience is like.

We can issue public reports, we can litigate, we can partner with other organizations. We have a number of tools in our toolbox.

Being able to go into these facilities just by way of an example, some of the -- about a year ago, with the separated youth, when that issue was hot, very hard for Congress people to get into facilities that were housing the immigration youth separated from their family as the border. Our organization was the first to have people get access to some of those facilities to monitor there. So it's a strong tool.

We've been inside in California of the largest privately operated immigration detention facility I think in the country. It's in San Bernardino in southern California. It has about 1900 detainees on a given day. Once we were in there, we found that at least a third had some sort of mental health needs, in some cases very serious, and many more had a range of other disabilities. Mobility, vision, hearing. Really across the board. Like any cross section, you would see in our communities.

We went to Orange County Jail, the largest county jail-based operated facility in the state of California housing ICE detainees, about 700-800 on a given day. We went to Yolo County Juvenile Detention Center where youth are side by side with detainees in that system.

We went to a number of private facilities that housed unaccompanied minors or children as well, the Office of Refugee Resettlement, another companion to ICE.

So let me talk about some of our findings. About a month ago, we came out with a report about the detention facility in San Bernardino and the experience of people with disabilities there. I brought a handful of copies. You're welcome to take them. We have them in Spanish and English. On our website are fully accessible versions both in Spanish and English, and I encourage people to take them, look it up online, or talk to me if you would like to get a copy.

Let me go through a couple of our key findings from our monitoring. First, this facility is private, operated by one of the major private prison companies in the United States. It is built and operated as a prison many years ago. If you walk in, it looks like a prison today. The way the system runs really feels like you're in a jail or a prison. People are in colored uniforms. Restrictions on property. Restrictions on when they can go outside, when they can eat, when they can shower. It feels like a prison.

I don't need to tell you, but for people coming to this country for the first time, asylum seeker, you've already heard earlier, people who bring a variety of mental health needs with them and histories of trauma, this is a shocking experience for them, to think that they are coming to the United States for safety, to escape persecution and hardship, and to face this, worse than the violence they were trying to escape we heard more than once.

We also looked at the medical system and mental health system there. We found it to be generally inadequate. They did not have treatment services or programming. They had very limited mental health staff. Maybe most disturbingly, we found that when people have a psychiatric disability, it gets worse or deteriorates when they're in detention, and it's met with a punitive response. One example. On one of the days that we were on site, my colleague Richard and I, were walking around the facility and we heard something going on just in the unit right next to us. Several custody officers sort of ran to the scene.

We figured out, we saw handcuffs actually flying over a partition. What's happening, what's happening.

We found out that a man who had been there for some time had been on suicide watch and they were discharging him from suicide watch, which means in a stripped down cell, very harsh place to be, all your clothes are taken away. He was being discharged from suicide watch.

As he was being discharged, he was continuing to have difficulty and was acting out. And sort of wriggled free from some of the staff and started moving quickly down the hallway.

Instead of bringing in a clinician and trying to work with that individual, they immediately took him to a disciplinary solitary confinement unit and put him into a cell there.

Where things got worse. He started banging his head on the wall and engaged in self-harming behaviors.

This went on for some time until finally a clinician we were talking to said, "We're going to send him to a hospital to get some treatment and try to stabilize him."

So we certainly have people with vulnerabilities, people get worse, met with a custodial and punitive response rather than getting treatment.

We also found with respect to people with physical disabilities, other kinds of disabilities, all sorts of problems with accommodations. I came from working in the state prison system on a case where people with disabilities, things were not great by any means but there was a system in place, through litigation, to track and accommodate people with disabilities and to make sure that they were housed appropriately.

As far as we could tell, that didn't exist in this facility in San Bernardino. There is no electronic system to track people. There is no system to make sure that everybody who needs to know if someone needs a sign language interpreter will get one. We encountered people who needed sign language interpretation and did not get one for medical appointments or anything else.

We found people not getting accommodations. One man required a walking cane couldn't get it for several months. We saw broken wheelchairs and a grievance system that was not functional.

One fun anecdote there, there's a requirement that ICE be notified every time somebody is denied a reasonable accommodation. That is a requirement through the ICE regulations and standards.

We asked the coordinator who would receive those notifications, how many times has this happen? How often do you have to deal with these situations?

He said, well, we've never denied an accommodation.

How do you know?

Well, no one has ever told me.

[Laughter]

So we had records that showed grievances, requests for accommodations that had explicitly been denied, we showed him, and he kind of looked surprised.

So disability accommodations were ad hoc and basically nonfunctional. This is a particular problem in a system like ICE where people are moving from one agency to another. So if they're lucky enough to get an accommodation at one point, it's not going to carry over when they get transferred. And that causes problems all the way down the road.

Last and critical finding that we this is that there's a lack of oversight and accountability. One example where ICE is not aware that people with disabilities are not getting accommodations they request or need.

Another example we found is that the group who operates the facility is not reporting suicide attempts to ICE, which is a requirement under their contract and the standards. It's an important thing to report to a government entity because that is a tip of the iceberg of a problematic system, an inadequate system of mental healthcare and unmet need.

We asked them how many suicide attempts had occurred at the facility in 2018, and they came back with zero.

We said, well, you know, we've spoken with people, we've had experts, we've requested records from people in the facilities where the clinicians had documented that somebody had attempted to commit suicide. We'll show them to you. What's going on here?

ICE looked at it and said, we'll have to get back to you.

They did, and they said, well, Geo group is using a different definition. And they were using an extremely narrow definition of suicide that essentially allows them not to report anything.

So there's an oversight issue. That obviously poses problems for advocates to try to get underneath and figure out what's going on, if there's bad data and lack of oversight and the information is in the hands of a private group.

Gives you a little bit of an overview of our findings. We started to figure out what's going to happen next.

I want to turn for a few minutes and talk about sort of another option, which is litigation and some systems work to try to improve conditions in these facilities.

First is to think about who do we sue. Certainly ICE under the regulations, just logic, maintains responsibility for folks in ICE, even if the facility is operated by a contracted entity. As I said, some of the facility are a county municipal contract, like Orange County Jail, and 70% are these private facilities.

Even with the private facilities, generally there will be a local municipality that is also on the contract with ICE. Essentially the reason we do that is to avoid the bidding process, which is the federal bidding process. If the contract is with a public entity, you can skip over that process. Carries its own problems but also carries an opportunity to go and say, you're responsible for this as well.

One question some of you may be asking is these are prison like facilities. So does the Prison Litigation Reform Act apply? And if so, I don't want any part of it.

The answer is almost definitely not. The law is pretty clear that detainees, civil detainees, are not prisoners which means that the very burdensome exhaustion requirements likely do not apply and it means very strict fee caps if you're successful do not apply. So that part is good.

Another good part for people who want to do some work in this area is that there are actually a lot of good government documents we can use. For example, ICE created standards written into the contracts that they have with detention providers. And those standards actually are pretty good. Whoever wrote those I think may have come to a conference like this. They're written well. They may not be worth more than the paper they're written on, but there are standards that people are supposed to be following.

Another is, there is an Office of Inspector General in DHS that seems to be continuing to do their work. So there are reports trickling up all the time about problems with the use of solitary confinement in these facilities, with inadequate treatment of people with mental illness and other disabilities, and a whole range of other issues. These are government OIG findings that we can use.

In California we're very lucky that we have the California Attorney General who just came out with their first report that I referenced earlier. That report came out end of February this year, with more findings of potential problems with solitary confinement, inadequate treatment for people with psychiatric disabilities and other needs. Really good tools for us as advocates.

Last area I just want to talk about are key issues and challenges to this sort of litigation. Key issues, disability discrimination, using the ADA and Section 504. And using the 14th Amendment as civil detainees entitled to a standard of treatment.

There has been some recent developments on detention conditions and standards in 9th circuit and elsewhere. This goes back to the rights of civil detainees in Youngberg. I think we moved in the right direction on this issue and I also strongly believe that it's a good opportunity for different advocacy groups to work together. A lot of the work on civil detention that our organization has historically done is people held through involuntary commitments in psychiatric hospitals and elsewhere to try and do the work of deinstitutionalization and improving conditions.

Well, a civil detainee held in a psychiatric hospital has the same legal status as a civil detainee held in immigration proceedings, at least according to the 14th Amendment, so it's a real opportunity for us to put our heads together on this front.

Essentially with the 14th Amendment, the mandate is, conditions for civil and civil detention should not be punitive. And if conditions are similar to or identical to or more restrictive as compared to a punished prisoner population, then you can infer that it's a punishment. And when you go to a place like Orange County Jail where you have ICE detainees and prisoners side by side in units, in some cases one cell over from each other, it's pretty easy to infer that the civil detainees are being treated like prisoners.

There are some challenges here. It's a different population. Immigrants are generally not as savvy about their rights and they're not as interested about some of these conditions issues because they are rightfully focused on their immigration proceedings and are afraid of putting their name on a declaration or lawsuit that could lead to retaliation. So that's a challenge.

Second challenge is just the enormity of the system. The system is a giant beast problem I call it. And people can be moved around. So if you are going to go look at one facility and contemplate someone in one facility or challenging conditions in one facility, well, they can move your clients out to another facility or to another state. Or they can move an entire class of people out. So you have to think about what the end goal is here, and that really is one lesson learned, how important it is to be keyed in with immigration advocates in thinking about how to challenge conditions without doing harm to people trying to make things better.

I'll stop there. Thank you for listening. I'll hand it over to Kathy.

[Applause]

MARC MAURER: Thank you, Aaron, very much. Before we hear from Katharine, I just want to say this: Those of you who have been working in this area, you know it very well. If there is a 2-minute drill that can give us background about what laws apply and how they apply, that would be good.

I'm familiar with the detaining of people in mental hospitals, and I know that system, but I don't know the immigration system, for example, and many of us don't.

Katharine?

KATHARINE GORDON: Thank you so much.

I am just very grateful to be here today. I think while this may be a new topic for this conference, it also comes right back to the heart of when the government started excluding people on the basis of their disability, on the basis of eugenics, and on the basis of immigration.

So I'll talk more about how those are connected since Ellis Island.

When I was initially invited to speak with you this year, the plan was I was going to talk more about my work with children who were detained by the Office of Refugee Resettlement in shelters across the country. I particularly worked in Houston, where one of the worst centers is, the Shiloh Residential Treatment Center, which is a center where children are placed if they have a disability, if they act out. Some children did have legitimate psychiatric disabilities. Other children had conditions like blindness, deafness, autism, intellectual disability, fetal alcohol syndrome, trafficking victims who were experiencing trauma.

Those children were routinely medicated against their will, against the consent of their parents. Oftentimes they would be given five or six psychotropic medications. Sometimes given metformin so that they would not develop diabetes type II as children. And Texas no longer places children there because too many have died in custody, but at the same time, the government still continues to do that.

So I was there talking to kids, hearing the kids' stories every week for two years every Friday. So Fridays for me are always, I think back to that experience.

And I did leave after a while, and I have found myself working with Al Otro Lado, an organization in Tijuana that works in San Diego and Tijuana, and it really focuses on the impediments to asking for legal asylum from asylum seekers. It's very clear under any type of international law or federal law that people have a right to apply for asylum. However, for the past several years, including under the Obama Administration, people have been metered. So only a certain number of people are allowed to ask for asylum each day.

So it's been traditionally about 100 people a day down to 40, and that is at a land crossing which is the largest in the world where between Tijuana and San Diego, about 300,000 people cross each day and only 40 or so people can ask for asylum.

So I've been working there as a pro bono coordinator. I've also been working there, especially since the large flow of immigrants since about November, and given the situation, I am so honored to be in the position of pro bono coordinator, because we have brought down over 1300 volunteers, about 4-500 attorneys to come down and work and bear witness. So the outpouring of support has been like nothing I have ever seen. So I wanted to just, as an introduction, just go a little bit into the history of Ellis Island. And I'm not sure if you guys -- you guys have heard of Henry Goddard, who came up with the idea of feeble minded and morons. Those are the types of terminology used to exclude people with disabilities from wide ranges of life in the United States.

What is important to realize is that those terminologies, that was partly due to his academic research on Ellis Island when he was looking at who was feeble minded who was coming to Ellis Island, and he determined with his researchers that about 40% of Jews, Italians, and Hungarians were in these categories. So 100 years later, we're still seeing some of that extreme exclusion.

And I wanted to talk a little bit about Jacobus tenBroek and the right to live in the world. And to emphasize again that it isn't an issue of a person with a disability has all these limitations, but so much of it is that the limitations that are placed on them. And he writes that the actual physical limitations resulting from the disability more often than not play little role in determining whether the physically disabled are allowed to move about and be in public places. Rather that judgment for the most part results from a variety of considerations related to attitudes which not infrequently are quite erroneous and misconceived.

That brings us to the Office of Refugee Resettlement and to the situation that children find themselves in.

First of all, I think it's important to acknowledge that the Office of Refugee Resettlement has not really thought through what disability means and does not have screening material, has very, very minimal understanding of what a disability even is. They have no -- they do a basic screening which if they identify a child with a disability, then they are subject to having a home study before they can go to their sponsor.

That's about the only discussion of disability. So what that means is that children who come to the United States are fleeing violence and are coming in order to be reunified with their parent. If they're identified as having a disability, then they have to go through an extra several-month long process oftentimes to be released to their parent or to other sponsors. So basically just being diagnosed as having a disability puts these children into an entirely separate category or channel, which means that they end up in -- we shouldn't be jailing children, I don't think, but in any case, children with disabilities are jailed longer because of this understanding of disability.

And again, one of the things as well is that the Office of Refugee Resettlement has standards much heightened for parents and caretakers who want to care for children with disabilities. While it's really clear on the part of the Department of Justice, on the Health and Human Services, and pretty much any kind of civil rights initiative that parents should have the right to parent children with disabilities and that children have the right to be parented by parents with disabilities, that hasn't really gotten through. So we have situations where children are diagnosed with mental illness and then it is determined that it's not in their best interest to be with the family because maybe the family can't take care of the child's needs, and so children end up in long-term prison-like conditions because they have a mental illness.

The use of psychiatric medications against children's will is disturbing. There seems to be month protocol. This has been subject to litigation and also a lot of the investigation that I had done.

So children are very often, when they're sent to this residential treatment facility, they're very often very quickly diagnosed with bipolar disorder, with schizophrenia, and with a few other conditions that allow for the use usually off label of antipsychotic medications. So one typical child was taking at the same time Prozac, Abilify, clonidine, Risperdal, and Percocet, and Seroquel. The kid is out of prison, and I recently had dinner with her and she was talking to me about her algebra classes. Very, very great kid and subject to this.

They also used as a control mechanism regularly injecting kids with benzodiazepines. On a weekly basis. It's hard to claim emergency when an emergency happens every week, but nevertheless, that's occurring. That happened against the consent of parents and many of these children are orphans, so they had no protection.

Another area that is beyond just the residential treatment center but is the use of medical and mental health professionals to find out damning information of children and to use that against them. Most of these children know not to trust the police, not to trust parents, not to trust anybody in their life given what they have suffered, but they do think that they can talk to a doctor in a white coat. This he think they can talk to a social worker or a psychologist who then writes down notes of everything that has happened to the child. For example, if a child has been threatened by a gang or has a family member in a gang or the child has witnessed a horrible thing, that gets flagged in their office of resettlement file and that continues with them, it gets shared with ICE, with the Department of Justice, and so children who have had a conversation with the social worker, with the psychologist, trying to explain, you know, when I was 12 I was forced to do weapons training. That becomes a way for that child not to be released from immigration detention and to likely be sent back to the country that they fled.

One of the challenges is how do we address this. One of the challenges with the Guantanamo Bay torture was saying that the psychologist should not be in the role of facilitating torture or facilitating lapses of medical ethics. So the question now is, what are social workers and psychologists and psychiatrists doing if they're in the position of taking information from vulnerable children and using it to harm them.

Another huge challenge has been the inability of advocates to really effectively advocate. They oftentimes are funded by the Office of Refugee Resettlement, so it's sort of like biting the hand that feeds you. It's hard to make claim, because they're technically supposed to be representing children in underlying asylum claims, and so it's hard for an attorney to try to press for conditions litigation or conditions complaints when the very existence of the attorney's position is due to the Office of Refugee Resettlement liking to work with you. That really does create a barrier, to say the least, and it does create high turnover and a lot of systemic issues that I think decreases the ability of children to effectively be represented.

So that's kind of the huge negative that we're dealing with. But a few things that I think are really important and I really want to focus on what Aaron has said about collaboration with immigrant advocates is so important. We have been able to now have litigation through the general litigation, the Flora settlement that gives people individual rights for a variety of conditions of confinement for children. We now have included in there Rehabilitation Act claims in there for the first time. So the judges looking into that are looking into Rehabilitation Act claims directly on that, and the immigration community is starting to understand that this is an area that they can work on.

Another area that was very important is the disability rights community being involved in the rulemaking process. When some of the -- I think the limitations of previous regulations were that nobody from a disability rights perspective was in the room, and now there have been a series of rulemaking actions where the disability rights community has been exceptionally active and has really, really brought their voice to bear at the very beginning. So I think that that's a huge development and something that everybody, many people in this room, should be very proud of.

Another area is just the broadening of community and of saying this isn't just something for lawyers. But this is something for every maybe.

The child I had dinner with talking about algebra, the reason she was out was because one of my volunteer's best friends from college said she was going to open up her home to this child she had never met. So she step by step by step fought with the Office of Refugee Resettlement so that this child could be released. So this was a case of a person who doesn't have much interest in legal issues, who was able to be transformative in this family's life, which I think is a really good lesson from there.

And then another thing as well that Aaron already talked about, sometimes it's very difficult to get access to organizations and access to shelters, so the way that the Disability Rights Bar Association and the NDRN have been able to go in and observe and monitor has been absolutely transformational. And that's a huge thing to, one bright spot in this situation.

An organization in Tijuana and San Diego works on people who want to ask for asylum but have been turned away with the issue of being told, we don't have capacity for asylum seekers. So that's created a situation where people are stuck in Mexico.

In response to that, we have been -- and I guess one thing that's important about people coming from different perspectives is that the origin of this project that I'm on now is a criminal defense attorney, Nicole ram owes, found out that people were being turned away from the port of entry, and nobody even thought that people should ask for asylum at the port of entry. Nobody for many years had even looked at the law to see what it required, and Nicole just looked at what the law said and so she for several years has been accompanying asylum seekers from around the world to the port of entry to sea the law says I have a right to apply for asylum.

Now this has gotten worse with a variety of issues of now it being almost entirely closed off and there's a lot of media coverage around there.

One part that hasn't made the media coverage is in light of these abuses, we've had over 1300 people come to volunteer. We've set up in just a few weeks individual, credible interview asylum screenings so that every single person who wants to learn about the asylum process can come to our office and have a meeting with a qualified legal worker who is supervised by an expert immigration attorney to learn about their rights and to learn about how to protect themselves.

Another thing we've institutioned is a rights-based approach to people who have vulnerabilities. We're not looking at it as this person is weak or this person needs special help. We're looking at it as this person, because of their characteristics, is more likely to be subject to discrimination. So we are identifying and flagging unaccompanied minors. We are flagging people who speak indigenous language as their first language. We are identified people who are at immediate risk of harm in Mexico. We also are identified people who have disabilities because we know of what may occur to them in immigration detention. So we're training all of our volunteers who come down every single day to learn about how to work with people with disabilities and to say this is an issue of not you need special help but more about here's how you can defend your rights and here are what your rights are as a person with a disability.

One area that we've done as well is looking at the issue of medical care and medical neglect and figuring out how we can create documentation for people when they cross over and ask for asylum. So we get doctors' notes to kind of show this person has a serious medical need. Customs and border patrol, you're on notice for this. Here's what happens if you don't do it and here's the likely harm. So that we have a written record for the person before they enter so that we can tell ICE and CVP, you have complete notice of this.

We're still fighting this and it doesn't get people to always care, but it does allow for disability to start to be litigated front and center.

And I think that, to just be wrapping up, the biggest thing that we can ask for right now is it is so important for people to come to the border and for people to come to the detention centers all around you and the immigration courts all around you. We've experienced a lot of retaliation because of our work, because we're suing the federal government, and including having our directors all be denied access to Mexico. One director, Nora Phillips, who has a connective tissue disability, was denied entry in Mexico for over 9 hours without water in retaliation for her work. And so the way that we can fight that is to come to Tijuana and to be reading Aaron's report and to be going to our detention centers right where we live.

Thank you.

[Applause]

MARC MAURER: So Mark Weber.

MARK WEBER: Thanks very much to Dr. Maurer and thanks to everyone here for the chance to address you. I'm really honored.

What I want to try to talk about today is the disability rights issues in connection with the proposed regulations having to do with public charges that relate to immigration. These here are not only to talk a little bit about what these regulations are proposing to do and their impact but to give you context how it is they come about and where it is they fit in.

Part of this is that traditionally, there has been, at least since the 1880s and probably a little bit before that, some exclusion of various categories of potential immigrants to the United States, to the point where by 1990 there were actually 33 categories in the immigration law, including what was then called mental retardation but also people who were, quote, insane, people who had physical defects, disease, or disability. HIV was not removed as a category until 2010.

There is a real connection here to the eugenics movement. That obviously hadn't started in the 1880s much but it was certainly in full swing during the height of the immigration period in the early 20th century. And as Katharine mentioned, there was this whole science of trying to show that one or another ethnicity had a higher connection to disability, had a higher connection to inability to care for one's self, had a connection to things that are going to pollute the native stock and in other ways harm the United States.

And it took so long to get rid of any of that stuff! As I said, it was 1990 before we got rid of all of these various categories, and it really didn't end until 2010.

The one thing, though, is that the public charge exclusion was never modified during that period in any serious way. And what the public charge exclusion does is excludes from entry those individuals who are, quote, likely to become a public charge. And that then has of course wound of being used in a way that the 33 categories were used before to exclude people from entry to the United States.

Couple of things that should be maybe mentioned about that have to do with what the proposed regulations are. The current law, which I've not really tried to produce in a slide here, but the current law does in general provide for the exclusion of people who are likely to become a public charge. Does not apply to asylees or refugees but does apply to pretty much every other category. For very short, temporary visits, it's not applied in any serious way, but it is applied to students, to people coming in as parolees, people coming in on an immigration basis to be spouses of people who have other kinds of immigration status. There are dozens of immigration categories, and it's applicable to all of those.

It can be applied specifically at the point of counselor admission, where oversees or in Mexico or elsewhere that's contiguous to the United States, you try to get an immigrant visa or a visa from one of those other categories, and you're required to get a medical certificate. In theory you can appeal the inability to get the certification that you won't be a public charge. Practically speaking people generally seem to give up.

Historically, recently, people who have gotten sponsors are not had too much trouble getting their counselor denials undone. That may change because the proposed regulations have language making sponsorship less determinative than it once seemed to have been.

Other things that maybe should be mentioned, the rules currently deriving from proposed regulations that were never finalized in 1999 had a field manual that was adopted in 1999 provide that what public charge means is somebody who gets more than half their support in cash assistance from the government or people who have subject to long-term institutionalization. Many of us are extremely critical of that. And now in kind of a way to prove that however bad you think things are, they can also get worse, the current proposed regulation is on the slide.

[Reading slide]

Basically, if you figure that out, that's about 152 bucks a month. That's hardly what I would think of as public support.

[Reading slide]

Now, there is a bit of a caveat here. Many people who are trying to get their status adjusted or to enter counselor offices have been excluded from a lot of public benefits since 1996 anyhow. So it's really quite unclear precisely how many people are going to be affected. But at least in recent years, many states have allowed various equivalents sometimes with modest federal support for these programs, even though the immigrants are excluded otherwise under the laws that were passed under Newt Gingrich's Congress in the '90s. So it could be a lot of people excluded.

The regulations actually even propose that Medicare part D drug subsidies are going to count. They're unclear whether they're going to include the CHIP program. So it's really quite draconian.

What's more, if you are trying to get your immigrant status continued or you're trying to get adjusted to lawful entrance to the U.S., it doesn't become a positive factor until you have 250% of the federal poverty guideline or what we really prefer they say is 400% of the federal poverty guideline. It might be noted and probably all of you do know this, of course people with disabilities have roughly three times the rate of poverty of the rest of the American population. So a whole lot of people with disabilities who are immigrants are going to be caught by this.

I did put the URL for the proposed regulations at the bottom of this slide. So if you go on to the web and get to the website for the conference, you can just click on that under the presentation that I got, and you'll find the actual regulations themselves.

Comments closed back in December, but they're still under consideration.

I did want to mention, and this is what I kind of suggested before, that vast numbers of immigrants are likely to be disqualified from entry, and what's more, and this was emphasized particularly strongly in the program that we just came from the breakout in, people are really being discouraged from even applying for benefits that they might be entitled to because they're simply afraid that ultimately they or another member of their household will never be able to adjust their status and will ultimately be subject to deportation. There actually is a ground for deportation on public charge, very rarely used but under the current politics I'm not certain that will continue to be the case.

I did want to mention a few numbers because nobody knows exactly what the numbers are, but thanks to the fact that Henry J. Kaiser made a lot of money many years ago in founding their foundation, they tried to put some numbers into play here. They said that 550,000 individuals living in the U.S. obtained lawful status in 2017. About 3,808,000 of them did so through a pathway subject to a public charge of determination.

[Reading slide]

They estimate that if the proposed rule led to Medicaid disenrollment rates of 15-35% among Medicaid and CHIP enrollees, between 2.1 and 5 million Medicaid CHIP enrollees would disenroll, which is a tremendous blow to public health in general for everyone.

Let me mention what I think of as kind of salient bases on which people might object to the proposed rules. And the first one perhaps the most obvious to all of us is the idea that it discriminates against people with disabilities. It really, really does. Not only is it true that these various factors such as income or really the whole idea of the things related to becoming a public charge may correlate with disability, but also disability is listed as a factor that the government is supposed to consider in determining whether someone is likely to become a public charge. It isn't even saying, well, it's a consideration whose impact may... It's disability is a factor. And it's a heavily negatively weighted factor essentially because of the way that the totality of circumstances test that they're proposing is to be applied.

What's more, the second thing that might be emphasized as well, you know, we have had the existing regulation which bad as it might be certainly is a lot more helpful. It's existed since 1999. Has Congress done anything to change it? No. When it was adopted, they said it was consistent with dictionary definitions and with traditional practice of what was then the INS and nobody challenged any of that. Oddly enough, the proposed regulations is a looking at dictionary definitions and historical practice, this modest level of public support of course means you're a public charge. Anyone who gets free or subsidized medical care is a public charge. So it seems rather strange if nothing else.

It appears to conflict with the 1996 welfare reform which led to some categories of immigrants being able to get these kinds of welfare programs. It seems totally irrelevant or irrational in many respects.

Many of us submitted comments to the regulations. I think the comments from the ACLU are terrific, the New York City bar, the Disability Rights Network submitted a great comment. So did DREDF and a number of other organizations.

For what it's worth, I submitted with Jessica Roberts and other disability litigators in Chicago, with the URL there at the bottom. My favorite comment was a five word one that simply says "Don't do it, you monsters."

[Laughter]

So we're a legal conference here. The question is are there any possible legal strategies here? One of which is attack it on the basis of being arbitrary and capricious, try to argue how it is consistent with current applications of the Immigration and Nationality Act.

Possibly the ACA? Because they're penalizing people who the ACA is trying to get on to Medicare, for heaven sake.

The second thing that I wanted to mention that might be a strategy to challenge it, remember the Hobby Lobby case? Many of us were not terribly fond of that when that came down, but it essentially said that the regulations that the Obama Administration adopted requiring contraceptive coverage were contrary to -- not the first amendment. They didn't say the first amendment. They said that they were contrary to the Religious Freedom Restoration Act. So does that maybe suggest to you that the regulations here in an unrelated area might be contrary to Section 504 which does bind the federal government?

Now, 504's wording with respect to the federal government is rather convoluted and maybe not all that helpful, but I think it might be a strategy, and it's one that maybe gives you a litigation look. This has been mentioned before: It's really hard to find a private right of action anywhere, but there is one under Section 504, so that might be yet a strategy that might be able to be adopted.

Will litigation work? Heaven only knows. I'm not terribly optimistic about the strategy of simply submitting regulation comments. 266,000 have been filed already. That may slow the government down, but I'm not terribly hopeful that we're actually going to get results from that process.

So any ideas that anybody has along these lines I think would be extraordinarily welcome. And there does appear to be somewhat unconnected but at least strongly felt coalition maybe, semi coalition, demi coalition that maybe could be formed with respect to trying to oppose what the government is doing here.

Thank you.

[Applause]

MARC MAURER: And thank you, Mark, very much.

I appreciate all of your comments.

Katharine was saying that the term "feeble minded" came out of the eugenics movement. There are two others that came out of the same movement. One of them was imbeciles and the other was idiots. And there's a hierarchy. I've forgotten it now. Some are more mentally incapable than others apparently, and all of these came out.

It shows you something if you recall that these tests were given to the recruits who went into World War I, and about 40% of the recruits who joined up at that time, if memory serves, were determined to be feeble minded. It tells you either how valuable the test was or something about soldiering; I don't know which.

Are there questions for these panelists?

Identify yourself, if you would.

>> I want to get clarity on the rule. Is that going to apply to people that are like family-based immigrants? And if it's family-based immigrants, they're required to have a sponsor, and the sponsors are required to have a lot of money to be able to sponsor them or they have to get backup sponsors. I mean, is that one of the cases they're looking at?

MARK WEBER: The answer is yes, yes, and yes. It does apply to people coming in as spouses or as family members. It's true that traditionally sponsorship had been a heavily weighted factor that meant you could get the visa. The comments that are attached to the regulations are quite disparaging of sponsorship. And so I'm skeptical that sponsorship will be treated the way that it has been before.

At the moment, kind of in recent years, the government had rarely gone after the sponsors when the individual needed public assistance, but I don't know whether that's going to continue to be the case here.

>> No, what I mean, it's just to get the visa? You're talking about them just having problems to get the visa?

MARK WEBER: Yes.

>> If the sponsor comes in and someone has a condition that might need some help, that they would deny the immigration visa?

MARK WEBER: It appears that that -- well, that is permissible and from the comments in the regulations, it strikes me that that is more likely to happen.

>> Thank you.

MARC MAURER: Other questions?

>> I have a question. I'm Hannah Levine.

Are you concerned if in litigation about given the Muslim travel ban case about deference to sort of what's considered evidence of discrimination for one to challenge this in court?

MARK WEBER: Thanks for the question. Yes. Not only is there something against Hawaii, but also cases going back a ways, Matthew against Diaz and others that have this very strong deference to the federal government.

There were earlier cases indicating that states can't discriminate against immigrants, even possibly immigrants who aren't here lawfully, at least in a number of circumstances.

But there's this very great deference to the feds with regard to immigration.

Now, it's true, Trump against Hawaii did emphasize national security which doesn't seem to be a relevant consideration here, but again, this will be an uphill fight if you're going to challenge it on litigation, which is probably why it would matter a lot to have a workable coalition.

MARC MAURER: Other questions?

>> Yes. I'm Eric Rosenthal with Disability Rights International.

I was part of the panel that spoke earlier on immigration and asylum. I appreciate the fact that this conference has given so much focus on this issue.

Some of the issues that I mentioned at that, that I was unable to follow up on, I mean, we're an organization, Disability Rights International, that documents the abuses that people would face in other countries if they are deported. So we are deeply appreciative of the efforts of immigration and asylum attorneys who are working in the United States to help people to prevent that deportation, because they truly do face incredible, incredible abuses if they are returned and they face the prospect of being placed in psychiatric hospitals, orphanages, or other facilities in other parts of the world.

Part of the discussion is that I didn't mention earlier in the previous panel, we've heard a lot about the separation of parents and children at the U.S. border. My organization has documented an issue that I just want to alert you to which is that children separated from their family as the border, as well as unaccompanied minors who are returned to Mexico are often not reunified with their families. These are children just dumped back into an abusive social care system in Mexico. Mexico has a large orphanage system. So a lot of these kids are going to be dumped into institutions even if they have parents when they are returned to Mexico.

We're going to be publishing a report on the situation at the end of April. So keep an eye out for it. Disability Rights International, looking at the impact of the people sent back to Mexico.

MARC MAURER: Comments from panelists?

KATHARINE GORDON: I mean, I think we're just so grateful that there is that international focus. Our organization is also working with parents who are returning to the United States who were separated from their children. Some of their children are experiencing extreme trauma, PTSD, and some of them are in the position of perhaps being adopted by foster parents, by other people because of that family separation. And if you think about the level of additional trauma that that's going to occur, especially with children who are Deaf or with many other disabilities. So it's important to recognize the whole context of this.

MARC MAURER: Other questions?

>> Yes. Victor from Florida P&A.

With regards to the (inaudible) rule, is there any time frame, outer limit, let's say you have an LPR here for 12 years and starts receiving some sort of public assistance. You said that there's a little used ground for deportation, but what about if someone wants to adjust for naturalization?

MARK WEBER: Naturalization is not clearly spelled out with regard to that. The greater concern that I saw advocates expressing with regard to people who have LPR status is that the government appears to be contemplating that if the person who has LPR status is away from the U.S. for more than six months, then the public charge exclusion would be applied to that person if that person tries to reenter. But the regulations are rather ambiguous about, that the proposed regulations, so it's quite uncertain.

But generally speaking, you're right. If there's an application for extension of a visa or extension of a non-LPR status, then the public charge exclusion does come into play.

MARC MAURER: I appreciate the comments of the panelists. It does seem to me that the people who get their courage together and put their energy into immigration into the United States demonstrate that they have something to contribute. And I keep wondering why don't we welcome them.

Consequently, my point of view on immigration might be different than some I've heard about.

I am thankful for you to come. I know that my own grandparents a long time ago were immigrants, and I am glad to be amongst so many other immigrants here.

We are now ready for the break, and there will be a little coffee. And furthermore, we have workshops after that, and we come back here at 4:15.

Thank you very much to the panel members.

[Applause]

[Break]

3:00 p.m.

 "Enforcing Section 504 and The Americans with Disabilities Act for Children with Diabetes in Schools and Other Settings"

SETH PACKRONE: I guess we'll get started. My name is Seth Packrone. I'm a staff attorney with Disability Rights Advocates.

SARAH FECH-BAUGHMAN: Hi, I'm Sarah Fech-Baughman and I direct the litigation program at the American Diabetes Association.

SETH PACKRONE: Disability Rights Advocates is a national legal nonprofit that does systemic and class action litigation. We've always done litigation on behalf of students with disabilities, but we started working with the American Diabetes Association in 2015 and have since litigated several cases on behalf of students with diabetes.

And what shocked me, and it was a conversation I had with Sarah, but what shocked me was just the extent of discrimination against students with diabetes, the fact that these students are still frequently completely excluded from programs based solely on their disability.

So the purpose of today's presentation is to talk about how to enforce Section 504 and the ADA for students with disabilities, with diabetes in particular.

We'll start with an overview of Section 504 and the ADA, and that will probably not be much new information for anyone in the room. I know I'm really selling the presentation at this point.

[Laughter]

Then we'll talk about some hurdles to the implementation of Section 504 and the ADA, and those go from pretty much nonexistent 504 procedures to underenforcement of 504 procedures and stereotypes about students with diabetes. There's a lot of hurdles.

Then we'll talk about some strategies that you can use.

So Sarah will talk about strategies for individual and systemic reform in this area.

Then we'll discuss some relevant litigation that the ADA and DRA has brought over the years to enforce Section 504 and the ADA and use those as case studies to examine how some of the hurdles play out in practice.

And then finally we will invite discussion about some of the legal and practical challenges in this work. Obviously we welcome questions at that point as well and will try to leave as least 15 minutes for that.

So starting with a law not included in the title of the presentation, the Individuals with Disabilities Education Act and its limitations. As most of you probably know, it has some important limitations about who it covers, where it covers, and what it covers.

In terms of who it covers, the IDEA does not apply to all students with disabilities who need services. For a student to be eligible, the student's disability must fall into one of their 13 categories, and the disability must impact the student's academic progress. Students with certain medical needs rarely qualify under IDEA. We'll discuss that later.

Second, the IDEA only applies to certain locations: Public schools. So first, it only applies to public schools, not private schools, not religious schools. So while the ADA doesn't apply to religious schools either, there can sometimes be 504 coverage.

Second, it only applies to schools, not to camps, daycares, childcare centers, or anything like that. Those are really important services for students with disabilities.

And finally, this is a little bit redundant of the first point, the IDEA medication regimens are not a typical part of an individualized education program or an IEP. So some school districts pretty much disregarding Section 504 altogether will try to shoehorn students with certain medical needs into the IDEA and include sort of a medication addendum on to the IEP.

Slide 4 discusses the ADA and the protections it provides to children with disabilities, and often these are for students who might not qualify for services under the IDEA. Title II of the ADA's prohibitions applies in schools and other settings in which public entities provide services to children.

Title III also applies to privately run daycare and childcare or summer camps.

So under the ADA, schools must provide student with disabilities to services. The ADA may be the only legal protection for children trying to attend daycares and childcare centers.

We included some other portion ADA regulations on the slide, but one we wanted to focus on is the regulation pertaining to service animals in public enemies -- entities. Excuse me.

[Laughter]

This is a case that Sarah brought to my attention, Cullman County. When a service dog is necessary. It shows that Title II of the ADA continues to apply in addition to Section 504 in schools.

So just a little bit on background, there's a 7-year-old child with diabetes who had in his 504 plan that he could have a service dog that would alert him when the child's blood sugar was unstable. But when it came time for a field trip, the bus driver, would not let the service animal on the bus without a handwritten request from the parent to the superintendent for the dog to travel with the child, an updated vaccination letter from the vet and a letter from the company that certified the dog as a service animal.

So the OCR decision states that in addition to 504, Title II applies. It specifies that the Title II regulation that applies provides that public entities shall not ask the nature or extent of a person's disability but may only make two inquiries about whether the animal qualifies as a service animal: One, if the animal is required because of a disability; and two, what work or task the animal has been trained to perform. And there are only several circumstances in which the animal can be removed, if the animal is under control and the handler is unable to effectively control it and the animal is not housebroken.

So the important thing there is that even though the child has a 504 plan, the ADA's regulations and the obligations that schools have under it still apply and must be followed by the school.

Just to discuss this Section 504 and its relevant regulations a little bit, in terms of where 504 applies, the regulation provides that it applies to preschools, elementary, secondary, and adult education programs or activities that receive federal financial assistance.

This means that it covers some programs that IDEA does not. For example, religious schools that receive any federal assistance fall under Section 504. We'll also discuss later litigation against the U.S. Army that shows when dealing with a federal agency, Section 504 is the only thing you have there as well.

Specific to schools, the FAPE definition under 504 is pretty broad. Appropriate education is defined as the provision of regular or special education and related services that are designed to meet the individual needs of students with disabilities as adequately as the needs of students without disabilities are met. And are based upon adherence to satisfy the other requirements of Section 504, including the least restrictive environment.

We want to highlight here that Section 504, despite what many schools think, does have a least restrictive environment requirement. And we'll discuss later how these procedures are frequently underdeveloped or not developed at all at the school level using the New York City Department of Education as a case study there.

The focus of the presentation is students with diabetes, but we also want to highlight that 504 and ADA are particularly important for students with certain other disabilities. For example, disabilities that require modification to the physical environment, including blindness and low vision, and disabilities affecting mobility.

Disabilities that require medication administration during school, which include diabetes but also ADHD, severe allergy, asthma, epilepsy, CP, HIV. And the underenforcement of 504 extends to these disabilities as well. I just heard from someone the other day about a big city school district that refuses to apply asthma plans in 504. They have asthma care plans. This is a big distinction because the rights don't attach to any kind of care plan that would attach to a 504 plan. Perhaps that's why they don't provide them.

Slide 7 just highlights some of the important differences between Section 504 and the ADA and IDEA. First, qualifying under IDEA is harder to qualify. The IDEA requires that your disability fall within one of its 13 categories and that it impact your academic achievement, where 504 does not have that same requirement.

Procedurally, in terms of the protections required under the IDEA versus Section 504, the IDEA has much more detail in the procedural guidelines. We included some of the relevant regulations here but we would also point you to the actual IDEA statute listed here. 504 lists a couple areas of procedural requirements that states must have in place, whereas IDEA goes through those same areas and provides details of what those procedural requirements must have.

SARAH FECH-BAUGHMAN: Okay. So Seth did a really good job of reminding us all of the wonderful protections of Section 504 and the ADA, but as practitioners, we all know there are hurdles to enforcing those wonderful rights so that's what this next section will get into.

So despite the growing prevalence of students with celiac and asthma and diabetes and other disabilities that require 504 plans, they remain less common than IEPs and students eligible under IDEA, which leads to schools that are much less familiar with Section 504, its procedural protections, and sort of what is best practice and typical under Section 504.

You know, we hear at the ADA from families who are told all over the country, by their school districts, that we don't do written 504 plans and we don't do meetings for 504 students. Seth mentioned a school district that does asthma care plans and diabetes care plans or individual healthcare plans or they're called by a number of different names. Those are also common for students with diabetes, and they're a great component to the diabetes care that's provided at school, but they're not a substitute for a Section 504 plan, and that's an important case to make to a school, that they serve really different purposes.

Some school districts as they are entitled to under the IDEA and Section 504 will use the procedural due process protections under IDEA as a way to fulfill their obligations under Section 504, and this is fine, but others that do not do that, they either will often not have any process by which a student who is being denied services or has a disagreement about services can challenge that determination or if they do have one, it's very underutilized. Folks don't know what it looks like or who to contact and so as a practitioner representing a student with a Section 504 plan, you may have to do a fair amount of digging to figure out where do I go next.

And another hurdle is that we commonly hear surprise from private schools about the fact that 504 applies to them. So in these cases, an attorney who is able to do friendly but assertive advocacy on behalf of their client may actually if find success in educating the entity about their legal obligations and working together to find a solution by showing them what it might look like if they don't meet those obligations.

And of course in a childcare or other recreational program setting, you really probably won't find any procedural way by which a parent has been turned away because of a child with diabetes could challenge that decision or navigate a disagreement about whether the services can be provided.

The next hurdle that I would like to talk about bears on state law. And so when advocating for a child with diabetes or many other disabilities that Seth mentioned that require medication administration at school, one of the chief issues may likely be who will be administering the medication. Many students are very lucky to go to a school that has a full-time nurse but many more are not. Increasingly, nurse shortages mean that nurses serve multiple schools, and even in schools where there is a full-time nurse, that nurse is not a super human so they can't be everywhere to all people at all times. They'll be absent or unavailable at various points. So the question really becomes who is going to be trained to provide the care in the event that a school nurse is not available.

For diabetes, there are two medications a student may need, the first being insulin, required any time a student eats, which is regularly, and then glucagon, a live saving emergency medication similar to an EpiPen. In nearly every state there is a law that defines what it means to practice nursing. Usually it's called the Nurse Practice Act, similar to the state acts that regulate law or medicine. They're designed to protect the public from folks who are out to pretend as if they're qualified to do something that they're not. And they define what it means to practice nursing and what actions within that practice can be delegated to someone who is not licensed as a nurse. They're very different in every single state, but the first place you should be looking if you have a question about who can administer my client's medication is the Nurse Practice Act. I cited a couple of examples, some very clear that medication administration cannot be delegated to anyone. Some are ambiguous. Some relate specifically to a certain kind of medication or a route to medication. The Massachusetts Nurse Practice Act specifies that any -- I'm going to say this wrong, but parental medications cannot be given, which means anything other than oral medication cannot be delegated.

But the ADA has been successful in passing laws or regulations in 35 states which create essentially an exception to the Nurse Practice Act that allow for lay personnel to provide care specifically in the school setting. Some of these laws are specific to glucagon only. Some of them include both insulin and glucagon, but that's the second place you should be looking to determine who can administer diabetes care to the client.

And I also wanted to point out that there are many laws that also apply to other kinds of medications. EpiPen. The Pennsylvania statutes that I mention there carve out EpiPen and inhaler extensions. So those can be found in the education code, the health code, the regulations, a guidance document from the State Department of Education. You may have to go digging for that as well but that's a place that can be helpful at least as it relates to diabetes.

And then the final point on that slide is just that if you are in a head to head battle with a school district, in a state like Massachusetts where it's very clear that nonnurses cannot administer medication, and we have not been able to pass a law, where you have a client who is in a school without a full-time nurse and where they will not allow a layperson to administer their diabetes care, federal preemption is one legal argument that has been sort of in play, where the rights of the student under Section 504 preempt the state law who restricts who can provide the services the student needs. I will say that's an argument with no decided authority on. The DOJ has submitted a couple of amicus briefs in cases that we've been involved with and I can share those with you. But if that's of interest to you, we would be very interested in working together on that.

And Seth touched on this as well. Talking about the litigation that we filed. But just to point out that the effect of excluding a child with diabetes from school or a daycare setting with be devastating for a family. Very similar to other disability discrimination of course. But specifically as it relates to health related disabilities that require medication, there's a little bit of a difference from special education services where if the school is not equipped to provide the healthcare that the child needs at school, then the child cannot go to school. Or if the parent is not able to take leave to either provide the care at school or keep the child home from school, the parent is put in the absolutely terrible position of sending the child to school where they will not receive their medication and thus will be in a life threatening situation. So this is sometimes a little bit more urgent than a special education case, where compensatory education or other ways of redressing that can be raised.

Okay. So some strategies then for individual and systemic reform. Of course there are many ways to advocate for clients. Negotiating with the school district to try to figure out a solution, availing yourself of whatever due process may exist, and filing with the Office of Civil Rights.

Just wanted to point out that if you are looking into advising your client and to filing with the Office of Civil Rights, they have taken the routine position that they will not get involves in second guessing the appropriateness of a placement decision. So if there is a disagreement about what services should be provided, OCR is not going to touch that. They will be really good at making sure that the school follows the procedural due process protections that they need to be following, having meetings and making sure that the right folks are at the table and evaluating the student, and also very good actually for where schools and parents, if they have an agreed upon plan but they're just not implementing the plan, it would actually say that filing with OCR is superior for those cases over litigation. And of course they have the benefit of being free and relatively easy to navigate unrepresented. So certainly a very important option for families.

And I also wanted to point out on this slide that last the ABA worked in about 700 families experiencing discrimination. So there's a huge need for helping families navigate this process.

And of course we've done a little bit of work on the systemic level where there are states or large school districts or entire cities that are acting pursuant to a policy or practice of litigation that can often be a good way to address those types of discrimination.

The DOJ has been a wonderful partner in this type of systemic reform. You might be familiar with the Department of Justice 2013 letter of finding in Alabama, whereby they actually used Title II of the ADA to reach a finding of discrimination because Alabama was using what were called diabetes schools. That's what we called them. Where they send students with diabetes to certain schools and only certain schools. Basically to centralize the process of school nursing. And the DOJ found very conclusively that that is not in line with equal access. And so just point that out to find that there are actually some places in which D OJ can be involved in the education setting where we typically think of IDEA and 504.

And of course DOJ has been very active recently in the childcare space. I was just talking with Steve Gordon out of Virginia, and in cooperation with the local attorney offices and the main justice, there have been 10 settlements in the diabetes childcare context alone in the last 3 years. And they involve very large entities. Kinder Care being the most recent one. If you're interested in filing a complaint, I would recommend that you jointly file with the local U.S. attorney's office and main justice because some of the offices have very active civil rights practices or even dedicated civil rights attorneys. We keep some data on that as well at the ADA.

One important point I wanted to make on this is that DOJ has the authority to assess civil penalties which of course you can't get under Title III. So that's a wonderful little tool they have.

While it can take time for the Department of Justice to conclude a settlement process, for students who are not going to get immediately back into the program, they're probably going to find another placement anyway in a childcare setting because it's such an urgent need. So another factor mitigating in favor of Department of Justice complaints is that you may run into standing issues if you're litigating a Title III case in a childcare context where the parent might find an alternative placement that they're very happy with, they might have difficulty saying that they really, truly would go back to that program that discriminated against their child and disrupting the balance, which of course you need to be able to say. Just to point that out.

The ADA has position statements peer reviewed and published specific to the childcare and education setting that are really a roadmap for what is the best practice for a student with diabetes. And these can be good gut checks for you as an attorney. If your client is telling you they want something that is in direct conflict with what our position statement says, that might be a red flag. May not be. But it's definitely a place to look.

And they're also really helpful for guiding expert witnesses and formulating expert reports.

And I sort of alluded to this a couple times but the ADA coaches folks through self-advocacy, but if they do need an attorney, we also have an attorney network for referral. So if you're interested in joining our attorney network, we would love for you to do that.

And then I as the director of litigation provide assistance as a big part of my job to attorneys litigating diabetes discrimination cases across the country. So if you would like to have a gut check, connection to an expert witness, legal research, really anything, we have an amicus practice. I would love for you to contact me.

And then DRA and the ADA have worked together in a wonderful partnership I would say in a variety of different ways, but one of the ways that I wanted to just draw attention to here to this audience, that the ADA has found a lot of advantage to know your rights presentations in communities, specifically major medical pediatric centers where children with diabetes are receiving their pediatric care. So for diabetes, it's pediatric endocrinologists. And diabetes is a little unique in that you're meeting with your endocrinologist quarterly, probably calling them regularly, so the practitioners are very involved and will know if there are hurdles to receiving that care at school.

But I would argue that that's probably also the case for other physical disabilities. And that those providers are really eager in many cases to get information that can help their patients get the medical care that they need in school. So if you are interested in bringing a systemic advocacy case on behalf of a particular disability, a great source of information might be if there's a pediatric asthma clinic at your local hospital, connecting with those physicians can be a great source of information.

Of course there are pros and cons to both individual reform as well as systemic reform. On the individual reform side, it can be easier to resolve those cases with just negotiation, and it can be faster of course which is important when we're talking about kids who need their medicine today. But if negotiation fails, there's an arguable need to exhaust under Fry. We'll not turn this into another panel on Fry.

SETH PACKRONE: I will later.

SARAH FECH-BAUGHMAN: But I think suffice to say that courts are having a little bit of difficulty grappling with Fry and what exactly, how exactly to apply it. And so with respect to diabetes, I think it can be a little bit confusing whether or not exhaustion is required, because we typically conceive of diabetes care as needing FAPE. So my advice is typically to just exhaust because you would probably rather say you checked the box than having to brief it.

On strategies for systemic reform, in schools or cities or states where you have evidence of a pattern or practice or maybe even a policy of discrimination, bringing that case on behalf of a class really can be advantageous because in some cases school districts will just resolve individual case after individual case after individual case without ever touching the policy. Of course we know that's problematic.

There are strong options when you're seeking relief that a student can't obtain a particular case. You may run into mootness problems on the other hand, where the school district may be wise to what you're up to.

And then I have a couple of cases in the section on relevant litigation that the ADA did before we joined with DRA. Actually just one case. But it's KC versus O'Connell, filed in 2005 in federal court in California. And in California, there is a very, very severe nursing shortage. And so couple of school districts were taking the position that they would not allow lay personnel to administer insulin. The suit was filed very quickly. Part of the relief was a directive from the State Department of Education to direct the school districts that they needed to allow laypersons to provide diabetes care if a school nurse was not available.

That was great. Very clear directive.

But then the American Nurses Association intervened -- didn't intervene. They filed a lawsuit in state court in California violating this violated the Nurse Practice Act. And we intervened in that case. And that case went all the way up to the California Supreme Court, who found that it did not violate California state law and that school districts needed to continue to do this. This was one of those cases in which the DOJ filed one of those federal preemption briefs and it was not decided on those grounds. But one of the biggest lessons here that I wanted to point out is that you may be surprised to find this a case on behalf of a child with diabetes a very strong opponent in the school nurse. Typically that comes from a place of fear over job security. Rarely is it a true disagreement that it is not appropriate for a layperson to administer the diabetes care, but often you will find the school nurse to be at odds with you. So I just wanted to kind of highlight that dynamic which played out in our litigation there.

SETH PACKRONE: The next case we wanted to go over is about a small mom and pop shop called the United States Army. And in 2016, the ABA and DRA decided it would be a good idea to sue the United States Army over its policy and childcare programs that denied almost all diabetes care to children.

They excluded children with diabetes from attending childcare centers altogether. The ABA heard about this issue for 10 years before the litigation. The harm it caused the families was truly staggering. For a child with diabetes to attend a childcare program operated by the Army, the parent had to commit to providing all the care to the student. The base refused to have staff administer emergency glucagon, which left the parents no peace of mind.

The location of the military bases left these families in particularly dire straits. It was often the only childcare option in the geographic region. So if the child could not enroll there, the parents frequently had to quit their jobs to provide care.

We heard from families across the country who were struggling to make ends meet because one of the parents had to quit their jobs to care for the child. Other parents would transfer from base to base hoping the policy would be applied differently. Sometimes they would find that it was.

I think here, what especially was driven home to me -- and I know, Sarah, you get this all the time, but from talking to these families, you learn that your child has diabetes, which is a tremendous time of change and adjustment for families, and you need to get your child back into daycare a few days later. And then you go and find out that your child is no longer able to attend and you have to quit your job. It just really is staggering. That's not to mention the fact these children face this huge life-changing thing are told that they're different and will be excluded because of their disability. It was really, really horrible circumstances.

As I mentioned, we filed suit on behalf of the ABA as an organizational plaintiff and the child MW. We only had Section 504 to proceed under.

We engaged in settlement negotiations soon after, and they adopted a revise policy that removed some of the categorical bans on services that could be provided and replaced them with a serpentine review process for approving accommodations.

We continued to hear from families that the new policy or the revise the policy was not being implemented and that families who had tried to go through the process for years were not willing to go back through a very long process just to find out if they would get the services because there was still no guarantee.

After the roll out of this policy, the Army moved to dismiss the case for lack of standing and mootness. We argued voluntary cessation, and the case was dismissed on standing and mootness grounds. MW's claims were dismissed as moot because she had been admitted to the local childcare facility despite the fact that she was still subject to the revised policy if she needed new care. The ABA was dismissed for lack of standing.

We've appealed the decision on our standing up to the 9th circuit and the case is pending there. Do we have a date?

SARAH FECH-BAUGHMAN: No. We've been noticed for argument three separate times. They keep pushing it back.

SETH PACKRONE: One of the big lessons learned here was that even if you have an organizational plaintiff that arguably has standing to challenge the national policy because they've had members in many states that were impacted by this and they've expended resources arguably in many states where members were impacted by this, there is a value to having class action, especially when mootness can be an issue. So it's just a reminder of the value of bringing a case as a class.

Additionally, just the severe problem of childcare and summer camps excluding children with diabetes was repeatedly driven home throughout this process. Just last week I talked with a family with a 3-year-old who had just been diagnosed and was attending a very well-known childcare center and was told they could no longer attend, to try back next year and maybe they'll find resources to get a nurse. So it really does happen all the time.

The last case we wanted to highlight is MF versus New York City Department of Education. This is a case that DRA and ADA recently filed in eastern district of New York. Over the past few years, they had heard about systemic issues in New York City schools. We heard that the 504 process was largely unstructured and varied from school to school. Beyond that, parents are often left to fill in the gaps when the school fails. So the cases of punitive class action filed on behalf of three individual children and their parents and the ADA as an organizational plaintiff for violation of Section 504, the ADA and the New York City human rights law.

Our plaintiffs, each of them have been put in danger at New York City schools because of the DOE's failures. So the lawsuit really is a systemic challenge to availability and quality of care in New York City schools which we tried to group into four categories which we think captures pretty much everything.

At the start of the year there's often a failure to have care in place. Not just on day one but for weeks and months into the school year.

Beyond that, even when care is in place, students are frequently excluded from field trips and after school activities.

Every day students are forced to miss class time unnecessarily for routine care without even considering whether that care should be provided in the classroom.

And finally, the cherry on top, failure to adequately train staff so which they do have staff they actually know what they're doing.

Just to go into more detail about what some of these families are facing, to start, when care is not placed at the beginning of the year, the parents have to be on call to provide care. One of our named plaintiffs, her parent had to get permission from work so she could go to school and work remotely and sit in an empty classroom and be on call to provide care to her child.

Finally when the school did provide staff, which we'll talk more about that later, the parent had to provide the training to the staff because the staff didn't know what they were doing.

So this problem at the beginning of the year really does stem from the underdeveloped 504 procedures that the DOE has. Many parents have never had a 504 meeting let alone a signed 504 plan. So not only is there no care at the beginning of the year, but it can be infrequent throughout the year because it's not written out or clear for a parent to challenge.

The DOE's failure to provide care on field trips and after school activities similarly puts the burden on parents who routinely have to attend field trips just as a condition of their child's participation. If the parent can't make it for a field trip, for example, the school either excludes the child, leaving them at school, or they cancel the field trip altogether. Neither of which is a particularly inclusive way of handling the problem, and you can only imagine what that does to the child and the parents.

Our complaint alleges that the DOE doesn't consider its LRE restrictions at all. Children almost always have to leave the classroom to get routine care in the nurse's office. Adding to this problem is the lack of training. We've had multiple parents who show up on day one and train the nurse and other staff about diabetes. And then when back up staff comes to the school, the parents get a call in the morning to go to school and train the staff or provide the care themselves.

But the lack of training has a more systemic impact as well because it leaves the people administering the care skittish about providing it. We've heard from one family whose child would be taken to the nurse's office whenever anything went wrong at all. If the child was sad, if the child seemed a little off, they would take them to the nurse's office because they were afraid it might be diabetes related.

If that staff member was actually trained, that obviously shouldn't happen. But the kid would sit in the nurse's office for hours while his sadness passed and the nurse said it had nothing to do with his diabetes.

In terms of challenges to reform here, as Sarah mentioned earlier, New York does have a stringent Nurse Practice Act. So certain care can only be provided by a nurse, namely insulin administration. This is a particular problem in New York where they claim there's a nurse shortage. So since the state has made the choice only to allow nurses to provide the care and there's a nurse shortage, the options are limited but it doesn't change the fact that kids need to be safe at school and need to be provided with care in appropriate settings.

Just to touch on the current status of the litigation, we've entered into a structured negotiations agreement with the city which is publicly filed in case anyone is interested. We requested a 90-day stay to give us time to negotiate and make document requests. We're in the midst of those negotiations now, and I should mention, Torie here from DRA is leading those negotiations too. So talk to her if you have questions about it.

One of the big lessons learned here is just about the workings of a giant bureaucracy and how that can really not work to the benefit of kids and families. Especially when that giant bureaucracy doesn't have reliable ways to track data. And the importance of being able to, if you Google New York City student data management, you'll come across a system called SESIS. They really have no way of connecting information to students and tracking where students are, and that's just a huge barrier.

SARAH FECH-BAUGHMAN: On the point of a huge bureaucracy, one of the things that has been surprising to me, in many cases in New York City, the policies and procedures, they have something called chancellor's regulations, are really good; they're just not happening at all. The chancellor's regulations I think require that 504 meetings happen within 30 days? And that hasn't ever happened for anyone that we've ever heard of. In many cases beating your head against the wall of just do what it says that you're going to do anyway is part of the conversation.

SETH PACKRONE: It's particularly frustrating when they agree with you and it's already written down in regulations and they still can't do it.

But the other thing that I think that's been really driven home, although we already knew it, is that the Nurse Practice Act is just a huge barrier to appropriate care for students with diabetes. It really does limit the options of the school for how to effectively provide care.

The legal lessons that usually arise in education cases have not been barriers or issues for us yet. We didn't exhaust our individual plaintiff's claims because these problems are systemic. On class cert, defendants are not opposing and we are awaiting a certification from the court on that, so that's where those stand.

So we've talked for long enough. We would like to have a discussion and answer any questions, but we just threw out some prompts about some of the legal challenges to individual systemic advocacy. Obviously something we've talked about a lot here is the widespread ignorance of the law. Parents don't have time to read Section 504 and ADA regs. Unfortunately seems the childcare centers haven't read them either.

The conflicting state laws make it difficult as well. It's often unclear who can provide care.

And obviously you have exhaustion and class certification as well, which I mentioned earlier.

Just the practical challenges, the underdeveloped Section 504 and ADA processes, maybe that's a bigger legal challenge.

Identifying students and families which Sarah I think has a lot of great ideas how to do that. Stereotypes about diabetes and the urgent need for individualized remedies when you're trying to do systemic reform. Oftentimes these are life and death situations or the kid can't attend school at all. So there is definitely an urgency here.

Did you want to add anything?

SARAH FECH-BAUGHMAN: No.

>> So for the school case in New York City, are you doing this under a reasonable accommodation or reasonable modification request theory? Or more that they just have a general obligation under 504 and ADA?

SETH PACKRONE: I mean, the thrust of the case is about FAPE, under 504 and equal access to education under ADA and New York City human rights law.

>> But could you also weave in just the whole reasonable accommodation --

SETH PACKRONE: Yeah, I mean, that's definitely at play. Our goal is to get a functioning 504 system in place in New York City so kids can get FAPE and get written 504 plans. Obviously that's a route that we're considering as well, especially when it comes to the Nurse Practice Act and the fact that a reasonable accommodation to that would be having unlicensed personnel administer some of the care under the ADA or 504.

>> Yeah, I mean, not to take up too much air time, but especially under New York City law, just what they consider reasonable accommodation. I mean, they're allowing people to be out of work for a year. So everything is considered reasonable unless they prove otherwise. It just strikes me as I wonder if some of these parents could also go about it in sort of making that kind of a request on top of what you're doing now, trigger different obligations possibly.

SETH PACKRONE: Interesting.

>> I just wanted to mention that the Department of Justice doesn't have the same standing issue with the Title III entities. So if you're coming across a case where a parent has said, look, the heck with you, I'm going to move my child to another camp or daycare center, and you no longer have standing to bring suit, it's a good idea to refer it over to us. I work for the U.S. attorney's office in the eastern district of Virginia. One of my colleagues is here from Rhode Island as well. I'm very happy to help you to find other contacts at the U.S. attorneys' offices because we have done quite a few of these and we welcome hearing from the community on those.

SARAH FECH-BAUGHMAN: Thanks, Steve.

>> I have a question I think in general for Seth. I live in northern New Mexico. Very poor school districts. The average rate of students who have competency in that is like 7% when they graduate. Dropout rate is 60%. So you get the image, right?

My question is, when we're talking about FAPE, appropriate education has to be equivalent of what is provided to the nondisabled students, are we in a position in a state like that where you actually have to raise the level of education for the nondisabled students before you can hope to get anything for the disabled students?

SETH PACKRONE: That's a really good question. I think that gets at whether you frame it as equal access or meaningful access. If equal access is a lower standard because -- and I mean I've seen this in our prison cases. We represent students with disabilities in prisons, and frequently the response is often, well, education sucks for everyone.

But the good thing about FAPE, especially under IDEA, is regardless of what students are getting, there are very specific requirements that students need to be given access to the curriculum. Obviously if you're under IDEA, you have a better argument for more substantive resources to go into that child's education, and that shouldn't be held back by the abysmal state of education for everyone. But it is an issue.

SARAH FECH-BAUGHMAN: I would just say that really the sphere of 504 in the educational context is to allow the door to be open for the student to have a seat at the table. Unfortunately, if the table isn't well set, it's not necessarily a vehicle to make that happen.

>> There are no special education attorneys in northern New Mexico. I've looked. There's nobody to bring any kind of case at all. But if there were, what would your suggestion be that would be the strongest argument?

SETH PACKRONE: You want to talk after? I would be happy to talk more about it so I can get more details. I would ask what the percentage of students with disabilities are and those sorts of things. But I would be happy to follow up after.

>> Okay. Thank you.

>> I have a question. And it's not related specifically to diabetes or asthma. But we have had parents recently contact us whose children have been prescribed medical marijuana for treatment of seizures, for autism, and school districts are saying not only can we not administer this medication, but you must take your child off the premises, administer the medication yourself, and then you can bring them back.

SARAH FECH-BAUGHMAN: (Nods head up and down.)

>> Okay. So it's not just me.

SARAH FECH-BAUGHMAN: That's definitely a common -- I mean, we haven't heard it in the diabetes context but I've heard it discussed in education conferences and whatnot.

I don't really have anything helpful to say, though.

SETH PACKRONE: Which state?

>> Minnesota.

SETH PACKRONE: Because there was a case in New Jersey. Are you familiar with that one?

>> Nope.

SETH PACKRONE: Okay. I very vaguely remember. That's all I've got. But this happened in New Jersey and they were able to get it resolved in a public school district.

>> They got it resolved or they got a judgment? Is there something in writing that I could look at?

SETH PACKRONE: It's an NJ.com article. I would have to follow up with you but hopefully we can track it down.

SARAH FECH-BAUGHMAN: The conversations I've overheard about it are really focused around the Title II conversation of whether that is in fact a reasonable accommodation to require that something that is still regulated on federal level but may or may not be an issue is permissible under state law, to ask that the nurse administer something that could cause her license to be removed or his license to be removed. Arguably not reasonable. So I think that's where the legal analysis comes down to.

>> You know what, though? I need to look into Minnesota department of human rights, yeah, because it's Minnesota law.

SARAH FECH-BAUGHMAN: Yep.

>> So just talking it out helped. Thank you.

SARAH FECH-BAUGHMAN: Oh, of course. Glad we got somewhere.

>> For private schools, aside from the fact Title III as opposed to II, still have 504, anything that's different about what's required? Same obligations?

SETH PACKRONE: So not a religious school, just a private school?

>> Yeah. I mean, I guess religious can be --

SETH PACKRONE: I mean, then you only have 504 as long as there's funding.

>> Yeah, they probably do.

SARAH FECH-BAUGHMAN: I will say that some private schools do not accept any federal funding burr you would have them under Title III if it's not religious, but that would be important to look into.

SETH PACKRONE: But then you don't have the FAPE regs. I think if you have a private school that gets federal funding, Section 504 applies.

SARAH FECH-BAUGHMAN: I'm not aware of any.

>> Okay.

SETH PACKRONE: Okay. Thank you, everyone.

SARAH FECH-BAUGHMAN: Thank you.

[Break]

4:15 p.m.

"Framing the Image of Disability in Advocacy"

MARC MAURER: And if we could have your attention, please.

For this afternoon, we have a topic which appears in its simplicity to be simple: "Framing the Image of Disability in Advocacy." And we have people to talk about it who have enormous experience in doing this very thing, and have enough to their credit that they have changed the nature of certain types of litigation in the United States and for all I know beyond the United States.

In order to get this done, the panel keeps changing on me up here. So the first person to present this afternoon is a partner in the LaBarre law office, and here is Scott LaBarre!

[Applause]

SCOTT LaBARRE: Good afternoon!

>> Good afternoon.

SCOTT LaBARRE: That's lame. Let's try this again.

Good afternoon!

>> Good afternoon!

SCOTT LaBARRE: Thank you.

So seems to me that framing the image of disability in the way that we want starts at home. There needs to be an effort to make sure that those of us with disabilities are, indeed, framing the image in a way that is positive and helps those of us who litigate cases.

Now, it is not only necessary for the fact that we want to put forward the best clients with the best attitudes, but also just for the movement in general.

So it's important how we think about disability as a community. And Dr. tenBroek thought about this issue a lot, and he stressed the notion to his fellow blind brothers and sisters that blindness was, if you want to think about it this way, simply another way of experiencing the world. And it didn't hold you back from living a full and successful life.

That was a very important message at the time, because the vast majority of those who were blind didn't think much of themselves. In large measure, that's still true. Lots of blind people out there and other people with disabilities who think their life as a person with a disability is less than, is inferior.

Now, Dr. tenBroek was amazing. I unfortunately never knew him. I in fact was born the year that he passed away, 1968, and I wish I would have known him because he seems like just an amazing individual. And he seemed to have an incredible sense of humor.

So let me bring you something from Dr. tenBroek from 1948. I have a serious question to ask the sighted persons present: Would you swap vision for a good chicken dinner?

On the face of it, this is an absurd question, for no one who has vision would swap it for anything. But for those of us who were blind, this question is not necessarily absurd. It is not that we prefer to have lost our eyesight but that having been deprived of it, we have discovered it is dispensable. There are even some blind among us who assert that blindness is a joy, for as they point out those who lose their heads are decapitated, those who lose their clothes are deluded. Does it not follow, therefore, that those of us who lose their eyesight are delighted?

[Laughter]

But the point is true. It is all in your perception and in your perspective. To me being blind is just another way of experiencing the human condition. I don't wake up every morning thinking that it's worse than or better than somebody else's life. It is just my life.

Now, in the context of legal matters, Dr. tenBroek had this to say. I'll find this in just a moment here, if this machine will cooperate with me, which is dubious.

So as early as 1966, Dr. tenBroek wrote, "The legal and constitutional status of the physically disabled, their status in society and in the economy is a reflection of underlying attitudes and assumptions concerning disability and the social policies that it's based upon. Those attitudes, ideally those two concepts should be isomorphic. Being handicapped should correspond to the physical limitations of blindness without super imposition of additional difficulties."

So the problem we face in framing the disability issues is not so much the physical issues and mental issues that we face, but rather the attitudes and ideas that people propound about our disabilities. Those are truly the barriers.

So when we think about framing the image, it's talking about how we attack the attitudes, how we deal with the superimposition, as Dr. tenBroek said, of difficulties.

And of course the place to start there is with the way disability is traditionally viewed as opposed to what we seek. Disability is usually viewed as a medical issue. That's what the vast majority of people think. It is something to be cured, something to be treated. It is not regarded as a civil rights issue or I think a better term a human rights issue.

So the first place to start of course is for us to frame it as a human rights issue, one of fairness, one of equal opportunity, not concentrating on whatever the limitations might be of the particular disability or disabilities.

That I think is the major task we have, to figure out how to frame it as a civil rights issue and get away from the traditional narrative.

Now, there are many ways I believe to do that. First of all, those of us who are individuals with disabilities can never shake the fact or I think obligation that we are in effect ambassadors. We are representing our community. And when we go forth in our profession, when we walk into the courtroom or whatever the setting is, we have to display the kind of attitudes and perceptions that we want people to have.

I remember very vividly a case that I took when I was a young lawyer. I was representing a blind man who had been fired by the Air Force when he went blind. He had been an auditor. And in this context, he was an auditor not only who looked at numbers. He was a CPA. But he was also doing a lot of physical auditing, went around to bases and checked some inventory, looked at airplanes, whatever.

And of course the Air Force said, you know, that's impossible. You must be able to visually observe all of this independently.

Now, this was a case in the late '90s, so we didn't have quite the technology we have now. So his main proposed accommodation was to use a reader and to use a reader to give him the visual information that he needed.

Now, not to interpret, mind you, the visual information, but to give him the information in a raw form.

The Air Force said that is not proper, that is not a reasonable accommodation, it fundamentally alters the nature of doing the job and we're hiring two people to do the job.

And so we of course sued the Air Force. I conducted a lot of depositions, did all the discovery work, and when we settled the case in the six figures, one of the things that occurred is the assistant U.S. attorney who was representing the Air Force came to me and said, you know what my real fear was? It was of you being in that courtroom, walking around, using Braille, talking to the jurors about how blind people do things.

[Laughter]

So it is critical I think that we put forward the best possible image of disability ourselves. That's one way of framing it.

And of course in the organizational context, and those of us who advocate with and through organizations, we have to be very careful about the clients and the cases that we take. We want to make sure that we're able to frame the issue in the best manner possible, which means that we can't take all the cases perhaps that we would like to take.

And we have to be careful not only about the clients. And incidentally, it's okay to work with clients on the image of, in many of my cases, of blindness that they're presenting and coaching them on what works better and what doesn't.

But of course it's not only the clients; it's the type of cases. As you will note, the National Federation of the Blind does not take every case involving blind people, does not take every issue, and we sometimes end up intervening in cases that we would not have normally taken because we were afraid of the issues or afraid of the particular clients, but the cases have gained enough traction that we want to make sure we get involved and send a certain message about blindness.

And of course, and this is a topic that could occupy a whole day, but the rash of, quote/unquote, drive by lawsuits. These are really starting to hurt us and affect the message that we were attempting to frame about disability.

So it's very important to keep these things in mind.

Now, I understand not everybody can do that. Not everybody is litigating with an organization. They are on their own, they have to pay the bills. I get that. But we need to be as careful as we possibly can be.

Now, before I turn this over to Eve, I guess I want to point out one case where it was mostly successful, but also on the other hand demonstrated that at the same time how far we need to go.

Five years ago now, we got a decision in a case called Cannon versus Palmer College of Chiropractic, a case where a blind student was enrolled as a student at Palmer. He wanted to get his doctorate of chiropractic. He went through three trimesters of school, and they told him that he would reach a, quote/unquote, stoppage point because the reasonable accommodation he was proposing with regard to interpreting X-rays was unreasonable. He was proposing to work with a reader, much like my auditor case, where he would get raw information from the reader about whatever images he was supposed to be studying, and then he would make his decisions.

The school said, of course you have to directly observe these images. There can be no interpretation, no middle person; it's unreasonable.

Well, we of course argued that, no, in fact, it was reasonable, that most chiropractors don't rely on their own eyesight when viewing X-rays anyway; they rely on the X-ray reports from the radiologist and so on. And, in fact, blind people have been practicing chiropractic successfully for really over a century.

And so we took this all the way to the Iowa Supreme Court. And we won. The court said the proposal of using a human reader was indeed reasonable and that the school discriminated against my client.

But it wasn't a unanimous decision. It was a 5-2 decision. And the dissent had something very disturbing to say about the decision. Justice Waterman wrote this dissenting position. He said, "I respectfully dissent. The majority elevates political correctness over common sense. I defer to no one in my admiration for Cannon and his blind attorney and the challenges they have both overcome. But there is a point at which an accommodation ceases to be reasonable, and it has been met here. What is next? Are we going to require the Federal Aviation Administration to hire blind air traffic controllers, relying on assistants to tell them what is appearing on the screen?"

I say why not?

[Laughter]

But so just imagine, though, if two other justices would have thought like Waterman. This would have been a 4-3 decision the other way. Because in that very sarcastic dissent, we have all the elements. The idea of, oh, I admire you and you're so amazing, but on the other hand, your accommodation, even though it's been proved to be effective for decades, is not reasonable. And despite all the evidence, he still bought in to the stereotypes and prejudice about disability.

So the way I interpret the Cannon case is that we're on the right track. We're mostly doing the right thing. But there's still a serious problem that we are battling and that we have not mastered the image of disability to be the best advocates possible.

Before I turn this over to Eve, the last thing I want to say is, you know, I hope that someday this symposium is no longer necessary, because we won't really have to think about disability rights. Disability will just be a part of the human experience and be considered to be an everyday experience and that we're not special or amazing or to be admired; we're just people.

Thank you.

[Applause]

MARC MAURER: The next person to present is a partner at Brown, Goldstein & Levy. She leads the effort of Brown, Goldstein & Levy to change understanding about disability. She has been a deputy assistant Attorney General. I hope I got that title proper. And she has left, however, the government and is on the right side outside the government and has helped to change the nature of disability in the United States based to on her work.

Here is Eve Hill!

[Applause]

EVE HILL: Well, some of that was factual.

[Laughter]

Thank you, Dr. Maurer.

Okay. So I'm pretty sure that I was assigned to this panel because sometime around this time last year I said, wow, wouldn't it be cool to talk about how we frame disability rights and advocacy?

I didn't say I knew the answer. I said it would be cool if someone would tell me what the answer was. And then I read the agenda and thought, oh, shit.

[Laughter]

So I've spent some time thinking about that. And then in the last hour, I rewrote it entirely.

So my subtitle is now: How to feel better about yourself in case you lose your case.

[Laughter]

Never gonna happen. But you know.

So my approach to this comes from experience dealing with judges, federal agency leaders, defense counsel. I have a lot of trouble reframing for them. Legislators, employers, and business leaders. And these are what Gloria Taughten would call persuadables, except defense counsel. Although sometimes they surprise you.

So what I am trying to do, and it requires more thought than I sometimes have time for, is take our values in disability rights as Disability Rights Advocates and make them, frame everything we talk about in terms of values that it's really, really hard to disagree with.

So the values I work with most often are freedom. Everybody is in favor of that. Opportunity. Ideally equal opportunity, but at least close to equal. Fairness. That's a big one. Even my other end of the political spectrum stepfather agrees with me on fairness. And safety and security, which is a double edged sword in this area.

And the competing values that are similarly hard to challenge right on their face, but which are the flip sides of these, are things like pity and charity, which are only available to those who are deserving of them. That's why we don't go with pity and charity.

And inability, which is not what disability means.

And favoritism, unfair favoritism, which is often what people see reasonable accommodations being or auxiliary aids or even removal of barriers. They see that as doing something special that gives this person an unfair advantage, especially in light of the recent testings scandal.

So what I do a lot is try and just not adopt the wrong framing. It's often really tempting to adopt the wrong framing. Sometimes you're trying to frame the issue. I kind of like this, this is a good one, because when the judge is actually ruling in your favor for all the wrong reasons, so they're doing it because they feel bad for the guy, they want to give him a leg up, sure, this rich defendant can do this and this guy deserves it and yada yada.

Judges don't want you to argue with them for some reason when they're ruling in your favor. I don't know why.

So basically all I do, then, is just not adopt the wrong framing for myself. And maybe, and just hope, I keep suddenly saying, this is my frame, this is what we're talking about, we're not talking about charity, you talk about whatever you want, Judge.

And hope that later that night he or she will go, what the heck was that person talking about? Maybe I ought to look it up. And maybe they'll go see the other framing.

But I think when we have the opportunity to challenge someone's frame, how they think about disability, what we're doing is I like to think of it as mind blowing. Agency officials and legislators just haven't thought about what people with disabilities can do. They think about what people with disabilities can't do. It's based exclusively on, you're blind, you have schizophrenia, you're bipolar, you have an intellectual disability, you have whatever. And it just ripples out from there and usually ends up with, well, you can't do very much.

So they assume we can't do very much. They have no idea how we do anything. They've never thought about it. And you can't just say to the legislator you're trying to persuade or the judge you're trying to persuade or even the business leader you're trying to persuade "You're wrong, people with disabilities can do everything." It's too big a leap. And as, again, Gloria, my hero, really should buy the book, said this morning, you have to take people where they are, meet them in agreement, and stay in agreement as you move towards your position. So when you get to your position, they're still agreeing with ya. And by then it's too late.

So taking them where they are, finding something you can agree on, and planting seeds, showing pathways, demonstrating things, raising questions in their own mind about their assumptions, highlighting how their own values conflict with their assumptions, and showing them that their frame is acting like a cage. That's the problem with frames; they are cages. You can't get out of them.

And so I have been thinking about this, you know, for an hour, and my expectation of framing is actually pretty small and also pretty large. I am actually in a trial, I think, not gonna have time to give someone a new frame for disability. What I am probably going to do is give the judge, the jury, maybe the defendant, never the defendant's lawyer, not a whole new frame but a bunch of questions about the frame that they already had that lead them to recognize the truth, which is that they don't know anything about disability, they shouldn't have a frame for it, they don't have the facts, they don't have the understanding, they have no authority to have a frame for my experience or your experience, so they might as well just say, well she's got a frame; I'll use hers.

So it's the mind blown strategy. Get them to question their frame, chip away at it, push it out a little bit. Or just toss it aside and say, okay, that looks like a frame to me; I'll take it.

So the goal isn't to attack their frame full on. That leads to this weird what was called system one this morning. The emotional system where your whole reaction is defend. You can't say my frame is wrong! I'm going to defend my frame to the death that triggers a dopamine reaction and actually makes the fight fun for them.

So you just start, here's what we agree on, let's move from there to the next thing we agree on to the next thing. Start in agreement, stay in agreement, and work towards your position.

So I thought about the hardest part in litigation and in legislative advocacy and in lots of things other than family is you're trying to expand someone's frame but you haven't gotten to talk to them first or you have gotten to talk to them; they haven't gotten to talk to you. The way I learn what somebody's frame is they tell me. They don't know they're telling me but they're telling me. The judge doesn't start off with a speech about how he thinks about disability or how she thinks about disability, and the jury, I hardly get to hear from them at all.

So we have to assume some frames. You have to start talking before you get to listen. And then you can watch. And that's a form of listening.

And you can't seem like you're lecturing them. Just doesn't go over well.

So a couple of strategies that I'm trying to use, and I am not saying I know the answer. I want you to remember this. She didn't know the answer.

So we start with sort of, okay, I assume your frame is right. Number one, I assume your frame is either pity or charity and/or low expectations and/or it's not fair to give this person something extra and it's probably too expensive.

So let's assume your frame is generally right. You assume most blind people can't do X. Fill in X. But if one -- and I say but I agree, most people can't do X. I also happen to agree that most blind people can't do X, I also happen to agree that most people can't do X. I am one of the many people who can't do X.

But if one blind person can do X, we should probably let her, right? Almost everyone will say, oh, yeah, yeah, yeah, we shouldn't prevent her from doing that. Sure, sure, sure.

Then you go, well, do you think she has to prove that she can do X before we let her do it?

Oh, no, no, no, no, that wouldn't be fair.

So you have moved a long way.

We should let her try then, right?

Oh, yeah, that would be fair, we should let her try.

So maybe because we don't know which one blind person is going to be able to do X, we should stop assuming they can't do X and just assume for the sake of argument that they might be able to do X. And we should do what's easy, reasonable, to get out of their way, as they try do X. Until they demonstrate to us that they can't.

That is putting the judge in this, of course I'll recognize when blind people can't do X.

Seem reasonable?

Yeah, yeah, seems reasonable.

Awesome! That's what the ADA requires. Let's use this frame. They wrote it down for us already. It's a law.

[Laughter]

And the analogy is, lovely civil rights analogy. So until recently and still today, Americans used to think women couldn't do, fill in the blank. Fighter pilot. That's what I would be if women had been allowed to do that. Chefs. The people who prepare locks. Sports casters. Football players. So our frame said women can't do these things so our frame said we're not going to let them do these things.

And then one did. And then we started to say, well maybe we should not stand in the way of that. Maybe we should assume that some women can do this until they demonstrate that they can't.

And then we noticed, hmm, we might have been preventing women from doing this all along because you know what? The seats in the fighter jets are not adjustable. Well, that's stupid. We can fix that.

Or there are no women's restrooms near the locker rooms in the stadiums.

Well, that's stupid. We can fix that.

That's the ADA's mechanism. The ADA says this is how we learn when our frames are wrong. Stop assuming, we stop forcing our frames on the people who could do other things that we didn't think they could do, and then we remove the stupid stuff that stands in their way.

It's not too much to ask. It's a form of fairness.

Another little strategy, and that is the one that I use most often whenever I can, is show 'em. You assume blind people can't do this. Well, my expert is a blind guy who does this and he's going to talk about how he does it and you're going to go, ooh, you must be amazing! And he's going to go, and this one is a he, and he's going to say, no, I'm just average, I'm not special. We could do this. Not saying it's easy, because you can't do it and my lawyer here can't do it, but I'm not special, I can do it, if you get out of the way.

Strategy three is sort of showing they don't even know what blind means because they don't even know what blind means. So we're making a lot of assumptions about what blind people can do and we don't know what blind means.

So start talking about what blind means. And if he has or had this little slide that showed different visual representations of blindness, none of which show what every sighted person thinks blindness is, which is total darkness. Because guess what? We don't know what blindness is! And people's eyes just go -- the brain goes pow when you show them.

Strategy four. Point out some of the things they never thought about that show that their frame is wrong. Preferably something really powerful emotionally that will create an internal conflict in them to challenge it. So this is another thing Gloria talked about this morning -- read her book -- was that there are two systems in our brain. System one is emotional, activated by stories and emotion and it moves really fast.

System two is the one activated by facts and logic and it's slow and frustrating and you just want to slap it.

And most of the time we in making these arguments about what civil rights mean and what people with disabilities can actually do are working on system two. And you know, the judge has gone home and ruled against you and three days later, he goes oh, all those facts, wasn't that interesting? Hmm. Too late.

So sometimes you gotta use system one. So this is the flood case that Scott and I worked on. And actually he did all the work. All I did was this one thing: Show up on a day in court when Scott wasn't available and have the judge say to me, this is about a blind childcare worker who got hired by the Navy, showed up, filled out the paperwork, and then they said, oh, my God, you're blind, and fired her before she ever got to start the job.

So the judge said to me, this was not a hearing, this was a scheduling conference, so I was not prepared, and the judge said to me "Well, how can you watch children if you can't see?"

And I said, "Well, number one, you don't understand what blind means. She can see. And as we go to trial, we'll talk more about how she can see. And I don't know, your Honor, but blind parents do it all the time."

So that creates the conflict in him of, I have never thought about this before, I have no facts to contradict what she's just said, she said it very firmly, I must say, and God I hope that's right because it creates a terrible emotional conflict for me to say, with my little fact brain, ooh, danger to the child, we should take it away. So luckily he didn't have time to act like some of those social service workers who then take the child away based on what they think are facts.

But he said, "Oh, well, I look forward to learning more about that."

So that's the kind of thing you have to do usually.

Are you cutting me off, Dr. Maurer?

MARC MAURER: No.

EVE HILL: Really? Darn.

MARC MAURER: You have at least five more minutes.

EVE HILL: Okay. So it's hard for someone to apply their restrictive brain to an emotional issue where they immediately get the story and why this would be wrong. So use that when system one is going to be enough for you.

It turns out that you can't call a judge or religious leader an ableist to their face.

[Laughter]

You can call a business leader or an employer or even an agency leader an ableist, but that usually doesn't help. Either because they don't know what it means and therefore it doesn't hurt them enough, or they do understand what it means and they get defensive and you're back into they're getting a dopamine feed and you're going oh, my God this is not what I was here to talk about.

So this is my failure story. Ready? Feel bad for me. I want to hear a big ah at the end.

I had an experience with a magistrate judge who listened to me calmly explain why group homes for children with disabilities can't be banned from residential neighborhoods because of, I don't know, the law.

And she expressed shock. Shock, I tell you. That someone could, literally this is the quote "wake up one day and turn their house into a group home for children with disabilities without getting permission from the city or from their neighbors."

And then she said "I don't want you to think I'm a --" she did not know the word ableist -- "discriminator. I'm on the board of a disability organization." And what I heard her say was, I'm not a racist; some of my best friends are black.

[Laughter]

And I really paused for an inordinately long period of time while I thought, that means this and this and this... Um... So I bit my tongue.

Which seemed at the time the obviously right thing to do and I have regretted it every single minute since then which has been over a year because her attitude is terrible. I have not reframed her issue, and she hates me even though I refrained from telling her what an ableist she was!

So she was framing it as a neighborhood safety issue. And I haven't managed to reframe it for her. Yet.

Okay. Now the ah.

>> Ahhhh...

EVE HILL: I'm sure it will turn out all right.

Okay. But as Scott said, people with disabilities, lawyers with disabilities, are ambassadors for everything, and this is a heavy burden. But one of the best strategies for mind expansion, and it happens quickly, it's incredibly effective, is having the decision makers interact with people with disabilities. Lawyers with disabilities, experts with disabilities, clients with disabilities, speakers with disabilities, audience members with disabilities. Pack the room. And especially other judges and other decision makers with disabilities. So I'm really kind of excited about Loyola's and other group's work to pipeline people with disabilities into judgeships and clerkships and professorships and leadership positions. But people with disabilities in the room taking the lead, having the conversation, making the point.

So this is a real success. One recent success, Mark Riccobono and I did this. This work attitude change. Boeing employee credit union over the inaccessibility of their app. We're nice. We wrote them a letter and everything. And I don't think they wrote us an inaccessible response. I think they didn't respond at all.

And they're a credit union, which you may or may not know are kind of at war with web accessibility requirements.

At first they weren't responsive. We said, we want to have a meeting.

So we all trucked out there, Mark and I, and we brought their three blind customers who were our clients and the head of the local affiliate and the Washington Attorney General's office but that had nothing to do with it, I swear.

That got them in the room. Oh, my goodness.

And Mark Riccobono and the three blind members talked about their experience, why they were members of the credit union, why they were considering not being members anymore, how hard they had to work to do the things that most credit union members get to do at the drop of a hat on the mobile app.

And you could see or hear the lightbulb go off over the heads of these fairly high officials, including the defense lawyer, that being mean to their customers who they think of as members, is not their self-perception. It's a stupid business strategy too. But it was actually that they're nonprofit. They're supposed to be nice. Grassrootsy. What are we doing? Being mean to the customers? So they agreed to fix the app and their kiosks, which we hadn't even known about.

[Laughter]

And I didn't say a thing until the end of the conversation when I said, "Oh, don't forget damages and fees."

[Laughter]

And they've turned a corner and now made their vendors agree that everything they buy from them will be accessible, they've toured NFB, they're talking to their colleagues, they partner with CSUN. And so we've reframed that --

[Applause]

We reframed that from annoying civil rights demand to loyal VIP customer issue. And that worked.

And so now the part where I get to feel not so bad about myself when I lose, even when a defendant is fighting you tooth and nail, you're reframing the issue for some of the individuals.

So depositions, believe it or not, are an a-ha moment reframing opportunity. I'm nice in depositions. I know it's hard to believe. But the people you're deposing, if you walk them through that conversation that we just talked about, you know, okay, assuming most people can't do this... What if one can? Should we really stand in their way?

You can, again, see the lightbulb, which looks cool on video. And that can lead to changes starting to happen.

Unfortunately, it can also lead to a mootness argument later in your case, which I'm not as happy about.

And then win or lose, there are opportunities to plant seeds and reframe things beyond the actual judge or the jury. A statement, post, tweet, all those things about the outcome of an advocacy effort where you frame the way you want to frame it. Judge didn't get it? Doesn't matter. This is the frame. You're getting lots of other people who again have never thought about it, don't know what people with disabilities can do, assumed a bunch of different things, and they may think for the first time, huh, maybe my frame is wrong. Wonder where I can find out more about what's real.

It's good to have a link where they can find out more about what's real.

And my last thought, today I learned that we're advised to avoid saying things like defendants or the government give people with disabilities rights or opportunities. Because that pushes us back into the charity model, pity model. And it conflicts with our independence frame, our freedom, our we can do whatever we want frame.

But the ADA says you give us reasonable accommodations and auxiliary aids, so I'm going to try to be more rigorous about saying, you don't give me anything. You remove barriers that you built. You allow access that I will make happen. And you don't deny me opportunities.

That's it.

[Applause]

MARC MAURER: You can understand why Eve is one of my favorite people. Even better, one of my favorite lawyers.

[Laughter]

The final person to talk to us this afternoon is the cofounder and executive director of Harvard Law School project on disability and visiting professor of the Harvard Law School. He decided that it would be a good idea to have a gang. He decided that one was good but a whole lot would be better. So he got himself a project whereby he could persuade people to get involved in this kind of work.

Here is Michael Ashley Stein!

[Applause]

MICHAEL STEIN: Thank you, Dr. Maurer.

It's a great pleasure to be here even if I need to speak after Scott and Eve, which is a challenge and I apologize to you in advance for my voice. I lost it somewhere on the way here from somewhere else.

My memory goes back to the first of a few tenBroek symposia, and I realized that I've within gently notified of it by Lou Ann that I haven't been here for a long time. Being able to see so many friends and colleagues and people that I respect and former students has given me great pleasure and I really should come back more often if you'll have me.

As to the former students, I take no credit for what you do, but boy, it makes me happy. Thank you for doing what you do.

The Harvard Law School project on disability or HPOD is now in its 15th year. I individually have worked in 43 countries, implementing the CRPD. I was also fortunate to have a part of the negotiations of that treaty, and my work has very much shifted from the U.S. to the global although we still work on the U.S.

And in speaking with Scott and Eve, I revised my thoughts to try to dovetail a little bit better with theirs. As far as advocacy. And I'll try to highlight things that have to do with those who are blind and visually impaired, although we tend to focus our work on individuals with intellectual disabilities.

So just to give you a nice overview and some fun stories before we all move on to heavy appetizers, we have been working in Bangladesh for many years. And one lawsuit that we brought up to the constitutional court had to do with exclusion from take the civil service exam by those who are blind. Bangladesh has a quota system for blind individuals to be included in the civil service, yet nevertheless they would not provide accommodations and/or exclude them from taking these exams.

And we brought the suit. It went up to the constitutional court. It wound up eventually being split into two parts, those that had to do with judges and the part for judges is still sitting at the constitutional court after about 8 years, something like that. And then the part for the regular civil service.

And I have a very clear and happy recollection of the day that we went to visit, because you could do this in places, we went to visit the constitutional court and the chief justice. And Hezzy Smith, who you heard this morning, and I and some of our colleagues went there and they carried me up the stairs into the constitutional courts. A grand marble building, very Victorian, grand, and of course no elevators or ramps or anything else to get into the building.

And we went to see the chief justice. And we went and sat with him and had a very long talk. While we were sitting there, we had discussions about why it is that blind people actually could be judges, because in the earlier case, while it was being argued, the Attorney General for Bangladesh made the statement that well of course there are no blind judges anywhere.

And we said, well, your Honor, may I approach the bench? Here's a list of blind judges from around the world. Would you take judicial notice of this.

And of course they had to; there wasn't much they could do with that.

One of the judges for whom was on the list and helped with an amicus brief was Zach Yaku of the South Africa constitutional court who probably has more gravitas than all the justices on the Bangladesh constitutional court for all time.

He knew more about American legal history than I did. My education is actually from U.K. But we managed to bond on a few things. And I remember sitting there and hearing from him saying to me directly to my face, well, of course blind people can be judges because judges have to look at a defendant and assess their demeanor. Of course a blind person would never know if someone was lying to them. Never ever.

And I was sitting there thinking, my goodness, I've been transported back to the 1950s, and he would not budge from that.

And other things like blind people learn to compensate, they can hear better and their sense of touch is greatly magnified.

I was thinking, you know, when I teach disability rights, we don't ever have people say things like, oh, and blind people are just so much smarter because they have to learn how to process information and organize it in their heads and don't have the ability to jot it down on a paper and reference it. Or perhaps we should talk about people with disabilities being better looking and more successful. We don't hear that.

So we had this conversation with him.

That judge is still sitting there, the civil service case has been settled. But to his credit, to give a nice end to this story, we talked about discrimination. He said, of course we don't discriminate against anyone here in Bangladesh. Other than, you know, putting to death infidels and that sort of thing. We don't discriminate whatsoever against people with disabilities.

And I said, "Well, Justice, I actually had to be carried into the courthouse. It's not accessible. It is not open to all your citizens."

And he was completely shocked. He had never thought of that. And he had to go around the building and take a look at it.

And then he did something which would never work in this country. He sat down and wrote a judicial order to the minister of construction that a ramp should be built on the side of the courthouse. And then he said, "When are you returning?"

I said, "I'm going home in 3 days."

He said, "Can you pass the courthouse on your way to the airport?"

I said, "Sure."

And surely enough, as we drove to the airport, there was this lovely ramp outside the courthouse.

In the Philippines, we worked with a parent advocates for visually impaired children group. It began as a group of six parents with kids who were blind or visually impaired. The network is now 6,000 families across the various islands of the Philippines.

We are now in the second generation basically of this group so that the parents who were in the first wave are teaching the parents who are in the second wave.

We did a walkthrough of Manila schools and identified 600 children who were not in school and we taught the parents to be case workers and they went ahead and worked with the other parents taking them by the hand and saying, I've done this, we know what to do, and 600 kids were put into school in one round.

They now do these annual reviews where they gather and move to get children into school.

But this began with a conference at Manila's law school. The dean then, who is on the international criminal court now, and a dear friend, gave us the venue. And it was unlike the U.S. where we can't even get CRPD denial ratification put into the newspaper. It was covered by television cameras, by newspapers, and we had parents speaking. And it was the parents telling the stories. These are not wealthy people. These are people living at subsistence or under. These are people for whom going to school with their children means not eating because they can't forage for food or get support. These are not people who are used to getting up and pontificating. We had to practice. And these parents, pretty much women, got up and talked about what it was like to take their child from school to school to school and to have the same stories given over and over again, it wouldn't be fair to your child. We don't have the resources for them. The other parents don't want to see that. Wouldn't they be better off at home?

The same things over and over again.

And we were assisting in this initial work by the Human Rights Commission, which until then had been chaired by a very formidable woman for many, many years who had helped actually write the Universal Declaration of Human Rights with Eleanor Roosevelt but who did not believe that disability rights were human rights and had not in the decades of chairing the Human Rights Commission ever brought a case related to disability.

Well, they had changed the composition of the commission. It was headed by Layla, who said to me quietly, "I know you work in this area. My older son has autism. Give me some cases and I will take care of them."

And we did actually bring litigation and complaints to them. They were all each one of these ones resolved within 3 days. And it sent an immediate signal to the ministry of education and the ministry of special education and others.

Madam Layla is an exceptional woman. She's currently a senator and currently in jail having been put there by the current President of the Philippines without charges. So our thoughts go out to her and appreciate her for all her work.

In Vietnam, sitting with several ministers the night before this conference, which was to be an open conference about writing the anonymous national disability law, we had had a series of workshops together in private rooms without audiences where we sat and went over the drafts and they were enormously open and transparent with me saying, no, we can't do that. Or that's not going to work politically. Or what does China do about this, because they always care about China. And then try to outdo them because they don't like China.

We were seeing the night before this conference, talking about what would happen the next day, and there were no civil society members invited and I'm sitting there with them 6 hours from Hanoi because for corruption reasons they wanted to be in this particular hotel, and I said to them, "No disabled citizens. No disabled law professor." And this was a big event for them.

And they said, "What?'

I said, "No disabled citizens. No disabled law professor."

And they said, "But you're different."

I said, "That's just the point. I'm not."

And so in the middle of the night they drove up citizens with disabilities, carried them it up the stairs into the inaccessible hotel. And of course only permitted them a couple of questions but I managed to get some of their questions in.

In China, a group of blind journalists has done exceptional work in promoting a real understanding of what disability life is like. Both through programs that we have supported, materials, human rights manuals and others, they have done narratives on the radio that describe the successes of people with disabilities and continuing frustrations and exclusions of people with disabilities. So a realistic portrait. Nothing with rainbows and flowers and unicorns.

Due to their very, very intelligent advocacy, which we have tried to support, blind high school graduates are now permitted to sit the exams for university, and they do so with accommodations. This began a year ago for the first time ever. So the opportunity for blind and visually impaired persons to take exams with accommodations, Braille, electronic format, and so on, has changed now for the first time. And that's due to their advocacy.

Obviously in China there is no litigation -- well, there is but only if you really enjoy going to jail. Or otherwise meeting your local official on a regular basis.

For some civil society examples in South Africa, a group I'm very fond of is a group that exists in four townships outside of Capetown. They have women with disabilities, single mothers whose children have disabilities, and they work on empowerment and visibility. And purple is their color. So in the area where they have received from private donors, not from the government, housing and an inclusive school, they paint their houses purple. Instead of hiding the fact that they have someone with a disability at home, they advertise it. Their houses are painted purple. Very often they will paint murals of the individual with the disability, including the children, on the side of the house. And the message is: We're here and we're proud. Not, we're going to hide.

Their inclusive schools, by the way, are so good that the kids without disabilities are often pressed by their parents to try to enter these schools and to register in them.

In Israel for many years I have worked with the self-advocates with intellectual disabilities supported by many. I get to see them two or three times a year for many, many years. If you Google tasumakom [phonetic] -- and I have no idea how to spell that. I know them by name and have attended their weddings and they talk about living in the community. They do it in a culturally sarcastic way but oh, we love those disabled people but not here; what if they left the gas on in their house? Or oh, we just adore them; they're so cute.

These advocates on a grander scale actually went to the Israeli parliament and explained to them why they wanted supported decision making instead of guardianship. They gave examples of what their lives were like. They spoke themselves, no one for them, and the guardianship laws were changed and the regulations were changed. Supported decision making is of course a work in progress. But they did that.

On a less grand scale, some of them lived in group home outside Jerusalem decided that it was too dangerous to cross the street without some help, and so they lobbied the mayor and got a traffic light put in. The point being that changing guardianship laws is wonderful and laudable and we should all try to do it and some of us are trying to do it, but human rights of course begins at home and around the table and has to do with making changes things that mean something in your life.

Back here in the U.S., along with the Massachusetts advocates standing strong, and here I credit the wonderful Hezzy Smith, we have been, working with them to talk about making their own decisions. And you'll see both in our website and on YouTube and/or SAMI's websites the rolling out of our video project on decision making and about how you support yourselves and how you make decisions and how you and your friends can work together towards decisions.

And it's been a very wonderful educational experience. On one level, you know, we began with a questionnaire and with filming the self-advocates, and about one quarter of the way through the self-advocates said -- wrap up -- the self-advocates said, we love you but we don't need you to do these questions for us; we're going to ask each other.

So the videos of the self-advocates asking each other. And then working with this in focus groups to decide what they want to have on the film and what they want to have covered.

It's also been exceptional learning experience because one of the self-advocates who is prominent and we've worked with for a long time initially resisted the idea of supported decision making. His argument was, I have been making decisions for myself all these years; this is almost demeaning. I'm my own advocate. What do you mean I should have supported decision making?

He now understands there are some areas he may want help on. So he supported it. And it has to do with where he's going to have help.

Our self-advocates in Massachusetts have been working towards changing the guardianship laws. In Massachusetts at times battling with some of the allegedly progressive organizations who seem to think that it's more about elders but not about disabled folks and that it should be experts who come in and talk to them for which Chris Griffen and myself said, don't ask us, ask them, they're the experts.

So the projection of disability and rights is one that over the world is moving forward. People are taking ownership either of the ADA or of the CRPD or of the national laws, and really moving towards nothing about us without us and projecting an image of being powerful and being self-advocates and controlling their lives.

And that's a wonderful process. I'm looking forward to seeing more.

[Applause]

MARC MAURER: Thank you, Michael.

Thank you to all the panel members.

Let's see if there are questions. We have just a few minutes for them. If you do, state your name.

>> Hi. I'm Celia McGuinness from Oakland, California, and I wanted to ask Eve a question.

EVE HILL: Uh-oh.

>> So you think you blew it in front of that MJ because she didn't reframe.

What would you say to her if you could have the chance? Because there are some people, to let yourself off the hook, there are some people who aren't going to reframe so what would you say now that you think you could find a better way of doing it?

EVE HILL: Well, I'm not sure. And I'm still going to try. There's still time. Unfortunately.

I think I might have done better at recognizing where her frame was. I mean, it's not an unusual frame in group home cases, the neighbors have rights and safety and security are important. So I would probably start with safety and security are important.

And move from there to safety and security are important for children with disabilities.

And so this policy, which pushes them into multiapartment, you know, multiuse, giant industrial -- they actually said industrial areas, go there and reside there. We want to have this balance of safety and security for the children. Yes, safety and security of the neighbors is important. And we want safety and security for the children too. Don't you agree?

But you have some concerns about the safety and security of the neighborhood. How could I allay your concerns about that.

And presumably she would say, well, you know, we're afraid that they're criminals.

We could say, actually, no.

And we're afraid they're, you know, violent.

No. We can actually show -- we will be able to show you what the kinds of disabilities are that most of these kids have. And although we can't identify the particular children because the home was never opened, we can talk about the kinds of disabilities they have and I can tell you that they are things like ADHD. Are you scared of that? Do you think that's a big problem?

And you know, what is it called? Borderline personality disorder which nobody is as scared of as they might be if they knew more about it.

[Laughter]

Just kidding, I'm just kidding. But yeah, borderline, that's good. I'm on the borderline.

And so there are things you have heard of. These are 16-year-olds, not serial killers. All the things you think about mental illness are not true and particularly for these kids.

Shouldn't the neighbors get to know?

The neighbors do know. My clients had an open house and invited all their neighbors. And you see this piece of paper? That's signed by their neighbors supporting them. Actually people in another neighborhood signed the petition in opposition.

So I might have, if I had seen her framing better, I might have tried to start with agreement with her and if I had seen her framing and heard Gloria's session, I might have got further than, okay, I'm not going to call you a name.

But thank you for the question and letting me off the hook.

MARC MAURER: Other questions?

>> Hi. This is Daniel Hodges. I'm a student at the University of Baltimore, and one of the projects that we've been, working on is trying to help professors and other faculty members incorporate disability rights into their broader diversity inclusion discrimination contexts. And I wondered if anyone had advice on how to help them not only adjust their current frame on where to fit in but how to help them understand that we do belong in that greater diversity conversation and where that all fits.

SCOTT LaBARRE: Is this on? There I am.

So I think the best advice I can give you, Daniel, is be a pest and be a pest again, and then come right back and pester them again.

It is not in their narrative. Normally it's not -- they haven't framed it that way. And you just need to raise consciousness. You need to tell stories about how certain barriers have really affected you and your colleagues and that for you this really say human rights issue.

I have been working on the American Bar Association now for, well, since 1992, whatever that is. And we've gotten a lot better in the ABA, but there's still always work to do. And this is what I mean by being a good ambassador. It's not always easy. And it requires work.

Last year there was a resolution speeding to the ABA House of Delegates that encouraged the federal judiciary and other state courts and just the whole judicial system to become more diverse. And they specifically identified every category under the sun except? What? Lawyers with disabilities and judges with disabilities.

And I thought, do I have to do this again? Do I have to stick my thumb out and say, hey... Don't forget about us!

But I did. And everybody said, oh, yeah, oh, my gosh, we're so sorry, how could we forget! I don't know how we could forget.

But you just have to be the pest and keep doing it.

And there have been a few other things since then where people have gotten it right off the top, so I thought, well, even though it isn't always comfortable being the pest, you've got to do it.

And I am glad to say, we talked about judges earlier today, but there is now an American Bar Association resolution encouraging that our judiciary become more diverse including lawyers with disabilities. So that's something we can use.

MARC MAURER: And while we're on the subject, there will be from time to time diversity programs on campus. Do your best to get disability to be involved.

EVE HILL: I think also if the civil rights professors are not seeing disability rights as part of the pedagogical spectrum of civil rights, they are really missing it.

MARC MAURER: You could go tell them just like that.

[Laughter]

I know they would laugh.

EVE HILL: It is not a different thing. They somehow come at it and say, well this is totally different. It is not different. It is not different. It is getting rid of the stupid barriers that were based on your assumption that no one would be able to do this. It's the same thing that we did with women. It's the same thing we did with limited English proficient people. It's the same stuff. It's moving your barriers.

MARC MAURER: I hope it works.

MICHAEL STEIN: We could talk for hours about this. But I would just point out two things. One is, the recent Harvard pulse survey answered 10 questions and the advertisement for it with every dean in all 12 schools sending it around by email to everyone is, "Some people don't feel welcome here. Come help us understand why."

And guess which group was not included in it?

But my short answer to it is, Jose Anderson and Michael Higginbotham and tell them that the judge understood this, supported it, and would be quite pleased if they would as well.

MARC MAURER: We have come -- thank you to the members of the panel --

>> Could I just make one comment? I'm Shawn Scott. One of the things I want to say to you because I am one of the few people of color in the room, is that race complicates this tremendously. So when you are talking about reframing, there are some people who will not change that frame when you have the intersection of race and disability.

The other thing that strikes me as I've been here, this is my fifth conference, is you want to be visible. Right? It is making the invisible in some ways visible. And as you do this and kind of you embark on this work, and you say, see me, see me, see me, one of the questions that I have, and I say this as a parent of a child who has a disability, is as we talk about voting and access to voting, I would throw out the question, how many people have been involved in voter suppression actions involving race? So if you want to be an ally, be an ally. I feel strongly about if you are kind of talking about inclusion on campus, are you an ally? For those groups from whom you are also seeking support?

Those are the questions I would ask.

MARC MAURER: To respond to you, I would urge that if you have connections with people with disabilities who are nonwhite, I would urge you to bring them. I think we concentrate on disability a lot in this route. We believe in doing it. But we want to welcome folks with other characteristics that are devalued to some extent in our country. And I urge you to help us.

We have come now to the end of today except that we have the reception where the hors d'oeuvres get passed and the glasses are filled. And I know that many of you are planning on that, so I won't delay it further.

Tomorrow morning we have breakfast here at 7:45, and then we get together at 8:30 for the next session.

I think it's been a good day. I look forward to a nice one tomorrow. And I thank the members of the panel.

[Applause]