Thursday April 24, 2014

8:30 a.m. – 5:00 p.m.

**2014 Jacobus tenBroek Disability Law Symposium**

**“Disability Rights in the 21st Century:**

**Creative Solutions for Achieving the Right to Live in the World**

Held at:

National Federation of the Blind

Jernigan Institute

Baltimore, MD

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MARC MAURER: Good morning to all. Welcome to the Jacobus tenBroek disability law symposium: We are now underway!

(Applause.)

Which perhaps is a better way to begin than just saying good morning.

I'm Marc Maurer, President of the National Federation of the Blind. Dr. tenBroek was the President before me. I never had the honor to meet him. I joined the organization in 1969, and unfortunately he had died the year before. So I never met him. But I've met his writings and his thought, and I have done my best to carry them forward.

In 1938, I think it was '38, late '30s anyway, Dr. tenBroek wrote about interpretation of the constitution. He pointed out that the constitution is a document which should be interpreted the same way last year as next year and the year after that. And that it should be interpreted according to its own terms unless there's a need to bring extrinsic aids to it, and then he talked about the techniques to be used.

Certainty is required in the law, except that my effort, and Dr. tenBroek's effort, has been to change some of the ways that we interpret the law. And he knew it, and I know it. The idea is that the law which applies to many should apply to more people than it did, and I have specifically in mind disabled Americans. And beyond, that disabled people around the world. And the right to live in the world was Dr. tenBroek's statement about how it is that although the law had been interpreted one way in the past, we should recognize that there had been errors and we should change them.

I come to this conference with the idea that we can change things, and that the certainty which applied to disabled Americans in the past which was a certainty that there would be two kinds of law, one for able bodied and one for disabled people, would not persist and that we could change things.

Despite the decision that came out of the Supreme Court saying that the 14th amendment does not apply to us, despite the argument that the constitution has been inadequate, to prevent the 11th amendment from preventing us to gain damage, despite the congressional assertion that it should, the objective here is to make change. And I note that in the room today we have a number of people who have been comrades in arms in the past, and as I said to one of you this morning, I think of you as old war horses.

(Laughter.)

Now, some of you are younger war horses. But the objective that I have in mind is to change the application of the law so that there is a greater opportunity to apply the right to live in the world. And I think that's what we're doing in this.

I note that there is a disability law gathering that's happening on the west coast. Some people think that perhaps it is a disadvantage to divide the disability law discussion, but I take credit for having helped to create that one, although I didn't suggest it. On the other hand, we have helped to bring the reality that there should be discussions of this kind so that the American Bar Association has decided to have one somewhere else. Is it bad to have two? No. It's a good idea. We should recognize that this piece of the law is important and we should encourage discussion about it in many different areas and realms. And we can afford to take a minor bid of credit for helping to create the one on the west coast as well.

I note that the American Bar Association Commission for Disability Rights is a sponsor. The AARP litigation division is a sponsor. Judge David L. Bazelon Center for Mental Health Law is a sponsor. The Burton Blatt Institute is a sponsor. The Civil Rights Education and Enforcement Center is a sponsor. The Maryland department of disabilities is a sponsor. The Quality Trust for Individuals with Disabilities is a sponsor. Rosen, Bien, Galvan & Grunfeld, LLP, is a silver sponsor. Scott LaBarre is a sponsor, and Disability Advocates is a sponsor. I thank you all for helping to make this practical.

(Applause.)

We also have our committee. Lou Ann Blake has been managing the committee on our behalf. On the committee, we have Peter Blanck of the Burton Blatt Institute. And Charlie Brown, who at the moment is sort of retired. Marc Charmatz of the National Association of the Deaf, and Robert Dinerstein from American University College of Law and Brian East, Disability Rights of Texas. And Tim Elder, who is doing law now in California. Or all over the place, but from California. And David Ferleger, Leslie Francis of the University of Utah, Dan Goldstein, Scott LaBarre, and Jennifer Mathis of the Bazelon Center for Mental Health Law. And Mark Riccobono from the Federation here, and Meghan Sidhu also from the NFB.

I appreciate the work of the committee in bringing together the scholars that we have today and tomorrow. It is an extraordinary gathering of legal minds, and I have had some suggestions already that might change the nature of disability law in the U.S.

Now, Lou Ann has announcements which have to do with how we're going to conduct this. She has put the program together and has been responsible for the details. So you have things.

LOU ANN BLAKE: Good morning, everyone. Just a couple of quick announcements. Lunch today will actually be served buffet style. So as soon as your 11:00 workshop is over to, please make your way back to the other side of members' hall where you had breakfast. There will be two lines. Get your food, get seated as quickly as possible, so we can have everyone seated by 12:30.

For those of you taking the issues with common carriers workshop, that one has been moved to the fourth floor conference room. Those of you taking the parental rights how to workshop, that one has been moved to the Betsy Zaborowski conference room. We'll have people to help you so you don't get lost.

That's it for me. Now Chris Danielsen will talk about our social media of the law symposium.

CHRIS DANIELSEN: Good morning, everyone. I won't take up too much of your time, but as director of public relations for the National Federation of the Blind, I want to welcome you and to encourage you to help us discuss this great event on social media. We have a Twitter feed which is NFB underscore voice. We are asking that people who are at the seminar and wish to tweet about it and share it on social media use the hashtag JTBlaw14.

Some of you have asked in light of that what the wi-fi password is. I'm sure you've asked for other reasons as well.

(Laughter.)

But you know, we'll facilitate this. If you log in to the wi-fi network NFB guest and use the password add2decade. That's the password on the NFB guest wi-fi network.

That's all I've got. Welcome. Thank you.

MARC MAURER: Very good. We come to the first of the presentations today. Two people are here to give a theme. Margaret Jenny Hatch is an advocate, and Jonathan Martinis is a legal director for quality trust for individuals with disabilities.

Now, Margaret Jenny Hatch is a leader, an advocate, an inspiration to people across the country. She lives and works independently. She is active in politics. She councils state leaders.

Because she has Down syndrome, she spent a long, lonely year living in a group home against her will. She was cut off from her friends. She was cut off from access to the life she built in her community. Many people with disabilities face an imposition of guardianship, as was she. She challenged this imposition. She asserted her right to make her own decisions. With help. A trial lasting six days occurred, but the outcome is that she won the right to make her own decisions. She will talk about that, and Jonathan will talk about the work that he did to help in the process.

To begin, here is Jenny Hatch.

(Applause.)

JENNY HATCH: Hello. Good morning!

AUDIENCE: Good morning.

JENNY HATCH: My name is Jenny Hatch. I have Down syndrome. I have always been very independent. I volunteer on many republican campaigns. I graduate high school in 2004. I was a global messenger and was involved with the smart ones. I have a job and I ride my bike to work. I love it. To visit friends and even to my church.

I did this by myself. I was very proud of my independence. I worked for almost seven years at my store.

In March of 2012, I had an accident. I was hit by a car and was in the hospital. I had surgery on my back. It was scary. And I had to wear a brace.

No one wanted me when I was getting out of the hospital. I had nowhere to go. I was so happy when Kelly and Jim let me come stay with them. They helped me get services but I could not get a waiver if I lived with them. I had to leave them in order to get a waiver.

I did not want to leave. I was moved from -- oh, sorry. I was moved from one group home to another. I was at one home and did not feel safe there. I was treated like a child. No one listened. No one cared. I told my case worker I did not like it, and I wanted to go back to live with Jim and Kelly. But she told me no, I couldn't, and I should just get used to living in a group home. I told her no.

The group home wouldn't let me talk to my friends or let them come to visit me. They did not let me work at my job. I kept telling them that I love my job. But they didn't let me. They took my phone and my computer away. I felt like a prisoner but I didn't do anything wrong. I had a temporary guardian appointed by the court. I didn't want. They took me to another group home where I didn't feel safe. The case worker -- sorry. The case worker there was mean to me. She yelled at me and even hit me. They would not let me talk to my friends or work at my store. They told me I had to work somewhere else. It was boring. I did not like it. I wanted my life back, but they told me to forget it. (Crying) Sorry. And move on with my new life.

I cried every night at the group home.

I was told I had rights. But that wasn't true. The group home took them away. They took away all my rights, my choices, and my opinions. My guardian hurt me. I was kept away from my friends, my dog, my church, and my community. I lost a year of my life being forced to stay in a group home. And forced to work at a job I did not want.

How do we make sure that a person's rights are not taken away like my rights were? Who will make sure that no one has to go through what I went through? Who will make sure that the group homes will do the right thing? Just because a person has a disability does not mean they need a guardian. Many times they just need to put in a little help. Living with a disability can be very hard sometimes. We don't need people to take away our rights and force us to work in a sheltered workshop, force us to be somewhere we don't want to be.

My life is much different now. I go to work and have my friends again. I go to the mall and to the park with my friends. I have my cell phone and computer. Jim and Kelly helped me and supported me. They helped me make good decisions. I am very happy. I love Jim and Kelly very much.

(Applause.)

Sorry. I'm not done yet.

(Laughter.)

I have to thank Jonathan for all Quality Trust has done because of their hard work, getting my freedom and my voice back, my life back. Thank you.

And one more thing. The group homes has been shut down. Thank you!

(Applause.)

MARC MAURER: Thank you, Jenny.

Jonathan Martinis is legal attorney for Quality Trust for Individuals with Disabilities. He has 20 years of experience representing people with disabilities in cases under the ADA, Section 504 of the Rehab Act, and the Individuals with Disabilities Education Act, and the constitution of the United States. He represented Jenny in the "Justice for Jenny" case. It's the first trial to hold that a person with disabilities has a right to engage in supported decision making instead of being suggested to a guardianship.

He was in the protection and advocacy office in Virginia before that.

Here is Jonathan Martinis.

(Applause.)

JONATHAN MARTINIS: Hi. I'm Jonathan and I get to follow Jenny Hatch.

(Laughter.)

But that's not real surprising because in a way we're all following Jenny Hatch, aren't we?

(Applause.)

And every time Jenny tells her story, and I mean every time, she gets me. And every time I have to remind myself that her story has a happy middle.

But when I first met her, and when I first met her I had to break and enter to do it. She was in a group home under a temporary guardianship, a segregated group home, behind a gate. She was working in a sheltered workshop. She earned a thousand dollars in eight months. When I say breaking and entering, I meant it. They controlled all access to her. You had to fill out a permission slip to talk to her, and on that permission slip, you had to say what you wanted to talk to her about and what you were going to say to her and what you expected her to say to you.

So after I walked in the door and talked to Jenny, I contacted the attorney for the guardians and said, "I'm going to be representing Jenny. I'm assuming I don't need to tell you what I'm going to talk about."

And he said, "No, no, no. You do."

So my first court appearance was asking the judge for the right to talk to Jenny about her case, which was an opposed motion actually.

So when Jenny tells you that her rights were taken away, the one that she left out? Her first amendment right to even have an attorney.

And when we got her case, we looked at her records. One of the first things we saw was the expert in the case that testified in favor of guardianship, and over and over again, that expert talked about Jenny needing assistance. She could do a bank account with help. She could do independent living skills if she had some help. And then the big one was when she was asked what Jenny needed, she said, Jenny needed people around her to support her, to give her the assistance that she needs.

And in discovery, Jenny's parents were asked, you know, if you think Jenny can't make her own decisions, how is it that you had her sign a 40-page power of attorney that talked about stock transactions and banking and decision making and healthcare? How could she have understood that? And they said, oh, no, she understood it; we explained it to her.

The lawyer and I got together. We had a bunch of meetings. We asked Jenny questions. After we reviewed it, we concurred that Jenny was capable of understanding that document.

Then there were other records from her service providers, who thank goodness took very good notes. Because she said Jenny was able to fill out her Medicaid waiver plan with assistance. She was able to apply for paratransit with support. So all of these things repeatedly that Jenny could do with assistance. We stopped and said to ourselves, hey, thanks.

(Laughter.)

And by the way, that is the extent of my clip art skills. I typed in "big cheesy grin" and that's what came up.

I do want to say thank you to the people in this room, I want to say thank you to people like Professor Dinerstein and Professor Blanck, to the Bazelon Center, to the Arc, to the National Federation of the Blind, to the ACLU, to everyone who has ever done a study, who has ever advocated for independence, who has ever taken a step forward. The people at the disability rights center of Virginia. These people, I say thank you to you. Because this is the case, I said to one person one time. This is the case where we will validate every one of those theories, where we will say that a person who is capable of making decisions with assistance has a right to make decisions with assistance.

(Applause.)

So with a slightly less cheesy grin, thank you. Because what all of those records proved is that Jenny is a person who needs support. She needs support to make decisions in legal matters. She needs support to make healthcare decisions. She needs support to make legal decisions. Which means Jenny is a person.

Ain't we all Jenny Hatch? Don't we all need support to make those decisions? Listen to her words. "I don't need a guardian; I just need a little help." We are all Jenny Hatch, except when you need help, you're being smart. When you go to H and R block, when you go to a doctor for a second opinion, when you talk to a lawyer about legal matters, you're being smart. When you admit you need assistance, you're being intelligent. When Jenny says she needs help, she needs a guardian.

And you know what? The guardian assigned to help assert her rights recommended that Jenny be kept in that group home, kept under guardianship, not allowed to see people, actually said Jenny's visitors needed to be monitored, said that's what she has to have because she needs help. And you know why? The basis for that opinion? Jenny bounced a couple of checks. Jenny ran up a high cell phone bill. Jenny gossips on Facebook.

(Laughter.)

Ain't we all Jenny Hatch? Jenny needs a guardian to keep from making bad decisions.

Quick show of hands, everybody. Who here has closed a mortgage? Did you read all those documents?

(Laughter.)

Bad decision. Where is your guardian?

Who here has consented to a surgical procedure? Did you read all those informed consent forms? Bad decision! Where is your guardian?

Who has ordered a pasta maker at 2:00 a.m.? Bad, bad decision.

(Laughter.)

We are all Jenny Hatch. The difference is, when you're a person with a disability, when you are Jenny Hatch, you are not allowed to be a person. You're not allowed to make bad decisions. When we make bad decisions, they're called learning experiences. When Jenny makes a bad decision, or any decision, it means she needs to make no decisions.

So obstacles in this case. We had a judge who said I have a first cousin with that intellectual disability. And I've been quoting the judge for saying affliction. But he said she needs somebody to take care of her. There are studies about guardianship for your own good, protecting people from their bad decisions. That's what we faced in this case.

So we had to give the judge an alternative, which, again, thanks to everyone who blazed this trail, is supported decision making. It's a fancy word, right? It's a fancy word for what we all do every day. Every time you go to the mechanic and ask him to explain something in plain English, when you say, what do you mean I need muffler bearings and you go somewhere else and they say there's no such thing as muffler bearings? Jenny's parents said she could do a 40-page contract if it was explained to her. We knew she could fill out a Medicaid waiver plan with support. So we knew she could do it. We know from published peer review studies that people with disabilities who have more self-determination are less likely to be abused. So when people say she needs to be protected? You want to protect people with disabilities? Don't take away their rights. And we know there are services and supports available through Medicaid. Jenny has a 25,000 per year nugget of gold that can provide her with the services and supports she needs. So that's what we hammered home time and time again. We had five experts tell the judge that.

And by the way, any of you all looking for experts, Bob Dinerstein, Bobby Blank, not so bad.

We put these experts on. The judge wasn't impressed. We had a psychologist who said she was capable of making decisions. And the judge said, shouldn't we start her in a group home and move from there? So we put on experts who said is, actually, no, independence is not something earned; it is a right. And since Jenny had shown the ability to be independent, there's no reason to do it incrementally.

The judge said, I don't know about this freedom thing. Because if there's freedom for people with intellectual disabilities, will there be true examination? And I can always be there if there's a guardianship. They can come back to me and ask questions if need be.

So we put on an expert on Medicaid who identified no less than nine sources that if someone had a concern could respond to Jenny's concerns in less than 30 days. The judge said his grandmother talked about an ideal world and we don't live there. And you talk about what can be, not what will be.

So at that point, I figured, okay, I need to say to this judge that I know you don't want Jenny not to have a guardian. But you don't have a choice. She can do this. Everyone knows she can do this. So as I told the ACLU, I'm going out swinging. An hour of closing argument going through the law bit by bit. An hour later, the judge starts reading. Jenny kept saying, "He's sending me home. He's sending me home."

And I just kept saying, "You can handle anything."

And the judge began reading. He had four pages. Judges talk slow. Four pages just defining guardianship.

Then he said the word "however."

(Laughter.)

Any lawyer here knows you don't want to be on the wrong side of however. Thank goodness we were on the right side of however, because the judge said, this guardianship will be for one year and then end. Not reviewed. End. It will be the people she wants to live with who are ordered to let her live where she wants to live and do what she wants to do. And this guardianship is over two things and two things only, both of which will end August 2 independence day. Only money and safety issues. Other things, Jenny makes decisions.

Even within that one year, they were ordered to use supported decision making. They were ordered to do what Jenny wants, to understand what she wants, to help her make her own decisions. And God bless him for this quote, saying a guardian's job is to make the decisions that the person would make, to use expressed interest, to do what Jenny would do, what Jenny wants, not what they think is correct.

What all that means? Jenny got justice.

(Applause.)

And you will forgive me. I really like this photo, so I will linger. The reason I like that photo is because I look my best. Time in soft focus.

(Laughter.)

Jenny is in the foreground, where she belongs.

But why did Jenny get justice? First, because she's awesome. But second, because she had help. She had the experts. She had a brief from the ACLU and the Arc and Bazelon. She had Kelly Morris and Jim Talbert, who have no idea who special they are. Every time I tell them, they say, "We just did what anybody would do." They took in an employee and made her a family member. They spent their time, money, effort. They poured everything they had into this to bring this person into their home and make her a part of their family and give her a life.

She had a judge who for all my jokes was willing to listen and learn. Take away any of those things, and Jenny is behind cinder block walls, in a sheltered workshop, not in a room overlooking the pool, not working with people, not improving her skills, not becoming the person who she is destined to be, who she deserves to be.

And what I mean by that is, we cannot let that happen, because Jenny got lucky. She got lucky for having all those things, and our rights should never depend upon luck. How many other Jenny Hatches are out there? How many other people could live the life that Jenny lives, make the decisions Jenny makes, exercise supported decision making like Jenny does but never get a chance because they're missing one of those components?

Our rights should never depend upon luck. And I submit to you, this is the defining issue for people with disabilities from here forward. Don't believe me? Think about it this way. If you're involved in Olmstead cases and deinstitutionalization, what good is it to have the right to live in the community if there's a guardian who says you may not? What good is it to have inclusive employment if there is a guardian who says I think a sheltered workshop is better? What good is it to have the right to life, liberty, and the pursuit of happiness when the life you live is what I tell you it will be, the liberty you exercise is what I allow you, and the happiness you pursue ain't yours? That is why this is the defining issue. Why in this age of miracle and wonders, iPads and Medicaid waivers, has the number of guardians troubled in a generation? It's three times higher than it was just in 1995. Why do teachers and lawyers and social workers and counselors still tell parents, when your child turns 18, two pieces of advice for you: Get a guardian and get SSDI. The Special Needs Alliance has a brochure that says, "What happens when I turn 18?" It's about a millimeter thick because it has two pieces of advice: Get guardianship and SSDI.

I had a presentation to give last year. While waiting, I saw the document and held it up and said, "If this is your advice, you're committing malpractice."

The world where there is still a predilection for protection over rights may change. We must learn from the Olmstead case. And I don't mean the one from 2000. I mean the one from 1928 that said the greatest threats to liberty come when we are our most well-meaning. When we want to protect people, to keep them from their bad decisions, we are denying them the opportunity to live a full life, and I submit to you that overbroad and undue guardianship does exactly that. It takes away, as Jenny Hatch says, my life and my rights.

So where do we go from here? What are our opportunities? We know our challenges. When I saw the roster for this gathering, and again, I am so honored to be here, I said, there's more than just people here. There are names here. There are people here who can get meetings. There are people here who can bring cases there. Are people here who can make a difference at the highest levels.

Jenny Hatch could go before the Virginia general assembly this year and help get a law passed to study supported decision making. If she can do that, then we can get meetings at the federal level asking for regulatory guidance requiring supported decision making. Everyone doing community integration cases, I always hear, what is step two? Step one, the state's professionals think you're okay for deinstitutionalization. Step two? There's no opposition. What happens if the guardian opposes? You put in the Olmstead plan the requirement to use the standards set out by Judge Pew to make the decision the person wants, and the person will make you solve that problem. We see new regulations for Medicaid waivers that push person-centered planning. What is that if the person doesn't get to make their own choices? You make one requirement in those policies requiring the use of supported decision making and you have created a world where Jenny can say, I want to live in the community and no one can say, oh, no, you're living in the group home. That's when we have change. And when we have that, when we have gotten there, then people with disabilities won't just have rights; they will have choices. And when that happens, we won't be talking about justice for Jenny. We'll be talking about justice for everybody. For Jenny Hatch. For Quality Trust for Individuals with disabilities.

Thank you so much for having us. It's been my honor.

(Applause.)

MARC MAURER: It's been a pleasure to have you too. I want you to know that I never send anybody for a muffler bearing.

(Laughter.)

Anyway, we have time for questions. Two or three. If you have a question, if you will identify yourself, that will be the way to do it. As Dr. tenBroek used to say to his classes: "I know who I am. Tell me who you are."

>> Sharon Weissbalm. So thank you, both of you. Jenny, thank you very much.

I was asked to speak this evening actually to the Baltimore County public schools. They asked me to come and talk about guardianship because that's what parents think they want. I always title my presentation: Alternatives to guardianship.

So there will be 30 parents tonight. And Jenny, I would like to be able to tell your story if it's okay. But what the parents come in thinking, and this is all to transitioning youth, 18 to 21, they come because the insurance companies, the hospitals, the teachers, the service coordinators, they all come with the idea that they have to become their young adults' guardian. So the biggest challenge I think, and I ask for your recommendations, is how do we get to all of those institutions and convince them to stop telling parents that? Because that's I think at least here in Maryland where a lot of the myths are coming from. Although I do that whole alternatives to guardianship and try very hard to convince parents not to go down that road, I think that's what is happening here at least. So I'm curious if you are bumping into the same things.

JONATHAN MARTINIS: Absolutely. At Quality Trust, we feel the same way. We believe that any movement towards supported decision making has to be multimodal, because unless the doctors and teachers and social workers buy in, then we just wind up fighting case after case after case.

I tell teachers: Read IDEA. Read transition planning, which includes services and supports to develop independent living skills. If they think someone has problems working decision making, why weren't they working on that at 14? Transition planning, you will hear should happen in elementary school, says Secretary Yuden.

I have been trying to stop teachers from giving that advice. The DCPS had to change their transfer of rights guidelines to stop pushing guardianship. But that has to trickle down.

With doctors, it's education, education, education. I'll be up here May 17th talking to doctors about exactly that.

But I think one way to do is telling people it's the right thing to do. But the law tells you to do this. If you don't, we will come after you.

MARC MAURER: We have time for one other.

>> Hi, this is Matthew Dietz. I'm giving a presentation in June to a group of guardian ad litems that are being trained to assist children with disabilities. How do we train guardians appointed by the court who may be a mom from a suburb how to include supported decision making when first encountering a child or a young adult that may need some training and advocacy on how to make choices and proceed from there for when the child becomes an adult?

JENNY HATCH: Yes. Thank you for the update for June. Guardian ad litem is Miss Watson. She's not a good person and she's not very nice to me. But yeah. The guardian is not -- it's very interesting that she wants me to stay in a group home and that's what happens. In my bike accident, and then I don't know why Miss Watson did all this crazy mess, but thank you for that update for June.

JONATHAN MARTINIS: She's right, by the way. Miss Watson didn't listen to her. To me, when I talk to GALs, I say, the first thing you have to do is read the law you're supposed to be working with. The guardianship act says you have to essentially exhaust all less restrictive alternatives.

So my question to them is, what else have you considered before you said guardianship? It's not a dichotomy, guardian or nothing. So what other avenues have you looked into?

I've said this a bunch of times. I'll know we're getting somewhere when there's an unopposed guardianship petition and the judge says, wait a second; what else have you tried. That is the pointed. I'm not sure GALs know about supported decision making. The attorney who Kelly and Jim hired in Jenny's case is also a GAL and she actually suggested supported decision making for the case and the attorney and parents went ballistic and withdrew their petition and said, forget it, we'll file again with a different GAL.

MARC MAURER: Thank you to both of you. There is a chant that the National Federation of the Blind uses. We have been using it now for as long as I can remember. It is: We speak for ourselves.

It gets to be quite an interesting, are good chant, when you have several hundred people out on the picket line. If you need any help along that line one of these days, we'll be there. We'll have a few signs and we'll talk about how it is that nobody speaks for us; it's up to us to speak for ourselves. We take that right. We take that responsibility. We will give it to no one.

It's great to have you folks with us. I'm glad that the law is moving in the right direction. Just keep up the good work, as they say, and when you need help, let us know.

(Applause.)

Our next piece of presentation here is a discussion of discrimination against individuals with disabilities in the criminal and juvenile justice systems. I invite our presenters to come. We have three for this. Michael Bien, the managing partner of Rosen, Bien, Galvan & Grunfeld. We have Talila Lewis, founder and president of Helping Educate to Advance the Rights of the Deaf, which as you observe has the acronym HEARD. And Joseph Tulman who is professor of law and director of the Took Crowell Institute for Youth at the University of The District of Columbia David A. Clarke School of Law.

If you will come up, we'll get underway with this.

We start with Joseph Tulman, who is the professor of law.

What's that?

JOSEPH TULMAN: On my way.

MARC MAURER: Glad you're here. Temptation to encourage you to step on it. Usually the professors get to say that to the students.

Anyway, Professor Tulman has pioneered the special education advocacy for young people in the delinquency and juvenile justice systems. His publications include articles regarding the unnecessary detention of children, and he coauthored and coedited a comprehensive manual regarding the use of special education advocacy for children in the system.

Here he is.

(Applause.)

JOSEPH TULMAN: Thank you.

Good morning. Let me start with an apology. I put together a handout last night so I will email it out so people can have access to it. But hard copies are going around.

We have the "privilege" in the United States of being the most incarcerated country in the world. By far. We didn't used to be that way before the ascension of Richard Nixon, to whom all evil goes back.

(Laughter.)

I don't know if you remember this, a lot of us remember the campaign in 1968. Remember George Wallace running as a third party candidate on an overt segregationist platform? And Nixon developed the southern strategy, saying law and order was important. And Michelle Alexander has done a wonderful job capturing what happened in the book "The New Jim Crow." She says we went from slavery through the Civil War to a period of cessation of slavery, and then Jim Crow bubbled up and became a less onerous version of slavery. In other words, slavery warmed over.

And then in the '40s, '50s, and '60s there was a huge movement in the country to abolish Jim Crow. And after that war was won, up came mass incarceration.

So we went from being a sort of normal country, having about the same rate of incarceration as the other advanced democracies in 1970. We're now over 750 people per 100,000. To put that into context, other democracies lock up 50 to 100 people per 100,000. We're over 750. We lock up almost five times more children than any other country.

Anybody want to guess what the next highest country is? South Africa. You look at South Africa's racial history and you look at the racial history of America, and you can see the pattern.

The pattern also is apparent with regard to what's happening in the schools. Children of color being pushed out of schools at incredible rates. People who are poor being pushed out of schools and into prisons at incredible rates.

What does that have to do with people with disabilities? There's an instrumental answer to that question and then there is a substantive answer to that question.

The people being incarcerated are both people of color and people who are from low income families. But they're also people with disabilities. The people being pushed out of schools are primarily or overwhelmingly low income people and they're low income people of color, but they're also incredibly disproportionately people with disabilities.

So what we've done, and I know a lot of people in this room have worked on deinstitutionalization movements. I represented a class of people with intellectual disabilities helping to close down Forest Haven, not far from here. You know, I was on that case for 14 years. We closed down an institution for people with intellectual disabilities. But if you go to the D.C. jail, you'll find overwhelmingly those people are people with disabilities.

That's the bad news.

The good news is that -- well, no, there's more bad news. Sorry.

(Laughter.)

When you look at the system of criminal and delinquency in the United States, first off, I would ask you not to use the term "criminal justice" or "juvenile justice," because if you're talking aspirationally, I think using the word "justice" is fine. But if you're talking descriptively, it's not a system of justice except for the line that Red Fox coined, which is "just us." So let's not talk about justice until the system really has some level of justice.

But the essential problem in the criminal system around the country is that you have so many poor people being pushed through now and so many people with disabilities and minority people being pushed through that system that you have defense attorneys court appointed around the country representing 400, 500, 600 people a year. So what you find uniformly is that these defense attorneys aren't investigating, they're not doing research, they're not filing motions, they're not preparing for trial. And virtually every person pleaded through the system is pleaded guilty. So it's not a system for justice. What you have is a system of pushing all these people through.

It gives us an opportunity, though. Let me just check the time. If you think of those attorneys taking 400, 500 clients per year, what does that mean? Like two clients per day on average. Lawyers can't do a lot in half a day's time except walk into court and plead somebody guilty. So we need to ultimately reduce dramatically the number of people in the system and get it back to the scale that it needs to be, which is some fraction of what it was in 1970.

But we can look at each of those court-appointed attorneys as a potential ally to our cause of disability rights. So instead of taking 4 or 500 cases a year, we can say to those attorneys, Hey, for the young people you're representing, learn disability rights. Learn the IDEA. And instead of just defending the individual, affirmatively assert rights of that individual in regard to education. In regard to equal treatment. In regard to accommodations in the criminal or delinquency proceeding itself. In regard to rights to accommodations, reasonable accommodations on probation and parole, in regard to the right under Olmstead to services allowing least restrictive placement through the system.

The defense attorneys are not aware of this set of options, these sets of rights, so they're not asserting them.

So in the handout, on the second page, what I've given you is just a list of the basic special education strategy for a child in the delinquency system. If we affirmatively assert the rights under IDEA for young people facing criminal charges, we can use the rights under the IDEA to get services to extract the person from the delinquency system and replant them in school.

What I found in representing kids in the delinquency system for the last 32 years is that virtually every kid I represented had failed in school, had not gotten appropriate accommodations and services in school, and was ending up in the delinquency system for lack of options. So we can assert those rights. I mean, you guys know the rights. A functional behavioral assessment and plan for someone with significant emotional and behavioral issues. A right to a whole array of services. And in a case where the person really needs lots of supports, multi systemic therapy or family therapy, the kinds of wraparound services, they are evidence based. If you look at the Surgeon General's report from January 2001, there's a whole chapter on family violence on what works and what doesn't work. Boot camps and incarceration doesn't work. Supported services like family therapy do work. In a case where the child really can't go home -- which is rare, though we seem to think it's often -- but when a kid really can't go home, therapeutic foster care makes a lot more sense. And again, it's an evidence-based intervention. It's an intervention that works.

Okay. In the limited time I have left, I'll give you a couple of ideas. First, some examples of young people in the adult criminal system. Let me tell you one story with a not so positive outcome and then two with relatively positive outcomes.

We represented a man named Marselle. I'll give you the case cite. It was litigated through the Department of Ed. Marselle has extremely significant needs for special education services. We won a hearing at the D.C. jail reasserting his rights, and a hearing officer said, "Yeah, he needs all these services." But Marselle had been convicted on some really serious offenses and was headed off to prison. We said to the sentencing judges, "Hey, judges, you can't send him to the prisons because they don't do special ed and he has all these services established that he needs." And just for your information, the sentencing statute in D.C. -- 24-403.01 to be specific -- says that the court shall impose a sentence that gives the right amount of time for the crime, that protects the community, and, thirdly, provides the offender with needed educational or vocational training. "Needed."

By definition, what does it mean, "needed educational services"? How about what the IDEA requires and what a hearing officer already found this person has a right to?

Not surprisingly, however, the D.C. Court of Appeals, the highest court in D.C., said, No, "shall" doesn't mean shall. And "and" doesn't mean and. We lost that case. We had good amicus support from national organizations, and the judges just didn't want to hear it.

We want to sue the prisons. We ask for your assistance on that.

Two good examples. I have a client I've represented since he was 13. I met this kid -- how am I doing on time? How long do you guys have?

(Laughter.)

I met this kid when he was 13, and we couldn't get the appropriate services through school. We won a couple of hearings and got some compensatory ed. D.C. is tough. There's a high school in D.C. where 11% of the kids are reading at grade level. Can you imagine? We have a high school in D.C., and during a hearing, I said to the vice principal, who really is the chief bouncer is his job, I said, "How many suspensions did you have last year?"

He said, "Last year we had 1400 in school and out of school suspensions."

"How many students do you have here?"

"1100."

Do the math. He said, "Well, it was mostly 300 students we kept resuspending."

So I represented this kid since he was 13. We tried different schools. He got incarcerated as an adult. But we still had orders for compensatory education. And he was also facing some serious charges like Marselle. We weren't going to get him out. But we brought tutors into the D.C. jail three times a week for a year. This was when the kid was already 27. We just kept the extendability in place and we educated this kid for the first time in his life bringing private tutors into the D.C. jail.

I got a letter from him last week saying, "Send me more books." He's now 31. Once he serves his sentence, I'm hopeful he will get out and be able to progress. But he never would have been educated without enforcing those rights.

A much happier story now. We represented another kid who failed in elementary school. This is the typical pattern. He never made progress in school. They expelled him from high school. Then he got arrested as an adult for unauthorized use of a vehicle, you know, stealing a car. He got locked up and sent to prison for over a year on a first adjudication, first conviction. That's kind of weird, right? But why? Because he had nothing going for him. He hadn't made it in school, he had no job, he had no family support, and he's mildly intellectually disabled. And the judges are like, "What do I do with this guy?" He doesn't seem to respond to probation, he gets no accommodations on probation, so they get frustrated and lock him up.

Then we met him. We tried to excavate his educational records. It was a mess. First off, we couldn't get the records. But secondly, the pattern was unbelievable, what hadn't happened for this kid.

We went to a hearing last February and got ordered extended eligibility because he was about to turn 22 and have him placed in a school here in Baltimore with his own apartment and supports. He's still there, doing great. One of my students is visiting him today. He's working at a Jiffy Lube setup that they have. We're going to transition him back into the community in June and get him a job and everything will be fine.

That kid, at sentencing, and I gave you part of the transcript from his sentencing hearing, the prosecutor was still asking for incarceration. The judge said, "I don't know how this placement thing happened where somebody got him placed in this school, but it's a miracle. And it's better not only for him, but it's better for me to put him on probation and let him go to school." So that was kind of cool.

Here are the punch lines for what you can do. I've given you a list of seven at the last page of the outline, seven projects to reverse and dismantle the school to prison pipeline. In systems change terms, what we're talking about, and here's some jargon. Get ready. We're looking for what we call reinforcing feedback loops. Where in the system that pushes all these poor people, people of color, people with disabilities, where in that system can we find U-turns that generate their own energy and resources? The problem is that we have attorneys representing 4 to 500 people a year. How can we reverse that dynamic?

What we did in D.C. is we started in 1990 to train the court-appointed attorneys who do delinquency defense and child welfare work. We did trainings twice a year in special education law for the court-appointed attorneys. And part of our message was, "Your clients have rights that you can enforce for them and with them, and by the way, if you enforce their rights and prevail, you can make market rate attorneys' fees instead of this piddly money you're making through the court."

When I started representing kids in 1982 as a court-appointed attorney, we were making $20 an hour out of court and 30 in court.

So we trained a bunch of attorneys, and within five years D.C. got to the point of having half the country's special ed hearings in one jurisdiction. Right? Because we marshaled an army of people to do special ed enforcement of the rights of people being pushed through the school to prison pipeline.

That's one idea of a project you can do in whatever jurisdiction you're from. Train the court-appointed attorneys to enforce their clients' rights, which reinforces itself because they will make money on that.

There are six other ideas on your handout here that do the same thing. Self-reinforcing projects based on disability rights.

(Applause.)

MARC MAURER: Thank you, professor. You took three minutes less than you were entitled to.

(Laughter.)

JOSEPH TULMAN: Oh, wait...

MARC MAURER: Talila Lewis is the founder and the President of HEARD, Helping Educate to Advance the Rights of the Deaf, an all-volunteer organization that works to identify barriers that prevent the deaf from participating in the justice system. Her focus is on advocating for the deaf and preventing wrongful convictions.

And it is a pleasure to have you here. Here is Talila.

(Applause.)

TALILA LEWIS: Good morning, everyone.

AUDIENCE: Good morning.

TALILA LEWIS: That's pretty good. I think some of you need a little more food and coffee.

But it's such a pleasure and honor to be here. I really want to thank everyone for organizing and making sure that we start this symposium with an issue that is near and dear to my heart.

I am a full-time law student at American University Washington College of Law, so I would like to first thank Professor Dinerstein for being my faculty adviser. And I am the founder of the disability law society there. So he also is the adviser for that organization. And he is my independent study adviser. And pretty much I just use him to my liking, so it's great.

(Laughter.)

So thank you. I think you've had accolades from everyone who has come up here, so that's wonderful. You're an amazing person and we appreciate you. So that's first.

Whenever I speak, I always like to center the space with folks who are not present. So what I would like to do now is actually, if I could get everyone to either sign or say one or two names of either an individual that I will give to you, who is currently incarcerated, or someone you know who is incarcerated. And by incarceration, we don't just refer to the, quote/unquote, justice system. We refer to people who are in psychiatric institutions, people who are young folks who are stuck in schools for certain disabilities. All those folks we consider incarcerated. So I want to remember them, who keep us doing the work that we do.

I'll give you the name of one. Felix Garcia. This is his sign name. He was given this name because he has a beautiful heart. He is currently incarcerated in Takoma, in Daytona Beach, Florida. It's one of the worst prisons that I have seen in terms of access for prisoners with disabilities and for elderly and deaf prisoners.

So if we can all just take a moment, a few seconds, to lift up somebody you know.

Thank you.

So a little bit about me. Most you already know that I am the founder and President of HEARD. I started this organization a few years ago, three years ago now, after some years before that of working on cases of deaf wrongful conviction.

So back in 2007 I worked at the D.C. public defender service, and my job was to correspond with prisoners from across the nation. Many of you are familiar with the D.C. -- all of our D.C. prisoners housed for longer than a year are actually housed in the Federal Bureau of Prisons, which has prisons across the nation. So indeed we have deaf prisoners or hearing prisoners from D.C. who are literally in California, in the middle of the country, and in places that no one can get to them. So their right to the D.C. public defender service in hopes of getting whatever relief they're looking for in that particular instance.

And I received a letter from a person who is deaf who in 70 words was able to convey that he shouldn't be in prison but couldn't convey in written English why.

So I then went to the superior court and pulled his case jacket. It was 2007 when I received that letter. This individual had been in prison since 1994.

When I pulled his case jacket, I found that the D.C. police department interrogated this person, who clearly couldn't read or understand written English, with a detective who could fingerspell. So what that means is someone literally spelled to him letters, which if you clearly can't read English, you being able to understand fingerspelled letters is probably not practical either.

And so from this interrogation and an interrogation with another deaf witness, also done with fingerspelling, came this conviction of this man.

So I have worked on his case. He's still in prison. I believe he is innocent. So I have been working on his case ever since then. But as I started working on his case, people in the deaf community started coming to me with other people with wrongful convictions. And I became overwhelmed. Each of the cases looks the same, the person interrogated without an interpreter, went to court but wasn't able to communicate with their own attorney because their attorneys weren't providing access to their own services via interpreter or whatever other necessary accommodation might be had. And all of these people were being funneled into prison.

So I then began contacting different organizations hoping for help and support, and I found that organizations that were competent didn't have the resources to take on these cases and those are the organizations that were culturally competent. Organizations that were competent in innocence didn't understand Deaf culture, Deaf communication. They're like, "That's so fascinating! Ahhh." And you're like, "Great. But can you help?" No, of course not.

So I reached out to community members that said let's create an organization that can do these things. So my organization is made up of bicultural, bilingual individuals working to create a system that is actually just for people who communicate using American Sign Language or who don't speak English.

So that's the background. My job here today is to paint a picture for you all. I had a video of Felix and William, another person in a prison in New York, that I won't show but I'll tell you what both of them said.

Background. I worked for about a year and a half, two years, with al-Jazeera America on the first documentary of deaf, deafblind, and blind prisoners across the nation, and I created the second, if you ask Elaine Gardener, sitting in the back over there, I created a national database of deaf, deafblind, and now a database of blind prisoners as well because our deaf prisoners started coming to us saying, please help this blind prisoner in our prison and what have you. But Elaine had also created a map some years ago. I will have a photo of that soon.

I digress. So I have this database. Right now it has just under 500 deaf, deafblind, or CODA, child of deaf adults, in the database. There are just four of those right now. To be clear, I want to give you an idea of what we're talking about here. My database has 500 prisoners from across the nation that includes Alaska. We had one in Hawaii, but that person has since been released.

The state of Louisiana recently announced two years ago that they had 2,000 hard of hearing prisoners and 38 culturally Deaf prisoners. In my database, we've only been able to find two prisoners from Louisiana. So I think that gives you an idea of the scope of the problem and how difficult it is to find people who have disabilities within the justice system. The fact that we only have 500, the reason for that is because there is no communication for folks with disabilities in the prison to the outside world. And I'll get now to what I've coined as the "deaf prisoner phone justice campaign."

So I started this campaign 14 months ago now. This is a campaign where we're lobbying the Federal Communications Commission and the Department of Justice to mandate national standards for communication access for people who are deaf, hard of hearing, or people with communication challenges in prisons. Right now, only five, possibly six prisons across the nation have video phones. There are thousands of prisons in the nation. So what that means for a person who is Deaf and uses sign language to communicate is that they literally have no contact with any family members who use a video phone. Why? Because the TTY and the video phone are not compatible. That's a regulation as instituted by our Federal Communications Commission. So they're not compatible. Which I think 12% of the relay volume, the total relay volume as reported by the FCC, is through TTY, whereas 75% is through video phone. So what we know, then, is that most prisoners who are in prison who use sign language to communicate can't communicate with anyone in the outside world.

There's a funny story. We were talking about juveniles and, quote/unquote, justice. One of the younger clients contacted me via video phone. We actually got one set up in his jail after much advocacy. He recanted the story about when he first got there and was trying to contact someone, anyone, an attorney, family member. And he asked the jailer, "Hey, I need to make a phone call." He was able to communicate that via pen and paper.

The officer then takes him to a room, sits him down, and says, "I'm leaving," because they actually can't watch your phone calls if you're on the phone with legal counsel.

And the young man said, he looks everywhere, under tables, he opened up cabinets, and finally he said, it must have taken 30 minutes of searching, he goes back outside and says, "Hey, you guys must have the smallest video phone in the world. Can you show me where it is?" And he was 18 years old. 17 at the time. He had never seen a TTY.

So understanding the difference in just technology and how it's advanced so quickly. So then they find that the officer comes in and says, "Oh, I don't know what a video phone is, but we have this thing. They told me this is for you deaf people."

The kid is like, "Great." And he's lifting it up. It's a big TTY. I don't know if you've seen one. He lifts it up, shakes it around, and goes, "How does it work?"

And the officer said, "I don't know; I thought you knew."

And literally the kid didn't make a phone call. Couldn't call an attorney. Couldn't call anyone. I found him very serendipitously through another advocate. That's a clear example of what's going on.

I do want to address sexual assault in our prisons, which is rampant generally with the whole population within our prison system and it's very, very sad. But what we have is a Prison Rape Elimination Act, a law passed by our Congress which is set up to do exactly what it says, eliminate the existence and persistence of rape in our prison system.

Unfortunately, despite the fact that there is a piece of that regulation related to communication access for folks who are spoken or visual language minorities, it's not implemented for folks with disabilities. So what that means, down in Florida where Felix is housed, I have been battling actually to get the Department of Justice to open up a case on this, and they did after three years of advocacy, because deaf and elderly and disabled folks are being treated so poorly there -- abused, raped -- it defies imagination, actually.

So DOJ opens up an investigation, and they corral all of the prisoners, including those with disabilities. There were 100 wheelchairs at this point of prisoners with disabilities brought into a room just like this one. And they put up a screen smaller than this, a little television in the room, and they play the Prison Rape Elimination video. Why? Because this was something they were supposed to show to all prisoners a year prior to that. And they show this video. No captions. No interpreter. And then they demand that everyone in the room just like this come and sign their name, walk up and sign their name saying they had seen and understood this video about prison rape elimination. Many of the prisoners said, "I don't understand that so I can't sign."

They said, "If you don't sign, you're going to solitary confinement." Many of these prisoners were sent to solitary for months. These are prisoners over 90 years old, deaf, in wheelchairs. And this happens all the time.

What we found is that because the system is so secretive, unless you have an attorney, an advocate, a loved one who is in prison, it's really difficult to know what's going on inside of the prison.

So what we're here to do is really get everyone here involved and raise awareness within our community. Because MLK has a quote. He said, "In the end we will not remember the words or deeds of our enemies so much as we will the silence of those who we thought were our friends."

And when I talk to these prisoners, I chat with them all the time and they say, "Where is the community? Why don't they care?" It's not about the awfulness happening to them by people clearly not concerned with their welfare in the justice system. It's about the advocates. Why doesn't anybody care?

So we're here to try to get everyone involved, raise awareness about what's happening, because this is something that we can change. I've seen a lot of change in the few years that I've been working. And I think that when we continue to push those in positions of power to change the system, and sometimes dismantle the system, I think it's possible to see change.

I think I will let Michael take over from here. And then I would be happy to hear questions about reentry education and psychological and mental health within the prisons, which actually, if you're deaf or hard of hearing or blind, you don't have access to any of those things. So, happy to have those questions later on, but I would like to give the floor to Michael because he's kind of a rock star.

(Applause.)

MARC MAURER: Thank you very much.

Michael Bien is with the firm Rosen, Bien, Galvan & Grunfeld. He concentrates his practice on constitutional civil rights law, complex commercial litigation in trial and appellate courts, he works on anti-trust and intellectual property matters, he has successfully litigated a number of actions on behalf of persons with disabilities; including civil rights class actions regarding unconstitutional confinement, denial of healthcare, and discrimination against individuals with disabilities, and unconstitutional proper issues and other civil rights matters.

Here is Michael Bien.

(Applause.)

MICHAEL BIEN: Thank you, Dr. Maurer.

It is inspiring to be here once again. This is an amazing community, and the opportunity to meet with all of you and to share ideas and inspirations, I always come away from this conference with so much energy and excitement and hope that we can really make changes, as said this morning. We can do it. There's a lot more to do. Meeting Jenny and hearing her story was so inspiring. Meeting Talila and hearing what she is doing. There's so much more to be done.

We on this panel are bringing you this dark message but also a message of hope. Our system in the United States is very, very broken, of incarceration. And the victims of it are vastly and unfairly people of color, people without means, and people with disabilities. We can show statistics that make it very clear that you're far, far more likely to be incarcerated if you have a disability, you're far more likely to serve a longer term with a disability, and there are lots of kind of obvious reasons for that. And we've talked a little bit about that.

We focus our practice on what happens to people once they're in the system, after they're convicted. It's quite awful. People in this room use various physical devices to achieve independence, to communicate, to participate in whatever they're doing, this conference, day-to-day life.

The basic rule when you're in jail or prison is everything is removed. There are even prisons that remove prosthetic devices. Everything is removed. Because they're all "dangerous," and you are dangerous people, and these are weapons. That's the presumption. And it continues to be the presumption in far, far too many jails and prisons.

Getting back any kind of independence, any kind of mobility, any kind of ability to understand, to communicate, to use a telephone -- by the way, TTYs are vastly unavailable. Forget about video phones. In most of the cases we're involved with, access to TTYs are not there. Either they don't know how to use them or they have time limits or they don't work or they have one in the whole prison and if you're not in that unit, you don't have access to it.

Prisons have all sorts of bureaucratic paperwork, hearings. If you want to see a doctor, you have to fill out a piece of paper and put it in the right location, find the right person. It usually doesn't happen so then you have to file a grievance to see the doctor because your first request wasn't responded to. All in writing. How does that happen?

Hearings happen. Attorneys are not provided for any kind of hearings inside a prison. Disciplinary hearings, all sorts of hearings.

Accommodations are rare. So we find people who have been in prison and then they lose their rights and end up in solitary confinement. They don't understand the rules. And there's not much there to help them.

This is the bad news. And I can give you more and more bad news, but I want to switch to the good news. The ADA and the Rehab Act provide very, very powerful tools to attempt to remedy these problems. You all know about these laws and work with them all the time. They don't seem to have penetrated the criminal justice system. They don't seem to have penetrated courts very much. You know, basically in court, if you get an attorney, you've got the attorney. That's all you deserve. The fact that the attorney doesn't know how to communicate with you or the fact that you don't understand what's going on in the proceeding, the fact that you can't testify or understand the testimony, you got your attorney.

So that's basically what happens to lots of people. And again, as we've heard, a lot of people really don't have their rights in those proceedings.

Full enforcement of the ADA and the Rehab Act plus the eighth amendment of the constitution due process clause can really start moving those barriers forward. The key, as Talila mentioned, identifying clients in jails and prisons, is very, very difficult. We're moving forward on a case against a county jail in California. It took us almost a year to identify clients with disabilities, to find them, to communicate with them, and to start signing them up. And of course in a jail situation, people are coming and going. So you have to find new ones.

But that challenge is something that I urge the disability rights advocacy organizations to take on. We need you to recognize this population who are your brothers and sisters and children and parents. They're just us. They are us. The enemy is here. It's the same people.

People get trapped in the criminal justice is system for all sorts of reasons. It's very easy to find yourself inside in America. And when you're inside, it's very hard to get out again. It's very, very difficult.

We need advocacy organizations, civil rights organizations, all sorts of organizations to recognize this group of people as part of our own community to reach out to them and help them. And then we need attorneys to see that you can actually do positive things to help.

I think the arguments we need to develop, which we use successfully, are anti-incarceration arguments. What America has done, the statistics that Joe presented earlier, is not good for us in any way as a society. It has not reduced crime. It's wasteful of resources. It does not make our community safer. It's created a gigantic criminal industrial complex like a military industrial complex where people make money out of incarceration. We have public corporations traded on the stock exchange whose business is incarceration. That is a dangerous thing when people are making money on incarceration. They lobby for laws to increase incarceration, and they're very successful. The Arizona immigration laws was a product of corporate lobbying.

We need to address that as a society. But one of the things we can do is point out, let's be smart on crime instead of just tough on crime. What can we do to reduce crime? What can we do to increase the likelihood that someone who screws up in some way, shape, or form -- and all of us do in our lives -- are given some resources to help rather than thrown away? We have throwaway people who we want to forget about.

In California it's estimated that one in four minority males is in the criminal justice system in one shape or another. One in four. So you're talking about someone who has been in prison, been in jail, been on parole, been on probation. Once you have that mark against you in our society, it's very hard to reenter. You can't get a job, you can't get into housing, you can't get a student loan. So we have all these obstacles for people to get out.

And for people with disabilities, the barriers are even higher. Why do people serve longer sentences? You get credits in prison maybe for finishing the drug program, an alcohol program, educational program. They're up a flight of steps and you're in a wheelchair. Or there's no sign language interpreter. They're not available for people with mental illness because they need "special care." So guess what? You don't get any of those programs. You're not eligible for diversion programs.

So again, there's so many obstacles. But we have very, very powerful remedies. The message, a couple of positive messages too are the Justice Department has turned around. You know, perhaps the most, for me, the most gratifying part of our new administration, as many problems as I have with it, even in the second term, is the civil rights division and special litigation section and what it's doing for disability rights and in prison and jails. Very powerful work. Those regulations are fantastic. The law is there.

The other good message is, the ADA and the Rehab Act provide full market attorneys' fees, experts for lawyers who take on these cases. And the message here is we are available. Many other prisoner rights people are available to people in the disability community to help understand the craziness of prisons and prison law and put together teams that can take on these cases. It can be done. You can even survive financially doing it. It's hard, but you can do it. But you can really make positive change.

So I very much appreciate the disability rights community opening itself up for this. We need protection and advocacy groups around the country to get engaged in the criminal justice system. Some are and some are not. This is part of our community. And unfortunately, people with disabilities are overrepresented inside prisons and jails. We need to stop that. It shouldn't happen. Thank you very much.

(Applause.)

MARC MAURER: Thank you, Michael. You have all conserved your time. We have a lot of time for questions. Or there could be commentary from the members of the panel. Do the panel members want to add anything before we go to questions?

JOSEPH TULMAN: Oh, sure is.

(Laughter.)

Is this on? Can you hear me okay? I want to amplify one of the last things that Mike said, which is, there's an economic basest for disability rights laws that pass through Congress. Those laws pass through Congress because of bipartisan support, because of the obvious stupidity of segregating people with disabilities out of the rest of the community in economic terms. It's self-defeating behavior to isolate people with disabilities and not integrate them into the economy and ensure that everybody is productive.

So this absurd ghettoization of people with disabilities in prison is incredibly economically self-defeating.

I forgot also to give the punch line to our work in D.C. over the last 25 years of teaching special ed delinquency attorneys to do special ed is that since 1993 the district Columbia, thank goodness, has closed three prisons for kids and opened up two new ones. We can reduce at least by two-thirds I would say, 90%. You know, we could really undue incarceration around the country. And a huge part of that can be pushing for enforcement of the rights of people with disabilities so that we're not incarcerating them.

MARC MAURER: All right. Other comments from panel members?

Shall we move to questions?

MICHAEL BIEN: I was going to say --

MARC MAURER: Sorry, I didn't mean to cut you off.

MICHAEL BIEN: I just wanted to add one other point too. How do people get help in surprising prison and jail? They get help from other prisoners, which is positive but the fact is, it's very dangerous. Everything costs money. And so we find that our clients are paying half their food to get showers or to get their food tray. Their canteen, their access to, you know, it costs money. And then frequently sex and sexual exploitation. Nothing is for free. And that's why a system of accommodation that depends on prisoners taking care of each other is a very, very dangerous, very, very dangerous system. And totally inappropriate. That's the kind of thing you'll find. That is what happens in societies when you leave people alone. They work things out. But much, much to our clients' disservice and danger.

So that's the kind of thing that's going on every day. And that's really what we need address.

TALILA LEWIS: I'll add to that. What I talk to my interns about is precisely what Michael just said, that currency and power in prisons belongs to those people who have information. And you literally do trade your body. We've found in prisons across the nation, this is not just in any one location, is that prisoners who are blind, they're mail is opened by another prisoner. So now the person says, I know where your mother lives. If you want to know where, you need to do X, Y, and Z for me.

Many of our wheelchair prisoners have to hope someone will bring them food because they can't get to the cafeteria.

Many of our blind or deaf folks have similar issues regarding making telephone calls to their wife. So now we have a hearing intermediary who may know a little bit of sign language who will intermediate between you and your wife's conversation. Can you imagine?

And the last thing I want to add is I would tell you what William and Felix said in those video clips. Felix said, there's a lot about prison that people don't know. When you hear things are going on and you're deaf, you never know what is going on. He said, everything that you own, people want to take from you. Your shirt they want. Your shoes they want. Your hearing aids, they want. They want sex. So that was Felix's quote in that particular portion. And he is our longest serving deaf wrongfully convicted prisoner since 1981. He has been sexually and physically assaulted, just like most others.

William, in his clip, and he's housed in Pennsylvania, he's released now, but he said in his clip, people with communication disabilities are always going to suffer in prison. And what was most noticeable about that particular clip of William, he had literally just the day before been beaten for not responding to verbal commands of prisoners. So when al-Jazeera America came to film him, he had black eyes and broken teeth. So it was perfect, right? It depicts perfectly exactly what we're all trying to show. We didn't even have to ask him the questions, right? Because it's there on his face. So that was what I wanted to share with you all, and I encourage all of you to actually watch the documentary. It's 25 minutes, short but powerful with Al-Jazeera America. Thank you.

MARC MAURER: We have time for questions. Please identify yourself.

>> Hi. This is Larry with disability rights advocates. This is a fantastic panel.

We're representing a class of juveniles in a county in California that are detained in the juvenile facility. About 60% of the juveniles are individuals of color with various disabilities, learning and physical. It's just been an incredibly difficult case to litigate, just to get to visit these juveniles is a process. And then to have them step up and be willing to be claimants or plaintiffs is quite a brave task. These people have to first exhaust administrative grievance procedures. And the people that run the facility are in those grievance procedures telling them, "You must sign this box to say your grievance has been resolved or you're not leaving this room." They have no lawyer, no representation.

We've been very pleased with the civil rights division of the DOJ. They've come in on our case with a position statement saying that the right to education is an essential right in juvenile facilities. And the Department of Education has come in on that as well.

So we're very hopeful of getting a good precedent on that issue.

But another issue in our case that the government has not yet really sided with us on fully is that they use solitary confinement as the immediate response of any violation of any rule. So we have juveniles with disabilities locked in solitary confinement for hundreds of days, becoming paranoid schizophrenic as a result. We're trying to marshal evidence that solitary in any facility, much less a juvenile facility, is a form of cruel and unusual punishment and is not effective for discipline. But we would welcome any support on this issue because it's as much a form of torture as physical assault for individuals with mental disabilities.

MARC MAURER: Comments from the panel?

MICHAEL BIEN: Larry, as I think you know, we just finished a trial about solitary confinement in California prisons of the mentally ill and got a good ruling in April which I can provide to people if you're interested. America uses solitary confinement very differently than any other place in the world. A lot of places, 30 days in the hole is a big deal. In America, if they find you after a couple of months, they might have a hearing about whether you're supposed to be in solitary confinement. We have people have literally been in for decades. There are no limits in America. It's an issue that is really being raised a lot now in the media. There's a campaign based here in the ACLU national prison project called "stop solitary." There's a lot of good information about international human rights standards, American Psychological Association has taken positions. The groups identified universally as those most vulnerable are juveniles and those with disabilities. But the evidence is any human being, if you think about what it would be like to be locked in a room by yourself with no activities. And when we talk about 23 hours a day, that's an exaggeration. In most of the solitary units that we visited, you're lucky to get out five or ten hours a week. And there would be many days that you don't get out at all. So anyone would have great difficulties in such an environment. For juveniles, it is a terrible, terrible thing. I'm surprised that the Justice Department isn't ready to go there. They have come in -- I always try to introduce the ADA people to the special litigation people. They're on different floors. Now they're starting to be more integrated. So when we brought our case and they brought a complaint against the state of Pennsylvania, for the first time, they are referencing both the eighth amendment and ADA and Rehab Act when they're looking at solitary confinement of the mentally ill. And I think both of these principles are important. It's discriminatory practice because people with disabilities are the ones who tend to get stuck in the hole for all of reasons we've talked about, but also they're the most vulnerable in those situations.

But anyway, great work, Larry, and I think there should be a lot of support for that case.

TALILA LEWIS: I can just add to that. So I worked with the ACLU national prison project and the disability rights project this past summer. One of the things that I'm working now with Amy, someone you should reach out to, now is they've just finished and it's still kind of ongoing but the stop solitary campaign which focused on juveniles but know we are focusing with the support of my database on prisoners with disabilities. And if you have information about prisoners with disabilities, juveniles with disabilities, who are in solitary, that's something that they would need the information on and they are doing a whole other campaign specifically geared toward that.

Also, last month I believe, the Senate had its second hearing ever on solitary confinement. I know I submit a comment about decompensation and how much more quickly decompensation happens for persons with disabilities. So for instance in the Al-Jazeera documentary, we showed one of our prisoners who is deaf who within six days tried to kill himself from being in solitary there. Are stories of deaf people and others with disabilities who literally within weeks, sometimes days, because they have fewer senses to lose in solitary. So idea is that you are robbing people of sensory inputs. If you're deaf, you're down one. Now you just have to rob a couple more. So you go much more quickly than the typical person with all faculties.

So there's Senate hearing testimony about it. The actual Senate hearing you'll see testimony on it. And then Amy Fedik I would recommend that you contact and I can share her info with you too.

I'll try to be brief on this, but isolation of prisoners with the same disabilities also happens often. So people who are deaf, what I've found from my research, is when there is a prison with many deaf people, so for instance, Felix's prison has 30 deaf people. They will house them separate and apart from each other so they can't communicate. That is solitary within the prison and that is what happens with most prisoners who are deaf. They are not housed together. They are literally in isolation even though they're with hundreds of other people.

MARC MAURER: Other questions?

>> I have a wireless mic if anyone needs it. I can bring it to you.

JENNY HATCH: I have a question for you, ma'am. I just let you know, I have been working with special needs with other people. I've been working with senator Posey. You're right. The committee needs to be done. But last time I was helping, we had an issue with other people and I tried to help with sign language to other people. My friend can't see and she is blind. And she's -- I just let you know, I am here to help people with disabilities with Down syndrome, Senator Posey, and my friend of mine. And I'm here to help with special needs.

If we try to sign language them, any questions for me and my friend of mine, Sandy, is a first people for first language. And if any of us, please contact Sandy Hardeman. She works every day in the morning and I was thinking about her every day. But I was down in Norfolk and I saw a lot of people with issues. And I tried to encourage them to help because I was there with Sandy. And the first language you know with people with disabilities with Down syndrome or anything, but I just let you know, this is my quick question for right now. I'll just let you know, if you have any problems or contact Sandy. Kelly Morris has about talking to Sandy on the phone every single morning. And I just let you know, I'm here to help with Down syndrome, with disability, with senator Posey, and the blind of people who cannot see. I'm glad to help them. I'm here to help with disabilities. But I just let you know, we have an issue with that too.

Every single Monday night, I see a lot of people with can't see who needs help. And I need somebody to help me help with disabilities, including Quality Trust. Thank you.

TALILA LEWIS: Thank you, Jenny.

MARC MAURER: Thank you.

Other comments?

Okay.

>> Hi. I have a question about really reentry. I practice primarily child protection defense law. I'm Carry Ann Lucas. I have many clients with disabilities. The rules of the community correction facility or just the onerous requirements they face. They have to hold a job yet they have to attend X many meetings often per day in addition to dropping UAs and all these other things that pay for all their treatments, regardless of whether they have disability benefits, they're still expected to work.

So who is working on these issues? Do you have any suggestions for helping these poor clients who just cannot navigate that system?

TALILA LEWIS: Just a month ago, I actually emailed the entire CSOSA in D.C. because for the second time in less than six months I received reports of a deaf returning citizen, which means people who are reintegrating into society. So deaf returning citizens hadn't received access to interpreting services. So I contacted the supervisor and everyone in her immediate chain, and within the day, literally, they said, we will have interpreters for the entire, both of those people, for all of the orientations, for all of their meeting was their POs, etc. So depending on the organization, I think it's about finding the person who understands the issue. And then always I dropped of course in my email, hey, you know about the ADA and here's what it requires. It wasn't a, you know, a mean email per se; it was very much like a nice and by the way, here's this law that is controlling. And sure enough, once it's brought to the highest person in the office, they can't do much but follow it in those situations. Prisons are a little more different but reentry settings seem to be better. Halfway houses, we can talk offline about that. That might be cause for a whole campaign.

Did that help at all?

>> It does. We can get interpreter services for clients through the state for all their meetings with their POs. The issue is when they get into the private community settings which then it's Title III and trying to get those entities to comply. But also so many of my clients have underlying intellectual disabilities as well. So just being able to understand all of the requirements and components and being able to organize and get to places on time, they really struggle with that stuff so then it's just a pipeline back to being incarcerated.

JOSEPH TULMAN: A huge proportion of the population of incarcerated people are there based on revocation for violating conditions of release, whether probation or parole. So you want to write a letter saying, here's 504, here's the Department of Corrections, we have rights to accommodations, here are the reasonable accommodations we're requesting. Then of course they won't do it. But you give them all the documentation first.

Then what I find is, if you can -- it's a carrot and a stick. If you can put that law in front of them and also go out and find the services. And I know that's a lot of work, but find the services that are appropriate, and say here it is; I've solved your problem for you, that's helpful. I know it's a lot to do.

One other quick idea, I'll try do it quickly, through the delinquency system, kids are ordered to get evaluated. Right? Ordinarily under 504 you have to ask if you're a person with disability, you have to identify yourself and say I want these reasonable accommodations. Have you read these evaluations that the court appointed psychologists do? They're boilerplate. So every kid has a conduct disorder and the remedy and the recommendation is throw the kid away. Constrain the kid. Right?

What if we made those psychologists who work for the court accountable under 504 and ADA and said here's a list of the disabilities, here is Tennessee versus Lane, here's Olmstead, here's what they have a right to under special ed, and we said here are all of the reasonable accommodations for TBI or whatever, all of a sudden the boilerplate looks like an array of reasonable accommodations which is their job. If they don't that, if they didn't put in the reasonable accommodations in the recommendation to the court, they would be violating 504 and ADA.

>> That's exactly what we do in child protection cases. Clients almost always need a psychological evaluation so I pull those guidelines regarding accommodation and include those and make sure the referral that goes out to the psychologist includes that information as well.

MARC MAURER: I want to thank you, Michael Bien and Talila Lewis and Joseph Tulman, for your participation and your suggestion that there are ways to get at some of this question of disability that had not crossed some of the rest of our minds. And I want to thank you for the insight that you've offered.

It is a dramatically necessary area of work and I thank you for the work you're doing in it.

Our next piece is --

(Applause.)

-- about Dr. Asch. So if Leslie Francis could come and David Wasserman.

Dr. Adrienne Asch has presented to this conference in the past. It is a sadness that she died last fall. But it is a joy that she lived. She was a bioethicist. She got into it by accident, because she went to a bioethics conference and she pointed out that all of the people making presentations about disability and the ethics of disability and the ethics of providing scarce treatment to people with disabilities and speculating about what disability meant in this realm were able bodied. Not a single one of them had a disability. And she pointed this out, and it resonated. So many other things have resonated since then.

To talk with us about Dr. Asch, to reflect, to offer tribute to a magnificent soul, we have Leslie Francis who is the Alfred Emery distinguished professor of law and distinguished with professor of philosophy at the University of Utah.

And we'll start with Leslie Francis.

(Applause.)

LESLIE FRANCIS: I've had the honor of being Adrienne's friend and her coauthor.

I'm here to honor Adrienne's scholarship, her love of bicycling, and her great courage. This may sound like a very odd mix, but I think they go together in many ways.

As a scholar, Adrienne was a clear headed voice on issues of social justice and disability in particular.

My favorite papers of hers and probably her best known papers concern selective abortion and disability.

Adrienne was an ardent feminist. At the same time, she unmasked how problematic assumptions about quality of life all too often infect decisions about prenatal testing and subsequent decisions about abortion.

She also pointed out confusions between judgments about quality of life and judgments of moral status. Judgments that have nothing to do with one another.

Adrienne, as the feminist that she was, believed in choices for women, including the choice to decide to have an abortion.

But she also believed that people should not make these choices for bad reasons and that women's choices should not be clouded by the kinds of misunderstandings that are all too common about the facts about disability, about ethics, or about ultimately metaphysical matters.

Adrienne learned to bicycle with her father, who bought a tandem bike for them when she was quite young. One of her last trips, actually, was a bicycle ride through Italy with her brother when she knew she was fatally ill. Several times I was the front rider with her at what bioethicists called bioethics summer camp. So I rode front up the mountain trail in Copper Mountain, Colorado. I rode on the rail trail with her on Cape Cod. And you know, sometimes you think about the person on the back of the tandem bike as a free rider. Not Adrienne. She was a remarkably strong peddler. I fear actually stronger -- actually I'm sure stronger than I.

Her descriptions of the smell of the landscape and the feel of the breeze made our trips amazingly enriching for me. And I can only imagine what it must have felt like for her to come hurtling back down the trail depending on me to tell her when to brake.

And courage. Adrienne took positions that people found challenging, disconcerting, and indeed unpleasant. She took risks, certainly on that bicycle with me, and she faced her illness in a way that once again I can only imagine. Thank you.

(Applause.)

MARC MAURER: David Wasserman is a visiting scholar from the National Institutes of Health, the department of bioethics. Here is David Wasserman.

(Applause.)

DAVID WASSERMAN: I had the privilege of being Adrienne's close friend for over a decade, which was admittedly a short period of time compared to many of her close friends. During much of that time I was her colleague at Yeshiva University center for ethics and I was her coauthor on disability and reproductive issues before and after my stay there.

Adrienne was, I know, passionately committed to the work and mission of the National Federation of the Blind. I recall her descriptions of the marathon scholarship sessions she participated in yearly which I cannot imagine having either the devotion or stamina to endure.

The annual convention was one of the highlights of her incredibly crowded schedule. Yet despite this commitment, blindness was not a central part of her identity. I became painfully aware of this fact in one of our very first encounters. On a panel, where I proposed the cultivation of disability-specific sub cultures on the model of Deaf culture. Adrienne dismissed this as, to quote her, preposterous. She did not want to belong to blind culture or disability culture or any other confining sub culture, which she regarded as a form of self-segregation. And I'm reminded of that by the remark about prison segregation by specific disability. She felt that it would be absurd for people with disabilities to impose that on themselves.

In an important sense, Adrienne didn't think of herself as blind. She was of course well aware of the fact that she couldn't see. But she refused to be defined by her limitations or to transform them into a source of strength and pride. Blindness was simply a fact of her life, which loomed large mainly because of social and attitudinal barriers. In a just society, it would be at most an inconvenience, like left-handedness or, as Jacobus tenBroek suggested, like baldness. Much like the man for whom this symposium is named, Adrienne saw the national federation as a civil and human rights organization. She was profoundly disappointed that so many liberals and progressives treated the civil rights of people with disabilities as, at best, poor relations of the civil rights of women and people of color. She experienced that treatment firsthand from the American Civil Liberties Union, which denied her an entry level job out of college. That would have been about 45 years ago.

Years later when she became a member of the ACLU's national board, she found that those attitudes had not completely disappeared, although in part because of advocacy by people like herself, or especially herself, they were greatly reduced.

Indeed, in many of her organizational roles, she worried deeply about tokenism. About being treated as the blind or disabled representative. She emphatically denied representing blind or disabled people in her civil rights work, a role she regarded as constricting and often condescending. Rather, she saw herself as bringing her experience with disability-based discrimination to bear on the project to which she had a lifelong commitment, the creation of a more just and inclusive society.

Blindness and other disabilities were just some of the many human variations that society would not only accommodate but embrace.

(Applause.)

MARC MAURER: I had the pleasure of inviting Dr. Asch to come to the national convention of the National Federation of the Blind to reflect upon Dr. tenBroek's work. She came last summer. She made a presentation which was entitled "Reinterpreting and Expanding the Right to Live in the World." She concluded it saying, "Let me conclude by challenging us with some questions that are just starting to get bioethical discussion. These questions that could provide us with plenty of opportunity for reflection and conversation. Resource allocation in an emergency is a big topic in bioethics these days. Different states, professional societies, and the government, are trying to decide who will get ventilators in a serious flu pandemic when there are not enough for everyone. Various allocations schemes have been discussed. Only people above or below a certain age will get them. Knowing that the very young and the very old might die without them. Only people with dependents will get them so that aging parents will not lose children who are caring for them. People will not lose their spouses. Only people with a certain estimated quality of life before and after the ventilator use will get them. And people whose quality of life is considered lower for some reason will not get them. Again, that might be blind people, because blind people is considered a deterrent to a life of quality. Conversely, blind people, as those worse off, should get ventilators first because they deserve compensation. Do we want to get priority for ventilators by claiming we very been worse off all the rest of our lives? Is that a price we want to pay for the privilege of staying alive? As people who believe it is respectable to be blind, legitimate to be blind, we may believe that blindness should not disqualify people to live in the world, but suppose genes could be modified before birth or visual implants given after birth or during a life to preserve or restore sight. Is blindness a characteristic that is incidental to anyone's self-definition? How should we help parents contemplating sight restoration techniques for their children or people contemplating sight restoration for themselves? I don't know how we as individuals or we as an organization will choose to answer these questions. I do know that just as we worked to change laws and practices in education, rehabilitation, technology, employment, and child custody, we must take our place in the bioethics debates now and in the future. Although some of these questions may challenge us deeply to think about what it means to be blind, we are up to that task. Reread Dr. tenBroek's historic article with these questions in mind. These thoughts can guide us as we go into this new intellectual and practical territory. And as someone who has been doing this work for about 30 years now, often feeling as though I'm alone on the barricades, I would like your company."

Dr. Asch said that last July. She believed in the legitimacy of human beings, regardless of characteristic. She believed in creating self-definition, in having the individual do it.

I will miss her. I was glad for her company. It was a delight to be on the barricades with her, and I urge you, as you contemplate what she has given, to find others who want to stand with us there.

(Applause.)

We're going to have a 15-minute break and there's coffee and other things available. Then we will get to the workshops. Do we want to cover which workshops, Lou Ann? You've moved some of them.

LOU ANN BLAKE: Issues with common carriers has been moved to fourth floor conference room.

The parental rights how to workshop is in the Betsy Zaborowski conference room.

The other two workshops are in the conference rooms as listed in the agenda.

Also, during the break, please do not sit at the tables. They are getting the tables ready for lunch. So feel free to bring your break food in here and sit here if you like but please don't sit at the tables. Thanks.

MARC MAURER: See you at lunch.

(Break.)

11:00 a.m.

"After a Reversal in the Appellate Court, How a Settlement Was Won in the New York City Adult Home Residents Case"

JENNIFER MATHIS: We have a little trouble with technology.

So hi. This is the workshop on I guess pulling a rabbit out of a hat, how we ended up with a settlement in the New York adult homes litigation after having gotten a favorable trial verdict reversed on appeal.

I am Jennifer Mathis, the director of programs at the Bazelon Center for Mental Health Law. I think most of you actually know us. We know you. The Bazelon Center is a national nonprofit disability rights mental health organization that does public policy focusing on community integration and Olmstead work. We are based in D.C.

This is my boss.

IRA BURNIM: Don't believe it. Oh, I'm Ira Burnim, the legal director of the Bazelon Center.

I told Jennifer that I wasn't going to be here today because I had to deal with the MVA, the Motor Vehicles Administration, trying to register a boat trailer, but they were very merciful, so I made it. But as you'll see, there aren't a lot of notes on my pad.

So I was just going to give a brief overview, turn it over to Jennifer to give you the meat, and then we'll take questions.

Rather than kind of tell you the story which some of you may know, the story of the case beyond what Jennifer mentioned, that we got a very favorable decision from the trial court after a seven-week trial that then got reversed on appeal. Our client was said to have lacked standing. We were able to nonetheless get a settlement that was not very different than the judgment we got after trial. The remedial work after trial.

So sort of the big picture I think, answer to the question how did this happen, was, one, we turned out to have a very good case. And I'll have to admit that we didn't know how good a case we had going in. We began kind of a project or campaign of bringing Olmstead cases shortly after the decision and after the disability community kind of thought through its strategy and did some political work first. And then we filed four or five different cases, one in Illinois with Barry and folks. And then one was in Connecticut, New York, I'm sure there were others. It just happened that this case developed in a way that was very powerful. And we also were lucky enough to get a pretty good judge, a judge whose wife was involved in mental health issues and had some understanding of the issues and kind of got it.

So it always helps when you have a good case and you can sustain a reversal in appellate court or trial court for that matter if something doesn't go your way but based on the strength of the case, strength of the facts, strength of the legal claim, you can kind of make adjustments and get where you need to go.

Obviously there was a certain amount of luck involved. We were going to refile -- it was standing ground. It was the P and A. We always had the option of refiling based on a class. And they are an important issue which Jennifer will discuss, ending up in front of the same judge. We were able to kind of get some advice on that topic. We weren't sure really until we filed the settlement whether we would end up in front of the same judge, but we did.

So strong case, little bit of luck are the two main ingredients here. There were some others that Jennifer will mention. So kind of the answer to how did we do it was, it didn't really take a lot of skill or thought. Other than picking the case in the first case and litigating it well. All of you could have done it as well had you kind of had the case we had. So to me that's sort of what -- we say it over and over again, but it's so true. Good facts make good law. And I think that was really the story behind this case and I think also sort of our ability to kind of get relief after this reversal. So I'll turn it over to Jennifer.

JENNIFER MATHIS: So I'll talk a little bit about -- I don't want to spend too much time on the case itself. We've done workshops on the case, what the trial evidence was. It passed tenBroek symposia, but just want to give some background about it for folks who aren't familiar with the facts in the case.

Also just wanted to say a word about why we chose to bring the case in the first place with an associational plaintiff, the P and A, rather than trying to bring it as a class action. So this was a case about 45, 4300 people with mental illness at the time that we brought it, which was July of 2003. We brought it as an Olmstead case challenging New York's segregation of individuals with mental illnesses in these large segregated boarding care homes, adult homes in New York. We limited it to boarding care homes in New York City that had over 120 beds and had a certain percentage of people with mental illnesses, which was New York recognized this category called impacted homes if they have more than 25% of residents have mental illness or 25 residents. As it turned out, any of those homes that are, quote/unquote, impacted, it's almost 100% people with mental illnesses. Virtually nerve these homes had a mental illness. At the time we filed we were talking about 26 homes or so. It got up and down a little bit over the years, but we were talking somewhere between 4 and 5,000 people.

We had actually been investigating it -- well, we were trying to develop it as a class action. And we were working with folks at Legal Aid in New York to find potential plaintiffs. Really I think what happened in the beginning of our case is that we tried very hard to take advantage of timing. We were originally going to file the case after a series of front page New York Times articles drawing attention to these homes and how horrible they were and got a lot of media attention for that reason. The guy who wrote the articles would be a Pulitzer Prize, chronicling people jumping out of the windows and basically bad conditions. That wasn't really what you're case was about, but it was a good backdrop for us to file the case because people knew these places were really awful. And so we were --

IRA BURNIM: Can I interrupt you for a second?

JENNIFER MATHIS: I knew you would.

(Laughter.)

IRA BURNIM: On the good facts make good law, we had been thinking about litigating a case on behalf of folks in a board and care home. We knew people in New York, particularly the P and A, but we didn't have any involvement in this particular situation. So it's kind of like don't be shy. If you have an agenda, we were trying to develop the law and find a place. But we literally just started calling folks in New York and said, are folks meeting about this; can we come. Which is how we got involved.

JENNIFER MATHIS: And a lot of folks called us too.

IRA BURNIM: Oh, that's good. Called you, not me.

JENNIFER MATHIS: Anyway, part of the reason we ended up not bringing it as a class action, at some point the guy who wrote The New York Times articles sort of succeeds in his mission of highlighting this issue of how bad it is. The governor decides, state decides to put a bunch of money into community services to fix this -- well, to get people out to of the homes and kind of fix this problem. So the guy who wrote the articles basically sort of declares victory, problem solved, and now there's this infusion of money that's supposed to go into community services in New York for these homes and suddenly it was a terrible time to file. Then what happens is the money actually doesn't go into community services. The legislature decides that, in fact, it will go to bonus payments for the operators of these places who have a lot of political clout with the state legislature.

So then suddenly, we're like, we need file tomorrow! So it was a timing thing. So we decide we don't have time to go back and try to go find new plaintiffs and it's not so easy to find sort of really clean good plaintiffs. It takes a little bit of time, partly because people are scared and it's not so much that people don't seem appropriate for living in their own homes, but so people are scared to say anything. So we end up filing it as a P and A standing case. So we go to trials. Seven-week trial. 2009. So six years after we filed the case. And we win this terrific decision, 200-page decision basically I laying out everything you would want to really describe where mental health system should be going essentially. The judge finds that, for one thing, pretty much all of these people in the homes can live in their own homes in supported housing, scattered sites, like anybody else, you know, regular buildings in the community, that these places are institutions, that they're segregated and that they are not the most integrated setting for virtually all of these people, that it doesn't -- you don't need to move as the state argued from one place to another to another to another along what they called a linear continuum of care in order to get to be appropriate for living in your own home; you would just move directly from an institution into supported housing and that's the way it should be and that's fine and you would titrate the services around the person.

If given a meaningful choice, it was found that most of the residents of the homes would choose to live in supported housing and that they hadn't been given a meaningful choice, they hadn't been given information, people don't know about it, people were told you will never make it in supported housing, lots of reasons why people needed to have kind of an architecture that would allow them to exercise meaningful choice. They had to have people coming and talking to them and developing relationships with them so they could sort of be given options and really understand what kinds of benefits would work and all of that in supported housing versus in the adult homes.

And he found that it would not be fundamental alteration to offer supported housing to all of these residents because it was really slightly cheaper to support them in supported housing than in the adult homes, because the Medicaid costs in those homes was so high, partly because it's a dependency model and so you're paying for people to be transported around in ambulances and the psychiatric hospital admissions for people in these places were through the roof, whereas people in supported housing take public transportation and don't go to the hospital as much and use different services. So you're not wasting so much money on expensive kind of services where people are doing things for you instead of you learning to do things yourself.

So as a result of that, basically the Medicaid costs for serving the same people in the institution versus in their own homes was about twice as high for people that look the same in the institution versus in their own homes. So for that reason, it was cheaper.

IRA BURNIM: $167 or something.

JENNIFER MATHIS: It was a close call. If it was slightly more expensive, it probably would have been fine. But it turned out to be a little less.

I think what horrified the judge is that years and years of reports from the state and counties talking about how horrible these places are, how segregated they are, how people don't have meaningful lives, how they should develop other alternatives, and Linda Rosenberg, our sort of star witness who was the former high up person, deputy commissioner of mental hell knowledge New York, had testified and said these are the same people who are in the adult home, the same people who live in the supported housing that people serve now in their own homes. There's no magic to supported housing. The state had painted this picture that if you lived in supported housing, you had to have a Ph.D. from Harvard and none of these folks would qualify.

IRA BURNIM: She was our John Dean on the trial, who had been inside and knew it all.

JENNIFER MATHIS: Exactly. So we win this decision, and it all -- two years later, it gets overturned. The remedy we got after the decision basically said that the state had to develop a certain number of supported housing beds every year for three years. They were supposed to develop at least 1500 units of supported housing for the people in the homes and as many more were necessary to ensure that basically by four years, everybody who was qualified for supported housing and wanted to live in supported housing could do so. And no new people were being admitted to the adult homes if they wanted to live in supported housing and they could.

And very good standard for who was qualified for supported housing. The judge said basically everybody is qualified for supported housing unless they fall into these very narrow categories like severe dementia or you're dangerous in which case you're hospitalized, or you have such significant medical needs that you couldn't be served in the state's existing Medicaid waiver program.

And we had a court monitor with a very big budget to do a lot of work. So that's where we were in 2010.

2012, we're in a very different place. What happened in between, the Justice Department kind of got involved at the end of the case, intervened and said, you know, this is kind of an important case and how the implementation of the remedy order happens, it's an issue of national significance. The judge said yes and they convened. Then the adult home industry tries to intervene and the judge says you were sitting through the whole trial and just sitting on the side and you could have intervened before, I'll let you file an amicus brief, but I won't let you intervene.

So they then file an appeal. They file both an appeal for the denial of intervention. They also file a third party appeal, kind of claiming it's a direct appeal. So they did a lot of briefing.

IRA BURNIM: Weirdly, you can be a non-party and appeal in the second circuit.

JENNIFER MATHIS: They're saying the settlement affects us in this very direct way.

So is the state appeals. They dependent make persuasive arguments. The adult homes took up our biggest weakness, which was standing. So they convinced the second circuit that there's no standing because -- it was not saying that P and As don't have standing. But disability advocates, which was our plaintiff, was a subcontractor, legal subcontractor, to the P and A, and there just wasn't a big record about, you know, standing of disability advocates because the state hadn't at trial raised the arguments in a serious way. They had basically just made some standing argument that was really about the merits and you haven't shown that people have a claim because you haven't shown that anybody is appropriate for the community. So that was really the only standing argument that they had made.

IRA BURNIM: The state had made.

JENNIFER MATHIS: Yes. So then when we get to the second circuit, the adult home industry is saying, well, you know, we don't have any record here demonstrating that DAI has standing, and the second circuit agrees, doesn't touch the merits at all, doesn't say anything about this 200 pages of decision on the maters, but just says there's very scant evidence here and we don't have information in the record about whether DAI, people with disabilities can elect the directors of DAI or make budget decisions or influence their activities, and there's no contract in the record between DAI and the P and A, we don't have agendas and minutes. We don't have descriptions of the advisory council members of DAI or information about how people with mental illness convey information to DAI. No evidence that DAI ever notified its constituents that the guardians were filing this suit.

The picture that the industry had painted was that DAI is this interloper and they really know nothing about these people, they came in, they filed this lawsuit, you know, we know these people, we love them, we're a family, we know them best, you know, don't believe kind of DAI came in and they don't know anything about these folks and they're saying all these people can leave and they're going to kill them and we're very concerned about their welfare. That's sort of the general tenor of it. But the standing piece was that they weren't appropriate representatives because the people that they claimed to be representing really have no input with DAI.

IRA BURNIM: I think the other thing happening at the time was that the law was turning on standing. So it was a kind of compromise decision at the second circuit. They didn't address the issue of whether P and As had standing. I think if they had, they would have said no. They had a fairly conservative panel.

But the other part of the story is that the adult homes had been very effective in New York politically. They have a New York State law firm that represents them. But for the second circuit, they got the Supreme Court practice, Patty Millet, who now is a judge, she actually worked on Olmstead, I think. But she was part of the Tom Goldstein, and then he left.

But part of what happened here is the industry figured out they needed someone to make this appellate argument because it was going to be technical and jurisdictional. And also I think Aichen Gum saw this was a Supreme Court case. So part of why, like Jennifer said, they upheld litigators and their version of Sam Bagenstos, who handled the case. That we did not expect and we had to deal with it.

JENNIFER MATHIS: I think Patty Millet had argued more Supreme Court cases than any other woman in the United States. Interesting.

Anyways, we then after we get this panel decision, we had to figure out what to do. Before the decision came down, we had some sense before the argument that maybe it would be a standing issue, that we would lose on, and that would be it.

So we were having some discussions before it came down about sort of what do we do. Do we need to sort of file a class action suit immediately, if we lose on standing? File the same case, file as a class action? Do we need to be ready to go so that essentially before the appellate court issues the mandate, we file the new case and so now there's a related case and then we can get the same judge. We really wanted to get our judge back because he made a huge amount of difference for us.

So we decide in the end we don't need to do that, that's probably not critical. We had actually started negotiating with the state before the second circuit decision came down. Because we --

IRA BURNIM: Really?

JENNIFER MATHIS: We started talking to them. We went up to Albany the next day and got the decision.

IRA BURNIM: Oh, right, right, right, right.

JENNIFER MATHIS: Because we all knew this was potentially -- it I was good time negotiate a settlement because everybody was at risk. Close to the beginning of that, the decision comes down. And it is on standing.

Apparently, the U.S. attorney had sort of assured us that the guy in the eastern district of New York that we were working with at the U.S. attorney's office said we will get the same judge, we don't need to worry about doing it as a related case. And so we ended up not filing --

IRA BURNIM: Which made us extremely nervous. We didn't really know Michael but he turned out to be right.

JENNIFER MATHIS: So we spent I think almost a year and a half negotiating. We understood that our trial judge was really pissed off that it was taking so long. And kept saying to the person who had been the former court monitor, what the hell are they doing.

So we finally get the settlement. As Ira said, it wasn't hugely different from the remedy order we had after the trial. It gives the state more flexibility. It still says basically everybody in the adult homes who is qualified for supported housing and wants supported housing should get it. And it's a period of five years instead of four. It still says everybody should be offered the most integrated setting. It doesn't set the same kind of schedule for the state to develop supported housing for the residents. It actually just says they have to develop at least 2,000 units of supported housing plus however much more they need accomplish getting everybody into the most integrated setting. And it says that by four years from the settlement date, that they will have assessed at least 2500 residents and transitioned them to the most integrated setting, but basically by five years they have to ensure that everybody is in the most integrated setting, has gotten supported housing if they're qualified and want it. It's a similar standard to what we had in the remedy order for who was qualified for supported housing. They added one thing to our kind of category that might exclude people from getting supported housing, the severe dementia and people with very significant medical needs and people who are in imminent danger. Their last category was something like people who need services that we just don't provide in New York through the Medicaid program or any other state program or isn't available through any other source.

So it was essentially the same. They wanted the flexibility because they had this plan to focus a few homes at a time because partly they're worried there will be chaos if all of these homes start closing and if they get below critical mass, they're going to close and they're worried about managing that process and having enough community alternatives for people when these places close and they want to do it in a way that they can focus on a few homes also for I think political reasons to make this more manageable. It seemed to us that cut both ways. That when you're targeting particular homes, you also engender a lot of activities in those homes to resist the settlement.

In any event, they had more flexibility. Also who is doing the assessments is a little bit different. We had the supported housing providers in the remedy order doing the assessments. They were doing this kind of seamless process of in reach, coming into the homes all the time, building relationships with people, exploring any concerns they might have, taking them to visit supported housing, explaining options, how things worked, and they were building trust with folks so that maybe somebody doesn't say right away I want to leave in a year or six months or whatever it is, that person may feel comfortable enough to actually say they want to leave.

Here in the settlement, we have a similar process of in reach, but it's the -- they wanted the -- and the supported housing providers actually do the in reach, but the assessments are do differently. There's an assessment process and person-centered planning process done by the managed care plans. So the state is setting up as part of the whole Medicaid redesign, they're setting up health homes and managed long term care plans and all the folks will be enrolled in those so it's the care plans that are assessing people supposedly with input from the supported housing providers, who are still doing the in reach. So we'll see how this all goes.

IRA BURNIM: More than supposedly.

JENNIFER MATHIS: Yes.

Okay. The other thing we thought was important was to ensure the assessments were done against the backdrop of having housing actually available. Because assessments tend to reflect what is available at the time in the community. So we have in the settlement an obligation to coordinate the development of supported housing with the assessment so that there is, when assessments are being done, there is housing available or it will soon be available. That actually was not in the remedy order. That was a new thing.

And I think those are the main differences.

So we are now about 17 minutes or so out. I just wanted to say, the other thing that was important in our settlement negotiations that got us to this place was the presence of the Justice Department. They were at the table with us. They were also going to file their own case against New York, and we were going to file a class action. So we all sat at the table together. For a bunch of reasons, partly because I think having the United States of America at the table seems to have a much bigger impact on states than we do. But also in New York in particular, the governor, who had a different take on this than prior administrations did, seemed to really care about doing something here, which didn't seem to be a priority for prior administrations. And he didn't particularly want to be a defendant.

IRA BURNIM: Yeah. It wasn't clear the extent to which he, based on his new health adviser, who was pretty good, he sort of understood that this problem had to be solved.

The other explanation which may be the true explanation for why Cuomo did what he did, is he had political aspirations beyond governor. But yeah.

Some of you, I don't know, some of you may have actually negotiated with the U.S. as your partner, which is always an interesting experience. They were terrific and they were terrific to have in the room, but we knew the case. They come in after the trial. So it's like we're taking the lead. And then it's like, you know, I think we need to get U.S. in the lead here. So then they would take the lead and the conversation gets into the details and we had to jump back into the lead.

So eventually what happened is the U.S. towards the end they pretty much took the lead in the negotiations and we met beforehand to figure out the strategy.

Also it was easier at that time because there was a lot of talking and exchanging of drafts at that time.

>> Can you talk about monitoring and the implementation, how you are measuring success and the enforcement mechanisms?

IRA BURNIM: There's a monitor who has now been recharacterized as an independent reviewer. So the Justice Department settled and said independent reviewer. Essentially a monitor.

Because of the flexibility in the agreement and because we weren't entirely sure that the state officials really knew what was happening on the ground, we were worried about the monitor. So yeah, when we got to that kind of the conversation, we said, well, we had recommended a couple of people, as had you after trial, so why don't we look at those people first. They didn't want anything to do with the prior monitor.

JENNIFER MATHIS: Who actually they had recommended.

IRA BURNIM: Yes. The judge had picked her. She was fine, we said, not as good as our people, but fine.

They proposed -- they asked us, well, you had proposed Clarence Sundrum, who many of you know, who had helped Governor Cuomo with a problem in the DD system, and said is it okay with you that he's working for us now, so closely aligned with the administration, and we said fine. When they said they wanted Clarence, we sighed a bit in relief there. But it's the basic structure that exists in institutional cases or cases of this sort. So the monitor can hire staff, their people are very familiar with New York and with these homes, they have complete access to information and to the physical premises and to the class members.

And in addition, there are four or five public interest organizations who are among the plaintiff's counsel. One traditional work is representing people in the homes.

JENNIFER MATHIS: There's also a lay advocacy group actually. Not part of the lawsuit, but very active and have always been in advocating for the residents of these homes. And weirdly, actually, the state wanted the independent reviewer to work with them because they were so familiar with what's happening on the ground in these places every day. So they actually made arrangements for him to work with them.

IRA BURNIM: So I mean we're kind of fine on that. We're all over. And the basic -- it's just implementation is just the beginning. So we expect, as always happens, that there will be certain funkiness and issues will arise, but the basic measure is that people have been given the opportunity to leave and given the information and the opportunity to make an informed choice. So is we'll be looking at how many people are leaving basically and making sure they get the services they need to be successful in supported housing. So they'll be looking at that side of the equation as well.

>> I had a question about the supported housing piece. It sounds like, I'm curious whether you all had any push back about the availability of housing.

IRA BURNIM: I'm going to speak to this because it's my pet peeve. So this is New York City. Do you know how many apartments are for rent in New York City below median rent? There's a gazillion. So we're not -- you know, if you look at the enterprises, we need to house four people and we don't have enough affordable housing, that's right. We don't. But if you have money in your pocket, like the state of New York does, and you want to rent apartments, you're fine. So you can rent apartments for thousands of people in a place like New York. In most places you can rent apartments. So the problem with affordable housing doesn't affect the implementation of these settlements. In many places what the provider gets, arranging the housing, is in addition to some money for case management and support services, the bulk of what they're getting is a rental subsidy. So, I don't know, 14,000 or whatever in New York.

After the judgment, New York was raising the same concerns and our monitor did a huge study, interestingly, and documented. You know, she called realtors, she did this and that, and basically it was kind of to shut up the state because, you know, she documented that there was a lot of housing to rent.

JENNIFER MATHIS: Right. And this comes up I think everywhere we go. Particularly in tight housing markets you here there's no housing.

IRA BURNIM: San Francisco.

JENNIFER MATHIS: Yes, exactly. We had a case in San Francisco where we hired -- this is even a tighter rental market than New York City, it's all inaccessible, your people have wheelchairs, it's a very small jurisdiction, you can't go outside into Oakland and surrounding areas, so everybody said, there's absolutely no housing, how could you possibly do this.

At some point, the city said, well, actually, we're looking at this supported housing model from other places and yeah, if we gave a rental subsidy, there's plenty of housing. That's always been true. It's a matter of money.

IRA BURNIM: It depends on the market too. If you're talking about sort is of the 40th to 50th percentile of rent, how they rank it, you can go on HUD's site and you see that number, you subtract the social security payment, and you know what the subsidy is. So look at that market. In some places, varying by neighborhood, but in some places, there's a lot of turnover in that market. So to have a long term renter who also comes with support so they're likely to be there long term, they're pretty good on paying their rent, and if there is an issue, there's a provider there 24/7 if needed, it makes a good renter. So they have relationships with large landlords in New York. It just hasn't been a problem to develop the housing.

We actually asked this question, trying to figure out what remedy to propose. It's like, no problem. We can find places to rent.

>> I'm sorry. I just have a really short follow up. But housing costs are not an entitlement under Medicaid.

IRA BURNIM: Right, right, right. So it's the comparison of -- right. The housing in New York, they provide supported housing to people with disabilities.

JENNIFER MATHIS: That's a discretionary program. If it's part of what you're seeking, you know, in a settlement or remedy.

IRA BURNIM: So we had to calculate the cost. It was state dollars to provide the subsidy. But that was true of some of the subsidy for the board and care in the adult home. So the argument is, you, New York, are paying to support these people in institutional settings. You have no obligation to support them at all. If you want to dump them in the street, that's your business. But if you spend money on them, serve them in the most integrated setting. All you have to do is, you can do that without it costing you any more. So there's a whole chart that shows SSI, how that gets affected, state supplement, Medicaid spending. And we were only looking at state dollars because the federal dollars don't matter. We were saying it would cost New York no less.

>> You mentioned the in reach, the supported housing. Who paid for that?

JENNIFER MATHIS: The state paid for it. And actually --

IRA BURNIM: It's part of the cost of supported housing. It's built in.

JENNIFER MATHIS: I don't think it's part of the $14,000 a year.

IRA BURNIM: I think their contracts -- they did an RFP for the supported housing beds and just made it part of the overhead.

>> Okay.

>> You may have addressed this, but does your remedy deal with at all whether a person gets moved to the adult home in the first place? And I'm asking for a particular reason. I run a law school clinic in New York and we represent someone whose guardian had messed up her housing situation and was seeking to move her to one of your adult homes. We fended it off in the guardianship proceeding, but I'm just curious, I imagine if I'm the sneaky adult home operator, I'm now looking for a new market of residents.

JENNIFER MATHIS: This brings up something we should talk about. We haven't talked about. There is this piece of the settlement which is making Ira cringe. It concerns a state regulation that the state did because they didn't want to be in the same boat after five years down the line after the settlement period is over and kind of recreate this problem by having these places still exist. I think it's the state's intention that these places will kind of be phased out a few at a time. But they wanted to be sure they weren't stuck with a bunch of people unnecessarily segregated after five years and get someone else is suing them or us suing them again.

So they did this regulation, which is sort of a middle ground regulation. They said --

IRA BURNIM: It closes the door to people with serious mental illness.

JENNIFER MATHIS: They took a subset of homes at places with 80 beds or more and said these are now transitional adult homes and essentially if they're impacted, if they have 25% people with mental illness or 25, whichever is less, then they can't admit any new people with serious mental illness to come in. And they were also supposed to develop a transition plan which they submit to the state to make themselves unimpacted. So figure out how to reduce it. So that depends on the state making alternatives available you but it gave them flexibility to work with homes a few at a time so they intend to roll out the housing.

IRA BURNIM: They're putting impacted adult homes out of business. So they may become homes for people with physical disabilities. I mean, they'll be equally bad, and that will be the next Olmstead case. But it's unclear what the industry will do.

JENNIFER MATHIS: The way they're doing this, several homes at a time, they've grant like waivers for some of the homes so they're focusing on particular ones. So the homes that get waivers can continue to admit new people but then they're going to focus on them later. Right now that's the way it's working. So the homes they're focusing on can't admit new people with mental illnesses, and what worries us is there's this provision because they felt this was so central to their being able to enter into the settle meant agreement, but if the regulation d is challenged, and it has been, it's in state court, in the regulation is invalidated in Cardrin Hall, then we're supposed to negotiate for 120 days and if we can't work something out, the whole thing is null and void. This is why Ira was cringing.

>> As you're using the term "supported housing," are the supports and services needed by the individual linked to the housing supplier or are they separate?

IRA BURNIM: Separate. Which is important. That's the structure in New York. It's important for a variety of reasons, not the least of which -- well, it's important for a variety of reasons.

The supported housing providers, you know, they have some money, it's a little bit of money, some expectation that they provide some is case management and support. But your service needs are met by the system at large. One of the issues that will need to be looked at is do the folks who move have access to the supports they need, which is supposed to be the job of the new long term care divisions. The high need group may need to become clients of specific teams. Others will need almost nothing other than the subsidy to get out. So you have that range.

I think one of the things that --

>> Could you use the microphone? It's really hard to hear.

IRA BURNIM: So the supports are separate. One of the things we've been worried about is there's this scattered site support housing going out and renting, you know, you subsidize rent so people can just live in mainstream housing, but then supported housing is, we build a building. I think there's a tendency for folks who do housing development, there's this federal model that's the building plus the services or the housing plus the services and you tend to get these single site apartment buildings full of people with disabilities.

I think the supported housing folks kind of understand that the world is changing, but they're really resisting. So it's an active issue about what the future of subsidized housing for folks with disabilities is going to look like. And one of the important considerations I think in getting it right is to separate out the housing and services.

JENNIFER MATHIS: I think we're just about at time.

>> How does the settlement agreement and the early stages of identifying who wants to move out deal with folks who might have guardians and whether the individual wants to move out versus what the guardian will permit.

IRA BURNIM: It doesn't address that. I think there are relatively few people in the homes under guardianship. That issue is always hard to address up front. And so I think in some other contexts, we've had to actually write about that. Generally what we do is we kind of define whoever is the beneficiary as, you know, the individual or substitute decision maker set up under state law.

If we find people are getting their choices trumped under guardianship, we'll do something about that and I think we'll have a sympathetic judge when we get there. We'll see.

JENNIFER MATHIS: It's come up with other cases where guardians are preventing people from even meeting with in reach folks. We have been able to do some things about that with whatever state law allows you to do, which in some states is pretty good to prevent guardians from doing that. In our case with Barry, folks in his shop have actually I think helped folks get out of a guardianship when it's becoming a problem. When the guardian is acting inappropriately.

IRA BURNIM: The further you are into the implementation effort and the more success there's been, the more likely you'll be able to deal effectively with that issue. Now it's a little abstract. What will the alternatives look like when there's 1500 people from the homes living successfully in supported housing, the equities will look different.

JENNIFER MATHIS: Okay. Thank you.

(Applause.)

Lunch and Keynote Speaker

12:00 p.m.

MARC MAURER: The law symposium, as you know, seeks innovative solutions. Tomorrow afternoon, after the law symposium concludes, we have the Disability Rights Bar Association. And Dan Goldstein, who dreamed up the Disability Rights Bar Association and encouraged a number of us to get into it, has an announcement about that.

DAN GOLDSTEIN: Some of you who are members of the DRBA have not yet signed up for tomorrow afternoon or even more important, tomorrow evening's wives with booze or whatever we call our dinner.

(Laughter.)

So for those of you who have been tardy in doing so, you'll be glad to know it's not too late. There is a table in the other room where you can sign up for tomorrow afternoon and you can write a measly small check for tomorrow's dinner. So I would encourage you to do that. Thank you.

MARC MAURER: So Dan, are we going to try to decide in the Disability Rights Bar Association dinner whether lawyers or fishermen tell the best stories?

DAN GOLDSTEIN: Maybe lawyers who fish.

(Laughter.)

MARC MAURER: I want to move to our next item here on the program, which is a spectacular item. This has to do with equal rights and education and for presentation, we have the assistant secretary for civil rights at the United States Department of Education, who has also before being in that position been director of impact litigation at public counsel, the nation's largest pro bono law firm.

She has also had experience, more than a decade of it, at the American Civil Liberties Union in southern California, and she served for a time there and the director. She has been a teaching fellow in the appellate litigation program at Georgetown University law center. She has clerked for William Norris on the ninth circuit Court of Appeals of the United States. She has a law degree from Yale, and she has a college degree from Amherst College.

Please welcome to the podium assistant secretary Catherine Lhamon.

(Applause.)

CATHERINE LHAMON: Thank you, Dr. Maurer.

I want to introduce another lovely person in my life, my daughter Danielle, sitting over there.

(Applause.)

Today so happens to be "take your child to work day."

(Laughter.)

I really appreciate you putting this event together so it could be more interesting.

(Laughter.)

It is really very, very exciting for me to get to be with all of you. This is a set is of issues that are near and dear to my heart, obviously, given what I do. Couldn't be more important. And I'm so impressed with, supportive of, your mission to increase access for low vision and blind people in the country and particularly access to education for that population, which I really appreciate and is something we work very hard for at the Department of Education.

I want to describe the three main levers that we have for the work that we do and then talk a little bit about those levers. I hope I can open it up for conversation among all of us. I am seven months in this job and I am looking forward to the remaining three years I have in this gig. I'm excited about what we've been able to accomplish and looking forward what we can do together in the future.

Some things are very important in the time I've been here and I'm looking forward what more we can do.

But there are three main levers for enforcing civil rights around the country. Data, policy guidance, and enforcement. We try to make the most use of all three of those levers. In my role in enforcing the civil rights laws in the country, the three big categories we enforce are disability, race, and gender, and the vast majority of complaints are within the disability space. It's a big part of the work we do. We've come a long way from the bad old days whether we excluded students, keeping them apart from the mainstream. I think we are moving in the right direction, but sadly, as I'll describe, we have quite a long way still to go, which is familiar for all of us and I would like for us to think together about the ways question work together toward the greatest end.

Starting with one of our three levers, our most recent use, is the civil rights data collection, which is biannual collection of the equity health picture of all of our K-12 public schools all over the country. This most recent iteration is the first universal data collection since 2000. It's a big endeavor for us. We are not projecting about the data that we are promoting, and we know that each data point represents a life of each of the 49 million students in our 97,000 public schools all over the country. So it's an enormous endeavor just because we get each kid in each school. But in addition, we have dramatically expanded the data that we collect in the life of the Obama Administration and including most recently in this collection.

So now in the Obama Administration, we collect, for example, data about school discipline, data about absenteeism, about bullying in school, about student attendance, about any of a variety of equity indicators for what's happening for our kids in schools. And we dis aggregate that data by race, gender, disability status, etc., so we can look at what's happening for each of our kids regardless of how they identify.

So we have learned some distressing new facts in this new data, and then we have to figure out what to do with it, because the data tells us what's happening. It doesn't tell us why or whether discrimination exists or whether there's a reason for it happening. We have to look underneath the data to ask questions. We hope it's something you will work with.

In the life of the Obama administration, we have made this civil rights data collection very, very public. It used to be something that we used within the Department of Education for our own enforcement work and grant making decisions, but we didn't make it as publicly available as it is now. It's now up on the web. Any researcher, any mom, any activist can get that information and take a look and see what does your state look like, what does your school district look like, what does your school look like. And then identify whether there are further questions you should be asking for things you should be doing to create change at your school, which I'm excited about.

I think it expands the reach of what we can do, in addition to what we do with our enforcement and what I hope many of you are doing in your advocacy. We can reach to all parts of the United States to get to all of our kids and do advocacy for them which I think is terrific.

I want to give you some low lights of that data and what we have seen.

College and career readiness, high school level, student, 12% of students nationwide, are students with disabilities but only 2% are in placement for college and career readiness. We know there is no reason that the disability impacts their ability to learn but we are not seeing our students fully participant in the rate they should be.

Staying with that theme, there are 7% of students without disabilities who participate in gifted and talented education programs, but only 1% of students with disabilities are participant in those programs around the country. So those data make me concerned. I do think we need to stop and think about what it is that we're offering for our kids in schools and what expectations we're setting and what message we're communicating to kids in schools when we have that level in disparity for students with disabilities.

Likewise, in the discipline space for our students in schools, we are seeing really stark disparities by race, really stark disparities by gender, and really stark disparities by disability status in discipline around the country. Students with disabilities are more than twice as likely to receive out of school suspension than our students without disabilities are. That's just categorically unacceptable. We shouldn't be seeing that for anyone. We want to keep our kids in school and learning. That's the better choice for everyone. But where we're seeing that level of disparity, where our students with disabilities are 13% of the students who receive out of school suspension, contrasted to students without disabilities at 6%.

Students with disabilities represent a quarter of the students who are arrested or referred to law enforcement, although they are 12% of the population. So again, disproportionately pushed out of school, which is very, very distressing when we think of the school to prison pipeline and what it is we're communicating to the students.

If you're a black student with a disability, your life outcomes in schools are not good. Our black students are 19% of students with disabilities, but 36% of those students who are physically restrained in school. So I think these data show us that we have a lot still that we need to be working on and looking at in our schools. And I'll describe what we're doing with that.

But I do also want to encourage you to use that data in your jurisdictions because I think it's critical for to us have as much reach as we can.

The enforcement work that we do focuses on a variety of areas. I had a conversation walking in with one of the lawyers who brought this issue to us. Just last month, we entered into a resolution with the University of Montana, Missoula.

(Applause.)

I take it I don't even need to tell you about it. I get applause before I even tell you what it was. Probably the reason I'm getting applause is that you all let us know there was a problem we needed to address there.

But the agreement was to ensure that the university's electronic and information technologies would be accessible to people with disabilities. They had not been in ways that were really distressing. Obviously technology includes the website but also online course registration, library videos, classroom discussions, electronic textbooks, and so forth, pretty much everything available at the school that had not been available to students who had low vision or were blind.

The provisions of the agreement require the university to make its education and information technologies accessible to all students with disabilities. We're really excited about it. We think it sends an important message consistent with the guidance we put out about making sure that our universities as well as our K-12 spaces are accessible to all of our students, making sure all students can fully access the resources available to them. So thank you for bringing it to us and ensuring a landmark agreement. I'm excited about what more is to come. As I mentioned, that is consistent with guidance we put out with the DOJ about kindles and E-readers so that we can make sure that the technology that our students have access to is available on an equal basis for all of our students.

(Applause.)

And thank you again for the applause. This is a good audience. I like this.

We want to make sure it's available to everyone. We put out that guidance because you came to us and let us know there was a serious concern. We were excited to have it out. We think it's important to have it out in the world but we are always dismayed when we continue to see places like the University of Montana not fully compliant. So in addition to telling them what we want them to do, we are ready and willing to enforce it as well.

I want to tell you maybe something you don't know so you can be a little surprised about what I'm sharing. We just this fall entered into a resolution agreement with the virtual community school of Ohio, which had advertised itself as an ideal setting, that's the a quote, for students with disabilities, which I kind of love that they had said that, except that they had been far from ideal. It's a virtual school, 1200 kids all over the state, with no brick and mortar classrooms. The virtual school was not accessible to students with disabilities. So it was far from ideal in that way. In addition to its failure to being accessible online, they also didn't have anyone who could assess whether a student had a disability. So if you came to the school already identified as a student with a disability, presumably the school might have served you. But they didn't have is a way to make sure that if somebody hadn't already been identified as having a disability, that that student could then be identify and served on the other end or that if you came and have been identified, making sure the IEP was sufficient and didn't need to be changed. So there were a number of ways that the school was not an ideal setting for students with disabilities. But we have entered into an agreement and look forward to working with them. It's an important message as we are seeing the emerging landscape of virtual schools, that Ohio can be the vanguard to making sure all of our kids are protected.

We also, more recently, last month, a good month for us, just entered into an agreement in South Carolina with their charter school district. All seven of those schools were also not accessible to students with disabilities. The new agreement says they will be.

So we had quite a bit of work in this space and it's been successful so far. It's frustrating to me that in are so many places around the country and so many levels of educational opportunity where we are moving forward with what we are excited about with technology and making sure that we had new ways of delivering education but forgetting we have to deliver that education to everyone. So we're here to remind all of our schools that we do need to do that.

Then I want to turn actually to the rigor of the courses offered in addition to just the access to the courses. The type that I was referring to in the civil rights data collection, we just entered into a resolution in New York with the Shenandoah school district over an issue that I was not looking for. The accessibility issue, I knew about. But this issue, a parent came to us and said her child's elementary school, the child's grades multiplied by a factor of 0.69 because she had a disability. I said is, that makes no sense, you must be wrong. She was not. It was not only that child or only that elementary school. But five elementary schools in New York in this district had a policy of multiplying all of their students with disabilities grades by a factor of 0.69 regardless of the type of disability. And just to shut their grades down. I can't understand what the rationale is. If you're going to on a blanket basis change a kid's grade, I think you change it up if you're going to change it. But they were changing it down for all of them regardless. So we can laugh because it's over but it's really not funny and it wasn't funny for those kids.

The resolution agreement was that all of the grades had to be reinstated and the staff trained to see our kids better served in New York.

But that one, you know, I have been a civil rights practitioner for 17 years. I've been thinking about this for a really long time and that one surprised me. So the ways that we can discriminate and the kinds of ways that we don't always treat our kids well turn out to morph a lot and we have to be ready to protect our kids in every space. And we are and I hope we can be doing that work together.

Also, in the realm of what we are thinking, we recently entered into a resolution in Colorado with a district that was placing all of its students with quote verified emotional problems, which is not a term I would use on my own, but all of those students were put into a special learning lab in which there was no teacher and no learning.

(Laughter.)

So again, it's funny because it's over. But it was not funny for the kids assigned to that lab. So we have now retrained all of the staff in the district and the kids will not be assigned to the learning lab. They now have an understanding that you do need to assess whether the learning provided to students with disabilities, including those with verified emotional problems, again, not my term, is appropriate for their learning and allows them rigor available.

So I mentioned when we were talking about the civil rights data collection also deep concern about the use of restraint and seclusion in particular for students with disabilities. We have put out guidance as the Department of Education, really trying to discourage the use of restraint period and to be clear that we need to have the same policies applicable to all students and not just those with disabilities. Restraint and seclusion should be a last resort. There's a charter school in North Carolina that had really badly treated a little boy in kindergarten. I tell you he was in kindergarten to say that he was tiny. He was five. He was restrained 37 times, in excess of 23 hours, in one year. He had an IEP, and the school didn't reconvene with people who knew the kid to figure out if there was something else they could do or whether 37 times may be in excess of what you would want for any particular child. Instead they told his mother and grandmother that if they didn't come to the school within 45 minutes of a call from the school, they would report that family to the Department of Social Services, which is obviously wrong and not the way a child should be treated.

That school now has to pay for counseling for that child and everyone in the school has to go to training on restraint and seclusion. We got to a place where we found a five-year-old restrained that many times and the school thought that was okay and even after the parents advocated, even after a complaint came to us, we still had to go through seven months of investigation to get them to understand that should not happen. That is not the country I want to live in. So we obviously have quite a bit of work that we need do in that area. I hope we will, in addition to the guidance that we have out at the Department of Education talking about what restraint and seclusion means, I hope to have guidance out soon specifically focused on disability and discipline from the perspective of the office of civil rights and what our civil rights laws means for students in schools.

(Applause.)

Thank you.

Turning to guidance that we do already have out in the world. We recently put out guidance about athletics access for students with disabilities. I am really thrilled about it. We said that all of our students should have equal access, including to athletics in school and that we should not be prejudging students' abilities or assuming that students with disabilities cannot fully participant in school or in sports and that we should be making sure that we do have opportunities available on equal basis for all of our kids. I think it's such a critical component. In my own life, my brother had CP. I grew up watching my brother play sports in school because he would bat and another kid would run. There were ways for him to participate and I want to see schools offering that kind of opportunity for those like my brother.

We have seen real change in response to that guidance as much as we got quite a bit of push back. We've been really clear about what the law is and we're pleased that there are places for example in Wisconsin where a kid who had always been the ball boy got to actually play because the district began three new adapted sports teams so there are kids playing and playing each other and are able to compete in a way that they never had before. So that's really gratifying to me to be able to see more opportunities like that around the country. Sometimes it doesn't happen just because we said it should. Sometimes it's because we make them. So an example about that comes from Ohio where a kid who used a wheelchair wanted to be able to compete on his school track team and first his school and later the schools against which he would have competed said no because they thought it would be unsafe for the kids who don't use wheelchairs to be running on the same track. We demonstrated to them that would not be unsafe and they said, fine, he could race, but his times wouldn't count for his team. So he wouldn't really be racing but would just be there. So now the state of Ohio understands that he and other kids like him can race, his times do count, and he's been really successful on that team.

(Applause.)

So I want to stop there with stories and turn in a moment to discussion among us. But I want to make a plug for what is now in the president's budget on the equity agenda. I have been really focused on the office of civil rights. That's the space I live in. But equity for students with disabilities is important across our educational landscape and is critically important for this administration. One key way you know that is that the President included in his budget a $300 million request for Race to the Top focused on equity and opportunity. That budget request includes a request that those funds would be used for social and emotional supports for students in schools, used for reducing out of school discipline. We know it is our students who are the ones most subject to it. So it's a key component. I really hope we will actually see it funded through Congress and then we can actually see it out in the world because we know through race to the top so far that we see states working hard to make themselves eligible. So it's a terrific lever for change. I am just so eager to see that fully funded so I can be part of seeing it used in schools all over the country. So I'm crossing my fingers for it and hoping you will be arm in arm with us pushing to see it happen so we can see it come to fruition.

Thank you for indulging my stories. I would love to hear your thoughts.

(Applause.)

MARC MAURER: It's an on this have you with us. And undoubtedly we will have time for some questions if you have time. Yes? Okay. Good.

The Montana settlement. I want to say, first of all, that we are very proud of that. It had something to do with us, as our member there helped to bring this and some of the people in this room were counsel on the case. So we appreciate your support.

A few weeks ago we brought a suit against Park on behalf of disabled students, especially blind students, because the common core was being implemented without accessibility. And Park agreed to do this. They're not very fast at it, but they have a big job. But there are a number of other people in the same space and they're building educational programs without access thought prior to the building, which means it will be very hard, maybe impossible, to get them accessible later. Is there anything we can do about that systemically?

CATHERINE LHAMON: Thank you for the question. There are two testing components that we have funded at the Department of Education for implementation of the common core. Both had committed to us that on roll out, so for the tests that ultimately count, they would be fully accessible for all of the students. But they didn't plan sufficiently so the test component would be able to accommodate students with disabilities. I have to say I was distressed when I read that and saw we hadn't planned as well as we should have on that as well. We collectively.

So I think the settlement is a good one and sent an important message to Park, which has agreed to Smarter Balance to work in tandem with them and the other testing companies that we can't wait to test our kids with disabilities on the tests that count. We need to practice for all kids in advance and make sure all kids have equal access to the tests and their life outcomes. Is there more work we can do? Yes. Does it have to involve litigation? I hope not. I hope it was an important message that will bring others into line. Is that the space I've lived in in 17 years as a civil rights lawyer? No.

(Laughter.)

And so we also within the Department of Education got an important lesson from the litigation and an important reminder that we need to be thinking in more flexible ways about the ways that we do our work. So I'm sorry. But I'm grateful we got it.

(Applause.)

MARC MAURER: I could keep asking questions but I bet other people want to. Lou Ann, do you have that mic with you?

LOU ANN BLAKE: I will go grab it.

MARC MAURER: Dan says he got one.

DAN GOLDSTEIN: I don't think I need a mic.

I'll preface this by saying I understand that OCR itself can't do something about this, but we do see a lot of funding by the Department of Education of technology of open source software or the purchase of technology. There may be boilerplate that says the grantee is going to apply but there's nothing like tell us how this is going to be accessible. Tell us what you're going to do in terms of accessibility.

So over and over, we're finding that like we found the enemy and the enemy is us. You guys are funding the problem. Can we get that stopped?

(Laughter.)

CATHERINE LHAMON: The question is can we make sure that grantees, recipients of federal funds, are not using or receiving federal funds in inaccessible ways and not being funded for readers, etc., technology that is not accessible.

And can we get that stopped.

Yes. I don't -- I'm not the person who can stop it by myself. I'm sure that others in my office will not appreciate my saying this, but please keep advocating so that we know. I do think, I meant it when I said that I'm sorry, that we needed to be reminded about Park. I think we had, as an entity, put thought into it in advance and not enough thought into it in advance. Again, this is the space where that's true. I confess that when I began thinking about this job, I was surprised that we needed to put out guidance about E accessibility and I was surprised to learn that all tablets are not made the same. So it matters which one you choose for your schools and for your kids.

So yeah, I think we all have things we can learn. Once we know that, I find it distressing that we haven't changed our practice for how we do our funding. So there are internal battles to be fought and you guys I hope will continue to lean on to us. I don't think I have a better answer than that, but I hear you and I think it's important.

MARC MAURER: Other questions? Identify yourself please.

>> I'm Amelia from the disability rights center Virgin Islands. I so appreciate your comments.

I'm particularly interested in the data collection piece. Because for us and for any other resident of the territories, we don't get that kind of information. It's very difficult to capture that. I'm in the middle of working on a project and one of the things that I did learn was from OSEP there was a registration of over 1400 children in special education programs. That's the number we've been familiar with. That has now plummeted to like 987 children. Those are our stats. So what's troubling me is how in the heck did we lose over 400 children in just two years. So data can be something that I'm specifically interested in and I don't know whether that's something that your office even has access to. But that's particularly troubling to us.

CATHERINE LHAMON: Just to make sure everyone heard the question, the issue was what data can we get access to for students in the territories.

And the example for why that matters includes a past registration of 1400 kids as kids with disabilities that has now gone down to 900 be something. So there's a loss of 400 some kids according to the data you have so what more can we find out and what has happened to those kids.

I would like to say that we can mandate to get the data from the territories, but I can't. We're speaking to Congress about that because I would welcome it. I do love data.

But you can also advocate for the jurisdiction to volunteer. We will collect data from anybody who will give it to us. So we would include it and report it and it would be available for us but neither one of us can make the territories give it to us but we can certainly ask them to and smut heat on their not having shared it.

And on the issue of the 400 children lost, I don't think those 400 kids are gone, right? What we aren't doing is categorizing them appropriately, right? And even the 1400 may have needed to be 2,000 or whatever. So the data is important, period. Once we have it, we can ask questions about what smells bad from what we see. But without it, we don't even have that.

It's something I am heart sick about. As much as I feel so grateful that I had the data for the 49 million kids I do have data for, I am heart sick for those I don't have data on. So I share your worry and don't have a really great answer about it. But I think we can both do the advocating we can.

MARC MAURER: Other questions?

>> My name is Louis Vendez.

One of our key initiatives is improving the condition of blind children.

My question is related to what role and what is the Department of Education doing to assure that blind children are receiving an appropriate instruction, including access to Braille and access to adaptive technology and access to other services such as mobility (inaudible) at an early enough tithe facilitate personal independence?

CATHERINE LHAMON: For those who couldn't hear, the question is from New York, and the focus is on students with low vision or blind students and wanting to know what is the Department of Education doing to make sure this category of students are receiving access to Braille instruction so they can be fully participant in school.

There are two answers that I think are sufficient and insufficient. So we both in the office of civil rights and also in OSEP are working to make sure that all of our students are served in school both through guidance and enforcement work and outreach. We are statutorily obligated to investigate any complaint that comes in. So we do investigate those complaints when families know to tell us that they're not getting access to services they need, and we also open our own investigations independent of complaints where we have a reason to be concerned and think we need to investigate.

I haven't seen complaints in that area from New York, so that doesn't mean that we wouldn't do something about it, but it might be worth investigating and I certainly welcome information that would let me know that we should go and focus specifically in that area. But the things that we're doing broadly are putting out the guidance saying this is what the law is expecting of you and that we're here and ready to enforce the federal civil rights laws. So on one hand I think that's good. On the other hand, we know places still don't follow the law. So it's worth making sure that we know.

MARC MAURER: There was a person on my left.

>> My name is Mary Vargas. I'm in private practice in Maryland. Our firm has a particular interest in representing kids with severe food allergies and anaphylaxis. We're increasingly hear complaints throughout the United States that families with children with severe allergies are being told they ought to home school their children and their children can either not come to school or come to school without any protections in place, without a meaningful 504 plan and we're finding that litigating these cases, through an individual level, doesn't solve a pretty big systemic problem that will only grow as the numbers of kids with severe food allergies is growing.

So I would appreciate any guidance from you on how to address this problem at a more systemic level and what you can do through your agency to let these families know that they actually do have an option of sending their children to public school and having them come home at the end of the day.

CATHERINE LHAMON: So the question is what are we doing about students with severe food allergies and making sure the schools understand they should be served in school. The question was saying that all too often the message has been that you keep your kid home from school and then we don't have that problem. So what do we do to make sure kids can go to school and come home alive at the end of the day and be safe at school.

It's very much on my radar. The question ended with, what can we do with it at the office of civil rights. It's very much on my radar. It's very much a civil rights issue. We have a number of areas this which I would like to get guidance out in the near term and that's one of them. When I say near term I mean in the lens of government. But we're working at lightning speed. But that's very much on my radar. In addition, I have seen an increase in guidances coming out not from government but more and more people saying here are best practices. I'm encouraged by that and think we need speak with the voice of government as well to be clear that this is a civil rights issue and our kids have a right to be in school and have a right to be safe. So expect to see that. But not tomorrow. But in the nearish future. And it's something that's a very active component of our enforcement work. I share your worry. I think it's very serious. And we will be doing our part to make that public and I think we also do need to keep on it.

>> If I can just follow up with that. One of the challenges is that families are given 504 plans that are essentially blank. When they believe their plan has been violated, they try take it to OCR and have it enforced and OCR has its hands tied to say there was no plan to there was nothing violated. So I guesses that the second part of it. How do we make sure the kids have a plan that can be enforced.

CATHERINE LHAMON: So the question was often kids with severe food allergies have a 504 plan essentially blank so our hands are tied because there's nothing to enforce in the plan. So we're stuck in our office.

I think that raises a larger question for us about the way that we do the work that we do. I am not a particularly a process person, but we are very process focused in general by our regulation about what we do with 504. But there's a hook there that says we can also enforce behind that. I think you'll see more of that in my tenure at OCR. I don't know how much more I should say than that.

(Applause.)

But for me I think we need to have the substantive right enforced for kids.

MARC MAURER: We have welcomed a member of the administration who is a person understanding of the needs that we address and who is with us seeking to make change. It is a pleasure and honor to have you come be with us, assistant secretary Catherine Lhamon.

(Applause.)

We have about 15 minutes until we get underway again. 1:30, please be on time.

(Break.)

"Next Steps in Olmstead Litigation"

1:30 p.m.

MARC MAURER: Matthew Dietz has worked on Section 504, the ADA, other state and federal statutes protecting individual civil rights. He is lead counsel for an action on behalf of institutionalize the children with disabilities in Florida. He's an adjunct professor of law at Saint Thomas University teaching disability rights litigation. He has many other accolades.

(Applause.)

MATTHEW DIETZ: Can we turn down the lights just a little bit? I'm going to start with a video about three words which should never be spoken together: Children in nursing homes. And while we get the lights turned down a little, let me tell you how I found out and became involved. I got a white paper on the fact that this nursing home was starting to get more and more children and taking the ceiling off. A colleague of mine was working doing Medicaid cases, and every six months he was seeing the same children involved in these cases. Every six months the number of nursing homes that they had were being decreased. And it wasn't for any reason other than the state saying that the families couldn't handle the children. So every six months these families had to fight for more care so they wouldn't have their own children's lives in their own hands.

Also, Al-Jazeera, fantastic with what they're doing piloting these issues. I'm just going present this so you can see it.

(Video.)

They were feeding these kids baked tilapia. No 11-year-old will eat baked tilapia. So every time I would see him, I would bring him some beef jerky and rap music. And we're trying to get his local services without bringing him home. And he may go home within the next month.

(Applause.)

But in Florida, there are currently the state claims there are 150 kids in nursing homes. In 2012 there were up to 280 children in nursing homes. In the past year, our actions, it is the Department of Justice, it's Rebecca Bond, all of us involved, my cocounsel, the ethics center for children, we have been fighting so hard. And so far three of the nursing homes have been shut.

(Applause.)

So we only have now 150. But they're packing them in. And they get children now.

As we all know, Olmstead is -- we know what the standard is. I've been coming to these conferences for four years and everybody talks about Olmstead about what institutional placement does to a person. When you're dealing with children, you are dealing with what institutional placement does to a family.

When he was in kids corner, they felt they were so generous when they paid for a bus ticket for his mom to travel from Orlando to Fort Lauderdale where he was sleeping. That's what institutionalization does.

They want their children home with their parents, but it institutionalizes the entire family, who lives with it and deals with it every day, from going to church to doing activities, from being all over the place.

One of the things that really demonstrates this is one of my clients, Taylor, he passed away. One of the things I hate is that they call these children by initials, depersonalizing them. They all have names and ages. He was 21 years old when he passed. They said he wouldn't live past 10. His parents loved him and cared for him. He had all of the enjoyments of life. He went to camp every summer. He had his sister there and his parents. Over 400 people showed up at his memorial service. The effect that he had on their lives was obvious. And how the family lived together.

He was my client the last few years of his life because as they kept on decreasing care for his mom on a daily basis, she would fight every six months to get more care for the child. The child would turn blue in the middle of the night and the mom would have to aspirate her child. She didn't want 24 hour care; she just wanted care at night for eight hours so she could sleep and not take rounds staying awake all night with her husband.

And then the state said, why can't the 16-year-old daughter take care of him?

Taylor passed. But in dealing with children under Olmstead, there's a three-part test. One, whether the states determine whether placement is appropriate for community-based treatment. The person doesn't oppose the treatment. And the placement can be reasonably accommodated.

I'm going to focus on children because that's what I've been involved with for 1,000 hours per year the past three years. It's a no brainer. There are very few children that would benefit more from being in an institutional setting than at home. And I have a scale here on this slide. They always have these pictures like with a quilt, with grandma's house on it and all the colors, making it look like it's a happy place to be. They call it intergenerational. It's awful.

On the other side of the scale are the benefits that these kids should have. Med waivers, PASSR, community services, and so forth.

On the left is Nick, who is wonderful. He has CP and is very involved with his family. Middle, you met him. That's my baby. And on the right is Amy, whose mom is fighting the battle to get her daughter care.

The preadmission screening resident review, the PASRR, that is the front line, the gatekeeper for going into a nursing home. This is the thing should be done prior to any person going into a nursing home and they should be evaluated once they get into a nursing home. This is to ensure that a child or any person at a nursing home is put in the least restrictive environment and only in a nursing home where services should not be provided in a lesser restrictive environment.

Now, there's two PASRRs done, one preadmission that when a hospital states that a person should be moved to a nursing home and they're thinking about it, the level one PASRR should be done. Of course if it's indicated that there's mental illness, a level two has to be done, which means a team specialist, that team has to meet to determine the status the child, what specialized services that child needs to develop, the transition plan in order get that child out and community-based services available for that child. It has to be done for each child.

In Florida, it was not at all. Well, not at all, sort of in a backwards way. Out to of 575 children in four years that were are in nursing homes, only 301 of them had a PASRR done at all. Only out of that 301, 195 children had MR, mental retardation, developmental disability on form, indicated. Now, most of these children do have a developmental disability. I would say 95% of them do have developmental disability. They weren't indicated as having a developmental disability, so PASSR level two was not done. Only 60 of the children had a level two PASRR. Only seven of the 301 were indicated having specialized services. And Florida had a policy of not doing the PASSRs on children under three. What does that mean? The PASSR is the key in and the key out. If there's not a level two PASSR, the person could stay there forever. And what was happening and is still happening in these nursing homes is once the child gets to be 21, they just roll them over to the geriatric side of the nursing home.

Now, resources available. The state of Florida has already said that community-based care is approximately 20% less than similar care in a nursing home. So in my chart, I have nursing home care, which ranges between $450 to $500 a day. This does not include any other therapies in a nursing home, and the only thing that's included in that is respiratory therapists. And usually private duty nursing includes respiratory therapy in them.

PPEC services is something for extended care centers. Pediatric prescribed extend care therefore. Don't get me started. PPEC is daycare for medically fragile kids. That's all it is. It's a segregated daycare. I don't know this was an industry that was lobbied to legislature and legislature said what a wonderful idea to save money by putting all these kids together in a segregated environment instead of paying for private duty nurses and instead of putting them into voluntary preschools.

Medical foster care. Parents in this system get $68 a day paired to the 450 to $500 that they get in nursing homes.

Licensed practical nurses and registered nurses, the average amount of care that these people get in Florida, if you look through the numbers, is approximately 6 to 8 hours a day of nursing which is a lot less expensive than a nursing home. So it doesn't make sense.

Why do they do it? The nursing home industry has a ton of political support.

EPSDT services. These are a lot of words on this slide. It's the 28 health care services listed in the statute for eligible children, private duty nursing services, vision, dental, hearing, to private community nursing services.

Resources available. The state had already agreed through Medicaid to pay for all services available to these children as required by the Medicaid statute. There is no reason why these children cannot have the care that they need. Dealing with children is different than adults because you don't need a waiver to get the necessary treatment for children. It's needed for respite care or home modifications or other items needed, but EPSDT covers it. The problem was, they cut the services for these children.

Now, Florida had a pretty nifty way of doing this. And the reason why it was so obvious is they had policies and procedures which caused the systemic violation of these children's rights. The first issue is are children at risk or not at risk. According to cases under Olmstead, the violation is mandated...

(Reading slide.)

The first thing that Florida did that started this downward tumble and putting kids in institutions and lessening the services they got at home was the definition of medically necessary. The definition of medically necessary was, punished in a manner not primarily dependent on the convenience of the recipient or the provider or the caregiver. That is the mushiest amorphous standard that could ever be made. But Florida defined it. And when Florida defined that, they said private duty nursing service will be increased over time as parents and caregivers are taught skills to care for their child and are capable of providing that care or as the child's condition improves. Every six months, 8% of the people who had services in Florida who requested services were denied on the standard that they stay up all night and take care of their child, that they could be responsible for services for their child.

Out of the obituaries in the paper for one little boy, and that is another case, Joey. He died in the middle of the night. It was awfully sad. Six years old. His grandfather was in charge, and the alarm went off and the ventilator needed to be checked. The child had to be aspirated. And the grandfather was asleep.

I don't know how many children that this happened to over the past four years while this has been happening. Parents and caregivers must participate in providing care to the fullest extent possible. Private duty nursing services are authorized to supplement care provide by parents and caregivers. When we initially filed this case, in the initial motion, the state changed its attitude after the findings from the Department of Justice. The state's initial attitude was, it's the best public policy to have parents in charge of their own kids. It's good financially, it's good public policy. That's what we're going to do. Parents should be primarily responsible for their kids.

Medicaid may reimburse PDN services rendered to a recipient whose parent or caregiver is not available or able to take care of them. Parents or caregivers are responsible if they don't have the knowledge or have a deficit, including ventilator management, catheter change, etc.

Now, one of the issues that we had is, Florida had the practice that said only nurses of certain education levels could do certain activities. Ventilator management, you have to be an RN specially trained. If you have private duty nursing, you cannot have an LPN do this. They wanted parents to do ventilator management for their own children.

Accordingly, the cost of decreasing care that Florida did in one year alone, they saved $25.8 million in savings by providing private duty nurses. Amazing. In one year. That's a picture of Marion, a little girl I love. She's medically fragile and she's still in a nursing home. She say sweetheart. There's no reason why she should be in there.

Now, one of the issues is Florida has not increased its funding for private duty nursing for home healthcare nurses since 1987. I have a parent up in Daytona who has 18 hours of nursing care that could be paid for her, but she can't even find the nurses to cover the amount of hours that she has because of Florida's failure to get a nurse. I have a chart here. The first item on the chart shows the amount of private duty nursing. For an LPN to earn approximately $20 an hour that comes from Medicaid. Now, with this, approximately $8 that nurses get from Medicaid go directly to the home healthcare agency. So RNs are earning approximately $21 an hour, when the normal wage, the Department of Labor report for RNs, they earn over $30 an hour.

For LPN, the normal wage that nurses earn, the Department of Labor numbers is approximately $23 an hour, and they only get in their hands from state provided Florida Medicaid approximately 15 to $16 an hour. So of course they can't find qualified nurses that are even going to handle these children.

Community-based services. PPECs, pediatric prescribed extended care. $176 a day. And what Florida said before this case, if a child is medically able to attend a PPEC center, PPEC will be provided instead of PDN services, you have all these children getting these services that were told you must put a PPEC if one is available. You cannot have PDN if you also have PPEC. Also, PPEC services were into the available again if the parents were home. So they said, parents, if you're home, you can't have a life. What parents would have to do is every six month fill out a chart with their work and school schedule in order to see what hours these were entitled.

Only 15% of those children in PPEC also receive wrap around services. Let's put this in perspective. PPEC children were also those who were medically fragile and complex, which is defined as children who need 24 hour a day medical supervision or care. The same people that got 24 hours of care in a nursing home would only receive PPEC care mean to care when they got home.

Medical foster homes. 727 medical foster children in Florida. There used to be 40 nursing homes. Now there is approximately 13. Medical foster parents get $67.90 per day. Again, the reason why there's just so few medical foster parents, medical foster care providers are responsible for the overall care of the children assigned to them. PDN is only for children who are too complex to be met by the medical foster care family. So there are very few families who are willing to do this for $68 a day. They do not get the necessary private duty nursing services they need. So it's very difficult for parents to have these children in their home.

So the interesting issues that I found, this is something I have to give kudos to my statistician from the University of Baltimore. Can you raise your hand, Professor Garland? He crunched all these numbers for me. He's phenomenal.

What I did is I separated the number of children. There were approximately 3700 children that were part of this class. This is 2012. What I found is from zero to five, 55% of the children were in PPEC. And you have to remember that Florida mandates, mandated before, that children shouldn't be funneled into a PPEC system and not get any other care. At this time, 280 children were in a nursing home in 2012.

And then when you go from -- and also children between zero to five was 816 children versus 950 for children five to twenty one. So there were approximately 363 children per year from one to five.

Then when you go up to six, there's about 120 children per year. So what happens to all of those children that are five and under once they turn six? There's still 8% there who receive PPEC care, but that's 8% of the six-year-olds essentially.

Thank you.

So when you look at those, you say, what happens to the 200 children per year once they age out of PPEC care? They get no services.

Home- and community-based waivers, residential services, group homes, home modifications, possess pit care. It's very important to have children signed up to get on the waiting list, which is 20,000 persons in Florida, when they're young. They cannot get a waiver when they're in a nursing home. So that's a huge problem in getting them to transition to home based services. So their parents have to have the money to equip their homes.

There are other services that children don't get.

The hardest part is informed choice, and I need a minute and a half for this. The state of Florida's issue is children, parents want their kids in a nursing home because it's the care for the children, they get what they need. That's the first thing that has to change. But also, what happens with these kids? You have kids put in nursing homes for three years, four years, five years, and the parents begin to see them walk when they're sent in, but when they get in the nursing home for three years, four years, the parents stop coming. What do you do with those children? The nursing homes have a financial incentive to keep a child in a nursing home until they're 18 at $550 a day. There is no what has to be done in Florida is medical foster parents need to be paid more. Parents should get to keep the custodial rights to their children and they shouldn't lose them once they go into medical foster homes. So there's alternative placements for those parents who believe they don't have the skills needed. There has to be more of a discussion on what happens to these kids now that they're in nursing homes and what options parents have. And what training the parents get. We have a whole generation of children in Florida that are children with disabilities who have not been given these rights. Now they're in limbo. A lot of these parents don't know what options they have. They can be caring parents with children with disabilities instead of just having the children be taken to a nursing home. And just one other point that I have to make. When I first got this case, the nursing homes actively market their services. They have nurses in the NICUs of hospitals saying, we can do a better job for your child. Send them to kids corner, send them to grandma's house. Look them up. They go to a place like family cafe, a place for developmentally disabled parents and families and they have a group there that says, look what we can do.

There has to be the same outreach and effort given to parents of children with disabilities to say, you can do it. And I think that's the first step of stopping institutionalization of children. Thank you.

(Applause.)

MARC MAURER: Thank you.

The next person on to the panel is Barry Taylor. He has overseen federal cases, successful ones, against the board of medical examiners, the Chicago council authority. He is currently handling a case with living large private institutions who are seeking community services. He also oversees self-advocacy training, the project of the agency, which in the first eight years trained 23,000 people with disabilities on the ADA and other aspects of disabilities, employment, special education, and so forth. He is currently an adjunct professor at John Marshal law school.

Here is Barry Taylor.

(Applause.)

BARRY TAYLOR: Hi, everybody. It's a pleasure to be here. I've heard of so many people over the years and I'm just thrilled to be invited and be a part of this today.

A quick reply is the protection and advocacy for the state are here. I'm glad to be part of that number.

Today I'm just going to focus on a few issues that are hot issues. The first are ones that we're working on in Illinois. The last one, we're not actually working on, but I feel it's an important issue. I just want to make sure we get to that. Hopefully I'll have time to get to that as well.

The first issue I want to talk about is kids transitioning into adulthood and the issues that go along with that. I think it's a nice segue to what Matt was just talking about. In Illinois, like in other states, we have a program providing in home nursing services to kids. You may have heard of it. Technically it's known as medically fragile independent waiver. Kids get home nursing services.

However, when they turn 21, they age out of this program. Under the adult program in Illinois, the amount of services is dramatically reduced. So as a result of this reduction in services, when kids turn 21, suddenly they get services that place them at risk of being institutionalized because their families can't put together the additional hours necessary to keep them in the home. Nothing else changes about their medical condition other than their age, turning 21.

One of the first things brought in Illinois, this case listed here, the state was unwilling to provide Eric with services at the same level he was getting when he was a child. He had been given 16 hours of nursing services. When he was 21, he was informed he would get 5 hours a day, a dramatic change for him.

This went up to the seventh circuit. At the direct court level, what they argued successfully was that it would be a fundamental alteration to require them to provide this level of services. The seventh circuit says, you were doing it before, what's the alteration? They talked about cost issues, but the battle of experts, got guys' expert won, they said actually it would be cheaper to serve them in the home as opposed to a hospital level of care which is what Eric would have needed which undercut the financial aspect.

So that was a great decision. But it was one where there wasn't a policy change. We brought a number of other individual cases including the groups case listed up here, got an injunction that settled. So a lot of these settled.

Someone beat us to the punch and thought of a class action. Good for them. This is really the same issue but on behalf of all kids who fall into this situation. In October of last year, there's a link to the decree here, but the main takeaway is common sense, that a person's medical services should be based on medical necessity, not their chronological age.

The next issue I wanted to talk about is what has been termed the reverse Olmstead or efforts to keep people with disabilities in institutions. People may remember back after Olmstead was decided folks trying to use Olmstead to prevent the closure of institutions or allow people to stay in institutions saying they had a right to stay in institutions. What they were using was from Olmstead. They were arguing that nothing in the ADA condones forcing disabled persons in community settings when they're unable to handle a benefit from them. And then they also cite that part of Olmstead that says there's no federal requirement that community-based treatment be imposed on folks who don't desire it.

Right after the Olmstead decision was cited, the first case that came up was Richard C. out of Pennsylvania. Fortunately the judge did the right thing here and said, you've got it wrong. It doesn't logically flow from Olmstead that said that institutionalization is required if any of the pre-Olmstead criteria aren't met. They're referring to that second one, do not oppose. They said if we oppose community placement, that gives us an ADA right to stay in an institution. And the court said, no, that's backwards.

Then shortly thereafter, there's another case, another Richard, out of California, Richard S., who agreed there is no basis for premature discharge from the community based on disability. They said it may be a bad decision medically or public policy wise but it's not disability discrimination so the ADA claim won't survive.

Those happened right after the Olmstead decision was decide. But in the last year there have been a couple of cases on this. The first one focusing on DOJ, and correct me on the pronunciation, Sciarillo filed by people with disabilities through their guardians seeking to prevent the closure of two state houses in New Jersey, proposing to transfer are folks to another state about 100 miles away. The argument there was again the same thing, that this violates the ADA and is inconsistent with Olmstead. The judge here had a good line. I like this. "Plaintiff's definition of Olmstead is untenable."

Then we get to crazy Illinois, where I happen to live. This is a case kind of similar. Our governor decided to close public institutions as part of the rebalancing initiative he's engaged in. And so these folks filed a suit to keep the institution open and prevent them from moving into the community. And again, DOJ was right there saying that this was not an Olmstead issue and the court should reject that.

The court did the same thing to start with and said is, yes, this is not an Olmstead case, because they're not claiming that it was a private placement into the community. Here's a great line.

(Reading slide.)

So basically the judge got right and said we're safe on the ADA issue.

But not so fast. The court said he was open to other possible non-Olmstead ADA claims. What?

(Laughter.)

And so what he did, he looked at the other parts of the ADA and said, well, raising the possible argument that they intentionally acted on the basis of disability or didn't make reasonable modifications to policy. So it's ridiculous. I think the state did a good job addressing this, but it's pending with the court. There was a preliminary injunction and it's pending with the court. I was hoping to have a decision today so we could talk about it, but not yet.

So I just think this is something I wanted to put on people's radar because I think the law is pretty good. The reverse Olmstead part. But it's kind of like getting to an ADA claim through the back door almost if the judge agrees with this.

So next I just wanted to talk about some of the work we've been doing on Olmstead cases.

Illinois is a very institutionalized state. When we brought our first case, we ranked 50th out of all the states and D.C. We were at the bottom. We also heavily relied upon private institutions. So we had public institutions as well but we had tons of folks in institutions that are privately owned by state funded. So we decided to focus our Olmstead cases on those because the numbers are so huge. We did a number of things that didn't materialize, but three organizations in Illinois, ours, ACLU, and access living in Chicago, decided to collaborate and bring these three cases in a coordinated way.

The first we filed is Ligas. About 6,000 people are living in these facilities, intermediate care facilities. A lot of them have 16 folks but some of them have hundreds of people and they're all over the state.

And so we brought this suit. Even our class certified. We want to make sure this isn't just folks in institutions. There were plenty of those. But also thousands of people in Illinois who are waiting for services and their families are just waiting.

Things kept moving along. We had people who really disagreed and tried to intervene. We were successful in opposing that. So then we reached a decree with the state to give opportunities to move all of the 6,000 folks in the institutions as well as an initial 3,000 people at home waiting for services. But we ended up running up against incredible opposition at our hearing. They had concerns about mandatory evaluations, the state's interest in having a single point of entry because these people kind of acted on their own and the state had no control. And the state also wanted mandatory bed closure. So every time we got someone out, a bed would close.

But because those issues were such hot button issues, a lot of people were upset. I think we set the record for the number of objections filed in the northern district of Illinois. Not a record I'm really proud of, but something that happened.

The judge had been with us up until the night before when he issued a ruling saying our case did not involve forcing people out of institutions. He also rejected the agreement. We thought we had a great case but it didn't go well. We had parents ready to go to trial.

We were in bad shape at this point. We ended up going back to the negotiating table. When he to negotiate with the people who objected. We ultimately reached an agreement and got a new class certified and brand approval of the new consent decree in June of 2011.

So under the decree we got over a six-year period any of the 6,000 folks who make a record of wanting to move to the community will get to move and those who want to stay will be able to stay. An additional 3,000 will also be served. And then I think one of the key things is that after six years the state has to develop a waiting list that moves at a reasonable pace. And you'll notice that language is language from Olmstead. So because we have more than 3,000 people waiting for services, we wanted to make sure those who weren't part of the initial group would also get served under some sort of reasonable basis.

The class is also a fluid class. Those opposed before could change their minds and join in. Sometimes when people see others going to the community, they end up changing their mind and moving. So that's great.

We got an independent monitor. Tony is doing a great job. So far, we have 2,000 people receiving services.

It's not perfect. We have concern about where folks are going and concerns about their employment opportunities. We have provisions in the decree, but it's not going as well as I think we would want it to.

We've also got some issues of places closing and relationships with providers, and we also have changes for state guardians.

So as far as lessons learned, I think we learned even though the judge is on your side, you need to be really aggressive at the fairness hearing. And I think we could have been more aggressive and done more organizing based on the objections.

We had two folks who eloquently testified and that was used against us. People said, well, those guys can live in the community but my child is way too disabled to live in the community. The judge ended up finding when he certified the case on the grounds that really undercut us as well.

We agreed to some things the state wanted because they thought they were good, but the state could have done those without a consent decree like the single point of entry and the closing of single beds. The judge called them on it. Look, you're trying to hide behind the consent decree because you're too cowardly to do it without one.

And I think we need to be more specific about employment provisions. So thinking about employment beyond could have made things a little bit easier as well as some of these downsized transitioning issues that I mentioned before.

The second case we brought, same cast of characters as well as the Bazelon Center, which was great given their work on the adult homes. This was for institutions for mental disease. Terrible name. Think about that as your home. There were about 4500 people living in those places and they're state funded. So they're not getting basically any federal money. It's really ridiculous.

That was certified in 2006. And again, we had a ton of objections. We didn't break the record, but we had over 1,000 objections in this case. We were ready ahead of time this time. And we were ready for the fairness hearing as well. And I think we just had a judge that got it a little better.

And in the New York adult home case, we had a provision of permanent supported housing being considered the most integrated setting for the vast majority of class members.

We've got independent monitor, Dennis Jones. About 882 people have been transitioned as of last month. But it's never easy. And the folks who oppose this, including the folks who run these IMDs, have challenged the decree. Fortunately the judge shot them down but it was a lesson learned that I'll talk about in a second. But there's the cite for that if you want it as well as a link for documents in these cases.

As far as the lessons learned, the quality assurance issue I think is a relevantly important one to think about. You know, one of the challenges that we had in responding to concerns about incidents that happened to people in the community is the way they defined "incidents" and called these things critical incidents but some you wouldn't think they were. We had a person who had been questioned by the police about an issue that he wasn't even involved with listed as a critical incident because he interacted with the police. It gives a sordid view. So we're looking at what those are now to feedback to the state. We wanted to show, look, there's a lot of horrible things that happen to people and you're focusing on isolated things happening in the community. So wanting a better comparison, not an apples and oranges scenario. The judge wasn't long with it and found there wasn't a problem, but I think that would have is maybe made things a little easier if we had thought of that ahead of time.

We also had a situation with some folks choosing not move in the community who I think we thought would be a higher rate of people choosing to move to the community. So I think we're talking about having more peer-based support and outreach than we had before, which may be something to build in as part of it.

Let me just go on to the next case. I want to make sure we have time for questions.

The third case is Colbert on behalf of people living in traditional nursing homes in Cook County, certified as a class in 2008. It's about 6,000 people involved in this case, physical disabilities as well as people with mental illness. We have a lot of young people with physical disabilities in nursing homes and a lot of people with mental illness in traditional nursing homes and we're doing that case with a pro bono firm.

That consent decree was approved in 2011.

The first year has been rocky on to the implementation of this case. They were supposed to move 300 people and they only moved 80. And they relied upon Medicaid managed care model proven to be one that is not very successful. So the state is in fix it mode. We designated a different state agency to work on implementation in the beginning of July to try to get things back on track in that case.

As far as lessons learned in that case, just the lack of expertise in managed care, they talk a great game but in reality, they don't have experience in this kind of work. One of the best things we did in this case, a good lesson, is that when things weren't going well, we recommended that the monitor pull some service plans and evaluations, and he quickly learned how terrible a job they were doing, which was really the basis for him finding them out of compliance after the first year.

There were a lot of hand offs and moving parts that just weren't working very well. So I think we're going to be working on having that move in a different direction, adopting the Williams model because that's a much more smoother process.

I just wanted to again, it seems to me that employment of people with disabilities is sort of really the biggest, hottest issue right now for people with disabilities under Olmstead. I just would hate for that not to be talked about. So I think folks are familiar with the case filed in Oregon, basically looking at issues of sheltered workshops, making sure folks have opportunities to have integrated employment services. Folks might remember the court initially dismissed this case. But I think one of the most important things the court said there is that Title II's integration mandate applies to employment related services even though people aren't at risk for institutionalization in a residential setting. And I think the DOJ's statement on Olmstead was critical here. The court relied on that. So that's a great thing for people to be using going forward.

And the case was certified as a class.

When the attorneys started this case, they were at the negotiation table for quite a while trying to decide what to do. The state used that information in putting together an executive order, an Olmstead plan, to root out the case. And Kathy said, a good lesson here is maybe we stayed at the negotiation table too long because we fed them things that they could use that they wouldn't necessarily do everything we said but enough to move up the case. So it's a tricky balance than.

The other thing is if you're thinking about doing a case like this, please talk to DOJ and folks who are really doing this because these are complicated issues and they were very strategic in what state they chose. And I think we as disability legal advocates in the community need to coordinate our efforts. Is this the right thing to do, is this the right state. That's just a request I'm passing on.

And then I'm going to actually not go through these in detail. I just wanted to make sure it was on everybody's radar screen. The great work that DOJ has done. There's a slide here on the agreement they had with Rhode Island and Providence last year and I'm sure you saw earlier this month the agreement with the entire state. It just looks like it will be a great blueprint for the rest of the country moving forward. I think one the key things to notice here is it's not just sheltered workshops but the day hab programs that are so prevalent in Illinois. Even more so than sheltered workshops. Both are critical and they have some good targets.

Also a shout out to the DOJ website. They have all the information on this case and literally every other case they've worked on. So if you haven't encountered that yet, that's a good place to get a lot of good information about what the federal government is doing.

I'll close with. That thanks for your attention.

(Applause.)

MARC MAURER: Well, I'm sure there are questions.

>> Yes, hi, I'm Kelly from AARP foundation.

MARC MAURER: Go ahead, Kelly.

>> We have litigation in D.C. and I just want to add one thing to what Barry was just saying, that you have to be very, very careful how you formulate your class now because I think some of these classes, particularly if you have an institutionalized class, you are setting yourself up for sub classes. We have to be cautious of that. DOJ really made a difference in make our class certified. They wrote a great statement of interest and made an argument to the court about our class which was incredibly helpful with the judge who was very skeptical about whether Wal-Mart would lose the certification or class. It was helpful for her to hear she wasn't actually on the cutting edge, that other courts had actually certified cases with Wal-Mart. So I really emphasize that you not only look at Olmstead cases of interest but the states of interest. From my office, we're more than happy to coordinate on having done all the heavy lifting post Wal-Mart, we're happy to share a few things.

MARC MAURER: Comments?

BARRY TAYLOR: That's a great comment. We were talking about this before. All three of our cases were certified pre Wal-Mart so we didn't have a lot of issues Kelly had to go through. In addition to some of the at risk versus institutionalized population, I think also the diversity within your population. So as I was saying, in our nursing home case, a lot of people with disabilities, I'm not sure we would necessarily structure the same way. We might divide that up differently. We just formed it all together and it worked. But with Wal-Mart, we would probably be more careful about that structure.

MATTHEW DIETZ: I'm still waiting, looking at my emails every other second to see if the case has come to a conclusion.

The biggest different I think between an injunctive relief class, and this, I think in doing motion class certification, almost all of the Olmstead class actions have been certified post Wal-Mart. If anyone needs briefing, I would be happy to share is the voluminous briefs that our side did as well as the statement of interest that the Department of Justice did in our case.

BARRY TAYLOR: Another case to look at that our sister agency did in Washington, they did a kid case that looks like a good remedy. So people are looking at kids issues in addition to the good work in that in Washington and maybe other states. But Washington is the one I'm aware of as a really good decree.

MARC MAURER: Further questions?

>> Larry Berger. Just a point of information. Cero versus Christie is on to appeal in the third circuit. I'm not involved in it directly. I know there's an amicus on the other side coming in a week or two. So hopefully that will stand.

BARRY TAYLOR: That's the case involving reverse Olmstead.

>> Right. They were closing two out of the seven developmental centers in New Jersey legislature and a committee and so forth.

BARRY TAYLOR: Thanks for that information.

MARC MAURER: Gentlemen, thank you very much. Matthew Dietz and Barry Taylor, thank you for your presentation.

It is important to contemplate what kinds of changes in structure are required by the Olmstead theory. It was originally applied to one set of circumstances, but as you know, it has been applied to others since that time. And the thought process that expands the coverage is an interesting one and has much to do with what kinds of rights disabled individuals can expect to have and I appreciate your making presentations this afternoon.

We have workshops now.

I hope that Sam is doing the second one. We've changed positions since last time you presented here, I think, Sam.

Third one, we have Larry doing that.

And the fourth, how to protect the tenancy rights of persons with disabilities. It's facilitated by Lauren Young.

When we get back for the next presentation, we are having a break before and after the workshops, so there's plenty of time for coffee and things, but at 4:15, we begin but not in here. We begin in the Utah auditorium, which is across the hall to my left. If you face the stage to the right, I was thinking that we should have access to the stage for people who use wheelchairs. We have a wheelchair lift but now I'm told it isn't big enough so we have to get yet another one or something. Those who tell me it isn't big enough, if you have recommendations, I would be glad to know. I remember the time Dan showed up here and said, you know you're violating the ADA.

(Laughter.)

Say what, says I?

He said, you know, you have some stuff on your website that's not captioned.

Oh, no, I said.

So I think it's all captioned now. And to the extent that you find out that we're violating ADA, I would like to know --

(Laughter.)

-- to report to me.

Time for the break.

>> One announcement. I want to remind all members of the disability rights association to please stop by the DRBA table. Even if you have preregistered to attend tomorrow's meeting, you my check in so you're admitted to lunch. And if you are planning to attend the dinner, you must stop by to give us your payment and also to receive your dinner ticket. You will not be given a meal without your ticket so it's very important that you stop by the table if you plan to eat with us tomorrow. Our table will be open until 5:45 p.m. today and we will be open tomorrow morning as well. We're located right next to the symposium registration table at entrance of the hall here. Thank you.

(Break.)

4:15 p.m.

"Rights of Parents with Disabilities"

MARC MAURER: Okay. The next topic is rights of parents with disabilities. Two people are making presentations on this topic. Carrie Ann Lucas, executive director, Center for rights of parents with disabilities, and Robyn Powell, attorney for the National Council on Disability.

Robyn Powell, National Council on Disability, which is an independent agency which advises the President and Congress on matters concerning people with disabilities. She was the principal author of the "rocking the cradle: Ensuring the rights of parents with disabilities and their children" piece. She has previously been a manager at the equal rights center in Washington and served as assistant director for policy and advocacy for the disability policy consortium in Boston.

We will start, then, with Robyn Powell.

(Applause.)

ROBYN POWELL: Thank you so much for the invitation to speak today about an often underdiscussed topic, the rights of parents with disabilities and their children.

I'm going to provide a very brief overview on the current state of parents with disabilities and the policy barriers facing these families.

I will then turn it over to Carrie Ann to discuss her professional experience representing parents in child welfare proceedings as well as hopefully her personal experience as a disabled mother. No, she says. Well, she's a lovely mother.

Anyway, so as many of you know, in September 2012, NCD released "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children." The report is on our website www.ncd.gov.

"Rocking the Cradle" is a groundbreaking comprehensive policy study which provides an overview of the current state of knowledge, attitudes, and practices towards parents with disabilities and their children. It analyzes how disability law and policy applies to parents with disabilities in the family law system as well as barriers prospective parents face in adopting.

It offers recommendations on how service systems can better serve these families.

A critical component of the report is the information we were able to glean from interviews with parents and prospective parents with disabilities as well as service providers, advocates, and researchers.

This report has received a lot of attention because it is the first of its kind not only in the United States but across the world, and it's definitely the first time that any federal agency has focused on the rights of parents with disabilities.

So why did we take on this study? In 2010, NCD first learned from disability leaders, mainly Kelly Buckland of NCIL that parents were facing discrimination.

In Oregon, a panel focused on the parenting rights of people with disabilities. The panel identified numerous discriminatory state lays and practices in family courts which result in capable parents with disabilities frequently losing custody of their children. Recognizing the importance of this issue and the gravity of it, NCD made parenting rights a priority.

NCD's "Rocking the Cradle" report has a variety of key findings which I'm going to quickly go over. So the first thing we found, which is not shocking I'm sure, is that increasing numbers of adults with disabilities are choosing to become parents. We're at a place where we're almost 25 years past the passage of the ADA. People are starting to really get out there into the community more, work, go to school, etc., and now they want the next thing. They want to be able to raise a family.

Currently, there are more than 4.1 million parents with disabilities in the United States, which is roughly 6.2% of all American parents with children under the age of 18.

I want to say that this number will unquestionably increase as more and more people with disabilities continue to exercise a broader range of lifestyle options as a result of social integration, civil rights, and new adaptive technologies.

I also want to note that this number is very much an underestimate, because no one is really tracking this. So that is a huge problem.

But again, this isn't just about the parents. Estimates indicate that at least 6.1 million children in the United States have a parent with a disability, which amounts to nearly one in ten American children.

Parents with disabilities are the only distinct community who struggle solely because of their status to retain and in some situations even gain custody of their children. Parents with psychiatric disabilities encounter removal status when their child is removed from the home at rates as high as 70 to 80%. Removal rates of parents with intellectual disabilities are as high as 80% as well.

There are also extremely high removal rates and loss of parental rights for parents with sensory or physical disabilities.

Fully two-thirds of child welfare state laws allow courts to reach the determination that a parent is unfit solely on the basis of the parent's disability, and in every state, disability is considered in determining the best interests of the child for purposes of custody.

Parents with disabilities are more likely to lose custody of their children after a divorce, which often results in many people with disabilities staying in unhealthy marriages out of fear that they would lose custody if they were to split up.

Prospective parents with disabilities also have more difficulty when it comes to accessing reproductive healthcare such as assisted reproductive technology. Moreover, parents face significant discrimination when adopting children both domestically as well as internationally.

However, in the face of all of these barriers and bad news that I've said, there is hope. Several programs show promise, long term sustainable impact, and potential for replication across the country. And with more funding, model programs currently serving American parents with disabilities could easily grow and develop nationwide to better serve this often overlooked population.

A big part of NCD's "Rocking the Cradle" report is recommendations. We didn't want to just say, this is terrible, so what. We wanted to actually come up with ways that could easily be fixed.

"Rocking the Cradle" sets forth concrete recommendations flowing from our study and charts a strategy for the future. These recommendations are directed toward the administration and federal agencies, Congress, states, and other service providers such as disability services, child welfare agencies, court personnel, attorneys, etc.

Today I'm going to highlight just some of the report's key recommendations.

First, I will discuss some of the recommendations that NCD put forth with regards to the administration and federal agencies. First NCD believes that the President must issue an executive order establishing an interagency committee on parents with disabilities. This really isn't a lot going on looking at the rights of parents with disabilities, the needs of parents with disabilities, or even really acknowledging that parents with disabilities exist. So we think this is a really important first topic.

Second, we think the Department of Justice and Department of Health and Human Services needs to issue guidance to states, to child welfare agencies, dependency courts, family courts, as well as adoption agencies on their legal obligations pursuant to federal disability law as well as increase investigations and enforcement of violations of federal disability law in these areas.

NCD also urges HHS to better support parents with disabilities and their children by expanding the definition of durable medical equipment to include parenting equipment, identifying and implementing mechanisms to pay for comprehensive care for Medicaid and Medicare beneficiaries, and expanding the definition of activities of daily living to include parenting activities.

Next I'll quickly go over some of our key recommendations towards Congress. First, NCD urges Congress to enact legislation that will ensure the rights of parents with disabilities and their children in accordance with the language set forth in our report. There is clear precedent for such legislation. The Indian Child Welfare Act was established in the 1970s and it was enacted after Native American families were encountering very similar treatment within the child welfare system.

NCD also recommends appropriation of funding for research on parents with disabilities and their families. When we were writing this report, we were just astonished at how little research actually exists on the topic.

NCD further recommends that Congress amend the Adoption and Safe Families Act to add specific protections for parents with disabilities. In addition, we urge Congress to shift funding so states have a better incentive to provide preservation services instead of taking the child away.

And finally, NCD recommends swift ratification of the U.N. Convention on the Rights of Persons with Disabilities because it reinforces the rights of people with disabilities to create and maintain families.

As I mentioned, we also set forth a variety of recommendations for states, service providers, and others, and we hope that they will enact these.

First, NCD recommends that states amend their child welfare laws by eliminating disability as grounds for termination of parental rights in adopting language set forth in our report. NCD recommends mandatory training related to parenting with a disability for all dependency and family court professionals. This includes the judges, attorneys, and evaluation personnel.

NCD recommends requiring that state statutes, rules of court, and professional standards include parenting assessments that are fully accessible to people with disabilities.

Moreover, NCD recommends that adoption agencies staff undergo training on how to fully assess prospective parents with disabilities.

NCD also believes that disability and mental health service providers must gather data on the parenting status of people they serve. A lot of research shows that mental health providers for instance have no idea whether any of their consumers are parents. It's not something they ever inquired on.

We also noticed that there's a huge issue with the legal community as far as the disability community know the disability side and the family law attorneys know that area. And so there really isn't combined effort, and we think this is important. You know, child welfare proceedings, parents are often represented by court appointed lawyers with huge caseloads and little if any knowledge of disability law. And family law proceedings, you don't have a guaranteed right to an attorney, so if you can't afford one, you may be out of luck. But if you are able to afford an attorney, parents typically must retain family law attorneys with little if any knowledge of disability law. And again, just as these lawyers know little about disability, disability rights attorneys generally know little about dependency or family law matters.

So until Carrie Ann is able to be cloned, significant attention is really going to be needed to bring these two bars together in providing effective and adequate legal representation. Carrie and I do have a variety of handouts on the back table in the other room. One of them is a recent American Bar Association article that just came out a few weeks ago on representing parents with disabilities and kind of how to and some tips. It's also available on the website of the ABA.

Quickly I want to provide an update on what's happened since the release of our report in 2012. Much has happened on the state level. Since releasing "Rocking the Cradle," three states, Tennessee, Washington, and Oregon, have passed laws concerning the rights of parents with disabilities. And Massachusetts currently has a bill before its legislature. Anyone who knows anyone in Massachusetts, I am not lobbying at all, but you should definitely encourage them to contact the judiciary committee in Massachusetts because it's kind of stuck right now.

Again, not lobbying.

There's also been a lot of collaboration with allies and non-allies really. Both the disability community and folks that we don't generally work with. The Child Welfare League of America, the American Psychological Association, and the National Association of Social Workers have all taken a very strong interest in this report. I met with each of them when we were releasing the report and I went in thinking they were going to want to murder me because I pretty much criticized them. But they all acknowledged that it's an issue and they've been working with NCD and others in the disability community on this issue.

In April 2013 we held a congressional briefing with those groups and it was very well attended. NCD is currently with these groups planning subsequent briefings on four key areas: Adoption, child welfare, family law, and assisted reproductive technologies.

Raising a family is a fundamental right that should not be denied to any segment of the population. This will require a multipronged effort. Nonetheless, the need for action could not be more timely or clear. NCD is ready to work with the disability community, the legal community, states, Congress, and the administration to ensure that recommendations in our report are implemented and that these families are given the opportunity to thrive.

I'm now going to turn it over to Carrie Ann.

(Applause.)

MARC MAURER: Carrie Ann Lucas is Executive Director at the Center for Rights of Parents with Disabilities. She is an adoptive parent, a single parent. She has four children. These children themselves have disabilities, and consequently, she has faced the challenges which she is discussing today.

Her children also have disabilities, and she has come to be very familiar with navigating the systems to provide appropriate community services. She has received a number of fellowships, and she has also worked at the Cross-Disability Center in Colorado.

Here is Carrie Ann Lucas.

(Applause.)

CARRIE ANN LUCAS: Thank you. I'm very glad to be here. Thanks for having us here.

Talking about this topic, it isn't discussed as much as we would like, either in the community of disability rights attorneys or in the community of people practicing particularly child welfare law.

Most of my cases are child protection cases. I run a small nonprofit in Colorado. We have two attorneys and one paralegal. That's it. We have 100 cases at any given time with the two of us. We work as court-appointed attorneys for parents in child protection cases. About 20% of our cases are family law cases. We only take primary family law cases, the initial divorce or allocation of parental responsibilities, because we feel partly that's where we had to limit in terms of what we could do and that's where we can make the most difference in terms of educating the court. When parents come back to court with a custody dispute, it's more about parents fighting than about the children. Occasionally we get cases where a parent has acquired a disability such as a brain injury or spinal cord injury or whatnot and they're coming back to court because that parent had primary custody and now the other parent is saying, whoa, they can't parent. So we do take those cases as well, and they tend to resolve much quicker and with less fighting and judges generally say it's worked for the last however many years.

There's some better case law to help out in the family law area. There's a couple of nice cases out of California, there's one in Oregon, one in Michigan. Several around that are helpful that we can use.

We also do a lot of appellate work in child protection cases. And we do a little bit of Fair Housing Act and ADA cases as well.

Upwards of 80% of the parents that we see that come through in child protection cases, and those are cases where social services has opened a case, either taking a child out of the home and placing them with relatives or with friends or foster care, or are threatening to do. So upwards of 80% of those clients have a clear, identifiable disability.

Of the other 20%, probably half of those do; it's just not as clear and it doesn't come out until much later in the case.

The disability we see the most is mental health, often combined with substance abuse, which is generally a symptom of the inability of the parent to be able to access appropriate services because they're just so poor and it's so difficult to access those. So people are self-medicating.

Next after that is intellectual disability, people who would be classified as having borderline intellectual disabilities, lower than average intellectual functioning. They definitely need support, and there are no supports for those people. They don't qualify for social security, they don't qualify for Medicaid, they often have difficulty with executive functioning and have difficulty holding down jobs, which means that they are poorer, which means they have more contact with social workers and different people in the system, and they just can't access community resources to keep them out of the child protection system. And those are the parents with the poorest outcomes.

And then parents with more severe intellectual disabilities, usually -- we have a nice system, at least in the eastern half of Colorado, serving those parents and actually have services for parents with significant intellectual disabilities.

And then after that we start seeing people with physical disabilities and other disabilities. We see a lot of deaf parents. There's a presumption of incompetence because of the communication barriers.

We do not see a lot of blind parents in child protection. There are a few. And usually those cases come to our office or the attorneys call us, they happen, and usually there really are child protection issues. And I would say in most of my cases, there's something going on. Now, if they were wealthy families, they would probably not come under the scrutiny of social services. All of our clients are low income.

In terms of how they come in, we get a lot of the dirty house cases. They got a referral about something, social services comes in, oh, gosh, the house is dirty, oh, gee, we see a marijuana pipe on the table. You know, they start fishing for things because even though their initial referral didn't pan out, they're looking for problems in the family because they've heard that family has various mental health or intellectual disabilities and they're looking for things or the parent is deaf and they come in without a sign language interpreter and then expect them to write notes back and forth when the parent often doesn't speak English or know English writing well enough to be able to answer complex questions about how they care for their kids.

So these families, a lot of them do need help. They don't necessarily need a court case, which turns the situation into a very punitive type of situation, but they end up in court partly because they are frustrated because they don't see they did anything that wrong. Their neighbor did something very similar. Gosh, their kids were left home for five minutes by themselves because mom and dad had a communication breakdown, someone came home late and the other had to leave for work, and social services is ringing them, while the neighbor that had happened to without a disability, they got a pass from social services. So then they become frustrated; they're not as cooperative.

We also see a lot of social workers not acknowledging the disability. Sometimes they do a great job and really push for appropriate services in place. You see that with the clients with very severe mental health or the clients that have the more severe intellectual disabilities. With our deaf clients, they often say, oh, they've communicated with me fine, and they have no idea there was a communication problem.

And they also don't acknowledge their own biases. "Well, the house was dirty." And it wasn't really dirty. The dishes weren't washed yet because mom has a physical disability and she can't do it so she lets the dishes pile up all day until the assistant shows up in the evening. We get a lot of those referrals.

I hear a lot from disability rights attorneys who get calls on these cases. One of the problems we see, and I don't know if any of you are familiar or heard anything about the case out of Massachusetts. It's a case where a young woman has a suspected type of mitochondrial disease. It's not been confirmed. One hospital says she has it; another hospital says, no, it's all a psychiatric problem, she really doesn't have this physical disability, and the parents are accused of medical child abuse.

The parents went out and hired a personal injury attorney to represent them in a child protection case, and it has not gone well, partly because that attorney did not raise some of the basic objections because the case is being heard in Massachusetts but the child was a resident of Connecticut. Massachusetts should have never had jurisdiction to have the case to begin with, but the attorney never raised the issue.

So it's really important in these cases if you get one of these and want to help -- and please do help, because the attorneys representing parents are overworked, underpaid. We get paid $975 for the first two years of a case. Unless it's a termination of parental rights, in which case we get another $1,000 for the trial, which is sometimes upwards of a week long. So we work for minimum wage sometimes.

So most attorneys would like to help because they don't know how to address these issues of disability. They don't know how to ask for accommodations. So even though we're constantly educating on that issue, we can't reach all the attorneys who represent parents.

Even in Colorado. I present at our statewide conferences at least every 18 months, and I still get calls all the time on basic questions like how do I ask for an accommodation or not even realizing that they should.

In cases that I am not the trial counsel on, where interpreters aren't sworn in for termination trials and confessions, they don't get interpreters in the cases, they're not calling witnesses, they're afraid to call the client because the client has an intellectual disability so they put on no defense for the parent at a termination hearing. That's actually the most common issue raised in appeals is ineffective counsel because they're not addressing any disability issues.

We don't have any standards for parent representation. So that also makes it more difficult. So there are not standards on contacting their client and so forth.

The American Bar Association has produced standards, but they haven't been adopted by hardly any states. New York public defender's office has adopted the standard. Washington State has adopted standards because their public defender's offices represent parents.

Some states, such as Mississippi, parents are not even entitled to court appointed counsel ever in their case, not even at termination. So parents, unless you can afford to hire an attorney, you will not get one in those states. So parents, regardless of their disability status, are at a distinct disadvantage. And this is despite a Supreme Court case in 1978 and affirmed again in 1983 that both said, given the resources of the state, what these parents are up against, they're entitled to fair procedures. Well, some states like Mississippi have decided that fundamentally fair does not mean access to legal counsel.

So I think it's probably time to open it up for questions. I could talk forever about different cases that we have going on. So let's open it up.

MARC MAURER: Okay. I appreciate your presentation, Carrie Ann.

(Applause.)

Let me just say, before we get to the questions, the National Federation of the Blind has a belief that laws that aren't enforced aren't worth having, which is to say, you get them adopted, then you enforce them. And the idea is that if you're a citizen of the nation that we find ourselves in, that you have the same right as other citizens. That is of course very naive in certain regards.

I remember being astonished in law school that you could have a right without a remedy. This has been carried forth in disability circumstances to a huge degree.

The child stealing cases, I hire people, I have represented them personally, and I hire people to protect the rights of individuals. The cases that get me most are the child stealing cases, that somebody can come along and simply because of disability say to a parent, you're unfit to be a parent. And without a hearing, without anything being done except that somebody said this, and maybe file a piece of paper somewhere, break up the family. This gets me more than anything else that we do.

We do a lot of important things, and a number of you who are in this room have represented the people for us, and we've got to find a way systemically to address the question of the child stealing cases.

I am prepared for questions. Please identify yourself.

LOU ANN BLAKE: I have a wireless mic for whoever wants to ask questions.

>> I have a question. Up here.

This actually isn't a question but a point of information. Several years ago, some of us here in the room were involved in a case, a custody case, of a blind gentleman being divorced and was told that he could not have his child and would have to have sighted supervision and visitation and so on.

So we sort of got tired of dealing with it. The courts in Maryland is the first to have passed legislation now that eliminates issues of disability in anything regarding custody, temporary custody, visitation, and so on. I'm not an attorney, so I don't have the exact statutes but it could easily be looked up. It's a strong case, I'm told.

CARRIE ANN LUCAS: No, unfortunately. Maryland is a state that allows direct file. So you can go directly to termination based on -- they can terminate based on disability and they have a fast track to be able to terminate parental rights on the basis of disability. There may be something --

ROBYN POWELL: I think family law -- the law is related to family law, because they still allow fast tracking of disability.

But the first state that did pass very comprehensive laws was in Idaho. Back in 2006?

CARRIE ANN LUCAS: I think 2005. Let's see. Missouri has done that. Washington State just passed one. And Kansas just passed one. Washington and Kansas as a result of Robyn -- Washington State is a result of Robyn's report.

ROBYN POWELL: And Tennessee and Oregon have also passed since the report.

MARC MAURER: Are there questions?

>> The Individuals with Disabilities Education Act --

MARC MAURER: Your name.

>> I'm sorry. Joseph Tulman from District of Columbia.

The IDEA has in the definition of related services parent training and school based social work services as well as other services. I'm interested in your thoughts about using those related services when you have a child both with a disability and a parent with a disability. We don't tend to see it in action very much, but I'm wondering what your thoughts are about using the IDEA related services to shore up the parent situation.

CARRIE ANN LUCAS: We use it a lot with early intervention services because often if the child is at risk of having a disability and having two parents with intellectual disabilities often gets them eligible for early intervention services. In our state in particular we use those to fund parent education. That's one of the issues we see with parents with intellectual disabilities and why they have such a high rate of termination of parental rights or permanent allocation of custody away from the parents is because the parents do need ongoing support past the Adoption and Safe Families Act, say if a child has been out of the home for 15 of 22 months, they have to take action to get that kid, and after a year the kid is supposed to be in a permanent home, which is where they usually stay. So we use IDEA services.

We also use Medicaid services if we can get the parents off a lengthy wait list that we have in Colorado for adult developmental disability services. Sometimes we can do an emergency placement. Between Medicaid and IDEA, sometimes we can prevent social involvement because the parents need ongoing education because they may learn what the six-month-old needs, but a nine-month-old's needs are different. So during especially those birth to three years, they need a lot more intervention than they do later on. Things don't change as often once kids get into preschool and particularly school age at those times.

We also have put in IEPs for homework assistance for parents with disabilities when the kid has a disability, so then we've eliminated that barrier of the parent helping the kid with the homework. We just put it in the IEP.

ROBYN POWELL: But that only of course applies if the child has a disability.

MARC MAURER: So let me ask you this question. We have certain tactics that we use for bringing attention to the circumstances of the disabled parents. One is a public discussion of it. Yet, in some cases, we've found that there is a gag order put on the whole thing so that you can't talk about what the state has done or I suppose if you know it outside of a legal proceeding, you might. But everything that happens in the legal proceeding is under a gag order. This means that you can't even under certain circumstances talk about the outrage of it all.

Is there a way around all of that?

CARRIE ANN LUCAS: It's very difficult. It depends a lot on the state. For example, in Colorado, while the proceedings are confidential, you can't access any of the court records, which is part of the reason why there is so little research is it's so difficult to get to the court records because you have to have court permission in order get to the records, because of the confidentiality of the children and the parents and so forth.

Sometimes that works to our advantage. I had a case where both parents with intellectual disabilities, there was video on the news station of one of the parents shaking the baby, where somebody else filmed it and sent is the tape to the news station. When social services did not intervene, in that case, we really want that courtroom closed because it's really best for the family to not have the news station there reporting on to the case. Because the parents are actually getting help. And that's one of the problems that we sometimes face when representing parents is sometimes we have parents who have done not nice things to their children.

Some parents have been downright abusive. I have a deaf parent whose baby had multiple skull fractures and other fractures. That said, that parent never had a fair chance to rehabilitate herself and become a parent to her child. And that's something an able bodied parent would have had. A parent without a disability would have gotten a fair chance, and that parent didn't because she didn't have effective communication with social services, with the court, with her own attorney. So that's where we have a breakdown in the system.

On to the other hand, courts are often open unless somebody asks to have it closed. So family members can sit in, but when cases start appearing on the news and there's media attention, judges issue gag orders. They're allowed to. They have wide latitude pretty much everywhere in the country.

ROBYN POWELL: I would agree.

MARC MAURER: Other questions?

You know, I think that the protection of families is a vital element and a central part of at least what we do and I hope that all of you do.

Carrie Ann Lucas, I appreciate your coming. And Robyn Powell, I appreciate your coming also. This is a part of the area of law which needs development as urgently as any other. So I thank you very much for being part of the symposium.

(Applause.)

CARRIE ANN LUCAS: I just want to say, we have a number of handouts. The ones that I brought from our organization are largely Colorado based, but some of the stuff in them is applicable elsewhere. And if anybody wants an accessible copy, they are on our website.

MARC MAURER: So now, tomorrow, we are going to get together, yes?

LOU ANN BLAKE: That's correct.

MARC MAURER: Where is it? We got together in the big room earlier. Where tomorrow morning?

LOU ANN BLAKE: Back in the big room tomorrow morning.

MARC MAURER: Okay. There is a reception, right? Now, we're a little early. Do you think it will be ready anyway?

LOU ANN BLAKE: I think there still may be cookies out there.

MARC MAURER: Do you have any announcements before you make sure they're done cooking?

LOU ANN BLAKE: I don't think so.

MARC MAURER: They don't have to cook the wine though, right? So we could probably move on to the spirits.

(Laughter.)

Any other announcements?

LOU ANN BLAKE: No.

MARC MAURER: All right. It's been a great day. And it's time to gather and share stories and some of them will be true.

(Laughter.)

And ask Scott LaBarre. He has a few true stories amongst the others. I will see all of you in the reception across the hall. Thank you all for being a part of the symposium today.

(Applause.)

(Symposium ended at 5:00 p.m.)