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**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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"Supported Decision Making as an Alternative to Guardianship"

8:30 a.m.

MARC MAURER: Shall we get underway this morning?

The first program of the day -- Scott?

>> I'm raising Cain.

MARC MAURER: Yes, yes.

Supported decision making as an alternative to guardianship. We have three people to present this. Peter Blanck, university professor, Syracuse University, and chairman of the Burton Blatt Institute at Syracuse University.

Maureen Henry, former executive director of the Utah Commission on Aging.

Jonathan Martinis, legal director, Quality Trust for Individuals with Disabilities.

Are we taking people in this order? We are? Okay. Good.

My background on Peter Blanck is that he is a university professor, which is a designation at Syracuse, and it is the highest faculty rank at the university. It has been granted to eight other individuals at the university.

He chairs the Burton Blatt Institute, and --

PETER BLANCK: My mother is not here.

MARC MAURER: You don't want me to tell them this stuff?

PETER BLANCK: If my mother was here, then yes.

MARC MAURER: Peter Blanck has been working on cases in which we've been involved now for something well over a decade, and he has been enormous contributions, both to the individual work that we've done and to the field at large. It is a great pleasure and honor to welcome him here.

One of the realities is that he fundraises. He pitches me for a grant every year.

(Laughter.)

And I have agreed to do this if he could raise some other money, so he will probably pitch all of you too. Inasmuch as I have been fundraising now since about 1969 one way or another, I know how important this fundraising bit is.

Peter has a book coming out. I don't know whether he will tell you about it, but it's going to talk about E-quality in the realm of access to information.

I am delighted and joyful to welcome to this podium Peter Blanck.

(Applause.)

PETER BLANCK: Little does Dr. Maurer know, when I ask him for money, the match is already in hand.

My brother is a neurologist, and he's, according to my mother, the real doctor in the family.

(Laughter.)

We have a special introduction for her.

It's always a pleasure and a great honor to be here at NFB. I really have a blessed time of my career as a Ph.D. and a JD. I get to be counsel and co-counsel with the likes of the people here in the room, but I also act as an expert witness sometimes based on my empirical work.

Last summer was kind of unusual. I was an expert in a case in New York City, in federal court, testifying before a relatively new judge, his first trial, his parents were there.

(Laughter.)

True story. His brother is the economic adviser for the Obamas. I forget his name. Furman. And that was with disability rights advocates and we won a very important case.

But I went from that to Hampton Roads, Virginia, with an attorney I never heard of before, Jonathan Martinis, sitting over here, who asked me to testify in Jenny Hatch. You heard about Jenny Hatch yesterday. And I have to say, they both were amazing examples, but going into that little state courthouse with a really senior federal judge who had been around -- state court judge, sorry, who had been around the block many times was really a fascinating experience also. Everybody heard the story of Jenny yesterday and Jonathan's fantastic remarks and we'll hear more about that today from Maureen as well. I'm going to try to act as facilitator. But I think Jonathan can convey this. He put on several witnesses. The witness before me was a clinical psychologist who basically talked about Jenny from a clinical point of view. And he got reamed by the state court judge. That's what I was following. This judge wanted nothing to do with this concept is of supported decision making. And there were a lot of things of course that made this case and the stars align.

The first ADA case I was ever an expert witness in was a case with Chuck E. Cheese. You may remember it. One of the largest verdicts ever, $13 million in punitive damages. It reminded me of that, this kind of so clear focus on what was going on.

I was to talk about self-determination, my research and writings in the area, longitudinal studies of individuals with developmental disabilities, intellectual disabilities.

But I ended up, and Jonathan can check me on this, what ended up having what I thought it was basically an amazing conversation on the bench with this judge, kind of like we're talking now. And relating back and forth to him things like, which most judges hadn't heard about, the change from the medical model to the social model, the concept behind Olmstead, the concept behind decision making as Jonathan has talked about.

It was really a privilege. You know, normally like the DRA case, that was a case of documents that would fill this room, a great case. But this was so personal, so interesting discussion with this judge. Jonathan can reflect if I estimated that correctly.

We ended up having an incredible outcome in the Jenny Hatch case, and it was one of those cases where you know that you're glad you were involved in that, one of those cases that you will tell your grandchildren. I can still talk about Chuck E. Cheese. One of those cases that you know is going to be a game changer.

So Jenny Hatch for me got me involved in a broader context. I hope today to convey some general thoughts. Maureen and Jonathan, I'll introduce them briefly, let them talk, and kind of facilitate the discussion today because you don't need any more talking heads.

Obviously Jenny Hatch is occurring in a context of Olmstead. Sam Bagenstos is here. He was involved with that. Second generation Olmstead. So now everybody is in the community; now what do we do? That sort of thing.

It's involving of course in the context of the U.N. Convention on the Rights of Persons with Disabilities. Going over to Ireland again to speak with folks who are extraordinarily interested in Jenny Hatch and concepts of capacity. In some ways, they're ahead of us on these issues.

And we're really talking about personhood, as was said yesterday. The CRPD article 12 talks about the concept of legal capacity, personhood, citizenship basically. My talk in Ireland will be about concepts of citizenship.

As Dr. Maurer mentioned, my book that is coming out this summer from Cambridge University press is called E-quality with the subtitle, the struggle for accessibility by persons with cognitive disabilities, which is the next frontier. On pro bono with Larry and Linda and others, a very small part, CNN, who for some reason has decided to not caption their website, their video clips, and who for some reason say that, well, if they captioned their website, we wouldn't be limiting their consumers but we would be limiting CNN's right to free speech. So we're in a new age of hyper real-time digital connected society, which as we know, this whole separate talk, brings with it great opportunities for inclusion and great opportunities for personal invasion as well. That's what that book is about.

We're also in a time where the Jennies of the world are coming of age under the ADA and the CRPD. Most of my law students now were born after the Americans with Disabilities Act was passed. Which is hard to believe. By 2040, the number of people Maureen will talk about, the number of people in the United States over age 65 will double. We have a whole group of individuals, if you read The New York Times daily, about the conditions facing our veterans with disabilities returning from Iraq and Afghanistan with the signature injury of cognitive disability, TBI, PTSD, and all of these forces interestingly came together in that little courtroom in Hampton Roads which informed my conversation for an hour or so on the stand. I don't think there was any cross-examination, was there? Maybe one question.

JONATHAN MARTINIS: The judge.

PETER BLANCK: Yeah, the judge asked me questions, which was fascinating. Just by way of litigation tip, Jonathan can tell you this, it was going so well that I tried to be argumentative with my own lawyer and not agree with him. Not in a false way, but to show I wasn't just up there, you know, sipping the Kool-Aid. I was trying to convey in an intelligent way the issue we were talking about. But he was one of the best lawyers, and I say this not lightly, one of the best lawyers I've of worked with. That case would not have happened but for the commitment of Jonathan.

I always say also, and this is a digression, that the expert, me, is only as good as the quality of the lawyers we get to work with. And the people in this room I've worked with are extraordinary.

So today I want to facilitate a discussion and give you a few observations about what I've learned from the Jenny Hatch case, what I think is important. Jonathan was introduced yesterday 20 years he's been litigating ADA cases, seminal cases. Since the Jenny Hatch case, we've been fortunate at the Burton Blatt Institute to partner in a small way with Quality Trust to establish the Jenny Hatch Justice Project about this issue of supported decision making. I urge you to take a look at it. It's really developing nicely. We have a manual. We had our first symposium last year and we'll have another one this year. Bob Dinerstein I don't think is here today but he is another great partner of ours on this endeavor.

Maureen I think, who is getting her dissertation, who has been an aging policy fellow on decision making, and who has been a director of Utah's aging commission, provides a very interesting perspective from the aging community very similar to many of the issues we're talking about in supported decision making.

So I thought in the good professorial way, I would identify a couple of exam questions for these guys to take about 15 minutes each to talk about. If you're a good law student, you'll write about what the hell you want to write about any way and you'll pass. At least at the better law schools.

(Laughter.)

As long as it's coherent. And then we'll have a discussion.

Okay. So point number one. My learning. This is the next book. Thoughts on this.

Number one. Generic system of personhood. So obviously, and I'm glad Maureen is here. We need to talk about issues of supported decision making outside of the framework of guardianship. Jonathan made this point already. That is, it's too late by the time you get into court in Hampton Roads to start educating the judge about supported decision making. We were lucky. The stars aligned. We had amazing counsel, we had an amazing client, we had a judge who was extraordinarily hostile to begin with who was very is open minded at the end. In some ways he split the baby within his context but he really opened the door to allow us to do what we want to do. He didn't have to go that way at all. The parents were right there looking him in the eyes telling him what they wanted. This was an older judge who was not a social rights ADA educated person. That's one point.

Second, as Jonathan said yesterday, clearly we need to make this a cross-disciplinary effort. So the docs, the gerontologists, the social workers, the counselors, everybody needs to be involved with this discussion from multiple perspectives.

Three, which I made in my testimony, Jenny Hatch and more generically this area, is not about at all parents versus kids. It's not about one group of individuals versus another. It's about support. It's not about against the guardian ad litem. In this case the guardian was uninformed on these issues, could you say? I don't know if we're being videotaped or not. But there's a record of this.

The guardian ad litem was amazingly adverse to our position, and that was very challenging to overcome.

So point number three, this is about supported decision making which means, as Jonathan used the example yesterday, what did you say, a mechanic with a muffler or something? It's obviously about a collaborative effort.

Fourth point to consider. Obviously we're talking about issues of legal force. We're talking about laws and policies and procedures. You mentioned the Virginia legislature is considering some study in this area. We need a law school and law professor types to develop model laws, model supported decision making agreements, so there are illustrations within the context of a legal framework that people can use.

Five to consider, and not in any particular order, mentioned last night over drinks with Chris and others, this is a life course endeavor. Talking about personhood. So it has to start early. It has to be continued with in terms of youth and transition. And of course as Maureen will talk about, it's very relevant at the later stages of life as well. This is not, you turn 21, you're out of the educational system, and let's start talking about self-advocacy and self-determination. That can't happen. It has to happen in third grade. Or fifth grade. Or sixth grade. And that's where the real changes will happen. It has to happen for traumatic brain injury for vets, the thousands of vets coming back, young kids basically, coming back to a society which will be challenging for them.

Next area, again, not in any particular order, we have to look in terms of the research or study agenda at federal and state systems. This was alluded to yesterday. Why wouldn't these services be reimbursable under CMS? Why wouldn't they be part of an IEP plan? In what ways can the service support systems, voc rehab, actively support this endeavor?

And last, I would like you to think about, the good researcher that I am, having just submitted a grant, the first of its kind, to the National Institute on Disability and rehabilitative research, there needs to be of course evidence-based practice, examples in empirical -- I had no -- I had really no empirical information to talk about that dealt with this area, although I purported to talk about a lot of empirical information in this area without a smile on my face. I extrapolated it from a lot of empirical information that I was aware of, but there were really no studies that I was aware of that looked at this. We have just submitted to the Department of Education a two and a half million dollars grant with Mike Meyers, who has done work on the Quality -- what is it? Center on Quality Leadership? With Quality Trust and probably in other group. They studied a thousand individuals? 2,000 individuals were studied in Washington, D.C., to look at them over the life course of how they make decisions. Never been done before. Relating it to a whole host of decisions and so forth.

I should say, by the way, that another question is supported decision making versus guardianship, is it one or the other? Eventually it may be other, but of course it's not an all or nothing thing. In the Jenny Hatch case, the judge was talking about the whole enchilada, but of course there's a whole range of mid-level areas that could be discussed.

One last thing, Maureen, this is for you which I think is important, now that I'm starting to study this and I'm talking a lot with my doc friends around the country who work under a concept called shared decision making, which is a similar but different discussion in the medical context supposedly about medical identity decisions, court decisions, and so forth. Some people would say that there are great limits to that dialogue and it's different than supported decision making. It's more of a guided medical decisions and really controlled by the docs some people would say. But clearly that dialogue is subsumed by the larger discussion. But the larger discussion is certainly informed by that context, particularly relevant for older adults where medical decisions increasingly are made by families or by proxy.

So with that introduction, I'll turn to Jonathan first and please correct me if I conveyed anything incorrectly.

I wish we had a videotape of that trial. You saw a little bit of his closing argument yesterday. Maybe opening argument. But it was worthy of television time, the way this trial played out. And in large fart was due to now my very good friend Jonathan Martinis.

(Applause.)

JONATHAN MARTINIS: By the time Peter got on stand, after multiple days of testimony, none of which had gone well, this was not a friendly judge. My cocounsel said afterwards, did that go as badly as I think it did? And I said, yes, it did.

(Laughter.)

So we put our expert psychologist on, got our points across, and there was little cross-examination except from the judge. I kept going back on redirect to make my points again and the judge would ream them. And the judge would ask why do you have more questions? And I would say, well, I feel I have to now redirect. So in that context, the last witness has a plane to catch in two and a half hours, Peter Blanck.

Peter sits on the witness stand and I ask probing intelligent questions like, "What can you tell us about self-determination?" And I back up. And 15 minutes later, after Peter has finished educating everybody in the courtroom about this incredible concept, I would ask another probing question like, "What is supported decision making?" And I would back off.

And so it went for about an hour. It was marvelous testimony, as you could expect. Peter is right. There is no empirical evidence on supported decision making. We knew that going in so we were making it up as we went along because there is some research that kind of deals with it, so I would say things like, oh, there are studies about independence, and we've got a witness with a 70-page CV and had did a few of them.

Then it was time for cross. Practice tip for attorneys. When you're dealing with a genius, don't try to be smarter. So it didn't go well for opposing counsel.

But the judge began doing his cross-examination and he started doing the same type of very initially hard fighting, how dare you questioning. And I saw the most amazing thing. Peter Blanck simply shifted in his chair and the two began chatting. It stopped being combative and started being this exchange of ideas, the end of which the judge thanked him. Didn't thank me, by the way.

(Laughter.)

But he thanked Peter. He said, you have given me a lot to think about; I hadn't considered any of this before now. Which besides being great for my ego, like hey, I did pretty well.

(Laughter.)

So that is the story. If an expert is only as good as his lawyer, I don't know who to hire again, but it went really well. Thank you.

So let's talk about supported decision making. As I was thinking about this presentation, and as you heard me say yesterday, supported decision making has to be something that isn't just the flavor of the month. In this field, we have a lot of concepts we put out, and it seems that every half decade or so a new buzz word comes out. And the new theory. The new way of doing things. Everyone is then required to do things under that theory, and they sigh and say, okay, what's the next thing, train us now.

I think if you deal with services and support, you've seen that. Oh, person-centered planning. How is this different? Well, supported decision making cannot be that. Because it's not a way of doing things. It's the way of doing things. We know this because we've all done that. When we talk about equal access for people with disabilities, what is it that we're saying? We're saying that people with disabilities should have the same opportunities and same rights and same effort that we do. What could be more basic than giving people with disabilities the same opportunities to make the same choices that we make every day in the same way that we make them, in the same spheres that we make them?

As I said yesterday, think about every decision that you make. Unless you shoot just from the hip, every time, you're probably doing some research or doing some thought or asking some people for their advice, especially as the decisions get more important. You're being smart when you do that. You're admitting that you don't know everything and you need a little more information and a little more help. That's called making an informed decision; you've asked for help appropriately.

Yet when Jenny Hatch or a person with a disability does, that their asking for help in a decision is proof that they can't make any decisions.

So as we push and implement supported decision making, that is the attitude that has to change. It struck me that the most impressive thing about supported decision making, the strongest thing about supported decision making, is also the weakest thing. And that's that we all do it. It is so easy to explain to people what supported decision making is because it's what they do every day. And that actually is the weakness. Because when you're talking to somebody is who has a preconceived notion of what people with disabilities can and can't do, saying to them that you want a person with a disability to do something just the way that we all do it is to put up their mental roadblock. Well, wait a second; people with disabilities aren't like me. I've spent a lifetime knowing they have limitations; therefore, they cannot do the same things we do. Automatically it becomes back into that buzz word bin.

So as we talk about implementing supported decision making across the sphere, it's important to communicate what it is and isn't very clearly. The way we do that is to make analogies with the way they do things. Put another way. You're talking to a special education teacher trying to explain supported decision making. Well, in general, it's a person with a disability receiving the information that they need to understand the situations that they face and the decisions that they make, so that they can make the best possible decision while receiving input from people they trust who have information about the things they have to make decisions about.

In other words, teacher, that's an IEP team. When an IEP team functions appropriately, the student-directed IEP is a model of supported decision making. So when we talk about decision making as a life course skill, it should start in school. It should start as early as possible with people who understand supported decision making from a professional standpoint; they just call it something different. So we advocate for student-led IEPs, we advocate for kids to be involved. We know from studies that decision making is a skill. It can be learned. It can be taught. And it is integral for independence. Therefore, it is an independent living skill. And what does the definition of transition planning and special education include? Instruction on independent living skills.

So when a school pushes a parent to become a guardian, to me that is a sin on multiple levels because it means they are admitting they didn't do their job from the beginning because if they thought that kid had difficulty making decisions, where was the transition planning from age 14 or before to implement instruction and decision making? Those of us who do special ed know that transition planning is getting greater emphasis, though one would wonder why it wasn't before. It's nice that it is now. But that is something we should be arguing for.

When I was supervising people in special education in Virginias I said every plan should have something on school, work, voting, and independence. All of those have decision making components to them.

And what we talk to counselors, especially voc rehab counselors, whose job it is to help maximize a person's employment potential, well, what could be more important for being employed at the highest possible level than decision making skills, critical thinking, and decision making with support when needed?

In other words, supported decision making is just proper vocal rehabilitation counseling. And if it can't be done through counseling, it can and should be done through VR services.

We heard on the second panel yesterday from folks talking about reentry from jail and prison and how it's difficult to find services. I talked with some of them one on one, and VR is the perfect vehicle. The vast majority of people coming out of the justice system have some type of disability and therefore should qualify for VR services. And VR is the sleeping giant of disability services. There's so much they can do; they just don't know it. They just don't know it.

And if we shake our heads when people recommend VR, and say, oh, they'll never do that, then we're giving them a break. We're letting them get away with not providing the services that they can and should provide.

Take a look at some of the things VR entities can do. I can boil it down to this. Anything. Anything a person needs to gain, retain, or regain employment. I have gotten VR entities to pay rent and buy clothing. Because those are things one needs to have a job. And if one has the potential to be employed, one needs decision making skills. So why shouldn't VR help people develop those skills, develop it through supported decision making? Why shouldn't they implement supported decision making? And that's something they ought to be able to comprehend. We don't have to call it anything other than what they already do.

In Medicaid planning, HCBS just came out with new regulations about stressing independent living skills. I said, again, what is more important than decision making? But more importantly they stress person-centered planning. I've said we have seen buzz words come and go and person-centered planning is one of the flavors of the month. My personal observation, what I am seeing in person-centered planning more and more is a group of people sitting around a person with a disability planning for that person or planning to that person. They are missing a critical component: The person.

Person-centered planning should be planning with the person, by the person. In other words, it should be supported decision making. So when we talk with service providers and we talk with Medicaid providers, we should be saying this is what you're supposed to be doing already. Supported decision making goes across the spheres. And we need to make people understand that, because otherwise it will never be understood; it will simply be a flavor of the month.

And I'll finish here. Maybe 15 years ago, no one really believed in powers of attorney or advanced directives. They were just things. The idea that a person may be able to say in advance at times when they may or may not be able to take care of themselves.

Then suddenly they began to gather team and legislative recognition. Now they're very well recognized. If you look at the uniform guardianship act, they require people to exhaust or come close to exhaust less restrictive remedies and the only ones they mention are powers of attorney and advanced directives.

Imagine if that regulation included recognition of supported decision making as a thing, as something that is done. Not as a concept, but as a true methodology. Understood and appreciated across spheres. We might get to that day when a judge actually asks in an uncontested guardianship hearing "What else have you tried? Have you tried supported decision making? Why don't you, and come back if it doesn't work."

Legislative recognition. And also through development of forms, supported decision making agreements, just like we have powers of attorney agreement, so that we can actually go to a doctor. A doctor who would otherwise normally say, look, I can't really deal with you, supporter, if you're not the guardian, because of HIPAA. Or a lawyer who says, I can't work with you supporter, the code of ethics requires me to only work with my client or my client's guardian. Even in the best of intentions, we would not get where we need to go across the sphere. But if there is policy or regulatory or legislative recognition of supported decision making in a tangible agreement that a person could present to a professional that includes a hold harmless, by the way, that says a professional following this agreement will be indemnified, then all of a sudden, we have a thing. We no longer have a concept. And as I said yesterday, when that happens, we stop talking about people's rights and we start talking about their choices. And that is truly when we will have equality for people with disabilities. Thank you.

(Applause.)

PETER BLANCK: Maureen?

MAUREEN HENRY: So I tried to get the questions out of Peter before we started today, and as a good law professor, he wouldn't give them to me. So now it's all swirling around.

I will start by talking about a generic system of personhood and how I think we've gotten to where we are in this issue of supported decision making, of guardianships.

We have a paradigm in decision making, primarily in medical decision making but also in making decisions about issues ranging from financial to where you live to the issue of voting that's come up a couple of times already. It's a dichotomous paradigm. Somewhere along the line, we decided that you can draw a thin black line between the population and you can put some of the population on one side and some of the population on the other side, and if you're on one side, you have full legal rights. If you're on the other side, you have no legal rights. Except as exercised through someone other than you.

So I'm cycling kind of to the bottom, and Jonathan's comments at the end, one of the concerns that I have about advanced directives and about powers of attorney as someone who both did a lot of them while I was in law practice but also who wrote Utah's statute and who has written a bill in Congress as well on this issue, is that in some ways that continues to support the dichotomous paradigm that there will be a point when you can't do it and at that point it's okay to take you out of the picture and have someone step into your shoes and make those decisions on your behalf.

So they help in some ways, but they don't get you all the way to this concept of personhood and keeping the person at the center of the equation.

I have spent much of the last five years in a Ph.D. program trying to figure out how we got where we are and be what we can do to change it. Much of how we got where we are is that this whole paradigm of capacity across the board, across the spectrum of decisions, comes from legal cases. You can track a lot of the language back to law review articles in the 1940s talking about the capacity to consent to contracts and the capacity to make a will. If you follow the capacity literature into the '70s and '80s and '90s when there were a lot of efforts to try to bring some sense and reason to the system, you find quotes from those 1940 law reviews about contract and capacity to make a will.

The challenge is that no one seems to have gone back to the question of informed consent and why do we do informed consent and the roots in autonomy of informed consent. And instead of going back and saying, what's the value in autonomy, we say, let's assume this is going to wind up in court, and so every decision is made based on standards that you would use to judge an irreconcilable conflict in court.

The problem is, most interactions in life don't get to court. And most interactions in life don't need to get to court. So one of the things that I think we need to do is really pull away from this model of a legal construct of capacity that assumes that you have to have a dichotomous outcome and instead start looking at this concept of figuring out how to make this work and keeping the person at the center of the equation.

Some of the philosophers who have contributed to this dichotomous state, for example, Buchanan and Brock, who wrote the well-known work on deciding for others, they say that decisional capacity is necessarily a dichotomous state. But what you don't see is them or other toes going back and saying, what is the harm that we do to people when we take them out of decisions about their own lives? So we have avoiding harm on one side, autonomy on the other side, and there's an assumption in philosophy and in law that those are two distinct states and there's never a focus on the fact that eliminating a person's autonomy causes harm. So in a guardianship issue, the harm is always about is this person safe at home, is this person going to be exploiting, is this person able to be rational. It's not about what is it going to do to this person when we say you can't live where you want to live anymore. You're going to be left in a doctor's office and your family and the doctor will go out in the hall and decide whether or not you're going to have surgery outside of your presence. What does it do to people when we take away autonomy on the grounds that it somehow is avoiding harm? You don't see that. You don't see that in the literature about capacity assessment. What you see is this assumption that you can divide everyone with a thin line.

So one of the reasons I have come to supported decision making is that it really does reflect the reality that you don't have a line where you can put people on either side. By assuming that we can draw a line, what we do is we say that if you're one titch to the right of the line, you get to do everything. And guess what? You don't get any help. Because you're on this side of the line. Now, if you're on the other side of the line, you're just out of the picture altogether. The reality is a big gray swath, whether you're talking about people with cognitive disabilities, when you're talking about older adults with dementia, whether you're talking about people with mental health problems, you have a big gray area of people who have the ability to participate to some degree in decisions even if there are places where they run into problems.

One of the things I hope we can do is to shift the research dollars. So in the past 30 years or so, millions of dollars have been spent by the federal government and by foundations helping to us draw that line. And evaluating the instruments that draw that line. And if you read all of those articles, none of them ever get to, well, what do you do? Sometimes they'll actually say, you should try to improve the person's capacity before you conclude that they're out of the picture, but most of them don't even say that.

They never say how can we use this information in order to identify areas where people need support and then keep the people in the picture, let them exercise the abilities that they retain, and then to those abilities bring in assistance. So in older adults, one of the major issues is short term memory loss with dementia. So how can you help support someone by having someone be that memory support? In other cases it may be connecting dots and figuring out, well, this is my goal, but how do we get from a specific decision, whether about medical care or residential, how do we get to my goal?

So I'm hoping that we can use the research that's been done to measure a lot of these things to point to where we need to go in the supported decision making area.

The cross disciplinary piece is also very, very important. Having worked -- I've spent a lot of the last eight years in government, in medical settings, and in legal settings. One of the things that I see is that judges and lawyers don't understand how the medical side works, and they don't understand the limits of the medical side. So you have judges who think that if a doctor comes in and says this person lacks capacity and needs a guardian, the judges think that there's something behind that. Then you have the doctors saying, well, we don't know what the standards are, we don't know what we're supposed to be doing, we're faced with some pretty awful situations of people who are in real trouble and all we know is to go in and say let's get a guardianship in place.

So there's this disconnect across those disciplines. And I think the American Bar Association has done a nice job at trying to connect psychologists, judges, and lawyers, and provide some guidance. I don't think it's all correct guidance, but for a lot of these reasons that we've already been talking about.

Jonathan, you're right about Medicaid emphasizing person-centered planning. There is increasing attention by CMS on quality measures as well as with the guidelines for facility-based care, but again, we're trying to get people outside of facilities but we are really bad at managing quality of services that are provided, so development quality measures is going to be important in that area.

The other point that you made, Jonathan, is cycling all the way back to the advanced directives and powers of are attorney. Utah has an advanced directive act that has essentially a model for shared decision making in that when a person lacks capacity, the surrogate -- and I don't like the word "surrogate" because it implies they're replacing someone. So in my dissertation study I'm using "decision companion" instead of "surrogate."

It's a very structured decision making process by the surrogate, with the first step being, ask the person what they want. Number one. Ask the person what they want. And then if you don't get what you need out of that, then think about, based on what this person has said specifically in the past, how would you apply that in the circumstance. If you don't have actual knowledge of something they've said about this specific decision, then what would they say about similar decisions. And then only do you get to best interest when, for example, in a hospital they have a homeless person and they have no one who knows this person and the person is fully noncommunicative, then really supported decision making isn't an option.

So we do have some models out there in Utah and a few other states that look at how to bring that together.

And one of the things that I did while I was in D.C. working in Senator Warner's office is we got a bill on medical decision making, but it does contain that structure as well. And boy, did we get push back on that.

So thank you.

(Applause.)

PETER BLANCK: So you both passed. You're going to go on to your graduate studies.

Now let's get some objective reviewers from the audience. Dr. Maurer, would you like know facilitate or would you like to facilitate?

MARC MAURER: Go right ahead, Peter.

PETER BLANCK: Not that you had any choice.

MARC MAURER: I know I didn't.

(Laughter.)

>> Good morning. I'm Tom from Philadelphia. I work at a large center for independent living.

I'm curious at many of the things that the panel has discussed this morning. There's a very big thing that's absent. And many of the things that you're discussing are things that have been around for years in the independent living movement, fundamental things or principles like consumer control, consumer choice, and dignity and risk, some of the things that Jonathan mentioned, the same ability to make a mistake and learn from that mistake. It just seems that why is there that absence or absence of acknowledging that, especially like Ed Roberts' mantra of "nothing about us without us" and that whole type of flavor that should be overriding all these systems, whether it's aging, under 60, home- and community-based services, reversing the institutional bias that exists, and so on. It just seems absent. I'm not sure if I'm missing something.

PETER BLANCK: It's a very good observation.

JONATHAN MARTINIS: If it's absent, it's because I explained it horribly, because in my view, the supported decision making model encompasses everything you just talked about. Not only is it nothing about us without us, it's I'm doing for me and you come along for the ride. That's the point. It's not decision making for a person; it's decision making by a person.

The problem, in my opinion, with all of the existing paradigms was not one of theory but one of implementation, or more properly, one of buy in. Disability advocates have known and believed forever in this model. We have all practiced forever in this model. Or at least preached it.

The difference is, we have not gotten the world at large, the professionals and providers, to get in with it.

So what I suggest, and actually I was thinking this, ironically enough, I'm suggest supporting the decision making of the professionals and providers by telling them, this is what you're supposed to do in the first place. So it is truly a person-centered, person-directed methodology. To me it is the difference between community integration and true integration into a community. The person integrates himself or herself into the community through this model.

MARC MAURER: I have an observation. I don't know whether this will stimulate discussion or not.

You recommend the rehabilitation system. We've been working with the rehabilitation system a long, long time. Back in the 1950s, there was a move by the rehabilitation system to say, if you join that radical National Federation of the Blind, we're not going to provide you services. And Senator Kennedy and Congressman Berring out of Arizona put in the Right to Organize bill, which eventually failed, but the implementing regulations in the rehabilitation program later said you have a right to join whatever organization you want or you can't be denied services based on participation in an organization.

Now, in the 1960s, we also got adopted the idea that -- Dr. tenBroek loved this thought. He said, you can't have a right to speech without having the right to be heard, which is to say the government has to listen to you.

Now, it doesn't listen very well, but Dr. tenBroek's argument was, the free speech right and the right to assembly means that you have the absolute right to have the government may attention. It doesn't have to do anything, but it has to pay attention.

So we got into the Rehabilitation Act this idea that choice is part of it. And the individualized employment plan, plan for employment, IEP, says that you get to decide what you're going to do. And you're right, Jonathan, you can get anything out of the rehab group, according to the law, that is needed for you to get employment, except one thing. There's one exception. And that is that the government cannot buy land for you. So if you ever want to know what the exception is, there is one, only one. It can buy you a Cadillac.

(Laughter.)

It probably won't, but it can.

(Laughter.)

But the reality of the rehabilitation system is that participation in decision making doesn't happen much.

So why I bring all this up is to say that there is not a solution to the problem readymade. Number one.

And number two, the work that you have been doing to get supported decision making into the legal structure is of importance and at least some of the direction that I think might help is that one or another of us gets busy and sues the rehabilitation department to help it know that participation in the individualized plan for employment does mean supported decision making.

PETER BLANCK: Redirect, counselor?

(Laughter.)

JONATHAN MARTINIS: Actually, you read my mind. I had the great pleasure of working with two young attorneys who are in the back row, although as I get older, they're all young attorneys. Julie Kegley and Karina. I had the privilege of watching both of them cross examine people from the VR agency. I watched Julie set the commissioner of the entity and say to him, show me in the law or your regulations where it says you can't do that.

And she won that trial.

So at the end of the day, it is important to speak that truth to power. We want them to come along knowing and voluntarily. We want to educate them. But sometimes a stick is required.

And I say again, VR is the sleeping giant of community integration. They can do anything as long as they want to, know how to, or are told to. To me, those are three options.

MAUREEN HENRY: If could I make a brief comment.

So I became the director of Utah's ADRC. I know ADRCs don't necessarily have a lot of respect in the disability community and it's seen that it comes out of the aging side.

We came late to the game and wrote our proposal in a couple weeks. We were told by the program office, you have to give equal weight to people with disabilities and older adults. So we did exactly that. So we funded as many independent living centers as we did aging organizations.

Much of my dissertation work has been influenced from what I learned from the independent living centers during that process of creating and launching an ADRC in the state of Utah. So I don't think that the issue is that we are not recognizing what's happened; I think that other -- it's the cross pollination. It's the cross disciplinary issue. As an aging person, I hadn't heard a lot of those messages prior to getting into the ADRC. So the aging -- and I think in that case, I feel like the aging side learned a tremendous amount from the disability side.

The other thing that I found really interesting, though, is that some of the best educators in Utah on really, truly person-centered planning were people who come out of the greenhouse model of nursing homes. So the person-centered planning people, some of the trainers were nursing home people training the independent living center, and everyone just felt like their worlds were a little bit upside down, but people on both sides really learned. So I think when you start getting people, and mental health is out there too and often doesn't cross paths, that what we really need to do is get all of the groups together and work on a concept that applies across all of the groups, recognizing that within the groups, people have different needs.

PETER BLANCK: Yes. And Lou Ann, do we have time for one more question? By the way, I should have said --

MARC MAURER: We have 12 minutes left. Plenty of time.

PETER BLANCK: This needs to be across the spectrum of disability as well. I was out working with the Sacks Institute in California. There's a book "The center cannot hold." That book approaches these questions from a person who has schizophrenia and episodic conditions and other issues. Another question?

>> Hi. In Maryland there is a lot of discussion brewing about supported decision making and whether there should be a statutory change in our law. And what I heard you say was, I think you supported that. But then I was curious, Marc, were you saying you thought we should or shouldn't build it into the statute? We have here a lot of those factors on what a surrogate -- we still call that person a surrogate -- what a surrogate or guardian, how they should make their decisions, whether substituted judgment or best interest. We have all those many factors in our law. We don't have anything yet on this concept of supported decision making although we have all the person-centered planning built into the process theoretically. So I was just curious, do you think we should be doing statutory changes?

MAUREEN HENRY: So I think it's a mixed bag. One of the things that I find in the medical arena that is just perplexing is how often doctors think they're not allowed to talk to patients who have surrogates. So there's this view that if there's a court appointed guardian, when I say, well, you talk to the patient, and they say, but there's a guardian. And I say, there's nothing that says you can't still talk to the patient.

So sometimes I feel like there's a tension between so legalizing this that people start to think if the law doesn't say you can do it, there's an assumption that you can't. So that's a concern that I have about it.

I do think that it helps to have some decision making structures out there, but I also think that we want to continually reinforce the message that there is no prohibition against supported decision making now, even though there seems to be a perception that there is. So I don't know, Jonathan, if you have...

JONATHAN MARTINIS: Yeah. There is no prohibition of supported decision making except no one knows what it is. I have gotten my greatest results from doctors by showing them law and saying, this is what you've got to do and if you don't do it, I'm going to sue you.

I'm roughly that subtle.

But the reason for including supported decision making in law I think far outweighs the risks, and I think the risks can be dealt with through supported decision making agreements. I just began drafting a statute on model supported decision making agreement that includes language like, "You may speak with my supporter as well as me." And I think in the model supported decision making methodology, the supporter is with the person, not instead of the person. So the doctor speaks to both, primarily toward the person, but also the person helps the person understand and make the decisions they need to make. And the agreement spells that out.

>> Please share those documents as soon as you can.

JONATHAN MARTINIS: Very happy to.

PETER BLANCK: Jenny Hatch Justice Project. That's where it will be.

>> Larry Berger. I'm sure you know that many people with intellectual disabilities do not like to go to meetings about themselves. Especially because, for two main reasons that I've observed, one is that they often turn into meetings about negative behavior of some kind that the person has done, and second, because these meetings turn out to be as they are now, amazingly bureaucratic. And, you know, we have 45 minutes and we have to get the form filled out and that kind of thing.

So I just wanted to say that I think the idea of starting in the third grade, not when somebody is 14, really starting early, is extremely important.

The other comment I have is I represent right now fortunately there's no legal issues because this was a gentleman who was in a developmental center and now he's out in a good supported group home, small group home, but he has had a guardian, his mother, for 12 years. And that really saved his life because at a time when he was so depressed about what was happening to him that he literally stayed in his bed all day and wouldn't come out, she was able to advocate for him. And she also has always tried to act for him even though she was formally his guardian like a supporter, somebody who tried to find out from him what he wanted and to express that to other people. So there are guardians out there, you know, the legal structure ought to be changed, I agree, but under the current structure there are sometimes guardians who are trying to do the right thing. So sometimes we need to be able to support those guardians as well.

MARC MAURER: Mr. Chairman, one other observation.

PETER BLANCK: Please.

MARC MAURER: I come to this thought -- this is new for me. Which is to say, when there's a meeting about an individual and there are meetings about us, we get staffed all the time. I don't get staffed anymore I don't think, but most blind people along the way get staffed. And when decisions are made about a blind person in school or in the rehabilitation system, take a friend. Take somebody with you. Because the system is always the same, which is to say, the guys who do this all day long come, and there are several of them, and then you're there and there are several of them and one of you, and they don't say, let's vote on this, but the idea is, let's all decide together. You think one thing and we think the other thing; don't you think you ought to go with the majority?

Well, I very often don't think so.

So take a friend. Find somebody who is with you and has your best interests in mind. This is what we've about doing forever. I never called it supported decision making before, but I'm going to adopt the terminology; it will really help.

(Laughter.)

And I'll say, you know, this is in law now. But take somebody with you. And I've got a much better -- the chances for success for your side of the argument go dramatically up when this happens. We have an organization to provide friends. The National Association of the Deaf I hope does this too and I think it does. Maybe there are some others. But one of the things we need to do is get enough people who know what's going on out there to have friends for everybody who needs to have them in these staffing meetings.

PETER BLANCK: Very important observation. And Jonathan, maybe you want to talk about this unless we're running out of time. The next generation of these cases is calls from parents who don't want to be guardians for their children, they want them to fly free, but they're required by state systems to be guardians so the children can receive services from that state system. So you have these other perverse incentives. I don't want to give away too much, but that's the next case.

JONATHAN MARTINIS: That is the next case. But to your questions, it's very nice to meet you; we've spoken on the phone before.

One, I don't think guardianship is evil. It's neither good nor evil; it's a tool. Use the tool the right way for the right job and things get fixed. Use it the wrong way and you can get hurt. So everyone you look at as an individual.

There are many guardians who actually practice supported decision making whether they know it or not.

We will be bringing a case in the very near future on one exactly like that, where parents were pushed into the guardianship system and they do not wish to be. And it is significantly harder to get out than in. And we hope that will be the next one for the Jenny Hatch Justice Project.

I think you're correct about people not wanting to go to meetings, and that is why we call for a complete change in the way things are done. Things are done to and for people with disabilities. It becomes bureaucratic. It becomes "sign here" so we can say we're done. We need to change that from a young age. That's why it needs to be supported decision making through the spheres. If the teachers buy in in elementary school, it will be so much easier for the ones in high school and transition. And later the VR counselors and later the doctors. Supported decision making is not the latest concept; it is a new way of doing things that respects people with disabilities rights to do the very things that we do every day.

MARC MAURER: I want to thank everybody who came. Maureen Henry and Jonathan Martinis and Peter Blanck, thank you for your participation in the program. Excellent point of view, it seems to me.

(Applause.)

We have coffee and then we will be doing the workshops. We have bias in the courtroom and accommodation of pregnant workers with disabilities and how to maximize compensatory damages in a disability discrimination case and FCC update on technology issues. And there's one other which is implementation of the CRPD, a status report.

We'll be back here, we have a break after those workshops for 15 minutes and we'll be back here at 11:15.

(Break.)

"Federal Communications Commission Update on Technology Issues"

10:00 a.m.

KAREN PELTZ STRAUSS: We're talking about how we're competing against one of the workshops on damages.

ROBYN POWELL: Cookies are good.

KAREN PELTZ STRAUSS: Yes.

>> Should we go make an announcement? That we aren't doing damages, but we can get you cookies.

KAREN PELTZ STRAUSS: Immediate gratification, yes.

Okay. I think I'm going to start. Thank you for coming to our session is. Is this on? I guess so.

So what we're going to do today is give you an overview of what we're doing in the Federal Communications Commission. Some of you may be familiar with some of the things we do, but we thought it would be helpful for the population that attends this conference to understand the kind of services that are provided through our programs in case you have clients who have needs, individual communication needs, that could be addressed by these services.

A lot of times people don't connect communications with other aspects of life. But in fact if we dependent have access to the telephone and television, we would be cut off to, as you know now, from employment, education, civic affairs, recreation, marketplace, virtually everything, especially with the internet. If you do not have access to the internet, you do not have access to a multitude of services by which you need -- through which you need to connect to achieve your independence, which seems to be a common theme throughout a lot of this conference this year.

Market forces, however, have not been alone sufficient to address the communications needs of people with disabilities. So, for example, a lot of times Congress is hesitant to adopt laws in the field of telecommunications, except that if you look at the population of people with disabilities, while together it's a very large population, if you divide up people by their deafness, blindness, cognitive disabilities, mobility disabilities, the population itself is generally not large enough to push the market to develop products that are accessible and that's the reason laws are needed. Generally they're also lower incomes and the need for adaptive devices.

So unfortunately, new technologies in the past created gaps for people with disabilities and the government has had to step in. That's worked in our favor. I'm at the FCC now but for many years I was on the outside as an advocate, trying to get laws in a generally deregulatory environment. We were fortunate to say, look, the market is not addressing these needs, so you have to address them for us.

So as an example of the fact that technologies often come about without taking into consideration these needs, in the mid '90s digital telephones came about and everyone got rid of their analogue phones, those big massive clunky things and got these new thinner cheaper phones that you could get with bundles not even having to buy the phone. But for people with hearing aids, those phones were not accessible to them. So they had to wait another decade. Literally a decade before rules went into effect in 2005 that could be hearing aid compatible.

Another great example are computers. When they first came about, they were fairly screen reader capable. But then graphics started coming about. And so that again created a new barrier. And as these technologies came about, no one was thinking in the development arena, the design engineers, disability was not on their mind. So they were just creating for the masses without considering people with disabilities.

Same thing happened with digital television. Digital television is great. HDTVs, greater sound, better vision, you know, clearer picture. But so many problems. I mentioned here captioning, but not only captioning, the lack of user interfaces. Flat screens, you cannot access a flat screen, access programs, record programs, change the channel, if you're blind.

Also, there were massive problems with captions. Captions were not integrated properly when DTV came about. Captions would block the entire screen or go too fast or too small. So many different problems. Most of the captioning problems have resolved themselves, and we'll talk a little bit later about the user interfaces which are now also addressed by new laws.

And timely, closed captioning. Generally we had a law in 1990 requiring all television sets with screens larger than 13 inches which I'll mention a little bit later, to be capable of showing captions. But what happened at the turn of the century, all of a sudden we had -- oh, and by the way, that law passed in 1990. The reason we went with television sets larger than 13 inches is because at that time I think it was 96% of televisions had at least screens of 13 inches or larger. But at the turn of the century, suddenly we started having these new devices start coming out. You know, everything from smaller laptops to cell phones to tablets. All shapes, all sizes. And we had a law that didn't cover any of those. So we had to go back to congress and ask for a new law to cover all these different devices.

So this slide -- and by the way, if anyone wants these slides, I don't know if NFB will make them available, but we can do that. They're kind of comprehensive. We probably won't go into detail. But this slide gives you an overview of the various communication accessibility laws that were passed by Congress in the '70s through -- well, from 1973 to 1996. The Rehabilitation Act has section 508 which requires electronic information and communications technologies acquired and provided by the federal government to be accessible. There was the Hearing Aid Compatibility Act in 1988 requiring hearing aid access to telephones. The Telecommunications Accessibility Enhancement Act of 1988 created a federal relay system. The ADA required relay systems by all common carriers. It also required access to emergency services for people who use TTYs. I already mentioned the 1990 decoder circuitry act. And in 1996 we got the closed captioning rules and also section 255.

Oh, let me just preface this by saying, wipe everything from your mind about the sections you're used to talking about in this conference like Title II. We're going to start throwing around new titles because we are in the communications sphere and we'll explain a little bit more about that later.

But the critical component of the 1996 act, as I mentioned, was requirements for closed captioning on television. The broadest anywhere in the world. And also requirements for telecommunications equipment and services to be accessible to people with disabilities. Telephones, fax machines, anything used over the public switch telephone network.

But what we found is that at the turn of the century, all of these laws that we worked so hard to achieve were outdated. Most of us had already been working at that point for 20 or 25 years. We were ready to retire, ready to go to the Bahamas and sit in the sun. And then something called the internet happened. We were like, oh, no, we are not done. We have to go back to Congress and fix this because all of these laws dealt with legacy technologies, analogue technologies, land line technologies. And now we had the internet with digital technologies, wireless technologies. And we still had some is gaps. We didn't have requirements for video description, we didn't have requirements for access to television by people who are blind and visually impaired. We again had limited capability of closed captioning. I mentioned we only had the 13-inch screens. We wanted captioning on all kinds of devices. We didn't have anything anywhere in the laws specifically covering people who are deafblind.

So what did we do? We formed a coalition. And again this was before I was at the FCC. We worked with various organizations around the country. And we decided we needed a new law. We started in 2007. What was fascinating was that when we first started, we started with ten organizations. Within around two weeks, we had thirty organizations. Within four weeks, we had like fifty organizations and it just completely snowballed. Within a few months we had 300 organizations, state, regional, and national. And we realized that we had hit a nerve, that the only thing worse than not having access to begin with is having access and then losing it. That's what was happening here. People who were accustomed to access in the laws we had gotten in the '70s to '90s were starting to lose it because television shows were going to the internet that weren't captioned. Hearing aid compatibility I mentioned. New technologies, communications technologies, were making phones that were no longer hearing aid compatible that had to be in the '80s and '90s. Again, computer access was being lost. New communications methods were being created over the internet that weren't accessible.

So we got the CVAA, affectionately known as the 21st Century Communications and Video Accessibility Act signed by President Obama in 2010, ensuring that people with disabilities are not left behind as innovations emerge. It makes sure that prior laws that focused on technologies were aligned and it fills in many gaps not covered by existing disability laws.

Over the past three and a half years, the FCC adopted approximately ten different sets of rules and orders implementing the law. I'm really proud of the FCC on this. We had people working throughout the agency. We have a Disability Rights Office that Elaine is part of. I'm part of the consumer governmental affairs bureau front office that helps oversee the Disability Rights Office. But we were not the only ones doing this. People from all over the agency, in all different bureaus. At one point I counted around 100 different people working on this piece of legislation. We met every single deadline, which we had put into the law and cursed at ourselves for having done this, many long weekends and evenings. We met every deadline except for one. You can probably guess when that one occurred. During the federal shutdown, we were in our respective houses and watched that day go by and we were like how could we have missed this deadline! But within a few weeks afterwards we met that very last deadline too for user interfaces or video devices. So I like to say we met all the deadlines that we could have met.

There were some areas of the law that didn't have deadline so we're still working on those.

So again, throw out your titles because we're going to be talking about new titles now. Title I here means Title I of the CVAA.

ELAINE GARDNER: I made her add the CVAA here so people wouldn't think we're talking about employment.

KAREN PELTZ STRAUSS: Our Title I is advanced communications, voiceover internet telephone service, SMS, email, texting, IM, videoconferences which actually isn't yet covered since it's only interoperable videoconferencing and there isn't any yet. You can't use Skype to call FaceTime, but that word was thrown in at the 11th hour by somebody in industry and basically eviscerated the whole provision for us. Long story. Bottom line, email, texting, SMS, all has to be accessible.

It also has to be usable. If you provide customer service or material about how to use the phone, that all has to be accessible.

I mentioned section 255 earlier, the telecommunications has to be accessible. That's if readily achievable. Bad standard for communications. We had wanted undue burden. Which is an easier standard to meet. Readily achievable means I think it's without significant difficulty or expense.

ELAINE GARDNER: Cheap and easy.

KAREN PELTZ STRAUSS: I'm mixing them up because we hardly ever even use it anymore. But bottom line, yes, it has to be cheap and easy and it was just too hard a standard. So we got it changed. Now actually the burden also shifted so you have to provide access now unless it's not achievable. And if you can't provide access, then you have to make your products or services compatible with equipment that is commonly used by people with disabilities, things like TTYs and other assistive technology.

In this law, industry has flexibility. This is actually different than what 255 had. 255 basically said that you have to make sure every single product and service you put out is accessible to people with disabilities, and the product itself had to be designed with accessibility.

The world has changed. We acknowledge that. There's something called apps now. And if you can do it through software, if you could do it through an adjunct device, go right ahead. There was a lot of resistance to that years ago, but now it makes sense. But you have to be able to provide the app at a minimal cost and also be able to support that app. So if you're not building it in, you have to make sure it's easy for people to access that app as they would for the device itself.

So this slide just goes through the accessibility components, the not achievable, everything I just said about compatibility and usability.

There's also a separate section in the CVAA that specifically requires internet browsers on mobile phones to be accessible to people who are blind or visually impaired. This basically means when you're entering a URL, activating home, back, forward, refresh, zooming, anything you need to do to interface with an internet browser. So what is the difference between, why do we have this separate section? Because this was so important to the blind community that we separated it out. But it's also very important to understand that this covers internet browsers for all purposes, while the other parts of Title I only covers access for communication purposes. So if you have a computer and you're trying to access, if you're a person with a disability and you're accessing the internet browser and if it's not a mobile phone, then you have to be able to access the internet browser to communicate with somebody, like email.

Here, if you want to access the internet browser on a mobile phone to access a website, you have to be able to do it. So this is a broader scope but a more limited population.

Again, industry has some flexibility to incorporate access into the device itself or to use third party apps. I said before, I misspoke. I said minimal cost. It's nominal cost. There's no requirement to make the apps themselves accessible. Unless it's the app used to access the browser, for example. But no requirement for other apps.

Both of these sections, this one is section 718 of the communications act. The other one I was just talking about is 716. They both took effect on October 8th. We are very pleased with the progress we've seen industry make. We are very, very pleased. We've never seen more buy in to a communications law other that maybe some of the captioning laws, as we have to this. 255 was not well received is and was basically ignored. I think there are reason there's law has been listened to more.

Every now and then we get asked for a waiver of our rules. This year we were asked to waive the requirements of the 716, which are access to advanced communication services for E-readers. This was tough because there is a waiver process that basically says that if you are providing advanced communications services in a device but it's not the primary -- it wasn't primarily designed for such services, you can get a waiver. The E-readers that were brought to our attention are not like the Kindle Fire or the more advanced E-readers that have regular capability to access the internet. These were the simple, basic E-readers. The case presented to us that we needed presented to us to decide in the consumers' favor was that these were being used as methods of communication over the internet. And it was a hard case. I see some people in the audience who visited the FCC on a number of cases. It was a hard case to make, because frankly it wasn't that easy to access these devices. Definitely not intuitive for somebody like me. Even though I work in this field, it takes me awhile to figure out technology. So we were torn between what to do because we wanted to reach a fair result and reach a legal result that was sustainable.

So what we ruled was a one-year waiver, because they're not accessible now and if they weren't, that would have been immediate violations. So we said you have one year to get these in shape. It's qualified to being limited to devices -- actually, Elaine, is in your slide? You were supposed to present this.

ELAINE GARDNER: No, no, no. We changed that.

KAREN PELTZ STRAUSS: We have purple and red coding.

ELAINE GARDNER: It's yours. It's a red slide.

KAREN PELTZ STRAUSS: Anyway, if the devices have no LCD screen, they don't have a camera, they're not offered or shipped to consumer was built in email, IM, VOIP, or other similar applications, and the device manufacturer doesn't develop advanced communications applications for them and they are marketed to consumers as reading devices. This was important. How were they promoted to consumers? We did a lot of work on the web ourselves and a lot of these devices lean toward use this as a reading device, not as a communications device. And if they don't have the capability to access ACS, then they can be excluded.

So it's a very narrow waiver. It's for one year. And I just want to say, and I think you do the next slide, right? I'm sorry. We're like working this out now. Right? Or do I?

ELAINE GARDNER: It's red.

KAREN PELTZ STRAUSS: Okay. I'm wondering if we have -- whether the correct one was entered. Because this is purple. We're airing our dirty laundry right in front of you. I'll finish up this section.

But anyway, so the bottom line is I wanted to just mention to that you one of the reasons this result was reached was because of our chairman. And I have to say a few things very positive about him. Chairman Wheeler has made much progress already in the four months he's been here and the result we reached was in large part because of him.

I also want to mention on this next slide that the industry also I mentioned that section 716 requiring access to advanced communication services is working much better than 255. And one of the reasons I think is because of the accountability measures that were put into the law that was drafted into the law before it got enacted. Specifically there were requirements to keep records. So if you're of drafting legislation, good idea to require a record keeping requirement because they have to be accountable. They have to put down in writing and keep records in case there's an enforcement action against them of the accessibility and compatible features that they are including in their devices and their efforts to consult people with disabilities.

They also have to certify their record keeping to us and provide contact information. And we have to submit reports to Congress every two years.

ELAINE GARDNER: Hi, I'm Elaine Gardner. I want to say before I get started, I've only been at the FCC for one year so I will turn to Karen quite often.

But I have to say, when I was a kid and I was thinking about the future, I thought about changes that would happen in my lifetime. And I think all the changes I thought of were maybe like transportation, being able to teleport, commuting to the moon. But transportation is pretty much the same as ever.

But communication, big changes. Communications changes just in the last ten years have been phenomenal when you think about mobile phones and how important they are in our lives and the internet.

The FCC is doing a really good job on keeping people with disabilities in the future and not, you know, letting the future pass by. I'm very impressed with the FCC and I'm very excited about the field of communications. When I was not at the FCC, I didn't know all these things that the FCC was doing, the CVAA, and I bet a lot of you don't either. It's an exciting field important for disability lawyers to know about.

The CVAA, there was no private right of action. I should say that. So if you want to leave for the next workshop right now.

But there was a very active dispute resolution enforcement mechanism. It's pretty easy for the consumer. The consumer actually gets call backs. Very consumer friendly. So if the consumer has a problem, they can contact the FCC and the FCC will work with them to either resolve the problem or take it up the next notch. And if it does go to enforcement, it's a very active enforcement mechanism as well. So I think it's a good tool for dispute resolution. And I think it works real well.

I'm going to talk about relay. I know that all of you know basically about relay. I won't go into what relay does.

I do hope you know that everything that you say to a deaf or speech impaired person through relay is confidential. So you don't have to ever think that the communications assistant can of repeat anything or even be subpoenaed to repeat anything that was said through relay. That's a big part of the law.

You know, when Karen and I first started out, relay was kind of voluntary. It was not required. Now the law is, since at least the ADA, the law is that relay has to be provided 24 hours a day.

When the ADA was passed, it was really only one kind of relay, and that was TTY relay. That's really changed a lot. There's a lot of different kinds of relay now.

Some is of them are, IP relay, which is kind of like TTY in that it's text but it's over the internet.

Video relay services is the kind if you have deaf clients you probably use most frequently.

There's speech to speech services. This is the kind I really didn't know about. If you have a client with a speech impairment, they can call this relay service and there's a CA, a communications assistant, who is trained to understand people with speech impairments better than other people can understand them. And so they work with that person and they do the speech for that person, where the person listens for themselves of course if they can. It works really nicely. It's a very, very important tool.

Starting back more than a decade ago there was ability to reach relay through 711. You're probably all familiar with that.

There's now Spanish relay services.

Captioned telephone services.

Oh. Video relay I didn't talk about very much. I think that most of you who have deaf clients know about video relay services. I hope you do. It is a way that you can talk to your client through a sign language interpreter. It's just as easy as making a phone call. You call their phone number, and they have a regular phone number. But when you call it, you get the CA, who calls -- you use that CA to talk to your client. So you hear what the CA says and your client is signing.

The beauty of that is that a lot of people born deaf, grow up deaf, their first language is ASL. So they're able for the first time to communicate via telephone in their native language.

I put this slide in because I think it's very important for lawyers to know this. As lawyers representing deaf people, you use video relay service to communicate with your client by telephone. It's important that you understand the difference between video remote interpreting, VRI, and video relay services, VRS. You'll notice that defendants or places your client is trying to reach will conflate these two.

VRS is funded federally, paid to make sure that telecommunications services are functionally equivalent for people with disabilities. It's not to be used by a hospital to communicate with their patients. That's not the purpose of this. This is a telephone service.

VRI on the other hand is an interpreting service that you use a remote interpreter to pull in some communications fast and easy like in a hospital emergency room. The deaf person and the hearing person communicating are in the same room. They pull in a video screen with the interpreter and the interpreter is off site and that's the way the communication is done. I won't talk about the limitations of VRI; that's a whole different workshop. But VRI has a function. It's great to be used.

But it should not be used -- VRS should not be used instead of VRI because it's against the law. You're not supposed to use VRS to save money. You see places doing this. You see police doing this. Don't do it. Any questions about that? Because that's like pretty basic.

>> Does anyone enforce that law? People misusing it?

KAREN PELTZ STRAUSS: There's no question that we've enforced it when we've found it. It's hard to find. But we have penalized people for doing that.

ELAINE GARDNER: I know prisons that do that. There's misuse of that. That's why I wanted to talk about that.

This is the slide on speech to speech relay. This is phenomenal. I did not know this as a private practitioner. I think it's so cool. Very, very good service.

Captioned telephone service is another one I didn't know a lot about. A lot of my clients, frankly, could really use this, especially the inmates. They don't know about this because they didn't have captioned telephone service when they went in. It's for people who have some hearing loss but still have some hearing and use their own voice to communicate. So they can use the telephone and still hear on this special equipment that you have to have for it. You can hear the other person's voice but also you have captions to help supplement your hearing. It's not done through -- I would have thought when I first heard about it that it was all done through the wonders of technology. Not so much. It's done through a communications assistant, a real person is there creating the text. So it's an expensive service. Again, this is funded by the federal TRS fund and should only of course be used by people who really need it, but it's a fabulous service for those people.

>> Just a quick question. I use that to communicate with clients, but we all know that captioning can make significant mistakes. It really depends on the quality of the captioner. How is there any assurance that what you're saying is, in fact, what is being captioned?

ELAINE GARDNER: I would say, first, any time you're using any mode to communicate with a client, whether interpreters, sign language interpreter, whatever, you ask a question to make sure that what you're saying is understood. But you're right. Of course you're going through another process, and you're not sure.

KAREN PELTZ STRAUSS: We have a current proceeding to actually look. I don't know if this is on or not. We have an ongoing proceeding to look at some of the quality issues. There is some quality assurance done by the companies. We have heard complaints. Unfortunately, it's mostly complaint driven.

ELAINE GARDNER: Some of the complaints are not so much inaccuracies as much as information dropped. Like one guy said he called and made the same phone call through two different services. It was a recipe. So he said, we're going to have is a salad with braised chicken and this and that. So through the one service, he got salad with braised chicken and tomatoes own the other service said salad. Details were dropped.

KAREN PELTZ STRAUSS: What he was doing was illegal, using two separate services at the same time so we're getting double billed. So he couldn't tell us he did that, but his comment prompted us to put this in a proceeding so we are looking at it now. We're not doing anything to him, no.

ELAINE GARDNER: Now, the CVAA was really important. It created some important changes in the relay service program. First, it required VOIP companies to also contribute to the TRS fund, a funding thing but it was important because more and more we're going to voiceover internet protocol.

It updated the service to include people who are deafblind. And also to permit calls using multiple forms of relay services, which is really important. I've had clients arrested and put in jail and the little regional jail all they had was a TTY machine. My clients were old enough to know what that was but if they wanted to call their wife who only has a video phone at home, how can they make a call from a TTY to a video phone, two different kinds of relay? In the old days you couldn't do it. Now you can. You can make a call from a TTY to a VP through two different relay services, connecting. You hate to think possibly maybe the communication isn't quite as good, but at least you can make that connection, which is important.

The National Deafblind Equipment Distribution Program was also launched as a result of the CVAA. And this is so important. For the first time, this really makes telephone communications somewhat accessible to people who are deafblind. Fabulous. Just incredibly, incredible technology, making people who have vision loss and hearing loss able to use the telephone. Many different ways because everybody is different. Everybody has a different degree of hearing loss and/or vision loss, but it works with each person to see what is the best technology for that person. We're talking about refreshable Braille, all kinds of different kinds of really interesting technology that is actually making such a big difference for these people.

>> About the distribution groups, how are those groups chosen and why do they suddenly stop participating?

KAREN PELTZ STRAUSS: We asked for public notices, asking for applications back in 2012. We received applications from a lot of different entities over the country. We chose them based on their expertise, their experience with the deafblind community, their knowledge of communications. But many of them are tiny. Like two and three people. And the administrative aspects of the program were just too great for them or they didn't give the program the time needed to put in. So we have been saddened by the fact that we've had about four or five entities say that they can no longer continue. It's not a lot of money. $10 million isn't a lot when you spread it across 53 programs, so they just couldn't make it.

So the Perkins School for the Blind in Boston has been great and they have picked up a lot of these programs. They're actually running I don't know how many right now but they're running quite a lot of them. And they have the capability on a mass scale to be able to handle it. But we're disappointed. Very disappointed. These local entities haven't been able to do it because ever financial difficulties.

>> I have another question. It may be a little off topic but before we get too far away from relays, awhile back I had read there was international -- I'll just say abuse of the relay system in order to kind of perpetuate scams or whatever.

KAREN PELTZ STRAUSS: So again, we're saddened at the fact that a program for assisting communication has been abused. We've had fraud in every kind of relay. We call it Whac-A-Mole. It seems anytime you have federal dollars, entities are trying to scam. You're talking about fraud of IP relay. There were Nigerian scams to call retail establishments in the United States and order mega amounts of products through the relay and scam the system through a way that could not be traced.

We've taken extraordinary measures to cut back on that relay, eliminate 90% of the registrants to this program and have a very comprehensive verification process for users now. So we think we have a handle on it now, but we have a team of people in our enforcement bureau and our IG's office actively working on these issues. Literally right now, as we speak, they are working on these issues. It's unfortunate. AT&T has pulled out, Sorenson has pulled out, Hamilton too. Three of the main relay providers in this field. Two of those, AT&T and Sorenson, were subject to major -- one entered into a consent decree having to pay back $20 million, and another company is up with the chairman's office now, another company that's also being asked to pay back millions of dollars.

ELAINE GARDNER: And that was just IP relay. There's other kinds of frauds in the other relays but they don't impact the retailers. They impact the TRS fund. They're ripping off the TRS fund rather than retailers. But those have been addressed as well.

>> Thank you. I just found that to be an interesting subject area, enforcement.

ELAINE GARDNER: It's kind of like -- it's never the same fraud. You have to think ahead of the fraudsters, because every year there's a new scam. You have to try to outsmart them.

>> I was told that Sorenson is going out of business.

KAREN PELTZ STRAUSS: They have reorganized. They went bankrupt. I can speak to you individually about it. We lowered the rate, they had debt, we took actions to try to get captioned telephone program under control. And they decided to reorganize. But they are nowhere -- they are not leaving the business. Just yesterday we conditionally recertified them.

>> You guys mentioned the internet browsers on mobile devices being accessible. That was October 8th? So she should be theoretically accessible now?

KAREN PELTZ STRAUSS: They should be and if they're not, we need to know about it through the request for dispute assistance process.

I want to add one thing. Elaine said, enforcement, what happens, if you bring the dispute to us, it has to be a request for dispute assistance before a formal complaint. But there's 30 days to resolve it. And the individual bringing the complaint can renew that 30 days in 30-day increments, but after the initial 30 days the consumer can say, I'm done with this company, we can't work it out, I want to go to informal complaint.

Once it goes there, it goes to the enforcement bureau and they must issue an order within 180 days. This is critical. We didn't have this process for 255 and complaints lingered on and on without resolution.

The 180-day deadline is scary to the industry. They know they have to have their act together because at that point, the enforcement bureau can start imposing remedies up to $100,000 per day for each continuing violation for a maximum of $1 million. So there's a real threat there. That's actually the second half of the threat. It's the record keeping on the one side that's kind of the carrot and then there's the enforcement forfeiture actions that are the stick. And that is why we think the law is generally working. There may be holes but we've only gotten around 10 or 11 requests for dispute assistance and none have gone to informal complaint yet.

>> So if a university is using a system that's not accessible, it would fall under this?

KAREN PELTZ STRAUSS: No question. Universities are covered under this law.

ELAINE GARDNER: As well as under the ADA. Or Title III. But yes.

>> Just quickly going back to the million dollar limits. For manufacturers of browsers, that sounds like just a drop in the bucket. You can make a business decision to pay the million and move on.

KAREN PELTZ STRAUSS: It's still a million dollars. It may be small compared to what Apple earns in any given minute --

(Laughter.)

-- but it's still a million dollars. You could bring in a case and someone next to you bring in this other one. It can add up.

When our enforcement bureau gets involved, we have found that companies listen. They don't want to pay a dime if they don't have to.

>> So the instances adding up for one million, that's one individual?

KAREN PELTZ STRAUSS: This hasn't come up, but if it's the same exact device, I'm not sure. But chances are there would be ways to multiply the fine. But it hasn't come up. As I said, we have not yet received a single informal complaint. They've all been resolved beforehand.

In the past, a lot of times people got a different plan or different phone and I guess some of that is happening now.

ELAINE GARDNER: Yeah. People get a phone and it's not accessible, so they just you go to an iPhone.

KAREN PELTZ STRAUSS: But at least they're getting iPhones for the same price they would have gotten a feature phone. We have jumped over the feature phones, the flip top phones. They're not accessible and still aren't. What's happening now is companies are giving out Smartphones.

ELAINE GARDNER: That's the problem we see still. Sometimes people just don't want a Smartphone.

>> You can still get flip phones for much smaller.

ELAINE GARDNER: The data plans are cheaper. They're giving them away.

KAREN PELTZ STRAUSS: If a company says to us we want to settle by giving a smart phone, they have to give the data plan at a lower price. So people take it. Like I said, we're jumping over the feature phones, which wasn't supposed to happen, but if that's what people want, that's fine.

>> Does the FCC have any authority over noncommunication for the end recipients of relay calls?

KAREN PELTZ STRAUSS: No. Not the end recipients.

ELAINE GARDNER: Do you mean liking whether they'll accept the call?

KAREN PELTZ STRAUSS: No.

ELAINE GARDNER: That's a Title II or III thing or whatever. That's like Max Sharmack's case.

This is just a slide about how to get in touch with the National Deafblind Equipment Distribution Program.

911. Big changes here. Back in the '90s, 911 was easy because what we fought for for deaf people was to make every entity that took 911 calls have a bank of TTYs so they could take a direct call. Because it's important to be able to get a direct call from 911. You don't want to go through relay.

Well, TTYs as you probably know, no one uses them anymore. So for quite a few years people have had to go through relay to contact 911. The next generation relay, what the FCC is striving for is to have 911 that can accept texts. Now, why is this important? Of course it could be very important for deaf people. It's very important for young people because young people, they can't even imagine there's something that doesn't accept a text. They don't even get that. You can text anybody. So they would naturally use text to 911 because it doesn't even occur to them that you couldn't.

Also in a lot of situations, text to 911 is critically important. In a domestic abuse situation or hostage situation. You can think of, just use your imagination how important this would be.

The FCC has issued rules to -- well, first, is going through a proceeding to try to roll out text to 911. There's already four telephone providers, mobile phone providers, who enable text to 911. The next step is that places who take the calls have to be enabled for this. There is a voluntary commitment to roll out by all major providers by May of this year. And right now there is a rule that the places that take 911 calls will have to have -- or rather the carriers have to have bounce back message. So if do you text to 911 in an area that doesn't take to 911 calls, there's a bounce back message that says your message did not go through.

But the next step is the 911 entities themselves having the capability of accepting 911 calls through text. Does the FCC have jurisdiction over that? No. No. That's a Title II issue.

KAREN PELTZ STRAUSS: Of ADA.

ELAINE GARDNER: Right.

KAREN PELTZ STRAUSS: Department of Justice has an open proceeding on it much they need to update their rules.

ELAINE GARDNER: Maybe some litigation? Just saying.

KAREN PELTZ STRAUSS: They're working with antiquated TTY rules. Nobody is using TTYs anymore except for a few people in rural communities that don't have broad band and some senior citizens that don't want to move to new technology. I think it's less than 10% of the population if that much. Literally we can tell from our TRS usage, it's going down, you know, a steep, steep decline. Not a slight decline. Almost vertical. I think it's under 10%.

You know what, I should probably cover the closed captioning. We have so much to cover. We really needed a whole day.

Let me just -- we only have like five minutes left. It's okay to take questions and to have this interaction.

We have an accessibility clearinghouse -- I'm going to go through these fast. But the accessibility clearinghouse is basically people can come and look in it and find accessible products.

The other like huge part of what we do is closed captioning. We're really proud of the fact that 100% of new programming if not exempt, which is small, must be closed captioned. In the year 2000 we required emergency information on television to be accessible to people who are deaf. And more recently in 2012 we implemented provisions of the CVAA requiring access to television once a television program has captioning on TV, when it's reshown on the internet, it now has to also have captions.

So that's basically the slide that I just mentioned.

We do have a couple of exemptions.

We're really proud also of some rules that we just adopted in February that were waiting for ten years. In 2004, deaf and hard of hearing organizations submitted a petition for quality standards because over the years the quality of closed captioning has declined because companies or producers try to save money and they don't pay as much more captioning as they probably need to. This is one of the reasons and I'm so enamored with our new chairman. When he came in, he said why is this proceeding sitting for ten years? We're going to get this done. And we thought, yeah, yeah, yeah, that's what they all say. And then we realized, no, he really meant it, and within four months we adopted very comprehensive requirements for quality. Captions have to be accurate, timed correctly, have to be complete, meaning chunked from the beginning to the end of the program, and placed accurately. And again, we're world leaders on this. A couple of other countries have had some -- do you have a question?

>> Yes. Access --

KAREN PELTZ STRAUSS: We don't have percentages. No percentages. Nonquantitative because we looked into percentages and it was just too difficult to assign.

>> We have companies doing a lousy job captioning.

KAREN PELTZ STRAUSS: This will be an evolution and it will probably be defined over time through complaints. But we have the rules in effect. And before we could not take complaints on quality. We had to turn them away. Now we can receive them.

So we provide some guidelines. I mean, we talk about how it basically has to track the audio track. The captions have to be -- and we also provide lots of examples. You know, you can't skip words. You have to use the proper acronyms, proper numbers, proper order of words. If there is swear words in a program, often captioners would drop the swear words. Breaking Bad. You know, I watch it with captions and it's like, what? This is really important. You know, for shows like that. The Wire. You know, etc. You don't get those swear words, you are missing a lot.

(Laughter.)

So things like that. They have to track.

So what we would want in complaints are videotapes to see. We'll watch it ourselves and see. The goal is being able to understand the program.

What we did say, however, is that there's different kinds of programs. There's prerecorded. If you have a prerecorded program, you have the opportunity to review and edit your captions. Meaning really it should be 100% accurate. We can't say 100% because people don't like when we regulate like that. So we basically said, we really mean it for prerecorded programming.

For live programming, we understand you can't review it or edit it. There will be some mistakes. But you still have to be able to understand the program and have a comparable viewing experience.

So near live programming. Late night TV shows. They're put together a few hours before they're aired. We're considering calling them live programming. But our definition includes anything performed or recorded within 24 hours of airing. We're not sure if that's the proper definition. We used it for some other laws that we adopted. Yeah.

>> So quality standards are just for programming then? Would it apply to the case of the client in jail?

KAREN PELTZ STRAUSS: They don't apply to captioned telephone. This is TV. When video programming goes on to the internet, the quality has to be as good as it was on TV.

So I mentioned you can file complaints. We also changed the rules for news programming. Realtime captioning of news programming, meaning word for word as it's being shown to the public, is only required for national broadcast networks and affiliates in the top 25 markets. And nonbroadcast networks, meaning cable and satellite services that are serving at least 50% of all homes.

Everybody else can use something called electronic news room technique. And that is basically using the teleprompter. They put the script in. So what happens if you script it and then you go out to the field during the program or you update the news and the weather and sports and it's not in the teleprompter? So for years everybody but the top 25 television markets basically the top cities, have had teleprompter created captions. It was a way of providing captions more cheaply initially. But the FCC had promised when it adopted these requirements in 1997 to review the rules and to eventually expand the number of markets that would have to have realtime captioning so that all news programming could be captioned.

Well, it didn't do that. We're in the year 2014 and it's the same 25 markets. So the consumers came to us and said, get rid of ENT. Move to realtime captioning. But the broadcast industry was adamantly opposed to this. They said their local newscasts hardly have money and they would be shut down if they had to caption. So they offered something else. Since the time that you issued your rules, we've changed what we can put in the teleprompter. Now we can put just about everything in and it only takes us a few seconds so that even if we're going to do an update, we can get that in fast.

But they haven't been. So what we did was we changed our rules to say, okay, you can keep using ENT if you were allowed to use it before. So if you're in the top 25, you can't start using it. But if you are allowed to use ENT, you have to make sure that all of these updates are also captioned. You have to get that into the teleprompter. If it's truly an on the field live, a traffic accident, you have to make an effort to provide crawls or other visual information to supplement what you have captioned through the teleprompter.

Will this work? A lot of people are skeptical. The deaf community was not happy with this compromise but they said, we will give it a try. Because there are problems with realtime captioning too. Realtime captioning, as I mentioned, you can't review it. And the biggest problem is the delay. Because a few seconds delay, that could cause problems for understanding.

The other problem is that when you have a delay and a program ends, sometimes you miss the end of the captions. So everybody said, okay, we'll give this a try. And the chairman came to one of our meetings and asked the consumers about it. It was great. And after a year we're going to reassess.

The law also requires technical compliance. So the video programming distributors have to make sure that their equipment is working, that they're passing through the captions, and we added a record keeping requirement on that. So we hope that that will work because a lot of the complaints that we receive are just because of technical snafus. You're watching a program with captions and some equipment wasn't up-to-date or a switch was touched. Record keeping.

We also in the same order, we just clarified a couple things. Our rules cover English and Spanish and bilingual programming.

And video on demand. That's covered as well.

Further notice, we asked for comments on a number of things. Part of the compromise and the way we got out the rules was we said that you can meet a lot of our quality standards by adopting best practices that we lay out in our rules. We provide a lot of flexibility this first time around, but we ask in the notice whether some of these best practices should actually become rules and not just best practices.

For example, I mention near live programming. There's a lot of -- even though near live programming, there's not a whole lot of time to review and edit the captions between the time that it's taped and the time that it's aired, there are things that a producer can do. They can give the captioning agency the script in advance, they can give them the taped show in advance. There are ways to provide the information in advance so that for example the captioning agency if they're going to do the captions live while it's actually being shown, they would at least have the proper names and other technical information that they might need they could insert into the computer. There could be fade outs at the end of programs for example where there are, you know, let's say I said there's a delay. If you have a fade out at the end instead of going straight to commercial, the captions can catch up. Of course that costs money and the industry doesn't want to lose those seconds. But we ask about it.

So I already mentioned IP captioning that CVAA requires. One of the things that we decided the first time around when we issued our rules was not to cover video clips. This was because of some legislative language. So only full length programming is covered currently in our rules, but there's a good expectation that this is going to be changed. The chairman has sent out signals that we'll probably issue an in order the coming months to cover clips. So in other words, think 60 minutes, daily show, they post clips on the web. There's a lawsuit against CNN in particular. Weather channel. When they're shown on TV and reshown on the internet, covering those. That's the issue here. We're looking at the situation and hopefully will come out with the right result.

Title II of the CVAA covers video devices as well. I mentioned before those user interfaces that have become so difficult to access because they're flat screens will have to be audio accessible. There also has to be an easier way to access the captioning. On my television set it takes about seven different steps to get captions, and I was really frustrated about that myself. The requirement from video devices to be accessible covers recording equipment and the cables that connect.

We also have rules in the CVAA that require video description. First time ever. We had had rules in the -- we had had a directive in -- well, let me back up. Those of us who were drafting the 1996 changes to the communications act put in requirements for video description which were taken out at the last minute. And unfortunately the FCC tried to adopt rules anyway and they were overturned. So we reinstated them. So I have been at the FCC when we drafted those rules. They were overturned when I left the FCC so we wrote a law putting them back in and then I came back and they came back in.

Video description is not as comprehensive as captioning. It's only required on the four national broadcast networks in the top 25 markets, though that will increase over time under the CVAA to eventually all markets. We may not be alive by then. It's like a 20-year schedule. It will eventually happen.

This was the hardest section. The hardest section to get passed through the CVAA of all the ones we got passed.

Covers the top five cable channels, History Channel, Disney, Nickelodeon, TNT, USA. It only requires right now four hours of prime time or children programming per week, but that will increase to seven hours about in a year or so. And we are actually conducting an inquiry now to expand these requirements.

So just really quickly, I mentioned before that in the year 2000, the FCC adopted rules requiring visual access for people who are deaf and hard of hearing to emergency programming. This is basically anything, you know, weather, tornadoes, terrorists, you have to provide emergency information that provides the critical details of what a person needs to respond to an emergency, including school closings.

However, the requirements for people who are blind, until the CVAA, only said that you have to -- if you're interrupting programming, you have to provide it in an aural form. Like it only required an aural tone. So basically if you're watching TV, you hear an aural tone. It was ridiculous. So the CVAA closed that gap and now there will be requirements. There's an implementation deadline that haven't occurred yet but over time within about a year or so you will have audio information through the secondary audio channel that tells you what the emergency is. So that's that.

Also, equipment. Just what I mentioned before. All kinds of equipment. Cell phones, laptops, everything must be able to pass through captions, must be able to convey the audio information required for video description and emergency programming.

So what's left? We still have some work to do. We have the video clips issue. The Access Board has been working on guidelines for section 508 and 255 most of our lifetime. I was on a committee like the prehistoric ages, I think it was 1996. I can't even remember anymore. That was the committee talking about the guidelines still not updated. We're waiting for those guidelines. They're close, right? They have another NPRM?

Okay. So we're waiting for those because if those are good, we think they are, we will then use them to update our 255 rules and our CVAA rules on advanced communications equipment. So stay tuned.

We have to update our hearing and compatibility rules for advanced communications services. Our National Deafblind Equipment Distribution Program is still in the pilot stage for the first three years so we have to adopt permanent rules on that.

Text to 911. Some of us want it to be realtime text. Right now it's just text.

And be we are undergoing a complete overhaul of our rules because IP communication is coming so there's a transition generally to IP and in addition to everything that we talked about today, we are heavily involved in that because the telephone lines, we're losing the PSTN. When we go to IP it raises all kinds of ramifications. Closed captions are passed through IP and there are problems. We have to be sure it's compatible with all kinds of relay services, we have to make sure the voice quality, Elaine is working on this, voice quality is okay. Because there's real discrepancies in voice quality. Sometimes it's great, sometimes it's worse. And TTYs. Oh, my God. Why bother supporting these anymore? Let's move to realtime text with modern technology. We're keeping this population in the dark ages.

We have our next biennial report to Congress April 2014. You may have heard we are cursing ourselves having to write this report every two years. But we did it at a time the FCC wasn't doing anything. Our next report is due in October.

We always update the accessibility clearinghouse. And we have some other FFPRMs.

So this is just a general future slide.

Leveling the playing field. It's good business sense. Everything that we just said expands markets. Apple has gotten it. They're great. They provide ubiquitous access to all forms.

(Left session at 11:11 to move to next session beginning at 11:15.)

"How to Work with the Media to Get the Disability Rights Message Across"

11:15 a.m.

MARC MAURER: Chris Danielsen has been working on this for some time. He tries to get the media to understand that rights are a part of the system dealing with disability as well as otherwise, and he has some ideas about how these rights are created and promoted because he's been in the legislature and also he is himself a lawyer.

He is a lawyer who is not necessarily unique but pretty close because he does know how to write.

(Laughter.)

Pardon me, Chris.

CHRIS DANIELSEN: That's quite all right.

MARC MAURER: Here is Chris Danielsen.

(Applause.)

CHRIS DANIELSEN: Thank you, everyone. This is always a fun conference for me because I get to put my lawyer hat back on for a couple of days anyway.

But now I'm presenting. And I hope what I have to say will be useful to you. I feel like what I have to say maybe be a little belaboring the obvious, but maybe it's useful.

So to start with, I hope you will indulge me as I read a brief passage of something to you. I think many of you have probably read it. But it goes like this:

"Waterloo, Iowa, a man stands at a bus stop. He wears blue jeans, cowboy boots, and a name tag pinned like a badge to his red shirt. It says, Clayton Berg, dishwasher, county sheriff's office. He has a scar on his right wrist. His backpack contains a jelly sandwich and a comforting pastry treat. The bus resumes him, moving herky jerky through the small town, population 68,000. He stares into the ordinarily life once so foreign to him.

"Mr. Berg comes from a different place. For more than 30 years, he and a few other men with intellectual disabilities affecting their reasoning and learning, lived in a dot of a place about 100 miles south of here. Every morning before dawn, they were sent to eviscerate turkeys at a processing plant in return for food, lodging, the occasional diversion, and $65 a month. For more than 30 years."

That repetition is the author's, by the way, not mine. That excerpt comes from a story called "The boys in the bunk house" penned by Dan Barry from The New York Times magazine appearing in March 2014. It is still on the web with a half hour video, telling the story of the men of Henry's Turkey service, who, as the author points out, worked for more than 30 years eviscerating turkeys in Iowa for meager wages and accommodations in an increasingly rundown and filthy bunk house. It reveals how the individual to which Mr. Barry just introduced us, Gene Berg, tried to escape the situation once and celebrated his newfound but ultimately short lived freedom by stuffing himself with his beloved honey buns while crouching in a roadside ditch.

It tells of how another man named Alfred Buzzby walked away in a snow storm because he was angry about being sent to his room like a child for some infraction or another that displeased his overseers and was found dead the next spring.

It tells how the townspeople believed or more accurately told themselves that these men had a good life, despite increasingly ominous warning signs like the withdrawal of the men in community events and a padlock and chain on the door of their converted dormitory.

Finally, it explains that when authorities were finally called to investigate the situation, they found a filthy, leaky bunk house where the men slept on moldy mattresses and ate with one hand covering their plates to keep roaches from dropping on to their food.

The National Federation of the Blind has also worked to tell the story of what happens to people with disabilities who toil in segregated subminimum wage employment. When the now defunct NBC program Rock Center with Brian Williams approached us on doing a segment on subminimum wages, we suggested that the producers talk with Harold and Sheila Leagland from Montana. To my knowledge, they spoke bravely and candidly about their experiences. Sheila, in particular, who is, by the way, a college graduate, spoke of her separation from a plant after returning from having knee surgery to learn that she would be restarted at a wage of 2.35 an hour for work that she could no longer do, standing up while sorting clothes by color and hanging them. The money she would have earned wouldn't even have paid for her to travel to and from the plant each day. So she quit.

Let me also take a moment here to thank the other advocates who participated in interviews for the Rock Center story. It was a great collaborative effort with some other folks. I don't know if any of them are here, but it was a good effort to work together.

Many of the other articles that have been written as a result of our efforts on the subminimum wage issue have outlined the policy debate surrounding this kind of, quote/unquote, employment, and some did so with reasonable perceptiveness and accuracy. Others not so much.

But few of them told a story, though in fairness, that is partly because many workers in these situations do not wish to discuss them for fear of job loss or other retaliation.

Mr. Barry tells a story. He introduces us to Gene Berg and others. He lets them talk about their lives before and after they came to the bunk house. We learn about the escape attempts, how some of the men taught the local two step before the townspeople stopped seeing them around as the abuse and isolation got worse.

Mr. Barry makes them real, not the subject of a policy debate. The debate is there, including a mention of President Obama's recent executive order including workers with disabilities employed by federal contractors and the new wage requirement of 10.10 an hour. But the focus is the men and what happened to them. The patronizing attitudes that their overseers and some of the townspeople held toward them are revealed. All those being interviewed probably didn't realize how what they said would sound.

In short, Mr. Barry tells the kind of story that I believe journalists want to tell, a story that will not only help people to understand an issue, but will move them probably to tears, possibly to outrage, and maybe even to action.

We might quibble with some of its terminology or characterizations, but its impact is clear. In the 271 comments left by readers on The New York Times website, the impact is clear. And that was just before they closed comments.

Comment sections are notorious for views that most of us wouldn't dare even whisper to a companion in the dead of night, including some about people with disabilities. But Henry's Turkey Service had few defenders. Quite a few commenters had the right message. One said, "What a warped sweet financial deal for Henry's Turkey Service in which these men are wages of $1,041 per month, but after deductions for food, lodging, incidentals, and occasional diversion, their take home pay was $65 a month with no raises for more than 30 years while Henry received $500,000 per year for services rendered."

I first heard about our theme keynote speaker Jenny Hatch, who moved all of us yesterday with her story of being abused and isolated, by a guardianship that took away her power to make her own decisions and live her own life, from an article that appeared in The Washington Post, written by my copanelist here today. I have little doubt that Jenny's story made what would seem an esoteric legal issue real to many Americans, and that it persuaded at least some that people with disabilities are capable of more than much of society believes.

Whenever I talk to journalists and try to explain that blind children are being denied Braille instruction, or that they struggle in higher education because of inaccessible technology, or regarding any other issue that the NFB cares about, I am almost invariably asked, who is affected? Can you point me to a person in my community? A student at my local college? Someone who is currently, I emphasize that, working for a sheltered workshop for pennies per hour?

Our most powerful press releases and pitches feature a story about an individual, not a procedural legislative move or our reaction to a policy pronouncement. Those get coverage, but it's usually not as good and not as frequent.

Last week we told the story of Anthony Lanzolatti, a student at a community college in Atlanta, who has been told that he is not allowed on campus without a sighted chaperone. And certainly not at any of the campus science labs. It's a fire hazard, you see.

The journalist dutifully covered our protest at the college campus, but the person they really wanted to speak to most was Anthony himself. Journalists want stories. They are not content to hear from paid spokesmen like me unless I can refer to my own personal experiences as a blind person, which is good because I am a blind person and I often can. But not always. I have never earned sub minimal wages. I was self employed once so I probably came close...

(Laughter.)

But this, the need of journalists for stories, it seems to me, is the great challenge and the great opportunity for those of us who want the struggles of Americans with disabilities to be trumpeted in the media. It is a challenge because the natural desire of human beings for privacy or to avoid potential retaliation or our concern that our stories will elicit the dreaded reaction of pity rather than the desired one of understanding sometimes make us reticent to speak about our experiences. It's a challenge for PR guys because we don't want to exploit or be perceived to exploit our brothers and sisters with whom we stand on the barricades. But I am coming to believe that it is our stories, properly told by us, with the help of those allies that we can find in the media that have the best chance of helping us not only change the law but to change the hearts and minds of members of the public.

As we help our brothers and sisters to overcome the challenges they faced, most of which are of course externally imposed by society, and not the result of the so-called disabling characteristics that they possess, and to live the lives they want, we also must seek those among them who will speak out as the men in Iowa, the Leglands, and Jenny Hatch have done. We must do this sensitively and with legitimate concerns. Sometimes we must negotiate to mask journalists' identities, but we must tell the stories.

A friend of mine who worked on legislative issues for us and may still be here, Jim McCarthy, are you still here? Well, anyway, Jim once told me that the most reliable predictor in his experience of whether of legislator would support our policy recommendations was whether he or she knew a blind person or another person with a disability. The sponsor of the Fair Wages for Workers with Disabilities Act, Congressman Greg Harper of Mississippi, has a son with Fragile X syndrome. He does not want to see his son, Livingston, consigned to a sheltered workshop earning pennies per hour. But most legislators, like most Americans, do not know or do not think that they know a person with a disability. We must use the media to the extent we can to help them come to know us.

That's my formal presentation, and I'm sure we'll have time for questions later. Thank you.

(Applause.)

MARC MAURER: Theresa Vargas is a reporter for the local enterprise team from The Washington Post. Her stories have taken her, among other places, into a home for transgender teens to a support group for those in wheelchairs or are who are using wheelchairs and who are survivors of gun violence.

She has been in a courtroom where a person with Down syndrome fought for the right to decide how she wanted to live.

During the peak of the recession, she and a photographer traveled across the country to record how Americans were coping.

Before she came to the Washington Post, she worked for Newsday in New York, and she has degrees from Stanford and Columbia.

Here is Theresa Vargas.

(Applause.)

THERESA VARGAS: I'm going to stand up since I'm short so I can see all of you.

Thank you for having me. I am going to be brief because I want to leave time for questions and I want you to be able to ask whatever you want so that you can get your messages out there. I know that it can sometimes be intimidating when you're dealing with this institution, whether be it a newspaper or an entire media organization and not knowing who to call and what to ask.

I'm glad my copanelist brought up Jenny. I know you all have heard from her. She is quite amazing. I'm sure she impressed everybody, as she impressed me right away.

So I got a phone call from Jonathan Martinis, who I think you've also heard from here. He had just called me out of the blue and told me about this case he was working on.

He had become aware that I had been working on another series of stories involving Ethan Say letter, who died being led out of a movie theater by deputies.

So Jonathan calls me about the fight Jenny was in with her parents and what was at stake, which is essentially her freedom to choose how she wanted to live. She knew exactly what she wants and exactly, you know, who she wanted to live that life with.

We talked. He told me about it. I talked with my editor about it. And I will tell you, this is say story that the Post didn't have to do. It wasn't directly in our backyard. It was a little distance away from Washington. It was one of those stories where we knew the local paper would cover it but we didn't think there were competitors for us. So we had to choose to do it, saying, as a paper, we think this story is worth the time. And this would take time. I would have to dig through documents, talk to the right people, and really put it in the context that all our readers would care.

So my first point, I just want to give you a few tips practically. My first point is, do your homework. The fact that you all heard newspapers are dying. I don't think we're quite dying, but we're definitely shrinking. So we don't -- you know, we may not have a staff member that actually covers that beat. For example, we used to have somebody who covered social issues and the welfare system. We no longer do.

So you have to find the right person. You have to find the person that will care about this story. You have to look at who has covered similar issues. You have to -- it could maybe be as easy as calling an organization, but if someone called the Post and said who might be interested in Jenny's story, the person answering the phone would have no idea. Jonathan did his homework. He knew who to call. He knew I would fight for this story with my editor. So there's that.

The second point is, you have to make me care, which Jonathan did. And when I say that, it's what are the broader implications. So with Jenny, as charming and compelling as she is, what struck me with her story was that anybody due to an accident or old age, any one of us out there could find ourselves in a guardianship battle fighting how we wanted to live. So I knew her story, playing out in a little courtroom far from D.C., you know, meant something. It would mean something to everybody. Anybody could relate.

And if there's no larger theme, then you have to find what is the most compelling aspect. Is it a person? My copanelist said, we love to hear stories. We need to humanize it that way. But if it's not a person, is it an irony? An injustice? What is it that sort of -- what is that string of humanity in that story that will make somebody who is not in that world, has no idea about that, make them care about it?

My final point is, once you have me, you know, once you've hooked me, you need to take it easy on me in a sense, because as I said, there are folks that this is not their regular beat. So I may not know the correct lingo. I may not know the right terminology to use or that all the history behind a simple word like "inclusion." All the legal and history behind it. So you have to teach me so that I can take that lesson to the broader public and spread that. And allow me to ask very stupid questions. Allow me to really explore it. Because you live this every day. A lot of journalists are juggling a million things and are jumping in cold.

So there's that.

One other thing. I'm glad my copanelist brought it up, but sometimes with these stories, there is a hesitation to let the person it's about talk. You know, there is this protective instinct which I completely understand. But it doesn't -- it really does hurt, first of all, the chances that we will do that story, but even beyond that. It makes a difference between us doing a quick hit on it and letting people know the facts of a situation, and making people care about it. And once they care about it, then it takes off.

So I will tell you, a colleague of mine told me to remind you all that I should grab this real quick, but he just recently did a story on a young man with autism that had faced abuse by two of his friends at school. You know, the parents were great about letting this young man speak for himself, and it made all the difference to hear his voice. And his voice was completely different than what authorities were saying which was this was brutal abuse that he faced. He saw them as his friends, he saw one of them as his girlfriend.

What that spoke to was really just how easy he could be manipulated, but also that he had a say in this too.

And I want to tell you as well, so even if somebody can't verbalize, even if somebody is not in a position to speak, they still have a voice. You can show me their room, their drawings, whatever it is that's important to them so that can I sort of bring them alive to the reader.

I want to read you a couple graphs. I believe it's the first story I did on Jenny. I did several. It's about this hearing. One of the hearing that's she had been kicked out of.

It says, "At that August hearing, Hatch was allowed back in the courtroom but she wasn't permitted to speak. A reporter's request to visit her was denied. Even so, interviews with those who have spoken with her and an examination of court documents show that in the months that have passed, she's been far from silent. On a bright pink poster board in Hatch's boxy, uneven penmanship are the words, "Bring my freedom of choice back. Bring my job back."

And I say that because this was a difficult story. We couldn't talk to Jenny for that first piece. I had to pull quotes from court documents. I had to sort of recreate her personality while never being able to meet her.

One thing we did, and again to Jonathan Martinis' credit, I wanted to get her voice in here somehow. I was denied visits with her. I asked him to videotape an interview with her. I gave him the questions. And so here's that part.

"In a videotaped interview with Hatch at The Washington Post's request, he asked her how she felt about the group home. Quote, I miss my friends, she said. Quote, I want to be at my thrift store. The conversation was brief and for the most part her voice remained steady and. So she smiled frequently. Then she was asked, if anything, if there was anything she wanted people to know about her. Quote, "I make my own decisions," she said, in a strong voice, "not you."

That's it.

And so I say that because he is absolutely right. We need people. We need their voices. And we are willing to be as creative as possible and as sensitive as possible, but you are the avenue into these stories. It's really up to you to sell us on it. And I hate to use that word "sell," but you have to sell me on it and I have to sell my editor on it and she has to sell her boss on it. That's the only way to get the wider message out there.

So I want to leave plenty of time for questions, which I'm sure you have. So thank you very much.

(Applause.)

MARC MAURER: Thank you, Theresa and Chris.

I often ask Chris to meet the press. I am asked to do so all the time. But Chris likes the press.

(Laughter.)

Consequently, I almost never do it. I consented last year to be on the NBC Rock Center piece because it looked like it might not happen without me and I very much wanted it to happen.

What occurred during that piece, if you look at it, there is some depiction of the conditions in sheltered employment. But there is a persistent idea that there's got to be another side to the story, that there must be a proper understanding of how the sheltered workshop system works and that there's some value and positive good and worthwhile aspect to it.

So just before I came back here, I was looking at a piece because I have been asked recently, if we decide to pay everybody a minimum wage payment in a sheltered workshop, and if we decide that we have to fire people because of that, is the National Federation of the Blind going to defend that decision?

And I keep thinking to myself, why do I have to pick these choices? But there's a persistent notion that getting a sheltered workshop together and paying people subminimum wages must have a positive side. There has to be another side to the story. It can't just be one sided.

So I would like to ask the two of you, how do you deal with that?

CHRIS DANIELSEN: This is tough. You know, out of respect for my copanelist and other journalists, I will say, I understand that you are often told that, you know, every story has or may have two sides. I personally don't believe that. I believe some stories have one side and some stories have five sides and, you know, maybe other people believe that too, even journalists. But I know that that pressure is on journalists. Sometimes I'm even asked by journalists, well, refer me to somebody who believes the opposite of what you believe. And I'm like, I'm not going to do that.

(Laughter.)

You know. But I mean, it's a tough thing. But I guess the best thing that I can do as PR for the National Federation for the Blind is to be prepared and say, look, I know what the other side's arguments are and here's what our response is.

Now, sometimes that is a tough thing. You know, in the sheltered workshop context, I get asked, all right, what's going to happen to these folks if they lose these subminimum wage jobs.

And my answer is, they will get put into rehabilitation or other situations where they will hopefully get trained for competitive jobs. Can we guarantee that every person who loses a pennies per hour job at Good Will will ultimately wind up in a competitive job? I don't know that we can guarantee that. I don't know that it's our job to guarantee that. There are supposed to be systems in place that allow for the rehabilitation of people with disabilities. And yes, those systems need to be improved, but our position is, and I tell journalists this all the time, they're not going to improve as long as there is this crutch of the subminimum wage sheltered workshop.

And that's our position. And I know that seems hard to some people.

But I respond to the other arguments that people have sort of preemptively in some cases because I know that -- and I also challenge the expertise of other people. Because I get asked all the time, well, you know, the experts at this sheltered workshop say that these people really couldn't do any other job.

And I say, oh, really? The experts at the sheltered workshop? Let's think about this for a second.

(Laughter.)

Let's think about this. Um, do you suppose those experts maybe have a little bit of an interest in keeping the sheltered workshop doors open? Just maybe? What's the basis of their expertise? Is it because they ask somebody to screw on bottle caps and because of motor impairments that's not something the person can do particularly well? Did they try something else that the person could maybe do better?

You know, Sheila in Montana, she asked, you know, I can't stand up and hang clothes anymore; I've had knee surgery. Can I answer the phones? I'm a college graduate. Surely I can answer the phones.

She was told no.

The job they had for her was hanging and sorting clothes. And sometimes pretty filthy ones at that, she told us later.

You know, I guess the thing that I would say while I have a journalist sitting across the podium from me is, you know, I think Theresa is a pretty diligent journalist, but my frustration with the press sometimes is, you know, dig down on what these people are telling you. Find out whether it has any validity. By all means, dig down on what we're telling you too. But dig down on what they're telling you.

But it's a challenge, because newspaper reporters are under pressure. And like Theresa says, there's a lot of things that are going to make a difference on whether you get just a quick hit, what I call the he said/she said story, the NFB says this and the sheltered workshop says this, and whether you get a more in depth piece. And I feel like it's my job be to sell -- to try to sell is, the in-depth piece. I'll let Theresa take over because I kind of got a little excited.

THERESA VARGAS: Yeah, a few jabs there.

As expected, I will say I rarely believe there's one side to a story. Even when we are talking about moral issues where it seems very obvious as a right and wrong. I covered crime for many years in New York and out here. So you would think it's obvious, there's a bad guy and a good guy. But with so many of those stories, there are so many nuances and why people do the things they do and why people believe what they believe. And so I think there are always multiple sides.

What I will say is, those sides don't always have equal weight. So we may have a story that, you know, it's 80 percent one side. But I need that 20% or that 2% to say there are people who will not agree with this and I will tell you what they say and what their position is on it. And let the reader judge for themselves what side they stand on and what they believe.

But if we fail to do that, to be honest, it's not in your interest either, because when someone sees a story that is heavily leaning one way, it feels like a puff piece. It just feels too sugary. It doesn't feel real or raw.

And to be honest, if we did that, you know, you're singing to the choir. People that agree with you will be like, that's great. But you're also trying to reach the people who don't agree with you, right? So that balance I think is crucial, to say, we acknowledge that there are folks out there that are not going to agree with this.

And I will tell you, there are oftentimes, so I no longer read the comments on my story. Because I write about very sensitive issues. I write about immigration and poverty and a lot of folks just on the fringe and on the edge, very vulnerable people, and I know that they are going to be torn apart in these comments and I often warn them. I tell them, you will be torn apart in the comments and you need brace for that. You may get, you know, 100 people that love you and send you wonderful emails in a lot of cases. You know, we write about people in dire situations and we get money that comes in for them and people want to help. Or somebody doesn't have a job we write about and somebody offers a job. Incredible moments and goodness that come out of things.

And then there's the comments, which are absolutely horrific and appalling.

So I don't read those.

However, I think the fact that those people are commenting is a good thing, because they read that story. It is about something they do not agree with, but for whatever reason, we got them to read through it. And that matters. That's who you're trying to reach. People agree with you? Fine. For example, Jenny's story, she's a character and she had so much at stake and it was such a compelling issue.

But I could not do that story without trying to talk to her parents, who wanted her to stay in the group home. And I read through these court documents and read their history and things that didn't even make it into the article. A lot of issues were going on there in her home at the time. But I knocked on her mother's door. I called her father. I spoke to her grandmother and grandfather. I tried very -- I put a lot of effort into getting that other side, because it wasn't a matter of here's these bad people who want to lock her away and hide her from the world. Even though it could appear like that on the surface. There was this string as well of here are these parents who think they're doing the right thing, who want to protect her. What parent can't relate to that?

So you know, it was not going to be a one sided story, and their voices are in there, even if I had to pull it from the court documents and eventually her grandmother spoke to me so I was able to get her on the record as well. But like I said, I think it's crucial to include those other perspectives. Even if you all are going to open the paper and not like to see them, I think they're in your benefit, to be honest.

MARC MAURER: Questions?

>> I have a question.

MARC MAURER: Your name?

>> Hi, I'm Virginia Marcus from Maryland Disability Law Center, and I thought the Rock Center piece was great and really got its power from the people speaking for themselves and Dr. Maurer and the others on the panel did a great job.

We're having trouble in the mental health community getting the people's voice in the media. And there is a group that is really sort of taking advantage is of that bias in that landscape. It seems like we only get a story in a big circulation publication on mental health after a shooting. And there's really no evidentiary link and it's damaging and moving the public policy discussion away from real issues and real answers.

Nevertheless, there's a particular group that's well funded from the pharmaceutical industry and they are really admirable in how well they've been able to use the media. So we're always responding to their frame. And it's like parrot, parrot, parrot. Their spokesperson is not a person who is well respected in the medical community. And actually that person makes up some of the numbers that they use that then gets repeated enough times in these various story where's it actually gets legs and people think they're dealing with something that's real.

It's been a real problem. I'm wondering what you would suggest. I mean, even the editorial board came out with a not good piece on legislation that impacts people with psychiatric disabilities that's about a topic of a lot of discussion in Washington, D.C., these last few months.

How are we going to get people with psychiatric disabilities to be able to have equal time? If all stories have two sides, why is this community missing time and time again?

THERESA VARGAS: I'm happy to take that.

MARC MAURER: Do you want to try it? Go for it.

THERESA VARGAS: I'll try it. It's a hard one.

First of all, I can't speak to the editorial side. Being on the news side, we never talk to them, their judgment, how they choose what to write about and what issues to take on.

You know, it's difficult without knowing all the context of what's going on there and what stories could come out that aren't coming out. You know, the reality is, we need pegs to do a story. For example, I couldn't just write about guardianship issues are happening in Virginia and a lot of cases happen every year. It wouldn't have made sense without the context of, here is this court case going on at this moment, and here is a person that's at the center of this court case. So there needs to be something immediate that we can latch on to and grab on to.

You know, lacking that, then there has to be a compelling human interest angle. There has to be somebody in the community that has some story to tell that we haven't heard before. If it's a mother struggling with her son for whatever reason. I mean, you know, there have been -- we would have to get creative about it is what I'm saying. And when I say "we," it would mean you would have to think creatively and then work with me or even just find a reporter that you think would care about this and talk it through with them and say what kind of story would appeal to you. Often people call and tell me that. And I let folks know. I say, call me, pitch an idea, if I don't like it, I'll tell you. But it may be something we can talk through, well, if we had this angle, if we knew this was happening. So if we could point to a trend, you know, increase in the number of psychiatric visits for this age population. Whatever it is. If there was a specific thing we could point to that matters at this point in time, why am I going to tell you this story at this point in time, like I said, it's difficult for me to speak without knowing all the context of what's going on in the community, but you know, yeah. So but that's the best I can kind of offer at this moment.

>> Great. If I could do a follow-up, because I appreciate that.

So we've got all that actually. So we should probably talk. We've got something that's happening right now. There is a bill -- I don't know if it's moving to mark up but it's definitely had a hearing recently in the House and it would really damage people's human rights on very scanty evidence that it's going to be effective. And you know, we also have people. As many times as I've been in these hearings and seen these articles over a period of years as an advocate for people with psychiatric disabilities, I've never heard anybody say, wow, that's a really fascinating story about that person. I would like to hear from that person and get their perspective. So we have people whose rights are at risk and really seriously threatened that are not having the opportunity to speak for themselves. And nothing about us without us has been our mantra since the disability rights movement was born. So we're really going to have to do something to address that problem with respect to this group of people.

THERESA VARGAS: Absolutely. And I agree with you. I will say, I know a colleague of mine at the Post did a story about a mother who feared her son who had multiple psychiatric problems would become the next school shooter. She spent time with him going to the doctor and seeing him break down and seeing his mood changes and talked to both of them. It was a really in depth piece that really just brought you into their world. And that was something, you know, again, you had to think creatively. There was no other reason to do the story. But we thought, okay, with school shootings, let's try to think outside the box.

And when you talk about sort of legislation and such, you know, recently I did a story, a bill at stake about increasing penalties for people who commit domestic violence in front of children. My editor and I talked and said, this is an opportunity for us to talk about the effects of domestic abuse on kids who see it, kids who are never touched but see it. And all the psychological problems they have as a result.

So like I said, I think there's opportunities there. It's just going to have to be a little more creative. It won't be obvious, unfortunately, which in other cases it's very clear what the angle is.

>> Great. Thank you for being open to that.

>> I wanted to follow up on that. This is Samantha Crane from the Autistic Self Advocacy Network.

One of the things that the protection and advocacy organizations and many disability rights organizations have been facing is that in a sense we're fighting a media war, right? We're not -- it's not that the articles aren't there, but sometimes when something will happen, there are a lot of articles and they're horrible. Right? Like if someone with a mental illness shoots someone, are that's when mental illness gets covered. And then you get stories like the one that you were talking about, about a parent who is afraid of their kid. And it's an interesting story, but from the perspective of someone who advocates for people with mental illness, it's exactly the wrong story that we want told.

We don't want to be talking about how scary people with mental illness are. We want to humanize them.

And similarly, like when there's an institution closure case, we get a lot of stories about how parents and families are so scared that they're closing this institution and where will anyone go. And none of the self-advocacy organizations or the organizations that actually are, you know, working toward this goal to get really great coverage in these cases. Like it's almost the opposite of what people were talking about before about journalists seek out the opposite view. You know, there will be a lot of cases about disability that don't have people with disabilities quoted in the article. You know, how can we work to reverse that trend?

CHRIS DANIELSEN: Can I take a stab at this?

MARC MAURER: Great. Somebody besides Theresa.

CHRIS DANIELSEN: She's getting beat up this morning. Poor Theresa.

I do want to say quickly, when a journalist is really doing their job, to me, even be if they are covering, quote/unquote, both sides and I don't -- I mean, I know there's more than one side to most stories but obviously I feel like my side is the right side.

(Laughter.)

But when a journalist is doing their job, things become very clear. Like I said, the Dan Barry piece, he interviewed Henry Turkey Service. He allowed them to try to explain what had happened from their perspective.

But yet at the end of that story, they didn't have any defenders. Or had very few. Even on the comment board.

And that's telling. That's telling because what it means is when you look at this situation, no matter how fair you are about it, it was just a horrible situation. And, you know, like Theresa said, sometimes you get that weight issue.

What I would say about this other issue is this. It's very important to have a proactive media strategy. And I'm not -- you know, I don't know what the media strategy of any of the particular organizations of people who have asked questions about this is, so I'm not criticizing. I'm just saying it's very important to be proactive.

If we are reactive, if all we're doing is responding to what other people are saying, then we're automatically at a disadvantage, because it's the other side that's framing the issue, and we're just responding to what is being said.

Now, how do we be proactive? I think sometimes that requires a little bit of creativity. As Theresa said. But I also think it requires building credibility. So one of the things that we do in the National Federation of the Blind is we're always telling the stories of blind people. We're always putting out press releases. We're always pushing stories out to the media. Some of them get taken. Some of them don't. But the point is, we're building our credibility as an organization of blind people, and eventually what we've seen is what starts to happen is that the media comes to us and says, well, we know who you are because we see your press releases all the time. They don't always say that in so many words, but they say, we know who you are and it seemed logical we should ask you about this. They ask us because they know we're out there, an organization of blind people that advocates for the rights of blind people, and when they have a question about blindness, they come to us. And that's happening more and more. It still doesn't happen nearly as often as I would like, but it happens more and more.

So I think it's important, even if you have to start perhaps by putting out stories that aren't about the issues raised by school shootings and about other mental health issues that you're concerned about, maybe that helps you build credibility. Maybe that helps people realize that you're out there. Maybe the journalism community as a whole doesn't know that your particular self-advocacy organization exists. They will know if you make the choice to work hard to publicize everything that you do, and then they will start to look to you when they get questions that are within your area of expertise and understanding.

MARC MAURER: We dream up reasons to send press releases to the press.

CHRIS DANIELSEN: Right.

MARC MAURER: How many do we send a year?

CHRIS DANIELSEN: Gosh, usually between 40 and 50.

MARC MAURER: Okay. And we do this because we want the media to know there are stories about blind people and that we know about them and we write about this stuff.

So what was it, a year ago or something, a couple of brothers in Europe decided that they were deaf and they were going to become blind and they decided to end their lives. Now, we publicized our opinion about that. Yes, Chris?

CHRIS DANIELSEN: Yes, we did.

MARC MAURER: And we did because we want to have the media think about it in the terms that we believe are true, and so we send out something. And if somebody then wants to know something about the psychological impact of blindness upon a person, they might talk to us. They might talk to somebody else. There is a, pardon me, Theresa, there is a habit on the part of the press to think that the government knows all about us. So they often ask government officials about us in disability terms when we would prefer that they ask the disabled.

But this is coming to be less true because we send out so much stuff that when the reporters look in the pile of reference materials that they have, they find our name a lot. And I recommend this to you. If you want to be the go to, write enough so that the reporters can't help but think of you.

Do you want to add?

THERESA VARGAS: I would, just briefly.

First of all, to respond to something you said, that story that I mentioned was not about a mother afraid of her child. It was about a mother afraid for her child. And I say that because yes, it was pegged to something very horrific, you know, that happened nationally, but the story really went into who this child was and this relationship between the two. And I don't think anybody could have finished reading it and not have had some insight that they didn't have beforehand about mental illness.

So that's just one thing. So sometimes, yeah, sometimes the peg is horrific. But I think good advocacy groups can put a stipulate on that, can take the horrific and put a positive spin on that and educate the community and use those as learning moments.

One other little thing about sending out a zillion press releases. You have to be very careful about that. I will tell you. You can send enough smart press releases. So things that, oh, that's an interesting idea, oh, that's interesting. But there are some organizations, and I will tell you, I get a million emails all the time and there are some organizations that will send me a ton of emails about we did this today and it's nothing, right? And we are doing this tomorrow. And it's nothing.

So then I just stop opening the emails because it's been nothing, nothing, nothing, nothing. So you know, and I doubt it's any of you all's organizations. If I haven't responded to your email, I'm sorry.

I just think you have to be very careful about the press releases you send out. Just make sure they are smart and concise.

MARC MAURER: We'll try to prevent them from being like Facebook posts.

THERESA VARGAS: Exactly.

CHRIS DANIELSEN: It is something that you have to think about. I say that we send out all these press releases, but we do think about, is this really a good idea for a press release. We still wind up sending out quite a few. But overall it's been beneficial, but yes, don't just send out a press release because you went to a restaurant and they had a Braille menu. I don't know. You know.

(Laughter.)

THERESA VARGAS: But if you started seeing more Braille menus and it was increasing and you noticed this, yes, tell us, that's a trend. We would be interested in writing about that.

MARC MAURER: Yesterday we had a picket Rochester. Did we press release that?

CHRIS DANIELSEN: We did not because we were there but it wasn't our picket.

MARC MAURER: If it were, we would have press released that.

I appreciate both of you coming and being candid about this. Getting the press' attention is important for the stories that we have. And very often they need to be different from the ones that were in the past. In the past it was a good idea occasionally to get a story about a warm, amazing disabled person. But there are substantive rights questions, and we're moving in that direction. And I appreciate both of you coming to tell us about how to do it.

So thank you, Chris, and thank you, Theresa.

(Applause.)

Let's hear from Dan Goldstein about the Disability Rights Bar Association before we close.

DAN GOLDSTEIN: Well, this marks the beginning of our bar association. Before folks head in for our excellent luncheon, I first want to say that the fact that we are at all organized and we are actually quite organized for this afternoon and for this evening's dinner, is entirely thanks to three people: Valerie, sitting over there at that table.

(Applause.)

William. And Meghan, who has a couple of announcements for you.

(Applause.)

And Amy should be presiding since she is the President of the Disability Rights Bar Association. She thought she was supposed to be in trial today in Taco Bell. I don't know why she thought she was supposed to be in trial today. I told her I would settle the case for her. I did that yesterday.

(Applause.)

After 12 years, Taco Hell is done. The combined attorneys' fees and damages for the four named plaintiffs is $5,375,000.

(Applause.)

MEGHAN: Thank you, Dan.

I have a few announcements regarding lunch and dinner for this evening.

Lunch will be held in the dining room starting at 12:30. To get to the dining room, you can take the doors to the left of where you're sitting facing the stage. We'll have people there to direct you on how to get to the dining hall.

The meeting itself will then begin back in this room at 1:45.

At the end of the meeting if you plan to attend the dinner, it will be held at a restaurant nearby here immediately following the end of the meeting.

You must have your dinner ticket with you to be served at the restaurant. So please bring your dinner ticket.

If you are driving to the restaurant, there are directions available at the DRBA table. And please note that the restaurant will validate your parking for three hours so bring your parking ticket into the restaurant with you.

If you require transportation to get from here to the restaurant, shuttles will take you to the restaurant. We don't have transportation back but we do have numbers for cabs available at the DRBA table as well and encourage you to talk to other folks to coordinate sharing rides.

I think that's it. Enjoy the meeting.

(Applause.)

MARC MAURER: Meghan has been working here as general counsel for some time. She is also working on a small Meghan, who is supposed to arrive sometime in August. So her workday has shrunk from 19 and a half hours to now only 15 and a quarter.

(Laughter.)

She has done extraordinary work here, and I am hoping that you can join with her at the Disability Rights Bar Association.

Lou Ann has an announcement.

LOU ANN BLAKE: After we conclude, if I can please see Dipa and Paula at the front of the stage, I would appreciate it. Thank you.

MARC MAURER: Lou Ann has done much of the work to put this together. And I have a --

(Applause.)

Along with others. And I appreciate her work.

I come thinking this. Dr. tenBroek died in 1968. And his work is represented by extraordinary legal thought and inspiration for hundreds of thousands in this country. I think had he been in this seminar in the last day and a half, it would have been fascinating to hear his incisive questions. But I do believe he would have been pleased. The law has to develop, but it also has to develop along with the thought process of the human beings who encounter the law and the culture of the society. And I think we are making significant progress. And I think that the people who come to this gathering are at the cutting edge of making that progress. And I appreciate all of you for coming.

We'll have another one next year. Thank you much.

(Applause.)

(Symposium ended at 12:25 p.m.)