

UNC Chapel Hill CEDI Lecture Series: Karen Diaz and Karen Erickson

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Literacy and Disability

>> So I've been a teacher, and I was a classroom teacher, but I've been a professor since 1995. I travel a lot for my job. I have a very narrow, specialized focus in teaching children who no one else thinks can learn. And so I get called to go all over the place and do some pretty exciting thing. And I spent a lot of time on airplanes, which means I spent a lot of time talking to strangers. And if anytime somebody asks me what to do, and I don't, what I do, and I don't think about it, I answer, I'm a teacher. And then you know, the next question is going to be, oh, you are what do you teach? Ah, graduate students? And most people who teach graduate students don't identify as a teacher first. But I'm a teacher. It's who I am to my core. I now do lots of funded research and development work. But all of that work is done with an eye toward how can I be a better teacher in order to help other people be better teachers.

So, let's see, I would have expected that that would have, let me...There we go.

I work with kids who have really, really complex disabilities. I'm now old enough that I sort of feel like I can use the word kids to mean anyone who hasn't graduated from college yet. And so I really am talking about that whole age range from birth until usually about 25. Most people don't know that in the state of Michigan, if you have a disability, you're eligible to continue to participate in public school through your 27th birthday. So they continue to provide special education services in the state of Michigan, through what they call post-secondary. But that is offered through your local school system that does the K-12 work for everybody else. So it's that full range that I'm interested in. As a classroom teacher back in the late 80s, and early, very early 90s in upstate New York, I worked with a

lot of kids who looked a whole lot like this. So really cute little guys, who everybody could see, well, maybe they do have potential because they're so tiny and so cute. And maybe there's something in there, and we just need to find that. But for me, the most exciting work has happened. Over the last, okay, the most exciting work has happened over the last decade, as we've worked with individuals with increasingly complex disabilities, who are older and older and older. And...

[Microphone feedback]

And what we're finding is that literacy and technology, and all of the ways that we can make the world accessible to people now has changed the game. And so for example, one of our very recent projects, we are teaching adolescents and young adults who have the most, most complex multiple disabilities, so they need people to take care of every one of their needs. And they have severe intellectual disabilities. And they're deaf and blind. And we're teaching those guys how to communicate in a symbolic way. So they can't physically sign because of their physical disabilities. And they can't talk because their neurological disabilities, and we're using 3D printers to print out the actual symbol. And it's taking time, but we're teaching these older, these adolescents and young adults, who've had a lifetime of not being able to interact with the world in any way, to start using these little things that look like blocks, to be able to communicate in meaningful ways and interact with the world. And as we keep pushing, we being my colleagues at the Center for Literacy and Disability Studies, Gary Bishop, who you will have met before, who's our partner in crime, and wow, has he opened up the world for us. As we continue to push the limits of who are these populations, and what are we doing, it only helps us understand everybody that much better. So we have always been excited about technology and what technology brings for this group of kids. But it's also really important to recognize the barriers that it

creates, and how different technology is if you're a kid with severe disability. So for example, this little guy is sitting in a wheelchair that he can drive with his knees, right? He has in front of him that is a communication systems. Probably about \$10,000. It reads his pupils. So it's an Eyegaze machine. And it's looking for where his eyes are converging on the screen. And then he dwells, or he continues to look in one spot long enough, in order to have it say the message that he's selected on the screen. So if you could see the screen, it's a grid with little pictures and each picture represents a word. But imagine this kid's way that he interacts with the world. It's everything he does, he's got this screen in front of his face, and how much that actually limits his access to lots of information in the world. So we finally are at a place where we can start thinking about the ways that technologies are available and accessible to an increasingly complex group of children. But we also have to think about what does it do for them? What happens when you're a four year old, who now is hearing lots of language, who can see anything that happens in the periphery, and can see anything that happens up here. But he has no ability to see anything that's happening on the ground around him, or from this height in front, because there's this big huge screen that's mounted in front of his face all the time, in order to give him a way to communicate. So there's this, give and take. And we have to be aware of those things. As we're trying to make some of these decisions. We look at, these are twins. Mom is very excited, got this new iPad, using it to interact with her son, who has pretty significant multiple disabilities. But look at what's happening. The boy who has the most significant multiple disabilities isn't even looking at what's in front of them. He's looking off to the side. It's the kids without disability who is, the world is available to him all the time. He's the one who's trained on the device. And this wasn't just some accidental snapshot, like you look at this, and it's over and over and

over again. That the boy who's mom is trying so desperately to support through the technology isn't really getting the kind of access that we would imagine. And having his twin brother, as contrast, is such a really important way for us to be thinking. So we have technology that allows us to give kids access to information to help us teach them how to read and write and communicate. But we have to be super thoughtful about that -- what is the impact of that technology, not just in terms of the opportunity, but in terms of the barriers that it creates? That this little guy might actually do better with a very different kind of presentation of information that doesn't make him divert his gaze that actually gets his gaze. Just yesterday, I got a -- I'm on several Facebook support groups. And I got a message from a mom, who has a adolescent daughter who's just started to have massive seizures. Computer screens, all electronics, can actually induce seizures in people. And at school, it's a one-on-one laptop school system. And so all the kids are working on technology all day long. Then add to that, that all of the required testing, she's a fourth grader, that she's going to have to take this spring is now all delivered online. And the doctors have said, you need to completely eliminate all screen time from this kid's life. Well, forget about the fact you have a 10 year old girl who has to hand over her cell phone, her iPad, and everything else. Now you also have a kid whose whole school is wired for learning that's technology-based and it's making her sick in order to do that. So we probably felt a little bit, you know what, there's a pretty simple solution that will allow her to have some access to at least the literacy learning and information that her peers are doing online. And that, to do just let this is. So take it off of the computer screen and project it up with an old fashioned light-based projector. And this is not going to induce the seizures. You would notice a huge difference if you're in classrooms where they have LCD

projectors in the front of the room in order for you to, you know, follow along in a three hour lecture versus one with a projector. This is going to be less strain for your eyes. But it really importantly for this girl, it's not going to induce the seizures that she's going to get if she's looking here.

>> An LCD projector would?

>> That, an projector? An old fashioned light bulb projector, you're good to go. Any of the projectors that are actual... So this, I'm blanking liking on that, you know how we have the cable this one?

V8?

The minute you plug into that kind of the old fashioned VCR? V? I can't remember this... V? It doesn't say on here. The make you plug into one of those, it changes the flash rate. And for, it's not, so you have to know what's the problem with the kid. Right? That's my issue. Right? So for her, there is this opportunity to get an old fashioned, not the ones that you can get to through an HDMI, but the ones that you can connect to through here. And it's going to change that refresh rate to a level that now she's going to be able to tolerate it. And so now they have a potential option for her to be able to do things like just keep up in school where all of their books, everything they do, is all delivered digitally. And we all think that this is awesome for kids with disabilities. That we can have, and the world is available now in a digital context. So you know what, there's a whole bunch of kids who, actually, it makes them divert their intention, it's hard for them to visually attend. And then there's a whole group of kids who might be very interested in attending, but it actually makes them sick and makes them have seizures, to be able to look at that sort of electronic presentation of data. We also find that these kids who have severe disabilities that have access to technology, there's always an adult attached to them. There's just always an adult

attached to them. And imagine when you were 12 years old, and in middle school, if every single thing you did all day long, you had some middle-aged person attached to you all day, every day. It's more of an issue for all of the boys that we know because they never have male caregivers with them at school. So you have, you know, somebody who's oftentimes older than your own mom is, who has done, it just don't know anything about your reality. A person who's now interpreting, translating, and deciding what you should have access to and not have access to. So you end up with a teenaged girl who is really excited because she finally has figured out a way to get into her photos. But somebody else decided what photos she should have in there. Right? Well, y'all just have to look at your own photos to know the ones that you're interested in are probably not the same ones that the rest of the world wants to go back and look at. We keep going. And we look at again, here we have two teenage boys. Both of them have intellectual disabilities, They're in a setting where they get to have their own tablet all day every day. And there's always an adult mediating their interaction.

Down the road at the elementary school, there's no adult there. These are kids huddled around looking at things together, figuring out, engaging in problem solving, getting that A-ha moment that kids need to have. But when they have significant disabilities, they don't get that same opportunity. In states like North Carolina, the kids that I'm interested in, with the most significant disabilities, are almost always educated exclusively in separate settings. They spend no time in their school day with peers without disabilities. Now, before I became a professor at UNC, I was at the University of New Hampshire. The University of New Hampshire, in that state, at that time, there were no special ed classrooms. All children went to the school that they would go to if they didn't have a disability. And they were in grade level classrooms that they would be

based on how old they were. And as a professor at the university, I trained teachers who were getting duly certified in both general ed and special ed from the beginning. And so, while when it's only kids with disabilities, there's always an adult in the middle, if there is a mixed group where most of the kids don't have disability, and one or two do, suddenly those kids start supporting and learning each, learning from each other. And so, we have this bias that somehow adults help. But if you look at the way kids use technology to access the world to become readers and writers today, for every one minute they're spending with adults, they're spending 20, 30, 60, 120 on their own, engaged in literacy, engaged in communication, engaged in learning about the world, without an adult constantly mediating it. And we have to be really thoughtful about that and continue to develop ways that we can help kids be more thought -- be, have more independent access, and more of that socially mediated access with their peers. How can we take advantage of. That you look at whatever today du jour version of Snapchats, and before that, and before that, and before that. None of those tools are accessible. They all require you to have good manual dexterity, they require you to be able to see, they require you to be able to, to engage with little tiny buttons. And that is so much of the social interaction that kids without disabilities have, as they're learning about the world. And kids with more severe disabilities just don't get access to that.

As we think about the kind of content that kids with disabilities have physical access to... So here is a little boy who physically, he can't use and he reaches out and touches the screen. his fingers to point, he asked us his whole wrist, And so he really can only accurately access two sides of the screen. And so it's dramatically changed the kind of content that he has available to him. So really, every time he goes to learn, he's picking a path. It's just a test all day, every day. Touch the red one,

touch the green one, touch the big one, touch the little one, touch Elmo, touch Bert, like, everything he does is the computer giving him a direction, and him responding in this binary way. And if he gets it right, usually something happens. If he gets it wrong he hears beep. And then he goes on to the next one. Well imagine what learning would feel like if every single event was actually a quiz or a test instead of an opportunity to explore and figure it out. And, and when we think about technology, and we think about the ways that we engage with the world, you know, like in my house, so let's ask the Google or I don't know, let's go ask the Google or like... We are just consumers of information all day, every day. And if every time, I don't know, I'll get on and if it's a website that's asking me too many questions before it lets me in, I leave. I don't want to stay and answer your five questions before I get to what I want. And for many of our kids with more complex disabilities, their entire day is a test. And they don't have the options. He doesn't have the ability to say I don't want to be here, I want to go somewhere else and do something else.

There's also a ton that we've figured out about the differences in the ways that we help kids with disabilities learn how to interact with and use the technology in order to learn about the world. This is not somebody that I know. But she looks just like somebody I do know, who would constantly say to me, just leave me alone, Karen, I'm doing my work. Just leave me alone, I'm doing my work. And this is what she looks like. Well, if you have a young adolescent who's this engaged, right? Like, they're just looking at that screen and their hands are going and they're typing away, you'd assume there's something happening here. All that was happening here was that she was copying text from everywhere she could find. She didn't understand that text, she didn't, she was just copying. So it looked like she was doing what everybody around her was doing. Well, once we start figuring out that that's what she's

doing, then we can start saying, well all right, how do we make that more meaningful? And so one of the things that we did that was pretty simple as we just turned on, in Google Docs, the option to have it read back as you're typing. So that in the very least as she's typing words, copying words, that she's seeing around the room, once she typed it, she then hears what it is. Right? So that we're giving her some feedback to begin not just engaged in a, for her a meaningful, but in terms of long term learning, not particularly meaningful tasks. So we want to look also about how it is that kids are interacting, what are they interacting with? What are they finding interesting? How do we build on those things that are interesting for them? How do we support them and having much broader access to information? How do we think about not just oh, cool, everybody gets a laptop, but what are we going to do with those laptops? What are the tools and resources that we can provide? How do we support kids in interacting with those tools and resources in ways that we know are meaningful to other kids? How do we get the social piece of that going, because we know it's a critical component of the reason most of us get on to our electronics for one reason or another. We also spend a lot of time thinking about some of the assumptions we make. Because we have access to technology, we often do things thinking that we're helping kids, that actually the research bears out to say we're making it harder for kids by doing some of the things we're doing. So here's a couple of examples.

Text-to-speech was sort of screen reader technology, it used to be you had to pay for it. Now, it's free on just about everything. If, if you have a written document, there's some free something on your computer or your phone or your tablet that will read it back to you in a pretty simple way. So that exists now. There are pay options, like there's one that I like very much called Snap&Read. The thing that's really cool about Snap&Read is it will take any

document, it could be for any text on the screen. So it could be Flash, it could be PDF, it could be anything that's on the screen, and you snap it, and it will read the text that's on that screen. The other thing it will do, if it's truly a digital text document, is, so something that is...it will respond to text-to-speech and natural ways. You can snap it and simplify it. And it will automatically simplify the paragraph of text that you've selected. So that's been a really important tool for lots of the kids that I work with who are in general education classrooms but aren't able to read and understand language as well as their peers. There's been a ton of attention in the US over the last decade around how do we make sure that all instructional materials that are used in public schools are available in a standard digital format that makes them accessible to the broadest range of people with disabilities possible. The original population was people who were blind and visually impaired. And so the original focus was, how do we take all the text that's used in public schools K-12, and make it digital, so that people who are blind or visually impaired can listen to that text. Very quickly, that went from just that population to the entire population that's called print impaired. So that would include people with dyslexia or language disabilities, people whose disability keeps them from being able to read. And it's been interesting because the original law specifically excluded people who couldn't read because of the level of their intellectual functioning. Okay? So we'll give you access to digitize text if you can't read because you can't decode the word. But we won't give you access to digitized text if the reason you can't read is you can't remember them, you can't... right, like if you have other reasons why you can't read. There actually is a standard, the National Instructional Materials Accessibility Standard. And any, any digital text or any text that is purchased with public funding now is increasingly, increasing requirements that

those texts have a digital version that is available following this NIMAS structure. And any digitized texts that are available in this NIMAS structure, then can be read in any number of free or for-purchase, screen reading kinds of technology. Bookshare is the link that I provided that you can follow from whatever your course website is, and Bookshare serves even if you're printed disabled, it doesn't matter how old you are, you can apply to get a Bookshare license for free. And they will provide you with access to textbooks and other things that are in a digitized format to be able to have it read aloud. Many of the digitized formats are just flat PDFs, and not all screen readers can manage those. So we have this NIMAS, we have this way that kids across the country through Bookshare, if they have a print disability can get access to the tools that their peers are learning and they can listen to the text or do supported and reading from the tech. And, and this is going to solve this huge problem. Everybody makes this assumption that oh, if we can make it possible for you to listen to it, then you're going to understand it. Right? It couldn't be further from the truth. I, this article, I shared it last night. And so it's being shared on the course website.

Okay. And partly it was because I was trying to figure out how to explain this. And I thought, oh, I wonder if I have a graphic in that article. And sure enough, there was one. This is a group of 51 kids who, school aged, so third through eighth grade, who are known to have language disabilities of sorry, learning disabilities, specifically dyslexia. And that's that population of kids who we make this assumption that if we just give them access to books that they can listen to, will solve their problem and they can have access to school. Right, like, they'll be fine. And in fact, if you look at our group data, when we went in and assessed these kids, what we found is that for the group of 51 kids, on average, they could listen with comprehension above grade level. So this negative means that they're actually

above grade level in their ability to listen and understand text. And on average, there were 2.3, 2.29 years behind in their ability to read words. So this is a group of kids who was absolutely right, if you're going to make this big generalization to say, well, we should give them access to text in digitized format. Because if they can listen to grade level texts, they're going to be able to understand it, and then they'll be fine academically, right? This is great. But you look within that group of 50, 51 students, only 33% of them listen at or above grade level. And in fact, eight of them listen two or more grade levels below their grade level placement. So they're eighth graders, they can't understand text above the sixth grade level. And so we think, oh, we'll just give them a, sign them up for Bookshare, we'll give them all access to their textbook in a digitized format, they'll listen to it, and they'll be just fine. No, they won't. Because they don't understand listening to text at the grade level that they're at. It needs to be simplified in some way. These two poor kids, three or more grade levels below. So they're eighth graders, but they have to have fifth grader lower listening to it, in order to understand it. Reading it, being able to read it independently, it's likely even worse than that. So we make these assumptions that oh, well, now we can take our whole library and we'll digitize it, we'll give every kid a device in our school, everybody will have access. And we're good to go. Well, even among the group of kids who most people assume that's the right solution for, it's not for all of them. We have to know who the student is, what they need. And we have to look more carefully at what they can read and not read and what they can listen to. And what's too hard for them. As we about providing kids with access to digitized text to be able to listen as the way that they access information and improve their literacy skills. The first thing we want to know is what's their listening comprehension level is. And another link that you have on your website is to the

Universal PAR, uPAR, from a company named Don Johnston. You can actually do that free of charge. There are school systems around the country that use uPAR anytime a teacher raises a red flag about a student. So anytime they're concerned about a student they use uPAR in order to look at how well, what's the highest level that the student can read silently, and remember, and answer questions? What's the highest level that they can listen to digitized text on the computer read and understand and answer those questions? And what's the highest level that they can listen to a human reader read, and answer those questions? And there is any much larger group of kids than most people realize, who do best with a human reader. Way better with a human reader than they can do with a digitized text. And so we want to be looking at, like what if we're going to use digitized text to support a student, what's the level that they can be successful at? And let's make sure that we're giving them text at that level, and not leaving them frustrated, because they're already doing it differently than their peers are. And they still don't understand it. Because now it's different and it's still too hard. So if we're going to make it different, can we at least make sure that it, they can be successful with it, because it's a whole lot easier to be different when it works for you. But to be different when it doesn't work is just incredibly frustrating. And we get shut down. So we want to target the text at this level that they can listen. And then for kids with much more significant disabilities, people are not thinking oh, they can just listen to it an eighth grade text. With those kids, we've made this the assumption, that if we create this stuff that's called picture-supported text. So we take this software now that lets you do this, you just type the text or you upload the text, and you click a button. And it matches these little pictures with each one of the words. Baltimore Public Schools did this with their entire elementary school library, posted all of them

up online. After spending, you can imagine the effort that it took, number one to get all of those texts created into a format that then you could upload them and add all these picture symbols to. Number one, it was a huge copyright violation. So it got taken down pretty quickly after it went up. This does qualify as the individual adaptation that you can make for individual kids. And so typically, when we have, when we used to think this was a good idea, we would suggest to schools that they would create this and put it on a CD and kind of pocket you use with your library card, put the CD in the back of the book in the same right? Like let's just put it in there. So the adaptation lives with the book and isn't online for anybody in the country to get, which was really where Baltimore Public Schools went wrong. But here's where else went wrong. We now have four decades of research that says when we do this, it makes it harder for kids to learn how to read. It makes it harder. Well, the reason for doing this is to help kids who need help learning how to read, right? And so then people say, well, I'm not really doing it to help them learn how to read, I just want them to be able to access the information. And having those pictures helps the kids access the information, right? In fact, it doesn't even do that. So here's an example, right? This, I will give you a big hint. If you're in the, my age category, this is a line from a children's book. Don't cheat. There's, so if you go to the next slide, you're cheating. But look at this, and see if we, go ahead, work with people around you. Submit a note if you're online and you think you can figure out what this does. It is a sentence from a children's book.

>> See?

>> Is that what you think that word is? Okay. See.

>> Indiana Jones?

>> See Indiana Jones.

>> Eye.

>> Your syntax is kind of falling apart.

>> See, Indiana Jones, eye... Is there anything that you know, and like, I'm pretty sure that's play. You think this one is play? All right. What else you think you could like say? Think... What do you think this one is?

>> Tree.

>> Pretty good bet.
know what's going on in the before.

>> The one before it is like, impossible. I don't

>> This one? A little bit nervous.

>> I, right? These picture symbols are super common. They're used all over the place with kids with developmental disabilities, particularly when they can't use speech to meet all of their communication needs. This software that allows us to go in and add all of these words to match, or pictures to match each one of the words, makes parents and teachers feel like they're doing so much. I adapted all these books, my kids are being really successful. But in fact, we have a room full of really smart people who probably when I reveal what this is have read this book more than once in your life. And you don't know what this says. The reason we're using the symbols is to help people who can't read the words have different access to it. But in fact, the only way you can figure out what the symbols mean is if you have the words to go with it. And as adults who are highly literate, we can't not read text once it's there. We can't not pay attention to words, it's how billboards work, right? If you actually stop and pay attention to the words that were on the billboards, we would have a huge problem on

our highways. But as adults who are highly literate, as soon as you've seen text, you've read the text. And so when adults see that, right? And then they can go all right, I get why that's after.

>> E comes after B, right?

>> No.

>> I'm serious, this is happening in schools, the highest selling literacy, I use that in quotes, curriculum for kids with developmental disabilities across our country. Shit, like this, week after week after week, to tens of thousands of classrooms across our country. And then we wonder why the kids aren't learning how to read the words. What the research shows us over and over again, it's because they're looking at the pictures, and y'all won't remember what this says tomorrow because you're just, you'll just, each one of you is looking at something, thinking, really? Yeah. No that's not the, it's play on my VCR, right? On my video, on my phone, that symbol means play. It doesn't mean the. Right? So we have just all kinds of problems with this. But everybody makes the assumption that if I'm going to adapt my, I can adapt the text and then it's going to work really well, right? There's some researchers right now who are doing work on this. And they continue to say, oh no, it's improving kid's ability to comprehend. And I'm going to argue it's not improving their ability to comprehend at all. It's improving their ability to figure out which answer is the right answer. Right? You don't even have to read those words. If I ask you a question, who's the main character? And there's a picture of a guy in a red shirt, a yellow shirt, and a blue shirt, which one are you going to choose?

>> Yellow.

>> Right? I didn't have to know what a main character is. I just am looking and there's red,

blue and yellow. And well, there was no red guy, and there's no blue guy. So the answer must be yellow guy. Right? And so there's, there's just this, if we're going to think about, we have all this amazing technology, we have all of these ways that we can make the world accessible. And we're not being smart enough about it. We're making assumptions that actually get in the way of kids being able to learn, instead of recognizing that, you know what we could do instead of, this is from a chapter in Hachet, and the way people are making Hachet accessible to kids with more significant developmental disabilities is by doing this. Well, what if instead, we just made a really, really simple version of it, that helps kids, one sentence and in one picture, one illustration at a time, get a sense of what happens to Brian, chapter by chapter throughout that book. That is what we did when we created Tar Heel Reader, which you all heard about from Gary Bishop, right? Who's our collaborator in computer science. And the thing that's been really fun about this work together with Gary, is Gary can, you know, make his computer sing and walk and dance and do whatever you want it to do. Like he's an awesome computer scientist. He is constantly pushing the limits of what's possible. He says about this all the time, it's just stupid simple, right? And he on a weekly basis gets one or more requests from the field saying, can you make it do... One of the very first request that day that we released Tar Heel Reader was can you make those little picture symbols show up above each one of the words? No, but we can, but we're not going to, because, right? Can you make it highlight the words while it's reading out loud? Well, we can, but we're not going to because actually having it highlight word by word by word is going to get in the way of your developing fluency as a reader. Because when good readers read, and actually about the time kids without disabilities are at Christmas time of first grade, when they're reading, they're not reading word by

word. They're no longer pointing and saying one word at a time, they're either actually making the same kind of saccadic movements that our eyes make. Taking in more than one word at a time, in order to use the surrounding context to help confirm what it is that they're doing as they're identifying words, one at a time. So as we're thinking about what are the things that we need to do, and we're trying to think about kids with more complex disabilities, thinking about technologies, we're thinking about what's possible, we're doing a lot of work to remember that technology and technology-based solutions don't always deliver what they promise. That sometimes teachers actually get in the way of learning. That we have to understand the learner's profile, what are their relative strengths and weaknesses? And that we have to remember that what, what it is that makes learners without disabilities want to engage with technology? And how do we make sure that we're providing it? So that's that, get the adults out of the middle. And then keep it simple. Right. Okay. I just realized what time it is. I'm going to stop now. Can we swap? And then, you know, have questions after? Okay,

>> Thank you.

>> Karen Diaz is is the mother of a 10 year old with ADHD and 6 year old with autism. She came to the United States from Mexico 11 years ago, and she's also an advocate for parents of children with disabilities. Through her own experience of looking for appropriate services and resources to fit her children's needs, Karen has also been able to offer support and advice to families in similar situations and need. Thank you, Karen, for joining us.

>> Hi. So as you can see, my main language is not English. So I will try to do the best I can. If you have any question please, or if you are not able to understand what I'm saying, please let

me know. Okay, so, I really want to give you my personal story about what I, what I've been doing with the families. So I have a chance to work with Latino families from El Centro Hispano, I don't know if you are familiar with this place. So I went through a program called Mother Reads. So I went to a training to help inform families to achieve the reading for the kids, because in Latino families, we don't have that. To read with our kids every night or every day for 10, 15 minutes. So it is, is what we trying to do to put in the families. So over the program, I have to be to the library with these families, at least once in their program. So I run the program for four times a year. So it were like four times we have the went to the library. What are the problems we had there? First thing, it is really hard to find someone who can translate. It is really hard to find someone who can do the tour around the library. So how we going to participate there, we don't know what it is in the library, how we got to get the resource from there if we don't know what the libraries offer? They have a bunch of resources for us. But we don't know. Another big problem I had there, as a person who was looking for this service and opportunity for other families is, I went there. I made it, let's say appointment with this person. But she never showed up. Every time I have to wait at the door. Is she here yet? Is she here yet? She never showed up. Every single time. I work on, with El Centro for two years. And it was the same thing every single time. And that's just me. I don't feel comfortable to do translation. So but I wasn't the obligation. But of course, I have this work on me. So I am the one who needs to explain everything to them. Also, another big problem is, okay, it was a group with families who have kids more than five years old. You cannot be around doing a tour in the library with a bunch of kids, less than five years old. Yeah. So with weeks of anticipation, I went looking for a place to drop off our kids. They said yes, you can be in this room or that room. Today, when we get there, that's too busy. So while we can

do with our kids? We provide the teachers, but you don't give me an open space, I cannot have control of 12, 15 kids at the same time. So, there are a lot of barriers we have to go through. And one of my biggest concerns for all of these, it is, the person at the reception. How you gonna get a library card to get the books you want for your kids if they're asking you, I want a valid drivers ID. Most of the people, or some of the people, you know, cannot get one. I need a bill with your address and your name. The situation is hard for our people. So, sometimes we're not able to share a bill with our address because we don't have one. It is always someone in house will have all the different bills because we don't have none. And another thing it is, I don't think nobody have a passport all the time in their purse. Doesn't make sense. So it's like, just we can not give you that. So why are you coming to me and tell me, use the resource, especially the ones in Spanish special, but how can I get access to them if you don't give me a card? I'm going to be here, you don't have a card. So there is a lot of, a lot of problem we'd have to say, to get the resource at the library. And in the other hand, I want to talk to you, as a mother of my kids with autism. So as Amelia told you, I have a six year old with autism. And I have a 10 year old, ADHD. So, how you can work, we just can't get all, who needs to do a project or have to work. But you have another kid, who cannot be allowed in the library? What I'm talking about? I've been asking to leave the library because my kid is too loud. I cannot share my phone to keep my, to keep my kid calm down in the time I have been my other one. So it's like with a tour he have his, and can you drop off Jonathan at the door? I'm gonna wait here for you. And you pick up your knapsack at the door I because I cannot get in. So it is really a problem when they send you their security person, which at the library is like, what is they want? My kid has the same rights that other kids have. But that is not possible. Because it is a quiet environment. But

I think we should do something. Something to be, to be open, to welcome all these families. Honestly, I don't go to the library. I don't use the resources I have, because I am afraid of any minute the security person will show up. But you have to leave, or you need to put your cellphone in your bag. I mean, I have something to do here, but how? You have a bunch of resources, how? I cannot even learn how to look for a book because sometimes I cannot afford to pay someone, okay, can you stay in my house because I need to go to the library. I think the library is for the kids to expand their, their learning, their love for the books, but if I'm keeping my kids away from there. That is no way, that is no way. So, another thing we have to face as kids with disabilities is if we go to a kids, kid session or kids time in the library, it is hard because, as my kids have sensory issues. So you cannot be in a loud space. Teaching will be too close to other kids. So there's no way. We have to walk away all the time. And me as an adult. It has been like a month ago, Jonathan needs to turn in a project but, or printer support. So I have to go to the library. What the world, how I'm going to deal with this? What I did? Take my kids, one with a cell phone the other one with an iPod and put them next to me where the computers are. But I cannot even enjoy the time because I'm just looking for the security. And shh, shh all the time. So I really would like for the person, I don't know what he's called. [In Spanish]

>> The director of the library?

>> The director of the library, yes, to think about options for us. One example is to have access at least one day, one hour, two hours a day, where we can go with no fear, we're going to, we have to leave. So other thing it is, maybe it is possible to have someone who knows how to deal or at least how to recognize what will people need. Because it is not the same when you have a kid with autism,

dyslexia, any kind of learning disability, that you can not see, you see a normal kid. So why it has to be different with this kid? I cannot see that disability, you know, but I know what to do with that. Because it is what I have to do every single day. And it's not just for me it is from this group, I am tired. It is the same complaints, a lot of the time. I cannot get the resource because that is not time. But if I am not allowed to. And suddenly, we have to stay away from the library. It is our treasure we cannot dig in because we have no choice. So there's any questions? Comments?

>> What do you want to ask?

>> So you said a day or special time where kids who have sensory needs or special sensory needs or different needs can go... Are there other things that would help make this space more welcoming? You said, you talk about the security. So I mean, like, what other things how do you, what other things do you find make that space more welcoming for you?

>> I think one of the, the biggest help we can get it is that information. Information for, for the person who works at the library. Is it, I think it is hard to educate all these person who works there. Because it's not like 10 or 20 kids to many libraries. But at least to have the basic, basic skills to recognize when you have to be a little bit more patient with a kid instead of just pushing you out. It's like, like a warning sign. Yeah, to be more, let's say open mind. Open mind for for those. And in the time, specifically, specifically time for our kids to be at the library. One is the sensory issues, the other one it is a time who know you, they're familiar with kids with disabilities who know about it, because my kid is really loud. So I would like to, love, to have like a sign in the door. So Tuesdays 11am, sensory-friendly or whatever so other people who are there doesn't become upset because it is really noisy. Obviously they are there because it is a quiet

place where you can work. But it's like okay, what I'm doing here, this is happening. So I will ask for them to have the opportunity too to know, so it will be at choice. I want to be there I want not to be there.

>> Any others?

I'm really nervous. It is the first time I'm doing this.

>> And it, I'm sorry, it seems like in the movie theaters have started having special times for moms with infants, or they'll have special times when the lights are on during the movie so that children with autism can have that sensory overload, they turn down the volume. Seems like that should be happening in our public space, like the library, it's like, yeah.

>> It's like, I can give you an experience. I did try to pull my kid into a regular movie. He was completely scared. It was for my son's friend birthday party. And I have to walk away five minute because it was too loud, too dark. So nothing work for us. So right now, with a sensory-friendly movies, everybody's making noise. So I feel like okay, you can do that. Because everybody there know what we're doing this. We're not really looking at the movie. As a parent, we are teaching kids a different way. They can expand, they can learn, they can be with other kids around them. And we can feel normal. Is it working? It can feel a normal life. Hey, I don't have to apologize here. Because it is what it is. It is a time for us. So that is, that is a really great idea. Yeah. It is really fun, those times are like once a month. And it is really early, 10am, but it works. It really works. Any other questions or comments? I would like to hear from you too. What do you think about it? Maybe I'm asking for too much? I don't know. Yeah.

>> I just wanted to say that even, I have a son with autism as well. He's 11. But even I can understand your experiences completely. And, you know, even in places that you think

wouldn't be a problem like amusement parks, my son is obsessed with roller coasters. It's one of his things. So we go to amusement parks. And sometimes he gets the sensory overwhelmed and he screams, you know what I'm talking about? And people say horrible things. And we're outside. We're literally outside. But because, you know, he's reached a certain age where I guess, boys, kids aren't supposed to scream anymore. You know, I won't use the phrase that I overheard while my kid was screaming because it has bad words in it, but I can feel your, your pain and right. I think you're really brave for sharing it, so.

>> I want to share this story that happened in a supermarket. We were in the line to pay. And I have Jonathan, my oldest. So, obviously he can completely understand. And I look at these two persons, they're cashiers, talking with each other and looking at kids, staring at us. I thought it was because we're Latinos. I mean it happens very often. So it doesn't bother me. When we walk out, Jonathan told me, mom why you don't say anything, why you don't speak up for my brother? What happened? I don't even notice. They say my brother, it is that, it breaks my heart. I don't hear my six year old doesn't listen to them. He was doing other things. But it is brother. Yeah, it is his brother. The one who have to pay the price. So it is like okay, this is a supermarket. It is noise all over the place. What is wrong with you? I did file a complaint.

>> Good for you. Yeah.

>> Maybe my language is not, is not the way it should be because I can learn more and more. But I'm no, I'm not quiet. If I have to speak up, I would do it. Either way I can when I'm here. Like, okay, I'm going to try to do it, but... Be patient. This is the first time I'm really talking with students, with professionals about my kids. What I'm, what we've be doing this past five years.

>> Another question, if you could get... is this working?

>> Yes, I can fix it.

>> Okay.

>> There we go. Okay. If you could ask, because usually a lot of folks from the library come. And they were actually really interested in hearing what you came to say. If you could ask for a program or programs, what would they be? In terms related literacy, books, or it could be like anything?

>> I was not ready for that question.

>> Okay, you think about that.

>> Yeah, but I think for small children, it will be really helpful to expand this section where the puzzles are and add more literatura... No puedo decir la palabra...

>> Literature?

>> Yes. Yeah, because that's a really nice way for kids. Like, my kid can learn and expand his language and ability to communicate with other kids. But there are not enough. It's like 14, 15 puzzles in each library. So this is not, that's not enough. Also, I would like for them to have like, like... blankets. Blanket with words on the floor. So we can work with them. Much, much that. So, because most of the, some of the kids doesn't like books. Like David, he now, it is, he's really into books. He loves books. He is reading a little bit. Yeah. And but before he was no books. No anything about books, or he might have he might rip it up, and we don't want that. We don't want that to happen because the resources of the library are great and I don't want to be like okay, my kid did this, and then I come in next week, and he rips another one. So that's not okay. So much even for the

small kids. And for the oldest, older kids, I would love a program, we can, you can, you can include literatura...

>> Literature. Fiction?

>> No, solamente hablo de historia, libros...

>> Such as books, reading books.

>> But another really way it will be like, introduce music. Yeah, instead used to have like, this book, the one who was talking about it, but have music in it, like songs . That's what I've been learning with my son. He's been able to understand and to learn from that as one of their resource, I can think right now. But if you give me time, I can give you a bunch of ideas. If you give me a grant, I can work with you to get it.

>> Yeah, yeah. It seems incredibly doable to come up with some way to think about getting some funding to do some training for public libraries that we could do locally, and then disseminate more broadly. And that at least helps people get some sensitivity for...at least? And to be more patient and to think before you just assume, oh, that's a parent who can't control their child or that's a child who's being a bad kid, or something. No, actually, this is them being their very best because they'd like to be here. And, and to have some sensitivity to that.

>> Just to be fair, some folks from Durham come every week.

>> Yeah.

>> So they've been coming to hear people talk about all sorts of topics on disability. And one of the sessions we're going to have, actually two of the sessions, so one is on Kim Tizzard, she's coming from the Autism Society. She's coming to do a training session specifically on

working with patrons who are autistic. And then, at the end of the semester, we have one librarian who is on the spectrum himself. He's going to talk about library services, right?

>> Yeah. And it's great.

>> It is, it is good to see, for me, as a parent, to see someone who is working, who is on the spectrum, but he is working, he's able to here reach his goal. It's like..

>> Oh, yes. There are librarians with PhDs, there are librarians with master's degrees there. Yes.

>> That's great.

>> I guess little comment, and it starts with, you were saying that you identify as a teacher first. And right now I'm in a course on library instruction, but librarians don't typically think of themselves as teachers. Like, that's not what we have typically think of ourselves are, but we are. So it's like, if, you know, we're trained to work with, you know, kids with disabilities, or be aware of these things. And we can teach others as well, you know, it's like, okay, this isn't a problem. Like, we don't think this is a problem, because, you know, this child is acting the way that the way that they are. But having this this space teaches others, I think as well, that yeah, about how to interact and react and who's allowed in spaces. I don't know if that makes clear sense, okay. Yeah, yeah.

>> It is really a great comment, a great idea. So what happened with me with my family? We have no clue. What I mean, I have like idea, but when it comes to me, to my children, it was like, I thought this never is going to happened to me. So it is a big change. When you see someone and you look at them it's like, right away. Oh, something has happened. She cannot control the kids and you say, it's like a judge. You don't know what happened. Your

mind changed like that. So, and what I will, my family to keep working on it. So I think if I can educate my family, I can share with others. Yeah, at least the basics. It's not specifically autism, but in everything.

>> Any other questions?

For Karen, for either Karen?

Okay, I'm going to stop the recording and I'm going to give us a break and you all can think of your question. Folks online, thank you for joining us.