Disability Series: What You Say and What You Do Matter: Presented by Karla Fitch

Hi, everybody. Thanks for coming out tonight. I'm gonna add, before we get started, I do want to do a quick accessibility check and let if anyone has anything that I can do during the presentation to make this easier for you. Any kind of access issues? Speak up? Speak slowly? If you need me to describe what's on the slides, I'm happy to do that. Is there anybody who needs any additional support for the program tonight? No. Okay, great. Then I will get started with it.

So, a little bit about me. I found Connecting for Kids right before my daughter's fourth birthday. I was one of those overwhelmed, first-time parents. I think I shared with one of the guests tonight, and no one in my circle could tell me how to help my child. So one afternoon, I was in the therapy office, and I found this brochure for Connecting for Kids, and I called the number because I didn't know what else to do at that point.

And I spoke to a woman for maybe 30, 45 minutes. She told me her name was Sarah, and she gave me all kinds of ideas on what to do for my child. Shortly after that, she sent me an email that I can only qualify as a brain dump. And it was just filled with thoughts. And after getting my daughter on track, I came back to that brain dump.

And I'm a trained technical writer, so if you don't know what a technical writer is, I'm the person that wrote those infuriating VCR instructions. I'm trained to take technical concepts and make them so that they are understandable for others. And I looked at Sarah's brain dump, and I said, I can do something with this. And so I started volunteering for Connecting for Kids, taking some of the information that we gathered together for families and making it more accessible for families. So I did that until about 2016.

And Sarah invited me to come on to the staff as a part time employee. And I've been with CFK ever since. In addition to all that, I parent a teenager. I have an incredibly supportive husband, a very cute dog, and a murderous cat. I identify as a person with two invisible disabilities. An invisible disability, in case you didn't know, it's a disability where you wouldn't know it if you saw me.

But I know it, and it does impact my life. I'm currently a student at Cleveland State University, and I'm studying for a master's in social work.

I do have my notes in front of me, which is why I'm making sure I stay on target tonight. So with that, I'd like to extend an invitation to you. I think it's important to invite people into this conversation, and that's because it's not easy. We're not going to get this right on our first try. And as you're going to see a little later in the talk, everyone is still learning how to get it right.

Even me, even other people with disabilities, they're still learning to get it right. Why is that? One of the reasons why is because ableism messes with these deep thoughts that you have that they're embedded with you as you grow up. And I really like this analogy from a class I was taking where the instructor had the students look at two lines like these two on the slide. Take a look.

Which one do you think is longer? Now, if you've seen this before, you know that they are the same length. But if you look at them, your brain is kind of telling you that top one is longer. And that's one of those core beliefs that's inside of you, that's one of those things that you just feel you know is right. And it's the same thing with what we kind of know in ourselves about disability.

We have these core beliefs that have just come up with us, and we're not really aware of them. They're just inside us, and they're something we need to kind of pick at and find out what's going on in there. So with all that said, we're going to mess up despite our best intentions. Others are going to mess up, too. But we are all in this together.

And I congratulate all of you for showing up tonight to show that you're in this together. So we're going to take it with a little grace. And if we do mess up, we're going to learn from each other.

So what is ableism? I really like the definition from a writer. Her name is Emily Ladau. She's a disabled activist writer. This is her book.

And I actually have a copy, my copy on the back counter back there. And I know Westlake Porter has this book in their catalog as well. Emily Ladau defined ableism as attitudes, actions, and circumstances that devalue people because they are disabled or perceived as having a disability. So that's a lot. And what does it mean?

Simply, it means prejudice against people with disabilities or against people we believe to be disabled. So a person doesn't even necessarily have to be disabled to experience that prejudice. Sometimes we look at a person and we say, “we think that person's disabled.” And that deep down core belief -- the line is longer -- that kind of kicks in on how we're supposed to behave.

And here's the tricky thing about it. It's all around us, even for people like me who identify as disabled. It's part of our core beliefs. So that's kind of what I was talking about in the introduction.

So, I mentioned in the beginning that I'm a graduate student, and I'll give you a short story from grad school this past semester, which happened to me. The content isn't super important, but I was reading the textbook and I was supposed to determine between two different assessments -- and which one happens first and what happens next. And as I read the textbook, it was really hard to tell which one was first and which one was next. And so I took the two citations from the textbook and I sent them to my professor, and I said, “Look, I don't understand. These look the same, and I don't understand which happens first.” And she wrote back to me:

“Hi there. I'm thinking that maybe you're overthinking this. And being very literal, these two paragraphs don't really say different things, but I agree that you could read them that way.”

I take things literally. That's who I am. I am a neurodivergent person, and I think very literally, and I think very black and white. And I'm trying to get better at that, but it's still something I'm not good at. And when the professor said that, my first feeling was to become very upset and defensive because she called me wrong, she said, you're thinking too literally.

And I sat with it for a while because thinking literally isn't necessarily bad. In fact, it makes me very good at my job. When I literally explain how to put a computer system together, people understand how to put a computer system together. But I needed to say something to my professor. So after some thought, I replied and I told her, I'm a neurodivergent learner. And I do think more literally than the average student. And I hope that you can help me to sort this out so that I can move on past this little block I have. And after I did that, what was really kind of cool is she said

“Hello again. My apologies. I want to be and need to be inclusive of neurodivergent learners. All these different names in different States and even districts are not necessarily helpful. You can always ask me very specific questions as I've worked in Ohio schools as a school-based mental health provider for a long time.”

So the moral to this story, the reason why I gave it out, is because first, even after spending two years researching ableism and kind of trying to learn to sit with who I am, it still snuck up on me and it still bit me, and made me feel bad when I didn't need to feel bad. The other thing is, by being able to deal with it, I was able to sell the advocate for that and go back to my professor and say, “look, I'm struggling here and I need help.” And I think that that's kind of the important moral for us as families of kids with disabilities is to teach them how to own this part of themselves and then use that to get the help that they need and compete on their level playing field with others.

All right, so we're not going to do a deep dive today into ableism, because honestly, we'd be here for days. But I picked out some of the things that I found were kind of most important in my research and kind of created a framework for us to talk about tonight. When we looked at Ladau's definition, we saw three things that were summarized in the word prejudice: actions, circumstances, and attitudes that devalue people with disabilities. So if we take those three things and kind of mush them all together, we can come up with two simple things for families: what we say, the actions and the circumstances. What we say are the attitudes -- I'm sorry, what we say are the attitudes, and what we do are those actions and circumstances that we create. Right.

So to get it a little bit easier, and because I love mnemonics, I created two the mnemonics for what we do: these actions and circumstances, autonomy, inclusion and dignity or AID. We can aid people with disabilities for what we say. Those attitudes, functioning labels, outdated and offensive language and euphemisms: FOE. We don't want to be the foe.

So I'm going to get a little bit nerdy for a minute and talk about theory. If you study human needs theory, and I think a lot of us have probably experienced this at some time in our lives and heard about Maslow's theory of needs -- I see some nodding heads. So Maslow's was the triangle, and on the bottom was your most basic needs, like food, shelter, clothing. And then as you worked up to the top part of the triangle, you've reached that level of self-actualization of “who am I as a human being?” And you can't get to that self-actualization at the top, “who am I as a human being?” -- unless you have those basics: food and shelter, a job, health care. And then finally at the top, you get that stuff you need.

So there's another theory, and this is by a couple of guys named Ryan Deci. And it's called self-determination theory. And this is the top part again. And that top part is what we want our kids to have. We want them to know who they are and be secure in who they are. Right? Ryan and Deci said we needed three things: autonomy, confidence, and connectedness.

So, the first thing autonomy. That means being in control of what you choose to do. There are two major ways that ableism can get in the way of autonomy for people with disabilities. The first is access, and the second is assumptions. So, when we talk about access, we're looking at the ways that people with disabilities are blocked from choosing certain activities.

The photo on this slide is shared with permission from Courtney Johnson. She is on Facebook at Just keep Stimming and on Instagram as well. And you can see that she's waiting to get in her car, which has been blocked by another vehicle that's been parked illegally. And I think if we have families of wheelchair users, you're probably familiar with the scenario where a car is parked and you can't get access to your vehicle. This act impacts Courtney's autonomy. She can't choose to get into her car because she no longer has access to her car.

So -- the assumptions -- and I've taken another example from wheelchair users. And this is another lady named Nina Tame. She's also on Facebook, and I believe she's under her own name. And she talked about when her husband assists her with pushing her wheelchair. And it's a moment of real intimacy between the two of them. I’ll read the quote from her. It says:

“My third wheelchair is the first one to deliberately not have handles. I've been moved by strangers before, and it's bloody mank.” (that's an English slang for disgusting.)

“This one, my husband, still pushes me. When I get tired, though, he places the palms of his hands on the edge of my back and his fingers wrap around my sides just enough so that it's hot as you like. It's a delicious, intimate moment that only exists because I'm disabled.”

Now, according to Nina and other wheelchair users, it's not uncommon for people to assume that they need help and start pushing a wheelchair without permission. And yes, this is one of those tricky parts of ableism because a lot of these people think that they're doing something helpful and kind.

But if you look at it from the perspective this story here, you can see how that's an intimate feeling to her. And when someone would come up behind her and push her, how upsetting and disruptive that might be. So that's an assumption.

And you have a handout. And as we're going through this, it's got specific do’s and don'ts. So, we're up here in the a autonomy. And so rather than going through them one by one, you can skim them and get an idea of some of the other on there. So one example of a don’t with autonomy would be don't touch a person or their adaptive device without permission. You just don’t touch others. Right?

And then something you can do to promote autonomy is to ask another person if they need assistance. Don't assume. And if they say no, then you respect that.

All right. Moving on to inclusion -- the I in AID. When people are included, we have opportunities to connect. And as we saw, this connection is important to getting to that self-actualization part of life. We need connections with other people to become our true selves.

In the years that I've supported families, at Connecting for Kids, inclusion is one of those topics that just seems to come up over and over and over again. The kids didn't get included in choir practice. They didn't get invited to the birthday party. They weren't given the flier to play the community sports. And a lot of times when this happens, people think that they are doing a favor. Oh, well, we didn't invite your child to come to this party because we thought it might be too overwhelming for them for an autistic child -- or yeah, all the neighbor kids are coming over to a pool party, but your son uses a wheelchair. We didn't think he'd want to come. So this is kind of the inclusion stories that I hear from CFK families

In this story -- and I really like this one -- it shows former President Obama and Haben Girma. And I didn't bring my copy of Haben Girma’s book, but the library does have her book. She's the first DeafBlind woman to graduate from Harvard Law, and she's also a civil rights attorney who works in disability justice for electronics. So she's trying to make websites more accessible for people. Really cool book if you want to read it. Plus, she's a great storyteller.

So in this particular scenario, she's using her brailer to communicate with President Obama. And you would think communicating with a DeafBlind person -- that sounds pretty intimidating. And it would be really easy to just say, “let's talk to some different disabled advocate, someone that's easier for me to talk to.” But in this case, she was included. And not only was she included in this conversation, but Obama invited her to give the opening address at the ADA's 25th anniversary celebration. And I did include the address link on the slides. And you'll all get the slides after this is over so you can look it up and enjoy the address. It's real short, but it's very well done.

So, we've already talked about an example of inclusion and how that affects ability. And the last area in that aid scenario is dignity. And in the example where I shared with Courtney Johnson, that was definitely a breach of dignity. Imagine sitting in a hot parking lot and waiting for your car to become accessible. That's a big issue.

Another issue that seems to pop up a lot in the disability community is access to disabled changing tables. If you take a child who is a bigger child into a restroom, where do you change them? And since I spent a lot of time on access, I talk a little bit about communication, too, in terms of dignity.
So Samantha Renke is an activist and speaker from the UK, and in an article I read by her, she tells the story of how she had gone to the veterinarian's office with her kitten. And in order to have the kitten treated, she needed to sign for the paper to say “yes, I allow treatment.” And the vet asked her if she was able to sign for the kitten, assuming that because she was disabled, she wasn't of a capacity to be able to sign for a kitten.

So again, another situation of indignity, where the language in this case was the issue treated her as someone “less than” and used language to indicate that she was “less than”. In addition to these, people with disabilities experience people talking with baby talk, talking down to them, or who just stare instead of saying hello. So to uphold the dignity, one of the things we can do is address the people with disabilities directly and talk in a regular range of voice, unless, of course, someone requests that you do otherwise. If they ask you to speak louder or softer because of their sensory differences, that's great.

But if I'm going to meet Samantha Renke, I wouldn't go to her and say, “Hi, how cute are you?” *(using high-pitched baby voice)* I would talk to her in my normal voice.

All right, so that's the AID. These are some of the things we can do and change to do a little bit better. Now we're going to move into what we say, which is the FOE. And we're going to address functioning labels, outdated and offensive language and euphemisms.

So functioning labels. This is one -- that this is tricky. And as a parent, I can say this is one part of disability awareness that has been hard for me, too, because as a child, until my child as an adult, I need to advocate for her needs. And I need to clearly tell people, “hey, my child needs this for school. She needs this for community.” A lot of times it feels like it might be easier to say, my child has a “high functioning disability” -- my child has a “low functioning disability,” because people can hear those and they make some guesses about how your child needs to be treated.

And I'm guilty of doing it, frankly. I was looking at some old Facebook posts and found it where I had done it. I was like, oh, I should delete these.

When you describe someone as high functioning, for example, that tends to be the only thing others see. And the reason why that's a problem is because these people who are high functioning don't get the supports they need in the community. So if I described myself as a person with high functioning anxiety, you're going to have less intent to support me when I have an anxiety breakdown. It's the same deal with low functioning, except the opposite end of the spectrum. When someone is described as low functioning, these people, they tend to get written off.

“This person is so disabled that I can't interact with them. They're so disabled that they have nothing to give back to me.” They tend to be objectified, and people don't tend to think of them as human beings. So in both ways, both high functioning and low functioning can tend to hurt people.

So what can we do? One of the things the disability community has advocated for is to use both strengths and needs to describe a person. So in an example, with a child who might have some disabilities with understanding and knowing what to do at the right time, you could say, “my child can understand what you're saying, but he needs extra time to respond.” So I haven't really said my child's functioning label, but I have said exactly what he needs. He needs a little bit more time for you to process what you've said.

Another example, “my child loves being around people. She needs help to move so that she can see you.” So this might be describing a child who uses a wheelchair. A third example, “my child is good at math, but he can get frustrated quickly. He needs some help remembering his coping skills.”

Again, we're not getting the functioning label into there, but we're clearly giving what this child needs in order to do and be successful.

So outdated and offensive language. On this one, we get into some of it where it's just obvious. One of the most popular campaigns that we tend to hear about is Spread The Word to End The Word. And the word they're talking about is the r-word or “retarded.” Now, this is an old diagnostic term, and many people who are older in the group will remember when this was the diagnosis. And when you spoke about someone who had a lower cognitive ability, you would call them “mentally retarded.”

And it brings a lot of questions of what happened. Why is that a bad word now? Why aren't we allowed to say it anymore? And it's an interesting thing about the way people use language.

So some of the very first terms to describe cognitive disabilities were “idiot” and “moron.” And these terms were, again, diagnostic terms. They were used -- and I forgot the person who authored it -- but there's a well-known work that was a classification of the levels of disablement. And as people took these terms and started using them in the commonplace, they associated them with things that were bad. The same thing happened with “retarded.” In the 80s growing up, I remember my friends, and if something we didn't like or something was bad, they'd be like, “oh, that's retarded.” And so that word got associated with something bad. And now we've moved away from using it.

So that's some of the obvious stuff. And then there's some stuff that's not so obvious. It's a little more subtle, and it really associates with some of the ways that we think about disability. You might see people say a “victim of.” This is common with people who have burns – a “burn victim.” Someone who “suffers from” something. “My child suffers from autism.” These put disability as a really negative thing and can be rephrased. Instead of “a victim of” -- a burn survivor. A person who is “autistic” instead of “suffers from autism.”

“Wheelchair-bound” is another one that's really triggering for a lot of people because people in wheelchairs actually do leave them. And I mention Nina Tame, and she has a really cute Facebook post that she did recently where she's gotten somebody to tie her to the wheelchair, and she says, “I'm not wheelchair bound. I can actually get out.” And so we want to associate these people as a “wheelchair user.” They use the wheelchair to get around, but they're not bound to it.

Even some of the words we use to describe our everyday lives like “normal” and “regular.” It implies that there's one default choice of what people should be. And I don't actually see anyone in this room who is the one default choice of what people should be. I see people with brown hair, white hair, brown skin, white skin, red hair, short, tall. There's no default, so there's no normal, there's no regular.

So I’m showing a picture of Lydia X.Z. Brown and they have a really great glossary of Ableist terms on their website. I will warn you in advance, they get a little sweary in there. So I've also included some links at the end at the end of your resource guide with some more G-rated resources. If you want to avoid the sweary parts of Lydia's, they have it so that there's like, lots of dots. And if you keep scrolling down past the lots of dots, that's when you're going to get to the sweary parts. But I like their particular dictionary because they give you options of what to say “instead of.” You see this word and here's what to say. So that's why I bring Lydia to the front.

And by the way, some of these words are literally stuck in our vocabulary. One of the words that was really hard for me personally was “lame.” I am so guilty of saying, oh, “that's lame.”

What do you say if you slip up? You've said it, and now you're like, oh no! The first thing you have to do is just own it. “Oops, that was rude of me. I'm sorry, I'm trying to do better.” And then you correct yourself. Instead of “that’s lame,” you could say, “well, that was not a great choice” or “that was boring.”

And then you just move on. Because the longer you dwell on the mistake, the more you're setting up that power difference between the person that you're talking to and yourself. And you're saying, “I expect you to accept my apology now,” and maybe the person doesn't accept your apology and they need to be free to do that. But in that time, as you're sitting there waiting for them to accept the apology, you're just making it weird.

Euphemisms are another one that are really tricky to navigate, and when I first heard this word, I had to look it up. So I'm going to share the definition with everybody else. A euphemism, according to Merriam Webster, is “the substitution of an agreeable or inoffensive expression for one that may offend or suggest something unpleasant.” So if you're thinking about common examples of euphemisms, people will often say, “he passed away” or “we put down the dog” instead of saying, “they died.” When you were referring to someone who is sick, they might say, “oh, they're under the weather.” People who get fired from their jobs are “let go.” So these are ways of sort of couching the language and saying it nicely so that you're not offending somebody.

We've also come up with more agreeable ways to talk about disability, because as we've seen, disability isn't everybody's favorite topic. And some of those ones that you see really commonly are “differently abled,” “handi-capable,” “challenged” -- so like “mentally challenged,” “physically challenged” -- and “special needs.”

And don't get me wrong, there are a lot of things about disability that are unpleasant. When I was working on this presentation, my fingers were so swollen it hurt to type, and that was unpleasant. But I'm not unpleasant -- at least not because of my disabilities. And to associate euphemism with the disability is saying that everything about the disability is unpleasant. So when we speak more clearly and just use the word “disabled,” for example, we avoid that whole association with the negative.

And this photo I have is Lawrence-Carter Long. He's the director of communications at the Disability Rights and Education Defense Fund. And he's also a standup comedian individual with CP. And he's the creator of the #SayTheWord campaign, which was response to Barack Obama's -- one of his State of the Union speeches -- I believe.

And in this particular speech, he called out all different forms of diversity. You name it, he called it out for diversity. He did not mention disability. And so Carter-Long came back and said, “just say the word, say disability.” There was a great article about him on NPR and they asked him, what do we lose when we don't say disability? And his response was:

“We lose perspective. In 2016, anyone who would dare assert that race doesn't matter or that they see the person, not the gender, would instantly and I think rightfully be called out as either naive or ignorant. Similarly, to suggest disability is simply a difference and has no impact on a person's life is a very privileged position to take. Most disabled people don't have that luxury. The ascertain flies in the face of reality and minimizes the very real discrimination disabled people face.”

For many of our kids, disabilities can be a lifelong circumstance. And I personally believe that helping our children to build a positive identity for themselves includes recognizing that they are different and giving them the language to describe their differences. Which is going to bring me to my final point about the program.

And when I was researching this project, I had a conversation with a mother, and she used the word “special needs” to identify her son. And I said, hey, the disability community has spoken out that they prefer “disabled” over “special needs.” And she replied to me that her son had chosen that word, that the phrase empowered him and it made him feel that he was special and that his needs -- it was a way for him to advocate for his needs to get met. It made him feel pride in who he was.

The reason I share that story is because the language is our own ultimately, some people will choose different ways of saying things and that empowers them -- and that is their choice. And the way we can really give them the autonomy, the inclusion and dignity is by respecting that choice. We can still educate them about the different options available and what the community prefers. But if a person says, I want to be called “special needs,” then we’ve got to respect them.

So some of the voices I mentioned in this presentation and I've included them at the end along with their information so that you can follow them. So when you get this presentation afterward, you'll be able to find them. And I tried to select from a diverse group of people so that we're getting different disabilities and different cultures and backgrounds included. And then I do also have the articles that I mentioned and some of the books that I've used to create the presentation and a lot of the books are on the back counter too, if you want to take a peek at them.