



ADA Live! Episode 113: Stories of Parenting with a Disability

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Guests:

- Dave Matheis, Kentucky Coalition for the Rights of Parents with Disabilities
- Jason Jones, Disability Specialist, Human Development Institute, University of Kentucky
- Kimberly Tissot, President and Chief Executive Officer, ABLE-South Carolina
- Kara Ayers, PhD. Associate Professor, Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD), Cincinnati Children's Hospital Medical Center, Division of Developmental and Behavioral Pediatrics

Host: Janice Baldon-Gutter- Senior Adviser on Diversity, Equity and Inclusion at the Southeast ADA Center

Recording: adalive.org/episodes/episode-113

Dave Matheis: Hello, I'm Dave Mathis.

Kimberly Tissot: Hello, I'm Kimberly Tissot.

Kara Ayers: Hi, I'm Kara Ayers.

Jason Jones: Hi, I'm Jason Jones and you're listening to ADA Live.

4 Wheel City: Yo. All right. Let's roll. Let's go.

Janice Baldon-Gutter:

Hello, everyone. On behalf of the Southeast ADA Center, the Burton Black Institute at Syracuse University and the ADA National Network. Welcome to ADA Live. I'm Janice Baldon-Gutter, the program outreach coordinator for Diversity, equity and inclusion at the Southeast ADA Center. Listening audience, if you have questions about the American With Disabilities Act, you can use the online forum anytime @adalive.org or call the southeast ADA Center at 404-541-9001. All calls are free and confidential. Now, according to the National Council on Disability Report that is already distributed, rocking the Cradle, ensuring the rights of parents with disabilities and their children. 6.1 million children in the United States have parents with disabilities, which is nearly 10% or one in 10 children. Despite the increasing number of people with disabilities becoming parents, the report also found that most still struggle with family, community and social concerns about the choice to become a parent.

In today's episode, we will be talking about the unique role of parenting with a disability, as well as a new book written by our guests, A Celebration of Family: Stories of Parents with Disabilities. And we welcome our guest today, Dave Mathis, the Kentucky Coalition for the Rights of Parents With Disabilities. Jason Jones, disability Specialist Human Development Institute, University of Kentucky. Kimberly Tissot, President and Chief Executive Officer Able South Carolina. And Kara Ayers, PhD, Associate Professor, Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities, Cincinnati Children's Hospital Medical Center, Division of Developmental and Behavioral Pediatrics. Please welcome everyone to the show.

Kara Ayers:

Thank you.

Dave Matheis:

Thanks you.

Jason Jones:

Thanks, Janice.

Janice Baldon-Gutter:

Great. *A Celebration of Family: Stories of Parents with Disabilities* tells the stories of 30 families where one or both parents have physical, mental, sensory and are intellectual disabilities. The stories illustrate the infinite variety of the American family. Why was it important to share these kinds of stories? Dave, can you speak to this?

Dave Matheis:

I've been working part-time for a Center for Independent Living in Louisville for the last few years and by law half the employees of a independent living center have to have a disability. So I was talking to a couple of the employees who had disabilities and were also parents and they were talking about some of the challenges and experiences they had. And we decided after doing a few panels at events led by Jason Jones, we decided to maybe we had enough material for a book. And I think when we sat down to starting put the book together, we had really three reasons why we were doing it.

First, we wanted to demonstrate how parenting is possible for everyone, even if you have disability and we have a variety of disabilities in the book. Second, we wanted to show how societal bias and discrimination still existed toward people with disabilities becoming parents, which Jason Jones expertly outlines the introduction to the book. And finally, I think a lot of the parents wanted to have a guidebook for young people with disabilities wanting to be parents, a guidebook to demonstrate how it was possible and what they might consider when wanting to do that. So that's why we put together the book basically.

Janice Baldon-Gutter:

How did you approach these families to tell those stories? What was their reaction to being asked to share their experiences, Dave?

Dave Matheis:

As it turns out, I knew a lot of parents with disabilities. So most of the people in the book I know professionally and personally and most just about anybody I approached was pretty receptive to being involved. There are 30 stories in the book. Two of them are reprints from other sources, but 21 of the 30 I knew personally, and then I found the other folks like Kara through contacts. I did not know Kara personally before we put the book together. So what I found incredible really, one of the couple impressions that doing the book made on me was that how open everybody was to talking about their parenting experience. Extremely open, sometime painfully open in a couple of cases. And of course, it dawns on you that everybody wants to talk about their kids and so there wasn't a problem getting people talk about it, that's for sure.

Yeah. Everybody was pretty open to it. I didn't have much trouble soliciting people. The one area we had an issue with was people with intellectual disabilities or autism couldn't get anybody in Kentucky, I could not find people with that disability who were parents who wanted to talk about it for some obvious reasons, they didn't want any attention brought to them. So I have to thank TASP, the Association for Successful Parenting for finding two people that fit that description for participant, one is in Cincinnati, Lindsey, and one is in Washington State, Ivanova. So thank Kara for linking me to TASP and those individuals.

Janice Baldon-Gutter:

Great. Thank you for letting us know that and if anyone else has anything they'd like to add, please do so. Jason, you wrote the book's introduction. It provides a brief history of parenting with a disability in the US. Historically, what was society's view of people with disabilities becoming parents and how has that view changed?

Jason Jones:

Well, I think you could probably make the argument that the view in a lot of situations hasn't changed. Maybe more we're not as brutal with the way that we go about doing that, but the attitudes are still changing. Early on, it was the movement for to just get rid of any chance for people to have children, if they had a disability through the eugenics movement, the idea that we would sterilize or we would force people to abort, those kinds

of things. And some of those practices still continued up until the '70s, where there were several states where they could just say they could force you to be sterilized so you would not be able to reproduce. And unfortunately that fall fell more on women than men.

And we still see stories all the time of people who lose their children because of just societal misconception of what parenting is and that you have an inability to parent, because you have a disability that you don't have supports in place. Sometimes these knee-jerk reactions are made at the hospitals right after a baby is born, where a nurse makes a decision that someone is blind or someone is deaf or someone has a physical disability and they feel like they're not going to be able to take care of their kids. Someone who's not connected to them at all. So we've seen over the course of the last about 100 years now, go from forced sterilization to now we're starting to talk about what we can do to eliminate some of these barriers and some of these misconceptions.

And honestly, to legislate at some point, we still have several states who can still take your children just based on the idea that you have a disability. It's just a perception, it's not necessarily the truth. And I'm glad Kimberly is with us all today because South Carolina's done some wonderful work, Kara is on, and they've done some great work in Ohio, and we're trying to follow in their line to get some of this legislation passed here in Kentucky to just bring us up to 2023 now. But it's scary to think, I'm 48 years old, and then in 1974, you can still be forced to have to be sterilized or to have an abortion just because you have a disability.

Kara Ayers:

I was just going to say I really like the way Jason said too that attitudes haven't changed as much as maybe that they've become more covert because we still see these things happening. It's just we're as a society a little more secretive about what the goals are. So girls, women with disabilities are still sterilized sometimes the excuse given now is that it's to help manage their periods or their menstruation. There was a very high profile case with Britney Spears and I think many people looked at that case as she was under guardianship or in California it's called conservatorship. But as part of that, she was also not allowed to have a form of birth control removed so that she could have more children.

So that case too was an example of how society's attitudes have continued to pretty forcefully declare that people with disabilities can't be parents.

Janice Baldon-Gutter:

Thank you very much for those comments. Anyone else? Any other comments? You're more than welcome to join in on the conversation for the questions. Any other comments on that particular idea?

Jason Jones:

And I'll just say that this has been an attitude that's not only just in the back of people's minds, but early on the idea, Buck versus Bell, one of the famous cases where she was forced to be sterilized after having a child. So she couldn't reproduce anymore. One of our most famous Supreme Court justices said basically one generation of imbeciles is enough in his opinion when they wrote to uphold that particular ruling, it's sad to know that that ever happened in our country. We see things and I point this out in the introduction, that we heard these things going on in Germany under the Hitler regime and we're so appalled by it, but the idea of eugenics started here, unfortunately.

Janice Baldon-Gutter:

Thank you very much for the next question. What are some of the unique obstacles that a person with a disability may face, Kimberly, Kara?

Kimberly Tissot:

This is Kimberly. I think the biggest obstacle that parents, what disabilities face in the very beginning, it's really just perceptions, misconceptions about how we may be taking care of our children and how that looks and that looks different for any parents with without disabilities or with disabilities. But I think when a parent has a disability, it's held to a different standard. If we're not doing it one way, sometimes we are judged. And I think as your child enters school, that is a different obstacle, too. As you're starting to deal with the barriers that students with disabilities deal with every day in the school system is just schools not being set up for children with disabilities, but let alone parents with disabilities

when we're going in there to have meetings and needing access to our children. I think overall it's truly the misconception about what we are, how we are everywhere. There are parents with disabilities throughout the country, everywhere and we're going to be in stores and your schools and everywhere and how people with disabilities just are not considered being a parent in society.

Kara Ayers:

Yeah. This is Kara. Yeah. I mean, when I think of what our unique obstacles are, it would be as Kimberly mentioned, those access barriers. But we also share so many obstacles in that, there's a lot of judgment and maybe it's connected to the passion that we all have around parenting, no matter if you have a disability or not. But there's a lot of beliefs about who is right and what's the right way. But when I look at approaches to parenting that have different names like gentle parenting or unschooling and there's opinions and judgments connected to those in different facets, it's interesting that our approaches are not viewed really in the same way and that all of us have the same general goal of raising our children to be the best they can be.

And under the scope of our values, whatever those may be, for whatever reason, ableism one huge reason, we are not given the same, I guess, bandwidth of freedom approach in parenting that you see that many non-disabled parents embrace pretty creatively. There's quite a range of approaches to parenting and parenting with a disability. The small differences that we may have often to me fits right in that spectrum. It's really not all that unusual or unique.

Dave Matheis:

And this is Dave, just to reinforce what has been said and connected to the last question. Some of the obstacles terms, perceptions start even before the birth. I don't know how, there's several stories in the book about medical professionals telling women that they cannot have children and shouldn't consider it. And the two people I mentioned earlier, Lindsey and Ivanova also talk about being in a hospital with their child at birth and fearful that they might take their child away right there in the hospital.

Janice Baldon-Gutter:

Any other comments?

Jason Jones:

I love what Kara says because basically at the end of the day, we always talk about this in these panels, but we're all parents, right? I mean, parenting is about 99% the same for everybody. Now, personalities of children and circumstances and geography and school systems and all that stuff are sort of all the things that we have to maneuver as well. And the disability aspect is just on top of that. But for the most part, I look around at parents that are my peers and I don't see a whole lot of difference in parenting. I've said it a million times, it's the best and the worst thing in your life. And I think any parent, regardless of whether or not you have a disability agrees with that.

It's the best thing that ever happened to you. And sometimes it's the worst when your kids are sick or when there's an issue, that stuff. But the worry's the same and that's always sad to me is that if you have to worry about things that are outside of the normal scope of parenting, then I don't know, I don't like to say things that's not fair. But it also creates a massive strain above and beyond the strain of parenting and which is the most difficult job in the world. So-

Janice Baldon-Gutter:

One of the things that stood out in the book was the resilience of kids to adapt to a parent's disability. Can you talk about that, Kara? Let's start with you.

Kara Ayers:

I am super fascinated by this not only just personally, but as a researcher. The term that we use in research to describe this in an academic sense at least is mutual accommodation. Which means that both of us parent and child are, that's the mutual part, are accommodating each other and working together. And I've never been a non-disabled parent. I'm a full-time wheelchair user. I'm also a little person. So sometimes that factors in even more than my wheelchair does in terms of what I can reach or how much I can

carry as a parent. But I suspect that non-disabled parents adapt with their kids as well. I can only speak for our house though, but to give some examples of how it works in my house, my kids, I have three kids, learned pretty early that for me to help with things like shoes, they have to climb up on a higher surface so that I can reach their shoes because it's not as easy for me to hop out of my wheelchair and get on the floor.

They also have picked up on little things that we've really never talked about that they just observe. I know my youngest now is five, she still likes to hop on my lap sometimes in my wheelchair, but she knows that it's easier for me to push her if we're on our hardwood surfaces. So she'll say, "Can I get on your lap when we get to the hallway?" And to me, that's telling me that she recognizes she wants me to carry her, but she knows that it's easier on the hardwood. So we're both adapting to each other. And you see this in families with all sorts of disabilities. Working together as a family is a big goal and value of my crew here. But I'd also note that my kids, when I think about resilience, I think about something that the kids are bouncing back from or overcoming adversity.

And that really comes more in the shape of how they bounce back and respond when we face negative attitudes from others. So my kids very early on have noticed that people stare at us in public, sometimes they've asked very loudly about why that's happening in public, but as they've gotten older, they have learned to be resilient in the face of that. We talk about it when it bothers them and we move on with our life. We don't let it stop us from doing what we want to do. But when I think about resilience in terms of what do they have to overcome, I definitely think it's more examples like that than it is figuring out the little quirks of our family and how we can best work together. Because to them, that's just their norm. That's always been how it is for them and they don't see that as anything hard or that they have to overcome.

Janice Baldon-Gutter:

Thank you, Kara. Anyone else? Dave, Jason, Kimberly?

Jason Jones:

I think one of the cool ways that my... Because Kara covered a lot of the ways that kids adapt to your disability, right? But one of the cool ways is in schedule. My kids know that in the mornings, we don't get up and get out fast. I mean, they do have to go to school and stuff, but one good example is at Christmas, a lot of kids are up at 6:00 in the morning and ready to rip open packages and stuff and my kids just chill because they know dad is probably not going to be up at 6:00 in the morning because it takes an hour and a half or so to get up. So they just wait on us, they wait on us for a lot of things through routines and that stuff. As they get older, they recognize it even more and they say, "Do you have to do this tonight?"

Or they start to adapt to the schedule, which is a neat thing that I've seen more as they get older. But when I was younger, it was something I really worried about even before having kids period was, "Can I provide the type of things that a lot of parents stereotypically provide teaching or throw ball or whatever those things are. It really takes care of itself. It really does. And it's a blessing sometimes to see how they do adapt. And I would agree with Kara wholeheartedly, the resilient part is the push against society versus the ability to make it in our own household because this is a safe environment that they do well in, when we step outside the doors, when they see the stairs. And now, we're going to be the age where they're their friends ask, "What's wrong with your dad?" And that stuff. And so they're forced to deal with that and that's difficult sometimes, but they get through it really well.

Kimberly Tissot:

Yeah. And this is Kimberly. What I would add too is from the very beginning too is your kid, they're very familiar with disability, so growing up in your household. They understand what adapting is. They understand that we may do something a little bit differently than other families, but that's just part of the way that our family does it. And so disabilities is a part of their lifestyle. And I think if you sit back and look at it, I see my kid and he's around people with disabilities, he's been around people with disabilities all his life and he doesn't look at you disability as being a negative thing.

Janice Baldon-Gutter:

I know I have grandchildren now and they're used to Granny J moving fast and now Granny J's a little slower with mobility and they'll look around the corner and they'll see me coming up the steps saying, "Granny J, can we help you?" So they are very resilient."

Dave Matheis:

This is Dave 18 of the 30 stories were done with Zoom interviews and one of the questions Jason and I came up with was, what adaptations or assisted technology did you have to implement to become an effective parent? And invariably the answer was some form of, I think my children adapted to me more than I had to do to adapt to them. And I just think that they learn what becomes normal for them, there's nothing to it.

Janice Baldon-Gutter:

They're so sweet and just resilient. They bounce back and they see things and they sense more than we think they do. Anyone else? Okay. Other steps a parent should take to prepare a child for the questions, behaviors, attitudes they might encounter because their parent has a disability. Kimberly, could we start with you and then we'll ask everyone else to chime in?

Kimberly Tissot:

Yeah. And I thought about this question a good bit. I don't know if I did any really true steps. I think that this was just such a natural process of parenting. Is my child just learning about disability and adapting? Of course, he has got in questions from schools or his peers asking, "What's wrong with your mother?" And he'll respond as, "Nothing is wrong with my mother, it is just who we are." And of course, he knows I have a disability, but he doesn't think it's anything that is different from other mothers. So I don't think he's exactly comparing us, but he just knows that this is part of our life. So I don't think I did any steps and just my parenting abilities very early on, Carter my little boy is adopted and we got him very early at six weeks.

And so there's just some things that I prepared for myself just with getting ready to parent him and know of course I could never carry him and walk at the same time. So I used to

push him around in a stroller versus carrying and little things like that I did and made sure and his bedroom was upstairs in our house and just made sure that if there was a fire that there was going to be a very safe route to get him out of there. You plan ahead like that. But I don't think I really planned ahead of the ableism that he was going to experience later on. I think he just conquered that pretty well on his own.

Kara Ayers:

And this is Kara. I definitely did, I'd say approach this in a structured way, probably because it was something that I was very anxious about. Jason mentioned sometimes we get these things stuck in our head, can we throw a ball? Or for me, it was how am I going to take my kids trick-or-treating, which is one night a year. But I was very anxious about that before having kids. And another thing I was really anxious about was how they were going to approach questions and attitudes from others like this? So I think for that reason maybe I did approach it with steps. And so we read a lot of books and I actually practiced with them scripts and not that they'd say word for word like a robot, but I wanted them to feel like that they had confidence in what to say when somebody invariably said, "What's wrong with your mom or dad?"

Because we are both parents in wheelchairs. And I also recognized, as Jason said, there is the really abrupt switch when that question maybe comes from a stranger or a random kid on the playground versus your friend you're hanging out with when you're 10 or 11 or 12. That's a big difference socially. So for us, we practiced it, we talked about it, we still do. And we talk a lot about tone, about how it's very different when a kid or sometimes an adult at the grocery store or something says, "Oh, what put you in that wheelchair or something?" That's very different than sometimes people will say it with a tone. I'm like, "What's wrong with you?" So it's probably my anxiety around this, but we do a lot of practicing and talking around that.

Jason Jones:

Yeah. Just to add a little bit, I think it's something that continually happens over and over and especially when somebody asks them in kindergarten, it's different than when

somebody asks them they're a freshman in high school, you have a different conversation. There's a lot more depth to the conversation, response and question the person that's making the question to. So it still comes up from time to time. I remember the first time it came up for both of my kids and they both came home and told me that they've got that question and we had to have that conversation. And what's oddly enough, and I don't know about the other people on the panel because I know Kara's husband has a disability, but they also get the hero worship of my wife.

That happens a lot where somebody says, "Your mom's amazing for taking care of your dad and all that stuff." I agree she's amazing for a lot of reasons. But it's funny because that's something that we don't think about too is that the other side of that is that they have to hear sometimes about how wonderful their mom is, which is not a bad thing to hear, but sometimes for the reasons that are assumed, I just like to think she loves me and she's not just here to take care of me. So-

Kimberly Tissot:

Jason, this is Kimberly. You're very right. My husband does not have a disability. And I remember when my little one was very, very young. People would look at him as he is the caregiver for me and my child. And I'm like, "Do you see how tired I am?" I stood up with him last night. So I don't think that they understand how you can not alone take care of yourself but also take care of a human, a child. And so it's quite funny that, "Oh, your husband's so amazing," type of stories. I'm like, "Yeah. He's amazing because he married me."

Janice Baldon-Gutter:

Thank you Dave, Kimberly, Kara and Jason. Anything on the live listening audience, if you have questions about this topic or any other ADA topic, you can submit your questions online or call the Southeast ADA Center at 1 404-541-9001. And now let's have a word from this episode's sponsor and we will return.

Speaker 7:

A Celebration of Family: Stories of Parents with Disabilities contains the stories of 30 families and every family, one or both parents have disabilities. The stories illustrate the infinite variety of the American family. And the course of discussing their family experiences, the parents cover a number of topics, many parents talk about adaptations and accommodations they made to be effective parents, but even more talk about how wonderfully adaptive their children were to their disabilities. The stories contain humor, compassion, and gratitude. They are proof that one thing you can get any parent to talk about is their children. Order your copy now.

Janice Baldon-Gutter:

Welcome back. We are talking with Dave Mathis, Kara Ayers, Jason Jones and Kimberly Tissot about parenting with a disability and their book, A Celebration of Family: Stories of Parents with Disabilities, some of the parents in the book Adoptive Children, what impact would you say the age of the child or the age and disability of the adoptive parent might have had on adoption approval? For those who are adoptive parents, could you share your thoughts on this?

Kara Ayers:

Yeah, I think Kimberly and I are. So my child was adopted at seven and he was adopted out of age order, which is somewhat unique in the adoption world, meaning that he became our oldest child instead of our youngest child. So my daughter was four at the time. I think that at some point, I think we reached and surpassed the threshold of unique or diverse. So with that, it became not all that a big deal, but he was oldest instead of the youngest. So my son is also a little person but has a different type of disability, different type of dwarfism. He has achondroplasia. So meeting him, he wasn't aware of what his disability was. He had never been told or taught that, he'd actually been told to say that he was younger than he was. So as not to stand out as someone so small for his size or for his age. So for us, even though we met him at seven, it was really just the start of him learning that he was a person with a disability and also having two parents with a disability.

He had likely in China, never seen adults with disabilities, adults in wheelchairs that were out and about and doing anything in society. So all of that was just really new for my son, which is when I say, "I don't know that one piece of it really stands out because there was just so much newness." But we've worked really hard on building his pride around disability. I do think it's very different. I see a difference between my daughters and him, but also my daughters don't have disabilities. But they had that early exposure books and stories and messages from us from even before they could talk. Whereas Eli really had not had any positive experiences related to disability before we met him. We've definitely tried to get those since then. And we're really fortunate he's been home longer than he was there, so now he's 15, he's been with us for eight years now and it'll always be a journey like all of it. So-

Janice Baldon-Gutter:

I think we had another adoptive parent?

Kimberly Tissot:

Yeah. Yeah. And this is Kimberly. I adopted my little guy when he was six weeks. And so he was in the child welfare system and he has a different type of disability as well. He's on the fetal alcohol spectrum, which means that he was exposed to drugs and alcohol before he was born. And so from a result, he has intellectual disabilities and so he definitely has a sense of disability pride. I think it has helped. I know most recently with me being his mom, I know that we have talked about ableism quite a bit because he's starting to experience that more in the school systems. And so it has been nice to be able to have those conversations where I have been able to truly understand the type of pain that ableism can cause. And so that has been helpful. But I will tell you, just getting to the adoption process, I don't think that truly age was part of our story as much.

I think it was more around the bias that the state child welfare system had towards people with disabilities. Husband and I went to go adopt and I was told right directly in my eyes that I was unable to adopt because of my disability. Not anything else. It was only because I had a disability. And so obviously, that is discrimination on the basis of

disability and not only a violation of the ADA, but also a Rehab Act because it is a state agency that is operated with federal funding as well. So it was more of that bias that those attitudes, it was not anything necessarily in their policies, but there was a glitch and an issue within state law that we did have to go back and change it later.

Janice Baldon-Gutter:

It's very interesting how the state laws vary from state to state, I don't know, many of these things.

Kimberly Tissot:

Oh, yeah. It is all over the place certainly. And I think it really goes to show too how much the ADA and Rehab Act is often disregarded in States. A lot of state laws just do not mesh very well with these huge pieces of Federal Legislation.

Jason Jones:

Yeah. Kimberly, it also varies how they're enforced. I mean, some states don't even enforce their own laws the way that they should be or they enforce laws that aren't really laws when it come to-

Kimberly Tissot:

Absolutely.

Janice Baldon-Gutter:

Okay. This question is related to our previous question of what have states done to protect the rights of people with disabilities who are or want to become parents? Kimberly, you've worked at the state level on these issues. Can you speak to this?

Kimberly Tissot:

Yeah. Yeah. So South Carolina in 2017 we passed a bill called the Persons with Disabilities to Parent Act. And that bill really came out of a lot of injustice that we saw, not

only obviously with my story of being denied adoption in the very beginning, but we kept seeing the story over and over, and over about parents having their children removed because of intellectual disabilities, because of being a wheelchair user. I mean, just really ridiculous reasons where our child welfare system wasn't even giving parents an opportunity to parent when they're very capable. So we decided to stop it. We wanted to make sure that we did everything in our power within South Carolina to not only protect the rights, but to stop all this discrimination from truly occurring. So in South Carolina, there was state law that said that any type of disability could mean removal, meaning that the Department of Social Services could come in and remove your child on the basis of disability, which is very old school and obviously not appropriate.

And so we wrote a bill, of course we had a first attempt and it did not do well because the bill, we added a lot about reproductive assistance as well. And so in a mostly conservative state, we had to really work on the language to beef it up to really meet the requirements of the ADA and the Rehab Act, but also to make sure that our child welfare system is educated, our court systems are educated. And so we wrote in 2016 and passed in 2017, a pretty progressive disability rights law here in South Carolina. And again, it's called the Persons with Disabilities Right to Parent Act. And it requires that no parent on the basis of disability will have their child removed. But it also puts on additional requirements for our state department, child welfare system, our court system, our law enforcement, to ensure that they are accommodating parents with disabilities, that they're making sure that they're have the correct supports in place to be able to parent and that no child is removed or no child won't be adopted on the basis of disability of the parent or prospective parents.

So this law not only protects parents who are giving birth to children, but also protecting people who are wanting to foster and adopt. So those prospective parents as well. Once you pass legislation, you pass legislation. And so there's still a lot of work to do around that topic. In our state, we are very fortunate of our organization, which is a Center for Independent Living. We have been able to provide modules and provide the training to child welfare systems, which is the best, coming from a disability-led organization to making sure that the child welfare system is understanding parenting rights from the

disability perspective as well and how to adapt to different parenting styles. And so it has been going really good. We've got several case laws now that this law really did come in and protect the parents' rights, so we are always still working on it and also helping other states. But our state became the 14th state to pass legislation and I think it's one of the most progressive pieces of legislation throughout the country as well.

Jason Jones:

She's understanding that by the way, the work they did in South Carolina is the gold standard that all the rest of us are trying to get to at this point.

Kara Ayers:

For sure. This is Kara. In Ohio, we do have a bill that just merely prohibits discrimination on the basis of disability. And we have been working for years to get that through. As recently as this week, it was to go to what we were hoping would be its final committee hearing. And this whole discussion emerged about, "Well, what will this cost the state?" And then the discussion went towards, "Well, students with disabilities in schools cost a lot of money and maybe this'll cost a lot of money, too." And so the discussion stopped. We had to reeducate the policymakers that, "No, we are actually not asking for what I would hope we ask for down the road," which is actual supports of parents with disabilities. Like Kimberly's discussing in South Carolina.

We are starting from the bottom basement of just don't discriminate. That's all we're asking. It doesn't cost any money not to discriminate. So this week, we've been educating our representatives again and we hope we have just till the end of the year, until Ohio, it will sunset and we'll for the fourth year in a row have to start over. But we're continuing to fight because it's important, but it's frustrating. But I'm really grateful that we have Kimberly and her work that she's done in South Carolina to look towards as that beacon of hope. We hope to get there someday.

Dave Matheis:

And this is Dave. And I don't know how Kimberly accomplished what she did. It's pretty amazing. We've started an effort to do something legislatively in Kentucky. We haven't made as much progress as Kara has, but I do want to thank Kara and Kimberly both for being generous with their time and with our coalition for the rights of parents with disabilities and for their advice.

Janice Baldon-Gutter:

It sounds like South Carolina is really the flagship. That's great.

Kimberly Tissot:

That's a great thing because we're not always the lead on things.

Janice Baldon-Gutter:

If there's a person with a disability listening who is considering becoming a parent, what advice would you offer? Are there support organizations and resources you would suggest? Let's go round robin. Jason, what would you suggest?

Jason Jones:

You should probably read this book. No, all seriousness. I mean, I think Dave would probably talk about this a little bit, but he said one of the thing three things we wanted to accomplish was one is to be a resource with the book in the first place. But the biggest thing to me is, and I've answered this question the same way every time, find somebody who has done it. I mean, there's no better way than to immerse yourself in the idea of and to get behind something that's already done and mentoring is such a huge deal. Find a parent. I'm always willing, if somebody asks me, it goes back to what Dave said. We all want to talk about our kids, as you ask me questions about what it's like to be a parent period with or without a disability, you're going to get an answer.

Most parents are going to be that way. But the best thing for me was I had another friend who was quadriplegic. He had a child that's about seven, eight years older than my children and I just watched him go through the process and then when he came my turn, I

turned to him and it made a huge difference. Find out somebody that's done it and don't listen to the noise. There's so much noise out there. I mean, when I hear that doctors say, "You shouldn't reproduce." Shut up, right? I mean, get out of the way. I think we put way too much talk and what doctors say, we forget at the end of the day, doctors work for us. We don't work for them, they're not our supervisors. Give me some medical advice if I need it.

But as far as staying out of my decisions that are going to affect me profoundly for the rest of my life, because I will tell you, there's nothing better in the world than when those kids get off the bus or when I get home after work or we're going to a game, whatever it is, seeing the world through the eyes of your kids, you can't beat it. So don't listen to the noise. Do the pros and cons if you need to, find a good person to mentor you and just pay attention to what the rest of the world is doing as far as disability. Protect your kids like any other parent would, but don't not do it because some idiot tells you not to.

Kimberly Tissot:

I love how frank Southerners can be, Jason. I love that. I would say to tell doctors to shut up as well, but in all reality, to know your rights, you are so protected under the Federal rights to be able to have children. And I know this is going to sound really cheesy, but don't give up. You have to keep pushing because like anybody with a disability in society, you're going to have those naysayers. You're going to have people that say, "You can't do something because of your disability," and you have to just push, push, push. Don't let anyone tell you no to having a family and especially if that is one of your ultimate goals.

That was my ultimate goal. I wanted to be a mom since as long as I remembered I wanted to be a mom. And so don't let anybody ever get in that way. Even if you need reproductive assistance for fertility, go through it, go do it. If that doesn't work, adoption, foster care. There's so many different options where you can be a parent, but you have the right to be a parent and even if your state has state law, Federal laws are still there to protect your rights and so use them as you need.

Janice Baldon-Gutter:

Dave, do you have any comments?

Dave Matheis:

Well, just what I add that in terms of resources for people considering being a parent there, there were three great ones on this call and there are good people to contact Kimberly also, if anybody wants to know about legislation, Kimberly's the person, Kara is really involved on some projects. One of them is a Disabled Parenting Project. They have a Facebook page. You can search that and find that. And I would mention again, the Association for Successful Parenting was, which is more focused on parents with intellectual disabilities, is a good resource and they do a lot of training. Kimberly can correct me on the name of this, but there's a national research center for the Parents with disabilities at Brandeis University and you can probably search them on the web.

Janice Baldon-Gutter:

Okay. I want to thank Jason, Kara, Kimberly and Dave, thank you so much for being on the show. The book is wonderfully done and the information you have shared today is so important. I loved it. I divided it all weekend. It was wonderful. And I'm going to read it again because you know how you read again and again. You pick up different things. I absolutely loved it. Listeners, you can access all ADA Live episodes with archived audio, accessible transcripts and resources on our website @adalive.org. Listen to the SoundCloud, ADA Live channel @soundcloud.com.adalive. Download ADA Live to your mobile device and your podcast app by searching for ADA Live. If you have questions about the American With Disabilities Act, use the online form anytime @adalive.org or contact your regional ADA Center at 1-800-949-4234. All calls are free and confidential.

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depth discussions on important court cases that shape disability rights and the Americans with Disabilities Act. Learn more and listen @disabilityrightstoday.org and we'll see you the next episode. Thank you for joining us.

4 Wheel City:

They watching. They don't want us be part of the city, man. They put all these steps, man. All these curbs we can't get over. All these inaccessible stores. 4 Wheel City. They don't want us here. We'll survive and we're going to make our own place. Our own world. The 4 Wheel City-

[End of Transcript]

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