Season 5 | Episode 21

Talking About Disability with Children

Laura Wifler

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Crystal Keating:
This is the Joni and Friends Ministry Podcast and I'm your host, Crystal Keating. Each week we're bringing you encouraging conversations about finding hope through hardship and practical ways that you can include people living with disability in your church and community. As you listen, visit joniandfriends.org/podcast to access the resources we mention or to send me a message with your thoughts.

Risen Motherhood co-founder and bestselling author, Laura Wifler joins us on the podcast today to share her story as a special needs mother and talk about her new book, which teaches inclusion, kindness, and empathy. Have you ever wanted to open the door to meaningful talks with children about disability, compassion, diversity, and God's love for them and others?

If so, Laura's new book is for you. It's a picture book called *Like Me*, a story about disability and discovering God's image in every person, and it helps kids understand love and be friends with those with disabilities. So welcome to the podcast, Laura. I'm so excited for our conversation.

Laura Wifler:
Oh, thank you so much. I'm thrilled to be here.

Crystal Keating:
Well, we are too. And I'd love to just start our conversation hearing a little bit of your story. Your darling five-year-old daughter Eden was diagnosed with disabilities when she was just two months old. So, Laura, can you please share some of this journey with us?

Laura Wifler:
Oh, absolutely. Yeah. My daughter Eden, as you mentioned, she was diagnosed with disabilities at two months, and she was diagnosed with what's called Rare Chromo. And Rare Chromosome Disease is really just a blanket term that doctors use to describe anyone who has a genetic disease that is incredibly rare or even entirely unique, which is what my daughter is where as far as doctors know, there's no one who is exactly the same as her.

Crystal Keating:
Wow.

Laura Wifler:
Yeah, it's pretty wild. So, when she was diagnosed, they gave us kind of a list of things that could make her different or could have her developed differently. And it was very long. It was a lot of pages, a lot of different things that could happen. And they also told us that, you know, based on other cases of other children and adults that they've seen, there is a pretty good chance that our daughter would never walk or never talk.

And so that was obviously just very hard to hear as a young mom. I had two other little kids at home in addition to my daughter. And actually, at the time, my husband had a broken leg, a pretty significant break, and he had surgery recently and it was a very trying time in our family's life. But God has been really kind and so my daughter is now five years old, and we've just been on this incredible journey to see her grow and flourish. And honestly, it's been like this discovering, this unfolding of who she's gonna become over the years, and I am just so happy to share that she does walk and that she's defied all of the odds.

Yeah. And then she is also talking. You may not understand her, not everyone always does, but she is definitely making her needs known. She is learning and growing all the time and it's really incredible just to see. She's in kindergarten this year at a local public school and yeah, it's just a lot of great things.

Crystal Keating:
Well good. Well, what does a day look like for your family, and how does Eden's disability affect your day-to-day life?

Laura Wifler:
Yeah. In general, you know our family does look a lot like everybody else's family, where we just have a lot of fun times. There are of course hard days and all of that good stuff.

But in general, disabilities, I think one of the biggest things that I've been surprised by is just the enormous quantity of time that it requires. So, she's of course, in several different therapies. She receives therapy at school, but then we also take her to a private location here in town where she gets PT and OT, and speech therapy.

So, all types of therapies there. And then also just a lot of extra doctor appointments. And then of course, just for myself, it's incredible what parents with kids with disabilities, kind of all of the ways you become an expert in different things, right? You are suddenly an insurance agent and you're a geneticist, and you're a doctor, and you're a therapist, and just all sorts of things. And I feel like I've really had a large learning curve of time that it's taken to learn the different areas that help meet her needs.

Crystal Keating:
Right. And we've heard that from so many mothers who join us on the podcast that they have to be extremely diligent as an advocate for their child. You know your child best and so when you're entering into all of these therapies and talking with insurance and doctors, you really

have to be focused. And that requires a lot of discipline. How do you keep yourself spiritually girded up as you go into each day?

Laura Wifler:
Yeah. Well, you know, I have found that as I have walked through some of the darker valleys of disability, the Lord has been so kind. In some of the moments, I haven't known where he is, you know, just like any grief or suffering, there have been a lot of really hard days where I'm not quite sure what God's up to and I'm not quite sure where he is. But I feel like over time I come out of that and realize, okay, the Lord was walking by my side all of the time and now I have a sweeter relationship with him and I see him more and so much of that came from being consistent in being in his word, even on days where I wasn't quite sure that I wanted to be in his word, or there were days that I was upset or sad, but also knowing that God can handle those emotions and that he is not afraid of all of the feelings that I bring around this topic. And so, I've just been so thankful because the Lord has certainly been with me and I've realized that even at times where I felt like Lord, I don't know where you are in this, I've come to the other side and realized he's been walking beside me, really holding me the entire time.

Crystal Keating:
I love that image about the Lord carrying us even when we cannot see it. One of my prayers that I tend to pray more often is, Lord, help me to see your hand moving in ways that I'm not noticing. And I can definitely resonate, and I know our listeners too, can resonate with that idea that, Lord, we can't always see you, but we do trust you. And I know that you're entrusting the Lord with your daughter, especially in regards to friendships and you've expressed that one of your greatest desires is for your daughter to be accepted by her peers and invited into friendship, and that is not uncommon whether you have a disability or not, right? That's the desire of probably every mom for their children and as Christians, we believe every person is created in God's image and sometimes, we say that so often it's like, what does that mean? And I think one of the things I've been reflecting on is that God is love. We have the ability to love and be loved. So how does teaching our typical kids this biblical truth, open the doors to friendships with peers who may look, act, and sound different than most other people?

Laura Wifler:
Yeah, well, the image of God is one of those incredible foundational theologies that so often I feel like, oh, I just, I wish every parent understood this, and child understood this and that it was just a huge priority for all of us because I truly believe that this really could alter the course of our culture if we had a good theology of the image of God and truly there's an element there as parents that we can teach our children that as they're made in the image of God, that means that they have been declared good. They have been declared right before God. They have been given this royal status from the garden and that now all of us operate from this place where we don't have to earn our goodness. If we're in Christ, we have been fully and wholly declared good and that we are his. And when we have that mode of operation, when we realize that hey, it's not about my achievements. It's not about my resume. It's not about whether I won or lost the game, if I'm valuable, or if I'm worthy, or if I'm loved, that status is steadfast.

Well, it really opens up so much for us in the way that we operate because suddenly life doesn't become about the earning more value or getting more success in order to feel like we're loved.

And instead, we can actually lose our lives and we can say, okay, I can lay down my life for someone else because I know where I stand.

I know who I am. My identity is secure and that honestly would change so much, not just for kiddos, but for us as adults.

Crystal Keating:
I was just thinking that.

Laura Wifler:
If we could really get that under our skin. And in my family, we actually have this saying that we say around our house, and we say, my life for yours.

And some days you'll hear my kiddos saying this, you know, kind of in jest as one friend or sibling needs a drink of water, and they'll yell my life for yours. And then they'll go, and they'll get this glass of water, but what we mean by that is that Christ gave his life for us and now we can lay down our life for others.

And that is a truth that I think only really works when we realize where our value comes from and how that is a truly steadfast, unchanging thing. And I think that it's been a fun little saying for our family, but it's also just packed with so much truth to be able to lay down our life for other people.

Crystal Keating:
Amen. That is so powerful. And you know, that to me speaks of the need also to live in community. How can we give our life for others if we're not in proximity to people who are also in the body of Christ? And we're gonna get there cuz that's a really important piece. But let's talk about your new book *titled Like Me, A Story About Disability and Discovering God's Image in Every Person*. How does this storybook teach kids to understand and love those with disabilities?

Laura Wifler:
Yeah, you know, *Like Me* is a fiction story. It really just follows the lives of two brothers and the younger of whom has significant disabilities.

And throughout the book, you're kind of following this older brother and some of his thought processes, and the mom is kind of dropping some wisdom as well, and throughout they just go throughout their day, you know. They get up that morning and they go to therapy. So, it shows what a therapy room looks like.

It shows them going to get lunch, them sledding that afternoon, reading books by the fire with their dad, and all sorts of things like that, that are just kind of, you know, pretty normal, pretty typical things. But as the book progresses, you really see the different ways that the disability is affecting the family and the ways also that God's glory is really shining through. And so, this book is designed to, of course, be a cozy read that you can snuggle up on the couch. It's kind of got this winter theme, which is really fun. But beyond that, my hope and prayer is that it really will springboard conversations about disabilities.

Perhaps it's from a child who has a younger or older sibling with disabilities, and they feel seen and related to. Or maybe it's with a family who doesn't have disabilities or anyone that's close to them with disabilities. But they can get a peek inside what it looks like and see some scriptural truths that are displayed and just begin to become familiar with adaptive equipment and just what life looks like when you have a person with disabilities in the family.

Crystal Keating:
That's so good. Well, let's turn our focus to the parents who may be listening today. You know, the statistics show that more than 3 million kids in the US have a disability. So, what encouragement do you have for moms and dads raising children who have disability, and what advice do you have for a parent who might be feeling alone in their walk with disability? I know we have both listening today.

Laura Wifler:
I know for any parent who is walking through disability, especially someone who perhaps is going through diagnosis or is at the beginning stages of getting used to what life might look like, one of the big things for me was learning to not grieve what I haven't been asked to grieve yet.

And I shared at the beginning of our conversation about how the doctors had told me, hey, you know, she probably will never walk. She probably will never talk. And of course, as a parent, we hear diagnoses, we hear statistics, we hear anecdotes from friends and family, and we think that's gonna be my story.

You know, we just go all the way there and we can't help but feel like that is going to be our future. And so, for me, I remember very acutely thinking. Oh, my goodness, you know, what am I gonna do? What's that gonna look like? Are we gonna need to remodel our house? I mean, I was going a thousand miles an hour when really all I had to do was look back at my little girl.

And nothing had changed between the diagnosis and what they had said and who she was right there. She was the same wonderful little girl. And I think that has been really important with disabilities because it can change so quickly, and disabilities can feel a little bit different than something like death where you receive sort of this news and it's horrific of course, but it's also like, okay, now we have to find a way to move on because that's not going to change.

But with disabilities, the grief can feel like, well, I don't know what else is coming and I don't know if it's gonna get worse. I don't know if it's gonna get better. And that type of grief is a bit unique and a little bit different. And so, my biggest encouragement is for parents, a mom or a dad to just remind themselves that tomorrow has enough worries of its own and God has grace that will meet you in that moment.

And for right now, we can trust him with where we're at to meet all of our needs. And that he knows, and he sees, and he is sovereign overall. And I think that if we can try to not look ahead too far, but trust that in this moment the Lord is with me. And to kind of look around and lift our eyes and see, okay, like this is a life I can do one more day of this, you know, one more day Lord.

And I think that has been really helpful for me to not go too far down the path. And then in terms of, you asked about a parent who might feel alone. It's really common, it's really normal. I think all of us, whether or not we have a true, you know, diagnosis or not, where maybe something like autism or Down syndrome where there's this category and you can find other like families.

Or maybe you're more like me, where, hey, actually there's no one else in the world who has what my child has. Either way, it can just be a really lonely road because things present themselves so differently and every child develops at their own pace and yet, my encouragement would be to find other people that are walking a similar path.

Don't expect it to be exactly the same. Don't expect everyone to understand or for there to be a cookie-cutter experience. But, you know, it's a wonder to live in 2023 and be able to go on Facebook. And in fact, I have found a group of moms and dads who are in a Facebook group. It's about 50 people, very small, but our kids are somewhat similar in their diagnosis.

And it has been so neat to be able to go in there and just even see that some of our children actually have similar features and that is just wild to see and just be able to talk. And you know, they're all on their different paths. They really are all very different. Yet we get each other in that way and not all of them are believers.

In fact, I'm not sure there is another believer in that group, and yet there is something really beautiful about walking beside those families. But then on top of that, you will need in-person community. You will need fellow believers by you. You will need those people that are gonna hold on to hope for you and that are gonna remind you of the truths of Jesus.

So, look for that in town. Look for that at your churches. Seek that out. Unfortunately, I think people can get a little nervous around disabilities, so you might have to strike up the conversation. You might have to be that person that is courageous and bold and says, hey, can, I pray for you? I'd love for you to pray for me, and for you to foster those conversations.

But I have found great hope, even with friends who may not understand the fact that I have a child with disabilities and all the intricacies of that. But they do know what it's like to grieve. They do know sorrow, they do know pain, and so, I have found great encouragement from them as we seek scripture together, look to the Lord, and we remind each other of the walk that we're on, and the hope of heaven that awaits for us.

Crystal Keating:
Well, and it's so true that although other parents may not be able to relate to you with disability, as you said, they can relate in grief and sorrow and even worry. To me this just confirms exactly

how we started the conversation before we started recording about Jesus' promise to us that we are not to worry about tomorrow, which, to me, I'm like, that's impossible.

We are always thinking about the future. But he knows us, and he said, I care more about you than the birds and the flowers. I'm gonna take care of you. Tomorrow has enough worries of its own, but I'm gonna take care of you today. And that's where I've been meditating. And it sounds like that's your encouragement as well, and it's like, Lord, you know, my prayer also is I don't have the faith to believe this.

Help me to believe this to be true in the midst of my grief and my sorrow. That you will care for me today and give me eyes to see how you're providing for me.

Laura Wifler:
Yeah. Those are some of just the absolute most powerful words in scripture, I think. I believe but help my unbelief and you know, I should have brought that up in one of your previous questions when I cling to God and I think that has been just my prayer the whole time, just, Lord, I believe, help my unbelief.

And you know I always think too of the words Jesus disciple says, Lord, to whom else will we go? You know, where else will we turn? And I think oftentimes that's what would happen is that I would come to the end, but then I would be like, but there is nothing better.

There is no one beside you that I want. And that has been just a huge encouragement for me to hold onto Jesus in the hard days.

Crystal Keating:
That is so good. He has the words of life, right? That's why they said where else are we gonna go? You've got the truth. So, you're it for us. All our chips are on you, Jesus.

Laura Wifler:
That's right.

Crystal Keating:
Okay, well let's talk about the reality of kids, especially young kids, who may not have much of a filter. I love kids and I've been around kids who have seen another child with a disability and the comments could be something as innocent as like, oh, why does she use that walking device to what's wrong with her?

And as innocent as these comments may be, they can be really embarrassing. So, what should a parent do in the grocery checkout line, or you know, wherever they're at when their children are asking real questions like, why is he sitting on a chair with wheels?

Laura Wifler:

Yeah. First of all, I would just say I have so much compassion for this, so just know that as I share this, my two older kiddos who are regularly developing, we have a lot of disability in our family, and we have just a lot of exposure to adaptive equipment and different ways of behavior and things like that. And yet they still have been known to ask these things in kind of ways that, you know, I can naturally feel embarrassed by. But what I would encourage all parents in is that, you know, you're, you've gotta go contrary to exactly what your natural instinct is. So instead of, you know, shushing them and kind of trying to hustle them away from wherever that incident occurred, instead, I think we can just pause and know that, hey, this is a curious, innocent question.

And your child is looking to you to tell them how to categorize the world. That's one of our jobs as parents, is to help our kids know what is safe, what is unsafe, what's good, what's bad, what's right, what's wrong. And so, if we shush our children and kind of hustle them out of there, we're actually kind of indicating to them that like, oh, this is bad.

This is a secret. We don't talk about this. This is not good. And so instead we can give them a warm smile. Move actually towards that person and we can show the child and say, hey that's actually a wheelchair. That helps that person get where they wanna go, that gives them freedom.

Maybe a child's wearing leg braces. My daughter used a walker and leg braces for a long time. And your kiddo asks what those are, and you can just say, hey those are leg braces, and you don't have to know, you know, the AFOs or SMOs or technical terms or anything but you can just answer honestly.

And then what I like to do is encourage parents to show sameness. So, take it one step further because what your kiddos doing in that moment is that they are noticing the differences, right? They're saying, I don't know what that is. That's different than what I'm used to. But one beautiful thing about how friendship forms is through sameness.

And so, we can show them and say something like, oh, that wheelchair's blue. Isn't that cool? That's your favorite color. Or, oh, those braces, they have footballs on them. Remember that football game we went to last week, wasn't that so fun? And so, we can find these natural, just small connections where I think our child then can say, okay.

I have a category for this is safe. I can see how there's similarities and then I think that helps the child. Typically, a kiddo, they're just gonna like waltz away. Like it wasn't anything, you know, and you as a parent are gonna be like, woo, okay, we worked through that, you know, and you'll be feeling perhaps some relief or some adrenaline in that moment. But, as you do that more and more, it'll become so natural, and it won't be hard, or it won't be scary. but I remember those days.

I have much compassion for those days. But hopefully, with a couple of tricks, it isn't nearly as hard as it seems.

Crystal Keating:

No, that's great advice. And you know, fortunately, people are more understanding, sensitive, and loving toward individuals with disabilities than they once were even developmental disabilities.

And so even so let's talk about the church. How would you like to see the church and culture in general continue to improve?

Laura Wifler:
I think there's so much improvement and I'm so thankful I often think to myself, Lord, thank you for letting me have a child in 2023 because things have really changed and I'm so grateful.

Yet, I think one of the things that culture and even the church are focused on right now is inclusion, which is good. But inclusion often looks a little bit more like tolerance. And what I mean by that is it can look like, okay, we've got the ADA checked off. We've got, you know handicapped parking. We've got wheelchair ramp access, things like that.

We've also got a room maybe for a child with sensory disorders or we have just made space for different people. But that's all that it stops at is making space. And what I would love to see happen in culture and the church is for instead, inclusion to begin to look more like friendship.

And what that means is that maybe we're altering the games at youth group so that a child with disabilities can participate. Or that means, you know, more than a simple smile, maybe we're going up to someone and maybe it's someone who's non-verbal and we're just placing our hand on their shoulder for a few moments.

I know with my children we've got a young girl that goes to our church and goes to our school and anytime we see her, we just go up and we just talk to her and she's not gonna reply back. We know that. But I think it's been so good for my kids to just have exposure to remember my life for yours, right?

This isn't about me, and we're gonna feel a little awkward. We're gonna not really know what we're doing. But we're gonna be there and we're gonna just spend time with her and we have no idea what's going on or what that might mean. And at the end of the day, my hope is that will be a blessing for her.

But more so, it's a blessing to my family and my children and to me, as we just begin to see the Imago Dei in other people. And so those are little things I think that we can do as a church to move that needle from not just tolerating, you know, in our inclusion, but instead to really move towards that friendship.

Crystal Keating:
Right. And you know, that is exactly why our ministry is called Joni and Friends because friendship is mentioned in the Bible over and over again. And you know, friendship was the very thing that God used to pull Joni out of the depths of depression right after her accident and so we understand that friendship is mutual as well. There's a benefit to both giver and receiver and

it's very different than service provider and, you know, recipient and there's a place for that. Thank God for all the helpers that God has provided, but I just love that emphasis. So, let's talk about church again. Let's talk to the leaders who may be listening today. How can children's ministry leaders and volunteers help the children they serve to offer friendship easily and quickly to a child with a disability?

Laura Wifler:
Yeah, this is a great question and I think a lot of it I really believe still comes by modeling. And as an adult, we are showing the behavior we would like to see out of children. And yeah, I also think there are a lot of beautiful opportunities, perhaps formal, perhaps informal. I know at my church, something I've been so grateful for is that they have provided an aid for my daughter, and she can participate generally in activities, but she needs a little extra assistance and ex extra help.

And it's usually an older kiddo at the church who wants to spend time with other children. And so, I think that's a great way to foster relationships or even with child-to-child within the church. Something I've been so grateful for is that they will have maybe a child who's a couple years older, not a lot older than my daughter, but 7, 8, 9, 10, and they will just say, hey, I'm gonna have you spend 30 minutes with Eden. I'm just gonna have you hang out with her and just kind of do what she wants to do, go where she wants to go.

Protect care, care for her. And that's such a gift for me as a mom. And then again, I really believe it's a gift for that child as they learn. And it's a gift to my daughter. You know, to have somebody just dote on her and love her has been so fun to just watch her light up for. I think all of those are great things.

And then lastly, I would say, again, if we're speaking to ministry directors would be to teach on this topic. Disability theology is pretty thin around the church, and there's a lot of ways that we can grow in that. And even when we're talking with young children, I mean, just giving kids a theology of disabilities, talking about the kind of stuff that you and I are talking about here.

Those kind of things at a child's level will do wonders for them as they grow, as well as the things like Imago Dei and other things that we've talked about that help foster those types of things where a child would say, I know who I am in Christ and now I know what I can do for Christ, you know, and I know how I can form relationships with others and different things like that. So, there's a lot of ways I think when we start thinking about it, it's actually almost countless, but those are a few to start with.

Crystal Keating:
Yeah, those are really good. And if you're listening today and you think, wow, how do I do this? Where do I start? We have so many resources here at Joni and Friends, especially for the church. Whether you're a leader or not, if you're part of a church, there's people you can talk to.

Just go to joniandfriends.org/church and you will find many training resources, videos, downloads, booklets, you name it, we got it. And if we don't have it, we'll find it. So, you can call us. We'd love to be a part of helping your church fulfill its mission, especially to people with disabilities.

So, Laura, I'd like to just wrap up our conversation with a quote from your book, *Like Me*. I love this quote, “God made you; God loves you. God is kind to you.” What brought these words to the surface for you, and why might parents want to speak these truths to their children, disabilities are not?

Laura Wifler:
These words were really formed out of a prayer for my daughter and when she was diagnosed soon after, I remember just thinking one of the things I was most fearful of perhaps, was that I wouldn't know her mind and I wouldn't know her heart and I wouldn't know how she felt or what she was thinking of.

And that was one of the things that was really hard for me in the time. And even now, can be something that I just keep earnestly praying that I can continue to know her and know her heart. But with that, I remember thinking, I don't know what she can understand or what she will someday understand.

And so, what are some of the basic truths that I deeply desire for her to know in the most simple terms? And so, this became a liturgy of sorts for our family that I spoke not only over our daughter, but also my other kiddos as well, where I just wanted them to know that God made them, that God loved them, and God was kind to them.

And that is something that I think for all children is just some beautiful truths that if they really do plant deep into that child's heart will really change their lives forever, if they believe those things. I know for me so often when I'm feeling alone or scared or upset, it's probably because I'm doubting one of those things, and I'm not believing those to be true.

And so, I think if we can reach our children at a really young age with something to remind them of the real truths in their lives, we are doing them a service as they grow up, and they can hopefully recall these truths and lean on them.

Crystal Keating:
Amen. Laura, it's been such a pleasure speaking with you today. Thank you again for joining us on the podcast.

Laura Wifler:
Absolutely. Thank you for having me.

Crystal Keating:
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