



God Hears Her Podcast

Episode 117 – Meeting Special Needs

Elisa Morgan & Eryn Eddy with Elrena Evans

Elrena: My dream, my hope for the future, is that some day the church will be that place. The church will be that place that you can call and say I just received a diagnosis. I don't know what to do. Can you help me? A lot of churches aren't there right now, but I would still encourage people to start there. Because there are churches that are there, and there are also churches who are willing to say you know what? We don't know, but let us come alongside you.

Eryn: Yeah.

Elrena: Let us learn with you. I feel like when you are in that moment where your entire world has just shifted, what you need even more than knowledge, is someone to come alongside you and maybe even someone to do the research for you and someone to just be the hands and feet of Jesus here on the earth, holding you, holding your hope even.

Voice: You're listening to *God Hears Her*, a podcast for women where we explore the stunning truth that God hears you, He sees you, and He loves you because you are His. Find out how these realities free you today on *God Hears Her*.

Elisa: Welcome to *God Hears Her*. I'm Elisa Morgan.

Eryn: And I'm Eryn Eddy. How do you feel when you hear the words "special needs"? Does your mind fill with memories from someone you love with special needs? Do you get uncomfortable? Do you wish you knew more?

Elisa: Well today, we're talking with a mother of five who has a deep want for people to learn more about special needs. Elrena Evans will be sharing some wisdom with us in this conversation. And she also has a book titled *Special Grace*. It's filled with written prayers for the day-to-day lives of people with special needs and the people around them.

Eryn: Elrena has so much to share with us about what she has learned from raising a son with special needs. We can't wait for this conversation on *God Hears Her*.



Elrena: I can talk a little bit about when my feet first learned to dance. I think I was born into the world dancing. I think that it was one of the gifts that God gave me. And dance for me, my entire life, has been one of the things that connects me to my faith. I tend to be very cerebral. And I can get tripped up on the logic and the doubts and the questions. And that's where my brain kind of would like to stay sometimes. But when I dance, it's like my brain is able to move past all those stumbling blocks that it also wants to set up. And when I dance, I experience the presence of God.

Elisa: That is beautiful. And it's interesting that you're using action verbs that are movement, tripped up, stumbling. You know, I love that. It feels very authentic to you.

Elrena: At one point, I got very interested in the science of why is dance what connects me to my faith. And so I got into studying the brain and all of the different parts of the brain. And I feel like the parts of the brain that control logic and reasoning are gonna trip me up sometimes. But the parts of the brain that control movement, the parts of the brain that control emotion, this is where my faith is rooted. And actually, at the launch party for *Special Grace*, for my book, I got to do something that was very special to me. After I gave a reading and did all of the things that, you know, people would expect; I danced. And I talked about how special education or special needs accommodation, at their heart, is taking something and presenting it in a different way so that more people have access. My son needs things to be presented in a different way so that he has access. And for me, that's what dance is. It's presenting something, the gospel, the love of Christ, the light of God in a different way. It allows me to access the material differently, just like special education does for my son.

Eryn: I want to learn more about how you stumbled upon learning that. When did you start experiencing connecting with God and dancing? Were you seven? Was there a moment? Was it when you were 15? Was it...and...and then...and what was the reason to start dancing in the first place?

Elrena: I think I started dancing because I was already dancing. It was just one of those, right? Like when you have a kid that sings all the time, like that's what this kid is gonna do, I danced.

Elisa: Oh, okay.

Elrena: And I was very fortunate. I think I had already started to make the connection between faith and movement when I was really little. But I was very, very fortunate when we landed in Pennsylvania to find a church that has a liturgical dance ministry. And I have been dancing with that ministry now for 33 years. The dance ministry has been such a wonderful bedrock for me, if I can use that word, like an anchor for my faith. And those moments like fast-forwarding a little bit, when my middle son received his diagnosis, being able to go back to that place where I feel safe, where I feel God, where I feel loved. And it just so
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happened that there was a woman in the dance ministry at the time that I'd known for years and years who is a therapist for children who have special needs. And it was just one of the ways that God was providing the things that I needed when I needed them.

Elisa: You're referencing such a core understanding of who you are, using the words *anchor* and etcetera and safe place. And I love that because when we know ourselves the way God made us and can access that core identity, we do have a safe place to run to. Take us now into the unfolding of your years. You met your husband. You have children. And then specifically, as you just mentioned, a son with a specific diagnosis. But...but help us understand the constellation of your family and how that unfolded.

Elrena: That gives me goosebumps, I love that, the constellation of my family. So yes, my husband and I have five children in our constellation. And I like to describe my kids, my family really, as quirky. We're...we're just quirky. We're not like middle of the bell curve people...

Eryn: I love it.

Elrena: ...in...in lots of different ways. Like we're hanging out at the end there, but we don't usually hang out like right in the middle.

Eryn: Can you give me an example of what defines quirky for your family?

Elrena: I can give you an example. Yes, when my eldest daughter was three, we were playing at a playground. And some little girls came up to her, and they wanted to play. And they asked her, do you like Disney princesses? And she says, no [inaudible] laughing, no. And then she goes, I like homophones. Do you like homophones?

Elisa: Wow, and what is that?

Elrena: And I was like oh sweetie. Homophones are words that sound the same but mean different things, like pear and pair and whether and weather. And she's probably got it, there's a Veggie Tales song. I won't sing it, but it's really funny. And it's all about homophones.

Elisa: Okay, okay, okay.

Elrena: But that's the kind of quirky that my family...

Eryn: I love that.



Elrena: ...the other night I was putting my youngest to bed. And just as it's, you know, just about sleepy time, he looks at me and he goes. I have a question. Here it comes, because you know what's gonna come out of his mouth. And he goes, what are the limits of jazz?

Elisa: Oh my goodness. How?

Elrena: It's bedtime, and you're eight is my answer.

Elisa: Yeah, yeah.

Elrena: But...

Elisa: Yeah.

Elrena: ...I said, what do you mean? And he said, I just want to know what defines jazz music.

Elisa: Yeah, yeah, yeah.

Elrena: And when jazz is no longer considered jazz. And I said, that is a question for Daddy, because I'm the dancer. He's the musician, and that is also a question for morning, so nighty night. But yeah, we're that kind of quirky. Everyone in my family I feel like, my kids...they are...they are very much themselves. They have their own take on the world. We've got some of what the world calls gifted going on, which can be its own challenge in and of itself. So my middle son, he did receive a diagnosis of having special needs. And something, this was another place that I just felt like God was there for me. The woman who did his initial evaluation called me because she had also evaluated my older son. And she had come to know our family pretty well. And she said, I want to talk to you before we go into the school and have the special education meeting and do all the official stuff. I just want to talk to you first. And she said, I think that you don't realize how atypical your middle son is because of who your other children are.

Elisa: Oh wow. So in some families, it's like super-obvious.

Elrena: Right.

Elisa: But in other families, it's just a tiny bit of a facet.



Elrena: Right. Like we were all kind of quirky anyway. We were...we were already having more parent-teacher conferences. When my eldest was in pre-K, her teacher called me in because she started the day every day by going to the teacher's desk and reading the lesson plans. They had worked out a deal, right, where you can read the lesson plans as long as you don't share them with the other kids. Because teacher wants to have, you know, a little bit of control over...

Elisa: What a smart teacher, yeah.

Elrena: ...but brilliant, wonderful, wonderful teacher. But I had felt that my middle son was even more different, different in a way that I could not quite quantify. From the time he was about two, there was just something else going on that I couldn't articulate. And I had talked to his preschool teachers. And I talked to his pre-K teacher, and I talked to his kindergarten teacher. And I felt like either I'm not articulating or...and they're all...like we're all seeing things here. But it wasn't until my three children at the time were enrolled in our private Christian school. And when my middle son was in kindergarten, they asked him to leave and not come back. And that was really a turning point in the trajectory of the constellation of my family. Because I had so much invested in Christian education, not just, you know, tuition, and after-school events or whatever, but all of my hopes and my dreams and the path that I thought I saw for my family was so entwined with being a part of Christian education. And so being asked to leave and not really feeling like I knew where to go. I didn't know what to do next. I didn't have resources. I felt completely adrift.

Elisa: Did you feel rejected, alone, betrayed?

Elrena: Abandoned.

Elisa: Yeah.

Elrena: Betrayed.

Elisa: Yeah, yeah.

Elrena: I'm sure I could come up with a whole host of synonyms that would fit in that yes.

Eryn: I am sure you felt that way.

Elrena: It was...and the thing I remember saying the most at the time is I feel hopeless. And one of my dear, dear friends, I almost can't tell the story without crying. So if I tear up...



Elisa: That's cool. We don't mind tears yeah.

Elrena: But a wonderful friend of mine was talking to me about having hope. And I said, I just can't. I...I can't right now. I feel so hopeless. And she said, I will never forget this. Then I will hold your hope for you.

Elisa: I love that.

Elrena: And she talked to me. And I just had this image in my mind. Emily Dickinson has a beautiful poem "Hope is the Thing With Feathers." And when my friend was talking, I could imagine like my hope is like this little baby bird. And I cannot care for it right now, but I can give it to my friend. And she will care for it for me. And she will keep it safe. And she will love it. And my hope will exist, because she is caring for it for me. And then when I am stronger, my hope can come back. And that was, oh my goodness, a very long time ago. And I actually, that's become a little bit of a shorthand in our relationship. When something happened recently that I don't want to go into, but a little hiccup in the raising of my son. And I sent that friend an email. I didn't even give her details. I just said, will you hold my hope for me? And she said, yes, I will. I will hold your hope.

Elisa: Beautiful.

Eryn: That is so redemptive of the Lord to give you a friend that reminds you that He sees you in the circumstance even when a Christian school could not see you.

Elrena: Exactly.

Eryn: He still gave you somebody that c...that's so healing.

Elrena: We were losing the Christian school, but we weren't losing the Christian community, right? God was not the one who turned His face, right?

Eryn: Exactly.

Elrena: So yeah.

Elisa: Right, right. So but even in this moment, you still didn't have a diagnosis. Am I right?

Elrena: No, we did not. And I am not 100 percent sure that we have an accurate diagnosis to this day.



Elisa: Okay.

Elrena: I feel like we have chased and chased.

Elisa: I see.

Elrena: My son is tricky.

Elisa: I'm hearing just these layers of confusion and feeling rejected and alone. So you know he's kicked out of this Christian school, but you don't have a real clear path of what it is.

Elrena: Right.

Elisa: And so maybe is that when you began to turn into the unclarity, the...the reality that it's gonna be unclear? And how do you parent that way? Am I hearing you correctly?

Elrena: Yes, I mean my most overwhelming fear at the time was for my son. Like what does this mean for him? What does this mean for his life? Where is his place in the world? How do I find that? God, help me. But I also had...so he was five at the time. So we also had...they would have been nine, seven, five, almost three...and or just turned three, and not quite one at that point.

Elisa: Wow.

Elrena: So that's a lot.

Elisa: Yeah, it's not like you didn't have anything else to do, right.

Elrena: That's a lot, right?

Eryn: [inaudible]

Elrena: That's...that's...that's when you just never have socks that match. And you're like, you know what? If they're close enough to the same size, and actually I don't even care. If it's ankle sock, knee sock, if you can put them on your feet...

Elisa: You're...



Elrena: But yeah, so our path forward actually ended up. I was taking my three-year-old to preschool. And this is the preschool through our church. And there was a sign on the wall that said, is your child having trouble in school? And it caught my eye. And I thought, well he's not having trouble in school, cause the school sent him out. But I think that might apply to us. And it was actually picking up that flyer and calling the number on the back that got us into the system, if you will, accessing special education, getting him his initial evaluation. Which again, when I had that wonderful conversation with the woman who did his evaluation, one of the things she told me was, we don't have an accurate IQ on your son. We don't have a number, because he did not want to do the IQ portion of the testing. And she said, and when I told him, I...I need you to do this, right? When we're done, like here's the reward. When we're done, we can play with blocks or whatever. But I need you to do this. And he tore the page out of the testing packet and ripped it up and ate it and then said, now how are you gonna make me do it?

Elisa: Oh my gosh.

Elrena: And then because he's himself, continued dialoging about, you know, where it was in his digestive tract. And oh it's past my esophagus. Like I don't think I'm taking this test, right? And...

Elisa: Man.

Elrena: ...which and...and those are behaviors that I had seen but again compared to my other kids like yeah, it's quirky. But it's not...it's not that far outside of our box.

Eryn: Right.

Elrena: We just have a bigger box. But he has needs that are above and beyond my other children. And that was sort of our launch into special education. And another way that I say God was totally going before me and preparing the way with this kid. So this child was born 8 pounds, 10 ounces, which you know isn't that huge, but he was my biggest baby. So he was huge for me. And he was face up with a ginormous head.

Elisa: Okay.

Elrena: And he was born with his fist on his head.

Elisa: Okay.



Elrena: So he came into the world like this.

Eryn: Ready.

Elrena: Like he was ready and...

Elisa: Challenger, yeah.

Elrena: ...they went to put the little baby hat on him, and the nurse said, oh this is not gonna fit. We need to go get a different baby hat. And I was like, yeah, tell me. I am aware. I just...

Elisa: A toddler hat, yes.

Elrena: ...exactly. I just birthed this toddler child. But I remember the nurse joking with me. She said, it's funny that he didn't break your tailbone. Because often a baby face up with a head this big will fracture your tailbone on the way out. And I was like oh, my tailbone was already broken. I broke it chaperoning a youth group missions trip when I was fresh out of college. I was hiking, and I slipped. And I didn't quite stick the landing. Looking back on that, I feel like God was saying, in the delivery room, I am there. I am already there. I will give you what you need to raise this child. I will break you, literally. But you will have what you need.

Elisa: So you looked back on that and remembered that.

Elrena: Yeah, and it felt...I mean I'm not saying God broke my tailbone. That's pretty bad theology. But...but as a metaphor, and the other way I saw it is people talk about when their child, son or daughter, receives a special education diagnosis or a special needs diagnosis, you have to find your people, right? I did not need to find my people. I already had so many friends in my close friend group. I had one, a very good friend, whose child has special needs significantly more severe than mine. But we met when she was pregnant with her eldest, and I had just had mine. Like so it was 17 years ago, long before any sort of special needs anything was on our radar. But when I had this need, my people, my community, they were already there. And that was just wonderful.

Eryn: That was going to lead me to ask the question, had you experienced any sort of introduction to understanding special needs? Or was it something that you entered into brand new and needing to learn immediately?



Elrena: I think the answer exists on a couple of different levels in terms of emotionally. When I was in college, I just started wondering, what if I had a kid some day who had special needs? What would that be like? And I had done some research on Downs Syndrome. And I started taking sign language. So I actually have two years of American Sign Language.

Eryn: Oh my goodness.

Elrena: I just felt. I don't know. It...it was like a question that existed in my mind. Like what if I had a child with special needs? The theoretical child that I was preparing for is absolutely nothing like the special needs child that I have. But I think that the existence of the question maybe made me a little bit more sensitive right off the bat.

Eryn: And aware? Yeah.

Elrena: And aware. And then my dear friend who also is a therapist. My kids tease me. They're like, Mom, all of your friends are English majors or therapists. And I'm like yeah, pretty much. But my friend, before my very first special education meeting, she was actually working in special education at the time. And we got together. And she sat me down, and she was like, this is everything you need to know. This is everything that's gonna happen in the meeting. This is the definition of every acronym. This was probably the thing that shocked me the most stepping into special education. There is an acronym for anything. And that first meeting feels like alphabet soup. It's just coming at you. But she had given me the cheat sheet. She's like this is what you need to know. Don't sign this until you figure out this. They're gonna want you to do this, but it's okay for you to push back on that and this, that and the other thing.

Elisa: That's wonderful.

Elrena: I was so prepared walking into, no credit to me, 100 percent credit to my friend. I was so prepared walking into that meeting that about 10 minutes in, one of the people in the meeting said, okay. Just come clean. You're in special ed, aren't you?

Eryn: Yeah.

Elrena: I was like I am not, but I have an awesome friend.

Eryn: Your story just demonstrates the importance of community even when you've been burned by it being able to still surround yourself, be vulnerable, ask questions, be curious, be susceptible to input. And I mean it's just so beautiful. I want to understand, like anybody that's listening right, that's entering into godhearsher.org



this; and they don't have a friend that has cheat sheets. And they're f...trying to find books, and they're googling. What are some practical pieces of advice that you would want to give that person?

Elrena: My dream, my hope for the future, is that someday the church will be that place. The church will be that place that you can call and say, I just received a diagnosis. I don't know what to do. Can you help me? A lot of churches aren't there right now. But I would still encourage people to start there. Because there are churches that are there, and there are also churches who are willing to say you know what? We don't know, but let us come alongside you. Let us learn with you. I feel like when you are in that moment where your entire world has just shifted, what you need, even more than knowledge, is someone to come alongside you and maybe even someone to do the research for you and someone to just be the hands and feet of Jesus here on the earth, holding you, holding your hope even...

Elisa: Yes, yes.

Elrena: ...when you can't. Because that beginning is so destabilizing. And the Internet has a lot of information, and there are lots of, I mean even more so than when my son was starting this journey. There are lots of places with resources and information. And I feel like the world of special needs is doing a wonderful job of advocating for its own and connecting. But I feel like, almost more than that or in addition to that, you need someone in your life, even if they know absolutely nothing about special needs, who will be there for you.

Elisa: It's one of those principles of really any kind of condition that takes us out of the norm, if you will. You have to adjust, you know. Whether it's okay, my husband has cancer. Or okay, I need to wear hearing aids. Or okay, we're moving into retirement. Or okay, my kids are gonna play three sports. I mean whatever it is, you know. With special needs, I'm hearing you say that it's kind of a world unto its own where the group, the tribe, is acquainted, well-acquainted with how to cope. But the rest of the world isn't as skilled. And so you can move in a bubble of support where you still need to receive care as you're giving care. But there is a translation challenge or a cross-cultural almost challenge. Is that what you're saying a little bit?

Elrena: Yes, and that's actually one of the reasons I wrote the book.

Elisa: Okay.

Elrena: So it actually began with a prayer. It was the fall after my son had been asked to leave the Christian school and had received his diagnosis. And we had started at our local public school the fall after that. So he's going back to school. He's got a new full-time aide, which is its own you know,
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whatever. And I was thinking about that, and I was thinking about...plus it's back to school. And you have five kids. And so the whole day has been like I bought you a lunch box. Where is the lunch box? What do you mean it's under the swing set and you filled it with mud? And like...and there's no socks. And you've been doing laundry like straight for four days. How are there no socks? So you're in sort of that place, and it's just like I can't do this anymore. And I was coming down the stairs, and I was thinking about that. And I was thinking about all the chaos of back to school in any family and then the extra complications that are in my family. And then I was thinking about all the emails I've been getting from my friends that week, things like, can you just pray for the locker? Like I am afraid that we're not gonna be able to actually open the locker. Can you just...all these prayer requests. And I sat down on the stairs. I'll never forget this. I was like we need a prayer. We need a blessing for the first day of school. And I just kind of went through all the things that were in my mind that my friends had asked me to pray for and the things that I was praying for. I wrote it down, and I sent it to them. And that eventually is what went on to become *Special Grace*. That was the first prayer. So I'm an Episcopalian. And written prayer is a huge part of my faith tradition. We have *The Book of Common Prayer*. We have other books of written prayer. I love written prayers, because I feel like they give me words for when I have none. But I started asking myself when we were at the beginning of this journey, where is the prayer for a diagnosis? Where is the prayer for a new aide? Where is the prayer for a substitute teacher? Because the Lord knows the substitute teacher in my child's class needs a special blessing, right? So I started writing these prayers, and then it sort of spun out from there. Let's have a blessing for sign language. Let's have a thanksgiving for a new mobility device. Let's just write all these prayers. And I also share in the book, I have seven personal essays that sort of tell the story of my family that are interwoven throughout the prayers. And the primary audience for the book is families like mine, families of children with special needs, families who get it, who feel like we're in the trenches, who sometimes feel lost and abandoned and so alone. And I wanted them to feel seen, to feel like there is a God who loves us and sees us and is making a way and caring for us, even when we can't feel it or see it. But my secondary audience was, in my mind, was people who aren't part of the special needs community at all. And that has been one of the most interesting things since the book was published and also hearing from early readers. I had a friend read an early draft. And she said, you know, I don't have kids with special needs. But I feel like I understand a little bit now. I feel like I had someone say I feel like I got to peek behind the curtain, right, and see what it...what it takes your family to get to church on a Sunday morning or whatever. So that's part of the reason I wrote the book is so that...so that maybe there can be another bridge between the special needs community and, I don't want to say everybody else out there, but...

Elisa: Yeah.



Eryn: I think you can say that. And I think that, and I'll just go ahead and say it. I think that you can say that. Because with anything that we are unfamiliar with, we get scared to ask questions. So sometimes we don't go near it at all. Which makes somebody feel more lonely, unseen.

Elisa: You are a bridge. I mean Elrena, you are. And God's using you that way. But you had said that your dream and your prayer is that one day the church would be the resource. And I...I think some churches really do get it. You know they really get that Christ has been called to the margins of life, and that includes all kinds of places we might not expect to find ourselves, but we are in. Would you pray a prayer for those who are listening and have a relationship, whether it's a chief significant relationship or a remote one or even just a church context one, with someone who is diagnosed, you know, with...with a special need?

Elrena: I would love to. May I pray one of the prayers from my book?

Elisa: Sure.

Eryn: Yes, absolutely.

Elrena: Is that okay?

Eryn: I was hoping...I was hoping you'd say that.

Elrena: This a prayer for special grace. *Heavenly Father, before the foundation of the world, You chose our child to be a dearly-beloved child of Yours. We are honored by the privilege of being Your hands and feet here on the earth. Thank You for the joys and for the sorrows. Thank you for the triumphs and the setbacks. Thank You for everything that makes this child a beautiful, priceless creation in Your sight. Thank you for the ways You have stretched us and grown us, opening our eyes to see You ever more clearly. Thank You for all the ways You have given us special grace, amen.*

Elisa: What a wonderful prayer. We hope the church, as a whole, will embrace differences and encourage others in embracing with love. We all have so much to learn from Elrena.

Eryn: Before we go, we want to remind you that the show notes are available in the podcast description. There, you can find a link for Elrena's book *Special Grace*. You can find that and more when you visit our website at godhearsheer.org. That's godhearsheer.org.



Elisa: Thanks for joining us, and don't forget. God hears you. He sees you. And He loves you because you are His.

Eryn: Today's episode was engineered by Anne Stevens and produced by Jade Gustman and Mary Jo Clark. We also want thank John and Matt for all their help and support. Thanks everyone.

Elisa: *God Hears Her* is a production of Our Daily Bread Ministries.