



Season 3 | Episode 36

Parenting a Child with Down Syndrome into Adulthood

Stephanie Hubach

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Crystal Keating:

I'm Crystal Keating, and this is the Joni and Friends Ministry Podcast. Each week we're bringing you real conversations about disability and finding hope through hardship and sharing practical ways that you can include people living with disability in your church and community. Be sure to subscribe wherever you listen to podcasts or find us at joniandfriends.org/podcast.

In celebration of Down Syndrome Awareness Month, Stephanie Hubach is joining us on the podcast today to talk about the joys and challenges of parenting adults living with disability. Stephanie Hubach is the author of the newly released 31-day devotional, *Parenting & Disabilities: Abiding in God's Presence*. She's also a researcher in disability ministries and mother to an adult son with Down syndrome. Welcome to the show, Stephanie.

Stephanie Hubach:

Thank you, Crystal. It's really great to be here. Thanks a lot for the honor of doing this.

Crystal Keating:

Mm-hmm (affirmative). Well, I'm so excited to talk to you. I'd love to hear about you and your family, Stephanie. You have two sons, Fred and Tim, and Tim lives with Down syndrome, right?

Stephanie Hubach:

That's right. So yes, our oldest son Fred, who we often call Freddy because he's the ninth of all the Freds in the family-

Crystal Keating:

Oh my goodness, because your husband's Fred also, right?

Stephanie Hubach:

So, anyway... So many... Yeah, so many Freds.

Crystal Keating:

Okay. Fred and Freddy, okay.



Stephanie Hubach:

But Freddy is almost 32 and he's married to Cecilia, and they live in Washington, D.C. And have a daughter Caroline, so our-

Crystal Keating:

You're a grandma?

Stephanie Hubach:

Yes, obsessed grandparents. We say we're over the moon for Caroline June.

Crystal Keating:

That's so cute. Love it

Stephanie Hubach:

Uncle Tim lives at home with us still. So Tim is going to be 30 in January. He has his own apartment in our house, which works out really well. And he has two different jobs, works at a local grocery store, so his nickname is Cart Man. And he also works at a medical office as an office assistant one morning a week on top of the five nights a week at the grocery store.

Crystal Keating:

Wonderful.

Stephanie Hubach:

He also loves to play music. He likes to cook, and he creates cooking videos that I post on my Facebook page. So if you ever looking for a great recipe, look up Chef Tim.

Crystal Keating:

Oh, I'd love to see those, that's so fun. What are some of his specialties?

Stephanie Hubach:

Oh, the recipes are relatively simple. So my absolute favorite is when he did one called Hunka Hunka Meatball.

Crystal Keating:

Oh, what a sense of humor? I love it. Well, let's talk about you as a mother. What have been some of your highest joys and greatest challenges raising a son with Down syndrome all the way to adulthood. I mean, he's nearly 30. How's that been for you?

Stephanie Hubach:

It's been an amazing experience. I mean, it is that paradigm-shifting experience to have a child with disabilities, especially if you had no real exposure to disabilities up to that point. And God has just used him as just an amazing blessing in our lives as a family and in my life individually. For me, one of the greatest joys has been learning to see the world through Tim's eyes. He's a



very insightful person even as a child. He often makes me look at things from what I've described as a 90-degree angle from where I would have seen it otherwise, a head turner.

Stephanie Hubach:

He really has this amazing way of just seeing the world through a different lens and expressing it differently in a way that is very attention-getting, and that God uses. His authentic faith... He has a very authentic faith in Christ and a genuine commitment to prayer. He puts me to shame. He is exquisitely sensitive to the needs of others, and he'll pray for people until his food gets cold over his dinner. One other thing just as a parent, really in terms of joy has been watching him, discover his gifts and grow in his faith and living out his God-given purpose as an image-bearer. In a sense, it's what you want for every child.

Crystal Keating:

Yes.

Stephanie Hubach:

And so Tim, he really has, for example, the best work ethic of any human being I've ever met. And every day when I drive him to work, he says, "Let's say the words." And this is me and he's going to say this, "Let's go and get those customers. Customer service for the glory of God."

Crystal Keating:

I love that.

Stephanie Hubach:

That's his work mantra right before he gets there. The greatest struggles, sometimes those great joys come out of great struggles. So one of the ways in terms of challenges, one of the ways Tim came up with this mantra from work is having to learn that he actually was there to serve customers and not to just collect and hoard carts. So, there were some challenging aspects at work in terms of really understanding, "Oh no, your job isn't really to collect carts, it's to serve customers." Because he was at one point blockading all of the shopping carts with trash cans so that people wouldn't take them because he knew he was supposed to collect them and he could not understand why these people just kept taking them.

Crystal Keating:

Yes. Like, "I'm doing my job. Hello?"

Stephanie Hubach:

Right. And here's where this affects me as a parent, as a challenging in a good way is first of all, just having to learn to slow down. And you can hear from me talking, I'm a fast talker. I'm just a lot of energy. And so, one of the challenges of having a child with an intellectual disability is that we tease that Tim has no hurry gene. He's got a speed and we've all learned to just have to adapt to that speed and then sometimes it's easier, sometimes it's harder. And that includes everything from walking along Tim at the same speed, talking to Tim at a speed. And that's an example where miscommunication happened with the carts, just trying to communicate a job without



really understanding, "Wow. How is a very literal person going to understand the role of this job?" You got to say in exchange for that, in exchange for having to slow down,

God gives great gifts to people for having slowed down. Everything from perspective to appreciating things you might not notice in a hurry to more patience. I think that the other key thing, I think in terms of a challenge is, at least for me personally and I think this is probably true for a lot of parents, is just the "dying unto self" for all parenting is a "dying unto self," right? In order to be a good parent, you have to die unto self. My educational background was originally in economics. Economists always talk about this thing called opportunity cost, which means to do one thing is to not do another. And it's always applied to things like spending money or spending time, but the time and energy it takes to order your life around the needs of a person who has greater needs, it just requires a dying unto self. And the good news about that is that while our human resources are limited, God's resources aren't limited. I think that's one of the things I've learned by faith over the years, that he's not limited with what we do.

Crystal Keating:

God has a way of making us more like Christ, through the significant relationships in our life. And I think there's been multiple guests on our podcast who talk about the shift of how their time is spent once disability enters their life. And I think it's very refining because you start to go, "Okay, what is really important? If we have to slow down, then how do we make the most of our time?" And I'm really interested in your son. I mean, even just him praying so long for his friends, that his food gets cold. What are ways that you've seen him bless others through his disability?

Stephanie Hubach:

Many people with Down syndrome have what... and I used the word earlier, what has been described as exquisitely sensitive personalities. They're people that are very in tune with the emotional, psychological state of people that they are around. So Tim for example, is just very intuitive, really picks up on sorrow, anxiety, hurt feelings, anger in other people. And the great thing about the ways God has wired him is he's not afraid to step into those things then. If he senses someone is hurt, he moves towards them. Not... So many typical people, somebody is hurt or angry, we do what? We move away. And Tim has a way of moving in, that's just one of the ways that he really blesses people. I've taken him to hospital visitations before and just been stunned by his sensitivity at the bedside to somebody who's in very difficult straits, that might just make somebody else freeze. And Tim moves in and leans in and connects with the person as well in the process.

Crystal Keating:

Right, because when we're in pain or when we're very anxious, slow, compassionate presence...

Stephanie Hubach:

Yes.

Crystal Keating:

It's very, very calming. It's very comforting. It's a sense of God's presence with us when you have someone like Tim.



Stephanie Hubach:

Yes.

Crystal Keating:

And it's disarming too I think, which is great. Well, as your son grows older, what are some of the significant changes you've seen in his life? And how has your role as a mother changed through the years?

Stephanie Hubach:

If there are parents out here listening, with younger kids with Downs, I want to encourage you that sometimes kids with Down syndrome, when they're, say under the age of 12 in particular, can be very high energy, whirling dervish of activity that's difficult to direct it sometimes. And we had a lot of medical drama early on, so there was a lot of that sense of relentlessness on that level and just on activity level when Tim was in, say his younger years in elementary school. But by the time he hit puberty, he really did start to center. And I've seen that with a lot of adults with Downs, that they tend to center some of the resistance that's more common in behavioral issues and stuff. And their younger seems to resolve itself more. It's not that it's not existed, but their maturity sets in.

Crystal Keating:

Well, and that changes your role even as a parent...

Stephanie Hubach:

Exactly.

Crystal Keating:

... in your position and how much time you're investing and he's becoming more independent and...

Stephanie Hubach:

So, he's become a much more self-motivated person. So when he was younger, it took a lot more active direction and coaxing and mental gymnastics at all times to try to figure out how we're going to navigate this next thing. And then now it's, "How do I relate to him as an adult where we're actually having a discussion and doing some interactive decision-making." I think we tried to really have a mutually respectful relationship with our children throughout their lives but that shifts more and more and more. For example, when Tim was little and very difficult to direct, I might've said, "We're going to the bank. Do you want to get in the passenger seat of the car or the driver's side passenger seat?" All right, you know-

Crystal Keating:

That's one thing we're doing and you get a choice about something else, but not going.

Stephanie Hubach:

Right. If you get a choice about the door, you don't get a choice about whether you're going to the bank. But now it would be more like, "We're going to the bank. Would you like to go to the



bank with me or do you want to stay home by yourself? If you stay home by yourself, what are the couple things you need to remember?" Do you hear the shift, the respect shift there as an adult to adult? And I think that's the biggest potential danger with adults with intellectual disabilities is to not treat them like adults. It's a bit of a dance because they still need more help than a typical adult does and yet you want to provide it in as respectful way as possible.

Crystal Keating:

Right.

Stephanie Hubach:

So, yeah.

Crystal Keating:

And I've heard the principle of treating someone according to their age is really important, especially when interacting with adults with intellectual and developmental disabilities. Would you say that's pretty much in alignment?

Stephanie Hubach:

Right. I think years ago, there was this thought about mental age and that's where people would say, "Oh well, his skill level's like a five-year-old, so I'm going to treat him like a five-year-old," and be like, "No, that person might have a skill level that's like a five-year-old and I may then have to adapt my information to that skill level, but I'm still going to treat them like a 30 year old."

Crystal Keating:

Well, let's talk about families as a whole living with disability. One of the issues that we hear time and again is just the isolation families feel and face either being misunderstood or not having access to the same community. So how can parents of adults and children with disabilities avoid becoming isolated?

Stephanie Hubach:

I do think some of it all hinges on our mindset, not only our mindset, but isolation can be from a mindset, and it can be from a physical reality and it can be from both. Right?

Crystal Keating:

Mm-hmm (affirmative). Yeah.

Stephanie Hubach:

And so-

Crystal Keating:

Right, because I spent some time with my cousin this weekend who has an adult son with autism and she said very bluntly, "I did not want to inflict my son on everyone else." She was like, "I knew that wasn't the right thinking but that's how I was feeling when he was young and there were behaviors that were really hard, even going to the store, so you just naturally want to stay



home to protect your child, you protect yourself." Her mindset really was, "I don't want people to feel uncomfortable." And they knew they couldn't sustain that.

Stephanie Hubach:

Mm-hmm (affirmative). As families, we can be all about educating other people not to treat our child as other, and yet in practice, we actually live our lives like we actually are other. And I think when we, in our own minds, stay connected with the idea of difference of degree rather than, "My life is totally different than anybody I know," even though there may be a lot of differences of degree, it still leaves room then for other people to find a handhold of connection with us. And I think the other thing too is just it's... And this is hard because a lot of times what parents are really struggling with is just the lack of energy and in the post COVID or -

Crystal Keating:

They're exhausted, yep.

Stephanie Hubach:

Yeah, post COVID, mid-COVID, wherever we are right now, everybody's tired of missing connection and trying to make new connections. But I think in the end, we still have to choose connection and-

Crystal Keating:

But I think that requires being vulnerable.

Stephanie Hubach:

Yes.

Crystal Keating:

And I mean, when you're talking, what I'm thinking is, there's a level of hardship and suffering in all of our lives. "It doesn't make disability all the same," that's not what I'm saying. But that the Bible even normalizes that we are in a fallen world and there are hardships that we all experience and when we start talking about it, we all need similar things, we need connection, we need comfort, we need encouragement, we need strength, we need friendships, we need grace, we need mercy, we need help. We need fun, we need just this sense of openness, but we have to start there and let down those walls, which is scary.

Stephanie Hubach:

Yeah. But that is, if you've read any of Andy Crouch's work, his whole idea is that flourishing takes place at this intersection between both our capacity for meaningful action to act on our lives and our exposure to meaningful risk, to be vulnerable. And flourishing takes place in both those things, they're not just one, not just the ability to act. And that's where I think we don't think correctly about this at times, because we'll think, "Oh, if only I had more control," for example, "I had more control over my circumstances." Like no, actually the vulnerability, it's required in order to move down a pathway of flourishing. And so I actually talked about that more in my book, *Same Lake, Different Boat*, if somebody was to look at that. But I think if you think about biblically, the whole idea of hospitality, right?

Crystal Keating:

Mm-hmm (affirmative), yes.

Stephanie Hubach:

It's always on us to be hospitable to the other. And sometimes when a family affected by disability, we still want other people to be hospitable to us and we forget, we also share responsibility to do the same. And we find often if we move towards people, even with a small amount of energy, even in a tiny way, it could be a cup of coffee instead of a whole dinner. We're not talking fine china here; we're just talking about connection. If we choose connection even in a small way, it always ends up reaping blessings for both parties. So I do think... I'm not in any way minimizing the isolation, I get it. I do believe it's real and I believe COVID has made it really harder. That said, we all still have to choose connection, choose to be faithful to God's call to hospitality towards the others and it goes from there.

Crystal Keating:

Jennifer Hill was on the program, she lives with CP, and she talked about loneliness being a hunger. When we're hungry, hunger leads us to go get food. And similarly, there's an ache in all of us for connection. How do we move past the fear and move toward connection? I mean, and I love that, it doesn't have to be a whole meal, just coffee, just start small so...

Stephanie Hubach:

Do you know what? That's a great analogy too, if you go too long without eating, you're going to eat things that aren't good for you. Go for the junk food.

Crystal Keating:

Yeah, so you're just desperate, you just do a full-on binge and then you feel terrible.

Stephanie Hubach:

There's almost actually a certain amount of discipline to not allowing yourself to get isolated.

Crystal Keating:

Yes.

Stephanie Hubach:

And I know that's not easy and I'm not saying that in any way, neither of us are, but I do think it does still involve some level of being proactive.

Crystal Keating:

So in your experience, what are some of the greatest needs of adults who live with intellectual and developmental disabilities and how are you seeing the church meet some of these needs?

Stephanie Hubach:

Well, if you start with the first one, which I think is every person's greatest need, every person's greatest need is to know Christ personally, to experience the grace that he provides and



salvation to be a recipient of the blessings of being part of the body of Christ and to have God-given purpose in life, right?

Crystal Keating:

Yes.

Stephanie Hubach:

And so, making the gospel accessible is really at the heart of what every church needs to be focusing on for every person. Every person, regardless of ability or disability or whatever combination thereof, the usual answer, "That's a need for Jesus." And so I say that's by far the greatest need. So if we neglect making our churches accessible to people with disabilities, particularly people with intellectual disabilities, that they can not only hear the gospel but understand it, not only hear stories about Jesus, be introduced to him in a form of discipleship. That's number one in my mind. Number two then is it becomes a very natural outgrowth of that, then when you're part of the body of Christ, is friendship. Again, that's just that... What's funny about disability ministry in general is I always tell people, it's not rocket science.

Crystal Keating:

That's good to hear.

Stephanie Hubach:

It's all different but it's all the same. Then again, it's different applications of the same basic needs; it's a need for friendship. And so what it takes to facilitate friendship with people with intellectual disabilities is just some vulnerability on the part of the typical person, who's wanting to get out of their own comfort zone. And if the person with an intellectual disability has a passion for SpongeBob, then learn about SpongeBob.

Crystal Keating:

Well, I was going to say, it has to come with an attitude of humility of like, "Who is my friend? What does he or she like? And how do we interact? And how can I learn to connect them?"

Stephanie Hubach:

And then basic things, obviously transportation. You can't ride, can't go out to breakfast with someone, and some things like that if they don't have a ride. And so being sensitive to what some of the background noise is in that person's life of what supports have to happen in order for things that we do almost instinctively in typical circles, without thinking about it, because we just hop in the car. In terms of at our church, I think places that I've seen a lot of friendships really flourish with people taking other people shopping or going out on breakfast dates or inviting them over for the holidays because they know their family's out of town, which is again, all typical things-

Crystal Keating:

Doing life together.



Stephanie Hubach:

Doing life together, positive sense of expectancy. If we're honest with ourselves, a lot of times, especially with people with intellectual disabilities, we have... Typical peoples suffer with a sense of low expectations and instead of looking at people with intellectual disabilities as people that we can learn from and enjoy, people that have gifts to share, sometimes we would just look at people with intellectual disabilities as consumers of our care. And that's a very disrespectful way to look at a different person because every human being has both needs and gifts; every human being has great value and also degrees of brokenness.

Crystal Keating:

Yes, we do.

Stephanie Hubach:

So anyways, so looking at people with intellectual disabilities with a positive sense of expectancy and expecting, honestly, to be surprised sometimes about the ways in which God meets us through that person and the ways in which their gifts might be packaged.

Crystal Keating:

Well, I'm sure you and your husband are thinking about long-term care for Tim. And I know many parents write to us in anticipation of the future. So how do you manage those emotions and what are some of the important steps parents should take as they prepare for their children's future?

Stephanie Hubach:

These emotions can be all over the map sometimes. We talk about how frequently we discuss this. And it goes all over the place... Sometimes a sense of anxiety or angst to other times to almost a complacency, "I don't want to think about this," to other times where you just want to run away to the other side of the world on a sailboat and land on an island with an unlimited supply of suntan lotion and little umbrella.

Crystal Keating:

Yeah, because that can be so overwhelming. And it's like, "Lord, what's the answer?"

Stephanie Hubach:

And I think, my son Freddy has been so helpful in this in a couple of different ways. Freddy's a very insightful person. And he said, "You know Mom and Dad," he said, "You would never plan my life. So you really don't ever want to plan Tim's either." He said, "That said, you need to prepare for it. And not just financially but in every way." So how do you prepare Tim for the time in life when you will not be here, or we will be less able to participate in his life? Just that little phrase, you wouldn't plan for it, but you need to prepare for, has been really helpful.

It's something you do with the person with the disability, not just do for them. One of the things we've been doing recently has been taking an online class. And so it actually helps to launch adults with intellectual disabilities into a higher level of independence. And I think one of the struggles in this whole area is that we have somehow, there's this idea that people with intellectual disabilities ultimately should be autonomous and completely independent. And I



don't think that's really a biblical concept to start with. I think really, what we're all called to is appropriate boundaries with interdependence. And so interdependent living is a whole lot easier to plan for than some autonomous independence, and a whole lot healthier.

Crystal Keating:

And that requires something of the community around you.

Stephanie Hubach:

Exactly. So one of the things that we're working on right now is, this terminology is not new, but that we're trying to put it into practice for our family and see how we can help other people just practice it in theirs and see if it works as well, is this idea of a circle of support. So giving Tim basically the choice of a group of people around him, that first of all, he chooses and that he enjoys and respects, and that can provide appropriate input into his life as we make decisions about little things and big things. We were in the middle of forming a group through some close friends of the family, some personal friends with Tim's from school, some people from church. What would happen then was even if Tim always lives in the apartment in our house, that's not necessarily a bad thing.

If he's in an apartment right next to the grocery store, an apartment in our house, as long as he has transportation to get there from here. But for example, if you have a group like that and forbid that Fred and I would get hit by a Mack truck, but if we did, it's not just Freddie in Washington somehow trying to help scramble to pull the pieces together for Tim in Lancaster, Pennsylvania. But it's his church, and his friends are already around him intentionally, and they already know all these things about him, about what makes him tick, about what he likes, about what he needs, about what he can do, about what he can't do.

Crystal Keating:

No, this is so big and I think, even for parents to begin thinking, "Who is in my child's life right now? Who are our good family friends? Who knows us? Who really cares? Who loves us? How do we start developing preparation for what's ahead?" And I think God honors that.

Stephanie Hubach:

Any of those emotions that we ping around in always just need to take us back to Christ. And to that God has got this. It doesn't mean we can sit down and do nothing, but it's that whole idea of ask, seek, knock and then he will open the right doors at the right time. And a lot of times, in ways we can't even imagine, in our own finite. So it involves our engagement but ultimately the needs are met by his hand.

Crystal Keating:

Yeah. Well, that's a good hopeful note to end on and thank you so much for joining us on the podcast. Stephanie, if our listeners want to pick up a copy of your devotional, *Parenting & Disabilities: Abiding in God's Presence*, where can they buy your book?

Stephanie Hubach:

Yes, they can get it on Amazon, christianbook.com, P&R books, and also engagingdisability.org,

Crystal Keating:

Right. It's such a pleasure to speak with you and I so appreciate your time. God bless you and your family, Stephanie.

Stephanie Hubach:

Hey, thanks so much, Crystal. Take care.

Crystal Keating:

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