

Every Child Can Learn Podcast

Episode 21: Faith on her sons with Down Syndrome (part 2)

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Ann: Welcome to episode 21 of the Every Child Can Learn podcast. We are back with Faith, who you might remember from the previous episode. Faith is a mother to twins with Down Syndrome and she supports families of children with intellectual disabilities. Please enjoy this new episode!

Ann: I couldn't agree more with your dream, first of all, you absolutely. What I was also curious about, of course, you're saying it's not so easy to find enough information. But fortunately, you've set up something where parents can actually get much more when it comes to information and maybe referrals, other services and such. So, I would ask you, if you could maybe tell the people listening how they can reach the center, whether on phone or physically or however you prefer. And also maybe which different categories of disabilities you mostly focus on. So that parents or teachers or anyone else can know that okay, if I want to get support for this, I can go here.

Faith: Okay, thank you. Yeah, we mainly work with children with intellectual disability, we are looking at Down Syndrome, Autism Spectrum Disorders, HDA...hyperactive, we are

looking at CP, those with mild condition that can easily be supported to train, like learn a skill, level of independence, or also supported to be integrated within the community, so we work directly with the parents, support training, giving the parents the skill, connecting the parents to the right people. So like train, we do workshops, and then get the right baby therapist, maybe the special education teachers to talk to parents on what they need to do to work to like to educate them. Yeah. And we have a website. Not very active, though, but it is there. I don't want to say that's not the right word, though. But we are on www.parentingspecialneed.com. Yeah. And the number would be +256778260347, again, +256778260347. You should be able. It's also on WhatsApp. So it connects with us. Thank you.

Ann: Perfect, thank you, I hope you will receive more calls once people have listened to this episode. Now we know I think as different people working a lot with children with disabilities and with parents, that there are a lot of myths, right? There are a lot of things, stories that people believe about living with a disability or having a disability. What do you think is the biggest myth that people still believe about disabilities?

Faith: That children or people with disability cannot live an independent life? I don't know whether that's the right word, like people feel like, I would say parents or families will do anything to make sure my child goes to school, even when they don't have money, they will try to look around my child, because this is a typical child they will do anything because they think and believe that this child can become somebody something in the future. And they forget that this one they believe, I think that's what they think this one is really cannot do much this one needs help. So they pay very little help or support or attention to this child, which is, I feel is a misconception. If you do equally a lot for this child, at least to the best of his ability, may need a bit of support, but can actually become fairly independent. So for me, that is the biggest myth that this child cannot with, let's pay more attention here because this one has a bigger, brighter future than this one. So that for me is a misconception. Really, of course besides what other people believe you bewitched, this child was a result of your punishment, you sinned or you decided to sacrifice this child, which is very often I don't like to pay attention to those things because it is really a negative energy. I prefer to focus on what

I think can make a difference in that child's life then also to the end, but also maybe this will come much later for people to learn to be a bit kind to families, to parents, when you see a parent moving out there with a child. I'll tell you one time my boys were about a year, maybe about a year and a half and they're big boys. So there's a playground where there's so many activities going on. And you go through Naalya around there, so I had a pram and the boys were sitting in one is behind another one is in front. Of course, they're not even walking well at that point, pushing this and moving with the kids. So this lady, I feel like she was, I think in her mind they were two ladies and they walked past and said, Oh, this one, how can you start pushing children in this thing instead of carrying them? And I'm asking myself, does she even know why I'm putting these children to walk? Of course, I would have wanted my own kids to walk too, you know, move by themselves. But I am trying to move to, it is helping me just to transition. But you're already judging me, based on why would you do this to these children? Why would you do this to a child, I'm like, okay, maybe you don't know what you're dealing with. And another time, I'm with another child that they love. Now, they're very inquisitive. They like touching here, trying this trying that. So in my neighborhood, then the child goes, Joel loves cars, so it goes, he's touching the car, and then the neighbor come and say, madam, you train your children. It's like, really? So in your mind, I'm doing nothing to train my children. So it's very harsh, it's like, you're not doing enough, but they don't know what you're dealing with. So if society can be a little bit kind to people that will also help.

Ann: Very strong message for all the fellow parents and even anyone else who might encounter a parent of a child with a disability, right? That you don't know what's happening in someone's life, you'd rather be friendly and supportive, because you just don't know you could have been putting in 200% compared to other parents. And still, you might not be getting everything perfect. No one is getting anything perfect. Yeah, you've already mentioned something very important. I was going to ask you what you think parents and teachers can do best to support children with disabilities. So kindness is already something you've mentioned. But maybe there are other things that you think would be supportive as well.

Faith: Yeah, one of the things I think the school, the parents can do, to make sure they can work together one, like I said, there is a very good will strong goodwill, if that's the right word from the government to make sure that our children are included, or they go to school, they don't stay home. But theoretically, that is really working. But practically, it is not on the ground. It's a bit hard for those few schools that actually accept children for inclusion. First of all, I'll tell you, I have a couple of parents who will tell you, when I first took my child with special needs, the school rejected when I took the child, the young brother or another one who is a typical child, they were very happy to take that child on. So then for me to make sure this child is able to go to school, I had to put it as a condition if you're taking this child don't leave this one. So you are being okay, it's okay, let's take because we are taking the normal one, now we can accept the other one as well. And then not much is done to help. Like my understanding would be how do we work with this parent, right from onboarding, bringing your child on board. So like, how we sit down the parent, this is what we think our child can do like setting up the IEP, this is what our child can do. This is where he needs more help. This is what I would expect us to work on by maybe end of term one, or end of year, my child should be able to, like basically, develop the IEP for this child, while you know, the child is onboarded like brought on board and you have at least a working tool, something we are working with to know that this child is not just here, passing time, okay, like, you know, you're paying fees and sometimes the fees is more than for every other child, because I've experienced that when I first took my kids, the others were paying a certain amount, I was asked to add at least 200,000 more on top because you know, your children need more attention. So you have to add, now I am adding more money, and I'm bringing the child on board. He's not being helped. So he's there for formality. I will tell you one time I offered I'm ready to work with you people, build your capacity, I will come and teach you and we started very well. This is how this one or two of the boys one is more hands on Jesse he's very hands on when you just get him to do the thing. Show him. He's going to get it and do it. Then this one is a kinetic learner. He's always moving. But even as he's moving, he's actually learning. And when you sing, or you read the book, he gets it very fast. So I was telling them, if I brought Joel and Jesse in your class, if you're going to give Jesse to do this, and then Joel, he's not going to sit. So but that doesn't mean you just don't pay attention to him. He's going to get up and move around. But as you're doing if every time you are reading trust me, he's going to

pick and one day I walk in they said Mama Joel, this boy surprised us we read a story, he was up and down, but when we were asking, the other kids were quiet. Then Joel mentioned what we read. So everybody was like what he was up and down. So but yeah, that is his learning style. That is the only way you know, so but this child, the teacher may not know, but I know my child, this is how this child, if I do this, this child, I realize he picks it faster. So if I have this kind of information, he can actually be very helpful to this teacher, and can know that, okay, this child, I'm bringing on board, I need to when I'm doing this, maybe I need to do more, you act to the words or you dramatize, yeah, that child will learn that, and he's not going to get it all at once. But if he's able to mention maybe identify ABCD, and may not be able to write because his writing is going to develop over time. That's good enough. But I'll tell you, My children stayed in one class in baby class, like for a year. And then I told them, I don't want them to be in baby class again, I want them to go to middle class. They're not writing, but they will literally tell you 'sssss' this is S which is ssss sound. This is "a", "a" they can you know, that he is not going to write he's not able to write it's not yet there. But he can identify most of the things he will name you a couple of things they have a bit of a challenge in like blending the words, but at least they know. So for me that was already enough. Why should you keep my child here, even if you keep him for another one or two years, they may never write. Because you're not even they need to work with a therapist to be able this fine motor and all this is done well is addressed, then they will be able to write. So you will keep so I tell them, you know what I need my child in the next class. Okay, mommy, it's fine. Then one day, I walk in, so what happens, I dropped the kids in the morning, they're taken to baby, middle class, as I leave, they're moved back to middle clas...baby class. So one day I walk in, I'm like, oh, so this is what is happening now. So one hand is okay, the parent want the child to be there. And then the I don't know, maybe it was both of us were not understanding something. So that is the things that happen, we are not yet able to communicate the same language or to understand how we parents can work easily with teachers, there is the part of I am the expert, and the other one is like, but I also want things to be done like this. So it's still a big gamble, I guess. So working to hand in hand, give a bigger contribution to this child's life. And therefore, besides that, we need to come up with a clear goal of what these children are not going to learn all the history of Uganda and all those and all that but you can at least adapt the little you can to the best of your ability. If a child knows

this is a map. This is Uganda, that's good enough, I may not know how to draw Uganda, but they have tried that kind of stuff. And then communication, open communication between the parents and the school so that the children are actually helped physically. And maybe that's how I would think.

Ann: Thank you so much. Sounds like collaboration is the key word here. Yeah, that's right. Yeah. And acknowledging the knowledge and the expertise of parents if I'm getting you right. Yeah, that makes a lot of sense. Thank you. I have one more question. The last one. Let's say there might be a parent or a teacher who is listening to this episode, who might suspect that either their own child or a child in their class may be having a disability? What would you recommend them to do? If that's the case?

Faith: Okay, thank you. I think the first thing is, you know, a child has some, you're suspecting the child has some condition. The first thing, of course, is to, if it is a teacher, it is important to involve the parent, let the parent know we think your child has some based on, for us we love evidence. But if you're able to clearly explain I guess, not using the jargons maybe the teachers also have their own jargon. Like we notice your child may be struggling with the pronunciation or cannot write others of these levels are already writing, we think he needs maybe this kind of support to make sure they stay in a good way, then, I guess then the parent should also be kind enough to listen because nobody will just spot your child out of the blue and say your child has a bit of a gap. So first would be to inform the parent, then see maybe if you have another place you can refer like for example, yeah, we notice your child has this problem, we thought we should bring you on board. And if you don't know there are a couple of people who can help this child. Maybe you go to this place, like basically guide the parent refer the parent where that parent can get the right support. But of course, when the starting point, like I know is that teachers and the parents, we can not diagnose so maybe to work with the doctors to get to establish really what is it that we are dealing with here? For me, I was fortunate my children are born with Down Syndrome, you literally see the features are different. And you're like, okay, this one is different. But the child maybe with autism is born looking like 100% normal. So it's very hard to know that okay, this is different is, but a doctor will know, and can be best to diagnose I mean, do the assessment and tell you all this, I

think this is what is going on. When I discovered I was expecting twins, you know, I come from this line where there are twins, my sister, the one I follow has two sets. And then actually three, she had three sets of twins, and then my grandmother and all that. So I was like, when is it going to be my turn? It had become like pressure on me. So when it happened I was so excited. And I literally told everyone, everyone's like, oh, you're expecting? Yeah twins. So you know, I was so excited. So when I gave birth, and then they tell me your children are special needs, I felt like oh, I think what people say is true. Why was I busy telling everyone? That was the first thing that came to my mind if I had not said this to people that I was expecting twins, maybe somebody was not happy? That was really silly of me to think that. But the truth is, you're given news, like some kind of bad news. Your brain is not working straight. You're asking you're questioning everything you're blaming yourself, maybe if I had not done this, this wouldn't have happened maybe if I've not done that. And sometimes, while you're busy blaming yourself, of course, the elders, you know, traditionally, our elders are like, you know, you come this child has a problem. I will tell you recently they told me there's a reason why one of my sons, Jesse, Jesse recently developed seizures. So he started behaving so differently. He was very vocal, he's talking, he actually calls the father by the name, "Hello, Wilfred." So this boy, all of a sudden stopped talking, like a lot changed. And somebody told me you know what, I think the reason why this boy's changing, he is behaving like this, because you did not give him the right name. Twins, Opiyo and Ocen, that's how they're named, I chose not to give them those names. The first twin who was supposed to have been Opiyo is called Gum, meaning blessing. The second twin who is Jesse now is supposed to be called Ocen is called Mich, like a gift. So he's like, you know, if you're not giving them these names, if you had given them Opiyo, Ocen, perhaps they would not be going through this. So those things still exist. And people will tell you a lot of things. So you will start debating maybe, right. Meanwhile, the clock is ticking. Yeah, the time is going, the more time you take the worse the situation will become. But if you, you know, accept and act now, my child has a situation, then you could see the doctor, for that I know where to start from. Of course these other things will still come around. There is a reason why this is happening to me this day, those will still be there, they'll continue to be there. But to me, if you act fast, go to the right people, the doctors will give you of course if you are not sure, take another opinion another doctor so that you compare the notes. If they still tell you the same

thing, then there is a chance that this is going on now you need to do you need to take action. So act now. Go see the doctors and do what is right before waiting to you know, your child has been bewitched, or sitting there lamenting and blaming yourself like I did for two months. Okay, dear. Thank you.

Ann: Thank you so much. Yeah, I can only imagine you're trying to figure out everything at once. Right? And especially if you have two children at the same time that you're taking care of plus your other children as well. Yeah, that makes a lot of sense. So if I'm getting you right, your message really focuses on it may not be you to blame for the situation that you're in. But you are responsible for handling it now. So that's why it's so important to do something, look for information, look for help. Fortunately, you've shared already how people can reach you and the center. So that's wonderful. And as Backup Uganda we know we always have at the end of the episode, you'll hear our phone number as well. If you want any information you can call us also. Thank you so much Faith, thank you for sharing everything you have shared, thank you for doing an amazing job, both in your personal life and generally speaking for other people as well. It's been a real honor to talk to you today. And as Backup Uganda we always like to say every child can learn. Thank you.

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