

Every Child Can Learn Podcast

Episode 20: Faith on her sons with Down Syndrome

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Anne: Welcome to Episode 20 of the Every Child Can Learn podcast. My name is Anne, and I am one of the founders and also the Uganda Country Director at Backup Uganda. Today I am delighted to have a wonderful guest here with me. Her name is Faith, but I'm going to let her introduce herself. Faith, you're very welcome.

Faith: Thank you so much. Um, I am really privileged to be here. Like Anne has already mentioned, my name is Faith Eunice Oyella, already by my, the virtue of my surname you already know I'm from the north, I happen to come from Gulu, but currently based in Kampala. I am a mother of five, out of the five two were born with special needs, Down Syndrome, and they are the twins. I am a school inclusion team member for Shimoni Demonstration School, where we work with parents within the community to create awareness and to encourage them to make sure that the children with special needs are not left behind, are part of the school community within their communities, they are included. I also happen to be a special needs, I mean, a special education teacher, a career that really came after the birth of my children. Before the birth of my children I had trained in entrepreneurship and business management and I worked pretty much with the women and

women in business. So this, the special need came as a new calling, and really redefined everything about me and what I do now. So right now, as I talk, I am one of the founders of an organization that works to support parents. It's called Achievement Center for Children and Family. We work with parents of children with special needs and our area of focus is connecting, creating resources, connecting parents to the professionals, like the special needs teachers, the therapists, the doctors, so that, I mean, if you have the right tools in your toolbox, in your toolbox, then you are equipped for the job. So this is the approach we use to make sure that the parents are equipped with the right information and are trained to do the right thing because they stay with the children and they're empowered to work with the children better. Achievement Center for Children and Family is in Kampala, Kira, and we started informally 2016. So a lot of our work has been informal with the parents, directly who are less privileged, you, we would go through to the community to meet parents who are mostly single mothers or single fathers. And we try to work with them, to guide them to train them on what they need to know about their child's condition and how best they can be helped or where they can go to find help. So basically, that is how we started. And then right now, we are fully registered. We've got registered way back in 2019, as a company limited by guarantee. And our work still continues in the same way now, but except now it is more formal other than the informal way we were doing.

Anne: Okay, thank you so much Faith. Thanks for introducing yourself and what you do. I've loved the idea of ACCF so much. So yeah, lovely to hear what you're doing there. I think you've already kind of explained why you started it. But maybe you can say something more about that. Because you said it somehow related to your own children as well, right? Would you like to talk a bit more about that?

Faith: Yeah, thank you, Ann. 2014 was when I gave birth to my twins. And just like every other parent, mother, expectant mother, I was really looking forward to receiving healthy babies. But God had another plan. So when I gave birth to the twins, in fact, the pregnancy was pretty much fair, like a stable except for towards the end, like to the third trimester. When I remember a doctor requesting that I do a 2D scan, which I had to do. And when I was doing this I, a lady asked me, the doctor, as to whether the twins were naturally conceived. And it

puzzled me. I didn't know why she was asking that. And then I said yeah, they were naturally conceived but later she again asked whether the children's dad was a tall guy. But definitely wasn't, he wasn't but she didn't explain much. Of course, I was a bit curious. I kept asking "Why do you ask that?" And she's like "Oh, no, we just said just, just for information purposes", but it came back to me after the birth of the twins when the boys were out and I was told they have Down Syndrome. That's when I flashed back and said, okay, there was a chance that there could have been a chance, she had noticed something different. But she could not openly tell me. So at this point, I'm told, after the birth of the children that the children have Down Syndrome, in fact, the information did not come in a very clear way. They just told me the boys have DS, which is something that I think our medical practitioners should try to change. There's a lot of time they speak in their own technical terms that the ordinary person may not know. To me, it came as these children have DS. So I was like, what is this, then another person says it's Down Syndrome. And they don't give you much information. So I get back home. And I'm very curious now, what is this DS? What is this Down Syndrome? The kids looked pretty normal. But, so there was a lot of question going through my mind. And then I realized, I didn't know who to talk to, where can I go for more information, I think, three weeks later I had to go to see a pediatrician, one that had really been helped me with, with the children I had before. And he also taught me, he said something that was, I don't know whether I felt a bit it was, it was a bit too much for, to take, because he told me one thing you should be glad is that you have three normal children, these two are not normal, abnormal, so to a mother receiving the news that your children are abnormal. Maybe it was me then thinking I was living in denial. I remember talking to myself and say, no, this is not my portion. It was hard. It was a very hard thing to take in. But at least he told me yeah, this children may walk, they may never walk, they may sit, they may never sit, the are normally associated, their condition is related to maybe heart defect. But for now, you really don't need to worry, they seem normal. Let nature take its course. So but for me, now every word coming, I was not taking it lightly. I felt like something has to be done, like, urgently. So he tells me let's come back and review after six months and see how they are developing. I go back and I became this curious parent now. I became a scholar, I started doing a lot of research to know what is Down Syndrome, what does it cause? What does, how is it caused and all this and I just got, I discovered there was a lot to it. It's not about the

parents of the children only there was this, is it they are prone to leukemia, or they are prone to, is it hearing problem, there was a heart defect issue. And being a parent, I quickly had to go, I didn't have to wait for six months, I had to go look for a heart...

Anne: Cardiologist?

Faith: Yeah, to do, to run a test be sure of that the boys are okay. Three months, about three months, about two months coming to three months, we did that test and discovered the first child had a hole in the heart. So the second one, there was suspicion. Now the question was now how do I deal with this, she quickly told me for now that it's not very, it's not life threatening. But you need to manage the situation. Anything that will bring on the heart to beat, to function very fast. Things like flu, you have to treat immediately when it occurs. And so I had to take that seriously. I came back and they told me to manage their diet, make sure they have enough rest, and they feed regularly. So I came back fairly equipped now with what to do. So I had to take it on board that managing the children, the babies, their sleeping hours, every four hours, they're sleeping, wake them up, feed, go back to sleep, when they turned six months, I removed, they were totally on vegetables, like I would blend pumpkin to the flours, everything. Anything that I thought would help and those that could help with brain development. Like I had put them on cod liver oil, a lot of things I just, I researched and discovered would be of help. I made sure it was part of the children's diet and they're taking fish, no beef, no salt. So it somehow helped though and then also how to start off the early intervention. I started doing the intervention myself, I would go to YouTube, watch all the what is being done somewhere else and try to replicate it in my house. So that's pretty much how I started helping out the boys. I tried to reach out to a couple of places that there are not many. I went to one place I was recommended for for physiotherapy, because then I needed to know how to help the boys to do the sitting and all that and I realized we were on different pages. Yeah, I would see them once every week. So the first week when he taught me how to put them to sit. The second week he taught me how to put them to crawl, the third week, that's when I stopped, and he told me we're going to put the boys on CP stand, cerebral palsy stand, something that would help the boys to stand. So I realized, okay, maybe this is too fast for me, I might have to go at my own pace. So I stopped, then came home. And

because I also felt like having my boys on a CP stand was a bit very traumatizing. So I opted to do it the way we do it at home, like I had a baby walker. But I didn't want it because I felt like there was effortless, they will just sit in and then you push them and they move. So I removed the boys from their baby walkers, put them, used our dining chair, so they push I pull, the chair would pull the chair, they're basically forced to follow the chair. So that that's how they kind of learned how to stand up, walk around, and then sit. The sitting part, we would use the corner, the corner of the house, sit, pause them to sit there a couple of minutes. The beginning was hard, they cried a lot. But along the way, they picked it up. I also read somewhere and they say it if you will, the by time when they were starting to walk, like they needed to be in an environment that would facilitate their growth where there are fellow children. So my son already happened to be in a school, that, a kindergarten. So when I asked the school to allow me bring in the boys, they were already about two, one and eight months. And they said well, we will take the boys in but if they're not walking, then you have to get extra help from home, which I was happy to take it up. So I enrolled with the boys for a full term, we were in classroom, when in a play class, so during activities in the classroom, I'd carry, them keep them standing. They were barefoot 24/7 in the classroom. And then when they're going out, put them on a nice cushy, pram, drum, and then take them out, put them off and like they're, to make sure they're part of the team at school. And the children really helped, they would come surround them. But what I'm trying to say is that I did a lot to help the boys. So after one term, in the school, of course the time, I bought some books from Down Syndrome Education Center, a colleague of mine helped and brought for me from the UK. So I also read and that they achieve, you put them on a treadmill, which will help with their walking, so I took them to a treadmill, would hold them, of course the people feared they couldn't, and I'm like okay, I will do it. I would hold them on the treadmill, they do the exercise, like instead of eight minutes I'd five minutes per child, it paid off, the boys picked up, they started doing a lot on their own. They started learning how to talk, which were, I was actually told they would never talk. So I felt like okay, maybe what the doctor told me is not 100% true, maybe there is something I can do to help. So that's pretty much the journey we had to go through. And they started learning to pick words. And then I, when time came when they were about three, I fully enrolled them in the classroom with the rest of the children. So but I felt okay, this is me a mother who is educated. At that point, when I actually gave up my

job, I was the executive director for Uganda Women Entrepreneurs Association, and I came down to say, I have to change this narrative of my children, they should be able to live pretty much a normal life to the best of their ability. It was not an easy decision. But also the other bit is that my husband has been very supportive. It's not the case with every parent. So when I, my boys enrolled, and I was home, I realized not many parents are privileged, not many out there able to do what I've been able to do with my children. So I felt the need, I felt the gap that I was going through, there could be several other parents out there who are going through a similar quest in life and willing and wishing somebody was there to walk the journey with them. And some of them that's when I actually started going out to meet other parents. That's the how the our informal journey started. So literally, when I meet a parent with special needs child, I'll try of course, most times they are a bit afraid because you're being judged. It's like your fault you give birth to this child is the reason why, so most of them live because of the stigmatization, I think they prefer to keep the child away. And you know, because you also want to live a fairly normal life. So pretty much that's how that dream for achievement center came in, to fill the need, the gap that I felt was missing, what was lacking in our system.

Anne: That's beautiful. Thank you so much. Thanks for doing an amazing job for your children. But it sounds like you're doing a lot for other people's children. I'm very curious, what would, if I were to come and visit the center? What what does a regular day look like for you there?

Faith: Oh, on a typical day, so most times we we do like right now. Okay. What's the one thing I didn't mention is we started off in 2019, we're based in Najjera, operated for about a year and a half. And then when COVID hit, we closed down. Now, we moved from, we have moved from Najjera, to Shimoni, to close to Shimoni now, where we are based in Kira. So most of our work right now is online, but we call for meetings, then we are, we share the meetings, we do more home visits with parents who are having this kind of children, we are trying to educate them more on the conditions of the child, or role we know where this particular child can actually get better help we make referral, or like, we have a very good working relationship with Naalya Children's Hospital, they actually do a lot of assessment for children with special needs like Down Syndrome and autism. And for free, this is something

that, like I said, if you know what you're dealing with, you're better placed to handle. So for us, this is like a plus, if I am aware that if I have a child like this, I can go to Naalya, I just need transport, they'll help me do their diagnosis, and then the rest, I can see how at least if I know my child has this condition, this is what I need to do, then it's a good starting point. So we keep referring parents there is this place you can go, you don't have to be guessing what you're dealing with, you can actually go and get this help. And where we cannot sometimes, at some point, I remember we had to work with the Rotary Club, a couple of parents needed wheelchairs, and they came in gladly to give the wheelchair which I feel like if you're in isolation, if you're alone, you don't know where to get help. And you might actually be, you think there is no nobody understand, nobody gets you, nobody is there to help when there are actually tons of help that you can actually get if you're knowledgeable where to get them from. So yeah, basically, that's so most of the work we do is a home visit, sometimes we go to schools and train the teachers, especially where we have the children that are included. I worked with two schools mainly for now, kindergarten, you know, like early intervention, if you intervene early, it can be there'll be make a difference when they are way up. So we help the teachers to know what to do with this child in class. Like where to position this child, you need to know this child's learning style, because you feel have to be able to help this child and you need to know how does this child learn? What are the things I need to do. And also for most parents, we are not unknowledgeable of how to help these children. The same, of course goes for the schools. But the difference is that the teacher will do what they do at school like general teaching. But if you just give them a more practical way, like for example, there are parents who don't know there, they really have a, there is a lot they know that if they had a chance to speak what they know about the child could come in handy, like could help a teacher or a third party, another person working with this child to best support the child, because they don't you know, they feel we as parents ours is to pay fees and you do your job. So then there is that gap. So educating the parents on how best they can also be involved in their child's education. And then working with the teachers where maybe the child like I when I first enrolled my boys for a whole term, they didn't know how to use the school playground. There are a lot of facilities there. So I realized they need to do something. So I would walk with them sometimes and to the school, and then teach them how to climb the slides, how to use the merry go round with bit of support. So by term two, they were fairly included. They

knew I can sit on this thing and then this I have to hold here and go but not because the school didn't know. But they had the old fear. Because even as parents we are very complicated. For example, I will tell you Anne, I would love to take my child to a place where this child is going like I serve you food and then I asked you please take your plate back, for me it is okay because then you let the child know that I'm done with this. I need to take back my plate. Nobody else has to do this for me. But I've interacted with the teachers and the school told me no, we can't do that, because the parent said we didn't send our child here to work. So it becomes hard. So they also leave it is a bit difficult for them to strike the balance. You might know what you want to do with the child. But what is the parent perception of how you're helping this child. So most times you end up babysitting the child, you know, this child is with special needs cannot walk, they'll either carry you. But that is already like you're disabling the child instead. But I also want, I get it, because if this child gets hurt, a parent will feel bad. So there is that, there is that wall between doing the right thing and making sure I don't go wrong with the parent as well. So I feel like if some of those, if the parents are informed on how best they can you know, how much you can do to help your teacher help your child, then we can work as a team together to make a difference. Yeah.

Anne: Wow, thank you so much Faith, it's wonderful to hear what happens at the center, at ACCF. And also, how you handle different situ... I have two practical questions. Actually, no one practical and one more of future, yeah, dreams, basically. Of course, people who are listening might want to know how they can reach you. Because their children might be going through the same. Maybe you can tell us, first of all, how they can reach you? And also what yeah, what kind of disabilities do you? Yeah, what categories of disabilities do you support really in children. But I was also very curious what your biggest dream is that you hope to achieve through your work? So that's a lot of questions in one, you can start one by one.

Faith: Okay, yeah, I think to start with my biggest dream first. To be honest, if one, I would really love to have a parents support center established, not just by, you know, like at national level, I wouldn't mind if in the future, if this is built up to some extent, and the government can take it up as part of like, like, like, can be part of what the Minister of Gender and Disability can do. Like the schools are doing their part. But we are the part which I feel we are

not doing enough is the support to the families or to the parents. So if they're like, like a, like, a way, like, there's a way that they're organized, the government can work through the Ministry, of course, to support parents, like if I know I have this challenge, I know it is being done, but very minimal at public hospitals. I will tell you a parent I met, the child is nine years old, has cerebral palsy, not severe, fairly prone, not severe, really condition. So she took, when she gave birth, the child had this problem. And then she went to Mulago, the children development center, I think, and she was told, she was seen for like less than 20, less than 10 minutes, and she was told, we will see you again, when this child is six months, is it six or nine months. And the next time she went back, she was not seen, by the time I was meeting her the child is nine years old. You can't help this child now. Okay, you can still do, but there is a big difference if you had done something earlier in life, or even if you had just trained this parent to know what to do with this child. Like I said, I was a very inquisitive parent, I went out of my way, but also because my husband supported me, I went out of my way to look for resources to do you know, educate myself more. And I was able to do a lot more for my children before they were five. And most people who meet my kids say oh, but these children look very typical. They are like every other child. I'm like, okay, because a lot was done early in life. But if I am not aware of what I need to do with this child, then I can't help this child. So that's why I feel like if there is a program that can literally run that supports this, like we know if, like we have, for example, The AIDS Support Center. Sorry to use that example, though. But yes, we have parents, I mean, like, you know, I if I have this condition, every month, I can go to this place, I can get help. And maybe they'll teach you what you need to do, what you don't need to do, you go back and you're able to take care of yourself. The same thing would be done for the families or the parents out here in the cou...at country level. And that is one, but again, the most even the most crucial I was in the Ministry and looking for opportunities that if there are things that they can do for parents, and I was told that was Ministry of Health, they told me the best we can do is build the capacity of a care, a caregiver, of course it's done to certain few people, maybe certain communities also, or through certain organizations. But before I went there, I didn't know there was something like that they are doing. But now you're telling me you're doing capacity building, that's the best we can do. Now, based on my experience, and my interaction with other parents, there are parents who are taking care of children with very severe needs. Where you, I'm talking about you doing

whatever you need to do to finance a doctor, maybe a medical doctor, I'm talking, I'm not just making up stories here, I'm telling you experience of parents have been with had to import a doctor from India, because their child needed help. And that's the only way they could do it. A parent tells you, we sold our house to make sure we had this doctor come and operate on our child. I have a parent who will tell you, my child is home. Not too long ago, about the time we had the webinar, I was coming from, actually the hospital to see one of the parents and she paid 36 million for one month, it's a CP condition, IHK this child is being aided to breathe through a tube. Every night in the oxygen, you're paying like 2 million, something like that, and you're working a normal job, you have other children, it's hard. So parents and families are dealing with a lot. Unfortunately, it may be our government not aware of it, we have parents or you have because your child is in really critical need and they cannot be transported. Like even if you have a car, you can't take your child in your car for, to, to get help in the hospital, you need an ambulance, it is happening. So you have to hire an ambulance, close to 300,000. That is just taking your child to the hospital, forget about the treatment yet, you're not we're not even talking about paying the medical bills at the hospital. And then we have children who survived on seizure meds, medication for seizures, it's a daily, something that you have to take every single day of your life. And every month you're spending over 300 in just medication for one child. And the medications keep changing. You go to the government hospitals, they are no medication, they're writing for you those drugs, they're very expensive. And I'm asking myself, if for some reason we're able to, you know, the AIDS community, people with HIV and AIDS can walk in that clinic, and they're given free, you know, you come every month on this day, you'll get your medication, why can't our government do the same? Why can't we get the government to at least provide medication, free medication for children who I mean, it is very hard, a parent told me sometimes not because we don't want to, sometimes you're faced with a situation where you have to choose between supporting other children, and supporting this child with special needs with very high cost of, you know, the cost of raising one child, it's like you're raising five others. But it is just one child talk about education. It's just, it's just hard. So my vision would be my goal would be to get the government to that level for their stake, parent support to parent families of students with special needs, as part of a government social responsibility. Like set up those kinds of medication, at least make sure the drugs are there. For parents to just go get that drug,

I can handle the rest. I can look around and do something small and be able to provide food for this child but the medication of 300 plus sometimes it is very hard. And most of this, the women, to be honest, are the ones on the forefront. Most times the men run away, they run away, and they leave you with the child and they blame you also. And sometimes society tells you how this is not from our bloodline. You can when you're dealing with a lot and now you have to look for money which is not there. So it's it's it's overwhelming. So my plea, my cry is to figure out whoever can come on board, if we can channel if we can work together to follow up on this and make sure that our country our government can do more for families of children with special needs. At least it would be a big relief to many to many people so that especially on the issue of medication, it's good to train the caregivers, but if they can at least make medication free for some of those children who are on 24/7 medication, that will be a big relief.

Anne: Thank you very much for everything you have shared so far Faith, I appreciate your willingness to share everything you have learnt and experienced. This episode twenty was only part one of our conversation and to make sure we give you enough time to speak, we will hear more from you in episode twenty one which will be part two. For now, let's keep in mind Every Child Can Learn!

Outro: Thank you for listening to Every Chance Can Learn. Please share your thoughts with us. Join the conversation on Facebook, or send your questions to 0772630078. Do you want to learn more about Backup Uganda and stay updated about our activities? Check our website on www.backupuganda.org and follow us on Facebook, Instagram, Twitter, and LinkedIn.