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Every Child Can Learn Podcast

Episode 10: Finding a school when your child has a disability

Intro: You are listening to the Every Child Can Learn podcast. The podcast is offered to you by Backup Uganda and Brainstud. You can listen to our podcasts online on our website, www.backupuganda.org. And if you are in Gulu, you can pick up the audios offline from Mega FM, Radio Rupiny, Divine Videos and Music Library. Head-teachers from the district schools can pick this podcast from the District Education Office. And teachers from city schools can pick their audios from the City Education Office. You can as well pick up the podcast episodes from the following schools; Highland primary school, Gulu Prison Primary School, Gulu Town Primary School, Mary Immaculate Primary School, St. Joseph Primary School, or Christ the King Demonstration Primary School. Do you like our podcast? Feel free to share it with your family, friends, and neighbors. The more people learn about learning difficulties, the better we can help our children.

Too-lit: Good morning and welcome to Every Child Can Learn podcast episode 10. And yeah, today we are very excited to have one of the parents who accepted our invitation and we are with here and you will get to know her very soon. But first, my name is Too-lit, a Frostig Trainee with Backup Uganda. And today we are with...

Regina Okello: My name is Regina Okello.

Too-lit: Thank you very much, Regina Okello, I am very happy to know you. And I want to say really thank you for accepting our invitation to share with us your experiences as far as this podcast is concerned. Before we get started, I think we'd like to get started on the present situation in our community. And that is talking about COVID-19. We understand COVID-19 sabotaged so many things about education in this country and worldwide. As a parent, we want to hear from you. How has it been having the children back home, they're not studying and you had to do a lot to ensure that they keep on track with their education progress, in a way at least. What have you been doing? And what's your general comment about the whole situation?

Regina Okello: Yeah, thank you so much. What COVID-19 has done, I think it's just extreme. Because that is one thing that no one expected and no one could imagine. At one point, something would happen like that. So when this thing happened, and the children were brought back home abruptly, that was in much two years ago, it was really like something which would take maybe one or two weeks, and the children go back to school. But as time went on, things could not be seen that way, the disease was just traumatizing and scaring everybody. You would even feel instead of a child going back to die, you rather have the child home for a while. But the while did not come- it was taking forever now. And the children themselves, it was like a life that wouldn't really satisfy them. They could not play because some of us were strict. Personally, I didn't want my children to be going meeting with others anyhow because at that time, everything was like a new thing. People don't know exactly how it is transmitted, how it can be protected. So it was like something which is in the blue. So I didn't want to take that risk. So what I did was to tell my children, please, for a meantime, stay home, but keep reading your books. I kept looking through the internet. I brought them certain class works to be done from different schools, those ones that were freely given out, I could print and I bring for them. And I encourage them to be doing in their various classes. I have children in primary schools and also in secondary schools. So I kept them a little bit busy, but you also know children needs close monitoring. And unfortunately, that time is so limited also for me. So when maybe when I go away, they try and when I come back, I asked them to give me what they have done. But somehow you will find that it is so minimal. You encourage them when you're there. They try and they do their best. Otherwise, that is how we moved on. And at some point, the schools started now the online lessons. But before that one, there was the TV thing that- there was learning on TV, learning on radio, I brought all these things for them. Unfortunately, I didn't really see much on the TV, the radio thing also, I couldn't see really much in it. So actually, I would say they did not benefit from that much as the TV was there. And when they're alone, now, they changed to their program. Also, they don't now concentrate on the word, the learning bit, they change to other channels. So it was not easy. It was challenging. Now with this one with a learning disability, it's not easy. I try the same way. I pick up so many materials from the internet that I come across that she's so interested in learning, very interested, but she cannot do it alone. And fellow children are not patient enough to help her. Even if they try, they get fed up. They can't be that patient to

support her. But I keep on like that. May be when I come back, she also knows I'm back. She comes with learning material. By me, I want to do this. So I just encourage her. She sits there if I'm not very busy. We can do with her. She writes, whatever she writes, what I do, I don't ignore, I appreciate it. And I guide her to write the good thing. And she tries, she tries but COVID-19 has been so challenging the expense. As a parent, the expenditure is exorbitant. Because children when they're home, they want to eat better. They're not busy, they're not so busy. So when you're not busy, the stomach is also asking you all the time. Yeah. So the expenditure arises. Yeah, that is what COVID has done to the parents.

Too-lit: Oh, yeah, thank you. It sounds a bit funny at the end. But it was a very tough time. And it's still and I just like the fact that besides waiting on what the government is doing, and the rest of the other institution, you as a parent, you took really a big initiative to help your children carry on with learning. And thank you very much. And we believe so many parents are going to learn from your initiative. Now, to get started, we want to understand what do you know about learning disabilities? And how did you know about this?

Regina Okello: Before I got one in my home, I knew there was learning disability, and there were some mental problems and so on. Another thing I also knew was like people have different abilities to understand. As I was in school, in the class, you find that there are many people being taught the same things, but they understand differently. Others are extreme. You find that what seems to be so obvious to them, they can't pick it. Yeah, so that is like a kind of disability but I didn't take it very seriously, before I realized my daughter was what also that kind. Yeah. And now, when my when I got my daughter when she was still a young baby. Everything was okay. The delivery was normal but when she's now growing up with the previous children, they were fast learners, they could cope up with the stages very fast. So by the age of one year, they would be talking walking, and everything would be what normal for them. But with this girl at three months, that's where I'd been wet beginning to put these children to learn how to sit. So as I tried to put her she couldn't. She was a very tall child. I thought maybe it was because of her height that she was not doing that one fast. Then I gave her that patient but it was not really picking, the girl was not picking up easily. Then it came to know crawling, everything was taking too long. I know started being skeptical. I said, now there could be something wrong. Unfortunately, she was a child that had very poor appetite.

Even for suckling in milk, the appetite was very low. I introduced the child to extend to other types of milk. Because I was working, I had to leave our home, she couldn't take, I could make porridge, she could not take, I tried babysitters, babysitters cannot manage. You find that when you get somebody, the person wants something that is easy. But now for her she was not very easy. So you find that you have to be changing, changing, until I gave up on babysitters. I had to carry the child when I'm going for work. I get up early. I make my porridge, I make my milk, I pack up the things. I carry her to the grandmother who stays also far, about 14 kilometers from where I live, I take the child there, I come back and work. The home is the other side of the town. I come back and work in it Town in the evening, I go back, I pick the child I come back home for one full year. That was very challenging, very challenging, but I really wanted her situation to be good. So for her to stand, it took us so long, I don't even know how many years and to call Mama, to start mentioning a word. She did it at three years when she was three years. That's when she started now trying to call Mama. And at that time, I had already taken her to my mother in the village because she was caring enough she had the time to take care of her she would do it like an elderly person. And an elderly person that loves the child. So when she was there, she was given the love that she required. And that's where she started now learning to call Mama and the age of three. Yeah, but before that, I thought maybe something was I don't know. So I had to seek medical attention for her all this long, that she had those experiences difficulty in sitting, standing and so on. I was close to the hospital, I went to like Lacor because of the appetite. They thought maybe she- she- she had these hygrophilous, the big head. So they thought maybe she had that condition. They referred me to Gulu hospital, they have C-center. I went there and I met the specialists who examine the child. And he told me there's nothing wrong with the child. The child doesn't have that. But the child was malnourished. She was malnourished, because I take her with my milk and porridge in the evening, as I go to pick her I'll find my things the way they were the whole day. She has not taken milk, she has not taken porridge. So it was so traumatizing. I don't know how much that trauma also participated or contributed towards her challenges. I just believe that could have contributed also to some percentage in retarding her mind. So that is why I decided not to take her to my mother. Because where I was taking her she was not getting the necessary attention and care. I could go and get my milk because I thought maybe if I take her with everything ready. There's no excuse that I didn't have the

time to prepare those things. So I make sure I do it before I go for work. And I take with everything but I go back in the evening and find everything that intact. So that has been the condition around the child. And when this doctor the specialist told me she did not have that problem. I asked him now what- why is she not doing things the right way. I was so traumatized. I wanted her to do what the other children didn't. Even if she was going to delay it should be a little bit but not just extreme. So it was like a hell for me. So that doctor helped me psychologically, he did not really cancel me like a counselor like that. But he told me this child is not sick. And the child is not weak, as you are saying it is you who is sick, not the child. Because you want this dial to do things the way you want, leave this child do things at her pace. So I looked at the doctor, and I saw sense in it. I said, okay, I think this is true. I'm really sick, because I really wanted this child to do things the way I want, and the way I've been experiencing with the others. So I realized I couldn't make anything work out in that child on my own. I accepted her the way she is. And the doctor advised me that you- you keep exposing her. So for me, I was waiting for her fast to talk. Then I take her to school. So now from AVSI, I again decided to go to Mulago, speech therapy. I went there. I also saw the doctor, the specialists, she was somebody from this side, we met her, she examined the child, she put a lot of good, beautiful things playing things in that room. So when this girl entered there, she was so interested, she needed so many of the listings, and not to use it from there, as she wanted us to, she picked what she could be said she wanted us not to do come with them. This lady was just watching her- what she was doing. So after that, after examining her, she told us that this girl is going to talk just expose her a lot. And she advised us even if she's not yet talking, go and take her to school, she will learn from there. So when I came back that was in second term of that year, when we came back, the child was already with my mother, we took the child back, we took the child to school, and we explained the situation to the teachers. So the teachers were so supportive to her, they knew her condition, they took her the way she is. And she, she was able to learn a few things.

So from there now, when the year ended, we picked her from there and brought her not to Mother Ludia, the same way. We explained the condition of the child to the teachers. The teachers were so supportive, the teachers were amazing. They were so loving. They knew her and they took her as a special child to them. So they were able to take to teach her. They

would expose her she could they take her to do everything that the other children do. And even if they're not, she's not doing well. They continue supporting her and keeping her there. So when she comes back, she would also be what interested she- she got the interests of learning a lot. So she continued like that. She was doing fairly, but not well in school. But they kept pushing her because she was also growing very fast. And now she's 11 she's almost of my, my actually she's my height. Very tall. She, she grew taller than even the person she followed. So she when- she was in Mother Lydia until P.2 when she was in P.2. She even did the exam but the teachers advice that we should let her repeat be to. You shouldn't take her to P.3. So I also took that advice. So she was in PE too by the time the lockdown came in up to today. I keep supporting her with those learning materials. She writes, When I come back, I come and we mark with her and we continue like that. That is how I'm maintaining. I'm seeing she's growing. I needed to begin exposing her to a lot of hands on building her for a future life. That is now where, my my target is

Too-lit: That was such an explanation. And you really narrated quite clearly how right from the start, and I am just so happy how you struggled with everything right from the start. The fact that you were able to notice that there were already some disabilities, though you are not much into the know what it was. And you took the initiative to see different therapists who could do what they can to tell you exactly what it was. And I just like the fact that when you came down, and they advised you to take her to school, even if she was not speaking, you took that up, and you took her to a school and you went to explain the situation to the teachers, and the teachers also welcomed it. This is something that most parents don't do, you find parents just take their children to school, and they think it is the teachers roles and responsibility to do everything. Now they can when they do not know the history of a child, but you give the teachers the history, the history of the child, and they had a foundation to start from out to hope your child, I would also want to understand further, what do you think, possibly now other parents who are having children who are facing maybe these challenges or disabilities could also do to help their children, those who may be you know, could not be knowing, just like, at first you didn't know, but you went on to find out from different therapists how they could help you, you know, they could diagnose the very condition that your child was undergoing?

Regina Okello: Yeah, I think it is very important. If you don't really understand a child with such a condition, you are you going to harass the child, you are going to beat the child, you are going to speak every negative things about the child, but when it's not the child's fault, and when the child does not know how to get out of it, and the child cannot get out of it. And even you cannot take the child out of it. So the most important thing is to accept the child, the way the child is, because it is the child and God, only two of them can do something about that condition, we can only support them, do it, even the teachers, they try to support the child so that God can do what he wants in the child. So it is just accepting that it is good. If there was some medicine that could cure that, you would say no, I'm going to buy this medicine and the child is going to get healed of this, maybe the medicine is there, but I don't know, I've not yet discovered and no one has ever told me. So it is to accept the child, the way the child is, and where possible, you look for any information that can help you get the knowledge, get the skills to support the child, because as a parent, you may not be having some technical skills that can make bring up that child's attention towards what you want the child to do. But some other people may be like teachers, trained people, they can guide you, how you can support the child so that the child can at least get something good out of what herself or himself. So my advice to my fellow parents is that first of all, they have to accept the child. Secondly, they have to be patient, that condition if you are not patient, you will live in get annoyed and you throw away the book, because you are going to say this, it is very obvious to you, but to the child it is not, to the child is very hard. So to another child of the same age, but without that condition is very obvious. So you will think the child is only being what disobedient or maybe the child is less interested and so on you will try to bring force and you beat the child but you will not really succeed in anything by doing that. So you have to be very patient, you have to move at the speed of the child so that the child can pick what you are giving. If you lead the child and you want the child to follow your speed. Then either you are going to close the mind of the child. Oh you will leave the child You think you're moving with the child, but when you are moving alone, and you will get frustrated, at the end, it's you will get frustrated because you have wasted your time. So I advise my fellow parents to accept the child to accept that condition. Be patient with the child, and try whatever alternatives can come your way to support the child, even if the child is not going to progress so much academically, you never know there may be some talents in that child. So exposing the child to a number of

maybe hands on things can make a future for the child. So I don't think the child of that kind is a failure, that child can do something. But in specific areas, yeah, it's only difficult to identify them. But with the help of God, and support of technical people, it's possible to identify and support the child in that direction. And at the end of it a child can be self-reliant.

Too-lit: You mentioned something earlier about getting involved into hands on, why did you decide to get involved on her on hands on skills? And was it something you saw her getting out you would see her do things around is something you see her do often and you think possibly maybe that something if you train now with hands on, she can, you know, do better. And that's why you're thinking, you need to get her into unknown skills.

Regina Okello: I kept watching her what she likes to do, okay, she was interested in many things, she would want to work on my hair, she would want to come and help me cooking, when I'm doing the cleaning should want to be there, she would want to go for water, the housework, I felt it's important to allow her if she has interest somewhere, like maybe working on the hair. Yeah, if God wants her to go that that direction, it will be okay i had to buy for her this toy is she so that she can be playing on the hair. So if it is her skill, she could learn as a child. And when she gets to some age, maybe you can take her to a more serious one. That is how I saw the need to support her in specific areas that she gets interested in doing. And then also knowing very well how things are moving on in school, as a parent, you will definitely know it may not be so Wally academically with what such a person, but the most important thing is to help her to learn at least the skills, the communication skill means and so on, that even if she gets any other work to do, she's able to communicate freely with the different categories of people, both the people that know her language, and those that does not know her language, and the mathematics of counting, looking at the money and that one that can help anyone to make a life. So the most important thing is how is she going to make a life in future this thing's makes me see a more viable project enhanced on than building her for an office, a white collar job.

Too-lit: I would want to understand further. You said the teachers were really quite helping now looking at the hands on skills that you want her to develop here. Hmm did you get

feedback from the teachers possibly how she was maybe more engaged into an honed skills, activities at school, something like that.

Regina Okello: At school, I was very close to the teachers and sometimes they could also give me some phonics and so on, so that she could be watching from home. They were so observant also on her they could try to see critically what her in Test is they will tell me, she she likes to be like a leader. Like, she likes controlling the class. Okay, she she wants to when the teacher is not that she wants to behave like she's the teacher, they were also very critically observing her. And they could also share with me, we have been very close, and I didn't have a specific time to go and visit them, I would go and visit them anytime. And when I see something small, I am concerned I normally share with them, we will discuss and we see how best can we support this, how best I'm like that, you know, sometimes these children they have challenges with their peers, the children in their classes can turn into a mock a mockery, they begin mocking such a child. So when I the child comes, and I hear so many complaints about that, I would go and share with a teacher. Normally she comes and mentions name of the children, they there are some lottery a student in classes, so the student can take advantage of them. And they bully them. So when I learned over that I would go and share with the class teacher so that the class teacher can talk to the child. And it has always been helping, and that is how we kept her interested in school otherwise, she would be fearing even going to school.

Too-lit: I want to take it now a bit beyond just the school here now. Well, looking at the government of Uganda through, its ministry of education and sports, we find that inclusive education that has been introduced to ensure that all these children learn fairly with the others. Well, what as a parent of such a child with these disabilities- how do you how do you look into this? Do you see that this is really working? And is it helping in in the school you've seen your child through. And as an- I mean, overall overview Oh, you know how you see it overall in the country.

Regina Okello: I may not really have so much information because my child was in a private school in the private school. Those teachers that were very close to her had some kind of trainings in special areas. So they were able to help her professionally. With my little experience in that area in the government sector, I think the government is not doing so much

in that area. It is still lacking those, those children are still sidelined. There's no match with the parents, we are just struggling like me, I'm struggling on my own. When I hear there is this kind of support. There is this kind of people who support in the area that is affecting my child. I normally go there to find out what does- what do they do? And how can my child benefit from that with a motive of building our future? You know, sometimes we look for for money. Sometimes they look for money. Yes, it's important because some schools that can support that are very expensive, and the parent may not afford it. But if there are people who can support financially and you take the child to such as pool that is specifically for that category and the support the child is going to get from there will really be something that is worth- that will also be okay. But there are others that give that that the other benefits are that is the training bit of it, even training you, the parents on how to handle that child is good enough, maybe they have wider information about such a thing, such a condition, and how it has been supported somewhere, you get that information, it will also help you to support your own. So that is really what I do. I go looking for it. If I get it, I'll apply on a child

Too-lit: I would want to think having all these years of experiences with such a child, you might have had so much insight now and you have developed so many ways of helping a child like this. How do you think and what would you recommend that other schools and maybe the teachers should do to help these children,

Regina Okello: The teachers actually when we take the student to that teachers, we take these children with a very high hope cause for us unless maybe the parent is a teacher may not really know so much how to handle the child to bring her or him from nothing to something so the teachers needs to really take the children with their hearts and give some bit of time for them. And also the need to provide the protection, the student needs protection. In class, we have different categories of people, some children as solitary as even from their homes. So they can be bullying these children and at the end of the day, the children will run away from school. So the teachers need to protect them from such kind of things, not really stopping them from relating. But at least that's excessive, that that that might know, putting a child like somebody who is maybe a mad person or somebody who is not really the same level with them, there is a way that they treat the child. So that would be the work of the teacher to protect the child. And the teacher should not also leave the parents out. Sometimes a parent

may not really have that initiative to follow up the child. So it's the teacher now when he or she identifies that difficulty in the child should seek to meet the parents and open the eyes of the parents so that the parent can see that, okay, this is a challenge in my child's life, I need to work hand in hand with the teacher, I need to do my part at home. And I also need to support because sometimes the teacher can try to help the child from there. And when the child comes home, we killed them. We shall be saying maybe I'm wasting my money you are you are nothing no, I am going to leave you and sometimes the parents really leave the child because the parent will see like this man is being wasted. But I think it's not a waste of, of money. The little the child gets from school is very important. If you leave that child, that child will now be hopeless and the child will really be useless the way you're saying but if you support and the teachers do their best, they give the attention required. They spare an extra time for such a child then the child will come back with something

Too-lit: Thank you very much, Regina. We have come to the end now. I would like you to give your general comments to maybe the parents as well teachers and generally the educational authorities in this community.

Regina Okello: Yeah, I'm starting with the governments actually we need support we need to be supported. If this way the school can be designated for such groups, that would be so good and much as there will not be a lot it, it should be inclusive of with the others so that they're also not isolated. But there should be special attention to such as school. So that's cool, could have different levels of that condition. Some may be severe, others mild. So they should have those different categories also, with specific things, especially their hands on and that they could do within the what they like the primary education system, the normal one, but within those special things, and the teachers that will handle them should be properly trained, and not overloaded with the number of children to handle, because for them, they will need to give a little more time to each child. So the number of pupils that they are handling should be very limited, that can allow them adequate time to support these children adequately. Otherwise, when there are so many children, the teacher is handling, you can't also blame the teacher for not giving extra time to the child, because the children are too many for the teacher. And maybe the special training given to the teacher is also so limited. And also the problem could also be on the teacher's side, you know, it is a dedicated work to help these children. So those

who go for that kind of special trainings should be the teachers with the heart of helping these children not getting the name that I am highly trained in, in the special needs and so on. When you don't have the heart, you will have the training, but you don't apply it on the child. And it's like the training has been wasted. So the government should do something, if maybe they could come up, maybe like over the review. They call on people, the parents with such conditions. Because it's difficult for us, the parents to look for ourselves, it's difficult for me, I know my condition, I maybe knowing one, or even none other parent with the same condition. So to come together and build maybe like our team, like an association- You know, sometimes the voice is heard better when you are in an association. So if they could come up, maybe like the District Education Office calls the parents is such a condition in their homes, they come together, they see how many they are in the districts, and what kind of support to give to them. So that this child, these children are not what left out. The government needs to do something about this. And also without the parents, we don't need to sit and look at the children go their way, we need to keep supporting them, we need to bring them up. We need to treat them exactly the way we treat the other children without that condition. We must not leave them out. But we have to take into our mind that these children are equally important. You never know that a child that is that you think he may not have a future. Maybe they want to take care of you. You never know. So that is my advice. But the government should come up and support this category. There is so far nothing being done to them that I've seen, and we can't look for ourselves, bringing us together may be a stepping stone to supporting this kind of people in this land.

Too-lit: Thank you very much, Regina, thank you for your sharing. It has been quite insightful for me. And I am very hopeful that this is going to help the parents, the government and the different groups that are working to see that all children with learning disabilities learn and as far as backup Uganda, we say every child can learn. Thank you very much

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 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.