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**I: How are you?**

R: I am good.

**I: We will start our conversation about epilepsy and the child you live with who has the condition. So, feel free and let's talk. Okay?**

R: Okay.

**I: As we start, I will ask you; which words are used in this community to refer to epilepsy? Which other names do you know that are used to refer to epilepsy?**

R: I only know how it's called in my language.

**I: [Laughs], what's your language?**

R: My language is *Garri Borana*, so we say someone is '*gagaba*' but you can write epilepsy.

**I2: You say someone is?**

R: *Gagaba*.

**I: So, you said you don't know any other name apart from epilepsy? You haven't heard any other name from the community?**

R: I have heard disability.

**I: Others say disability?**

R: Yes, if you have a sick person that is someone with a disability.

**I: Any other? You have said disability, epilepsy and you told us *gagaba* in your language, what does *gagaba* mean?**

R: It's when the epilepsy condition attacks a child and they fall so we call the act *gagaba*.

**I: It attacks someone and they fall? Okay. Is there a reasoning or explanation behind the different names used for epilepsy? you told us *gagaba* means to fall and the other one that**

**you know is epilepsy or disability, why would they say someone with epilepsy has a disability?**

R: I just heard that, when a child is born with the epileptic condition the child is not able to support themselves, is not energetic, has no strength, doesn't know anything, doesn't talk, is as someone with a disability.

**I: The fact that the child can't talk, can't support themselves, is not strong is the reason they view them as disabled?**

R: Yes.

**I: Which are the common symptoms of epilepsy? You do have an epileptic child, right? So what symptoms did you see or what do you know or maybe you saw others in your community and you became aware that if you spot that you will know a child has epilepsy?**

R: When I live with the child, he has the epilepsy condition.

**I: What?**

R: We say Epilepsy is sickness.

**I: What symptoms did you usually see that you now know when you see such you will know the child has epilepsy or it's not epilepsy?**

R: When a child has epilepsy, he does not look like the other ordinary children, his body —

**I: You said he doesn't look healthy as the other ordinary children?**

R: Yes, he looks sickly, he's not healthy, he doesn't feel well.

**I: What do you mean when you say he doesn't feel well?**

R: He is not strong, he has sickness.

**I: What symptoms did you see in your child that made you feel he has epilepsy?**

R: He was born with it.

**I: So how did you know he has the condition when he was born?**

R: I had excessive bleeding before he was born due to delayed delivery, after being born the baby was not able to hear, then he was put on oxygen and I laid him to sleep. At around 10 the baby got the condition, he started shaking and body stiffened.

**I: Is that the moment you delivered him or what time was that?**

R: It was right after giving birth, the baby did not cry, [inaudible speech].

**I: So, you said the baby did not cry, was shaking. How was he like?**

R: First, he was put on oxygen in the hospital and slept until 4pm, at night around 10pm he was there, in the morning he began trembling then he got sick.

**I: Is that the time you knew he had epilepsy or --**

R: Yes, I knew while in the hospital that the child has epilepsy, he was born with it. After 9 days I took the baby home. For us, we don't take patients to hospital due to such illness, we take them home and a Quran is read to them.

**I: You take them home to be read a Quran?**

R: Yes, after being read a Quran for the first time he got well, after 6, 7 months he was not like the other babies, he can't sit he only sleeps, he has no strength, he does not do like the other children. Around 1 year and he still can't sit down, for close to 1 year he was not attacked by the illness and then got attacked when he was around 2 years old; his whole body was shaking and became stiff, eyes popped out and he falls

**I: What does he do?**

R: After falling he becomes stiff and wakes up after 1 hour.

**I: You had said they are read a Quran? That such illness you don't take to hospital? Why do you prefer to be read a Quran than being taken to hospital?**

R: This illness doesn't need an injection, too many injections causes the body to dry up, it needs a Quran because this illness is like a ghost. When a Quran is read it runs or goes away.

**I: So, he is read a Quran because this thing is like a ghost when a Quran is read it goes away?**

R: Yes, now when he is born with it, it enters his whole body. If it enters at that time it goes away but being born with it, it means it's already entered the whole body, he now has the illness. It's hard to go away.

**I: You said if he is born with it, it's hard to leave?**

R: Yes, it's hard to leave.

**I: But if he was not born with it, it can leave when read a Quran?**

R: Yes, it can leave.

**I: And you said it doesn't need an injection because the body will?**

R: The body will dry up, us, we believe in the Quran.

**I: You had told me that, one reason that made the child have the illness it's because he was born with it?**

R: Yes.

**I: Are there any other causes of epilepsy?**

R: I don't know I feel like---

**I: What do you think would be the causes of epilepsy, you had told me being born with, there are other children in your community who have it right? what would be causing the epilepsy apart from being born with?**

R: Sometimes we say its people's eyes.

**I: People's eyes?**

R: Yes, others say it's genetics, others their families don't have it so I don't know where it comes from.

**I: What do you mean when you say it flows in the family?**

R: When your family has the illness, others can get it, if your uncle has it you can get it.

**I: How does the eyes one come about? The one you mentioned about eyes?**

R: The one about eyes; if a child is beautiful, someone can look at her with evil eyes like women and... Sometimes it's through food when one person doesn't have and the other is eating there, other children can look at your children all that is through eyes.

**I: I haven't understood the one about food.**

R: Look, someone has food, he's eating the food, the other one doesn't have, he sits and looks at you, it can be passed through the eyes.

**I: So, who gets it, the one with or without the food?**

R: The one with the food.

**I: When he looks at the one with the food, so who gets it?**

R: One with the food.

**I: Okay. I have understood.**

R: That's how the eyes one is. But to others, it's God who brings the illness, all is brought by God but others say the other reasons but all is God's command.

**I: You had told me a while back that they are read a Quran because it's a ghost, how does the ghost come about?**

R: Ghost is like the Devil, we believe Ghost and Devil are the same thing, it can enter you.

**I: It entered him.**

R: Yes.

**I: Have you ever heard of sociocultural causes in your village as a cause of epilepsy? Ever heard people from upcountry insinuate somethings as causes of epilepsy?**

R: No.

**I: So, you have never talked about anything in your upcountry? You said you come from Garri?**

R: Yes, I have never.

**I: You have never gone there and heard people say it might have been caused by a certain thing?**

R: No.

**I: In your opinion, how has epilepsy affected the life of your child? Are there any activities that he can't do that other ordinary children do?**

R: He doesn't know how to talk, others talk, he can't feed himself.

**I: He can't feed himself; he can't talk?**

R: Yes, he can't walk like the others, he doesn't have strength he is sick, even his legs if he stands up he can fall, he can't jump he falls. He can't play with the others he just sits here looking at them—

**I: He doesn't play with them?**

R: He can't even study at school, my child doesn't know anything. There are those with his condition but they can study because they have some brain but mine cannot study.

**I: What makes him not able to study or play?**

R: If someone has a brain, he can study if he lacks that he cannot.

**I: You feel it's because he has no brain?**

R: Yes.

**I: What makes him not able to do those things?**

R: It's this illness.

**I: How do ordinary people in the community treat your child or those children with epilepsy?**

**You live with people who have no epilepsy, how do they treat your child?**

R: Other people love such a baby; they can sit with him while others don't want to because such epileptic children wear pampers as they can't go to the toilet and sometimes, they poop on themselves and the pampers can have odor. Others don't want the child to come near them.

**I: Why don't they want to?**

R: They don't view the children as children but others love the child so people are different.

**I: So, on the note of not wanting the child to be closer to them, how else do you see ordinary people behave towards or treat people with epilepsy?**

R: It's only that.

**I: Is there any other you have seen towards your child? Because you told me he doesn't play, he sits and looks at the others, would the others be willing to play with him and all that?**

R: Who? The child?

**I: Yes, your child, would those who are well be willing to come and sit with him where he is?**

R: My child or the other children?

**I: Your child.**

R: My other children or all children?

**I: Those other children out there. Are they willing to come and sit with him as you said he only sits because he can't play?**

R: Yes, others can sit with them---

**I: And others---**

R: Others don't want to sit with them.

**I: What could be the reason?**

R: They feel as if the epileptic person is not an ordinary person, so they look down upon them.

**I: So, you feel people look down upon them?**

R: Yes.

**I: They feel he doesn't look ordinary?**

R: They feel like the child doesn't look like the other children. People look down upon them and don't want to sit with them.

**I: Okay. As his parent, how do you feel your life has been when taking care of the child living with epilepsy, how has your life been affected and as well the lives of those you live with? Do you have other children?**

R: I have other children; I gave birth to 10 children. I remained with 8, one got married and one passed away. So I live with 8 children, we live a poor life because I don't have a job and some are schooling. Then there's this one who is ill and he needs pampers, he needs to eat, sometimes he's sick.

**I: He needs pampers; he needs?**

R: He needs pampers, he needs food, he needs his pampers changed, since he's at home, he's hungry all the time yet I lack, sometimes I lack pampers and I borrow from my neighbor. He cries when hungry and now that he can't be taken to school, it makes me feel bad.

**I: How does, as you said the lack of pampers, him wanting food, you and your husband not having a job and having other children who are schooling affect your lives due to his condition?**

R: He just sits when there are no children.

**I: What?**

R: What did you say, I haven't understood you.

**I: As you had told me about your child needing pampers, he needs food because sometimes he cries, you have other children who need your care and you and their dad have no job, so you as the family members how do you think his epilepsy condition has affected you as the ordinary members in the family?**

R: That child?

**I: Yes, the condition of that child.**

R: There is no problem he has brought to us; he has his own issue as he can't walk on his own but he has only one problem.

**I: What's the one problem?**

R: Him and the other children can interact, the only unique issue is the need for pampers and some other little needs. Otherwise all the other problems are general to all of them.

**I: What are your hopes for the future for your child? How do you want him to be in future, what are your plans and desires for him?**

R: This child?

**I: Yes, because he keeps growing.**

R: It's a struggle changing the pampers considering the other children are schooling. I want when he grows up a little bit, I get support so that I can take him to a boarding school.

**I: You wanted to get?**

R: Support for boarding school.

**I: Who do you want to take to that boarding school?**

R: The child with epilepsy, are you asking about all the children or the sick one?

**I: I am asking about the plans you have for the child with epilepsy, the hopes and wishes you have for him in future when he keeps growing.**

R: My hope is for him to be able to study so that I can take him to school. The government can help take him to a boarding school.

**I: Is there any other?**

R: You can help me if you get any donations or support.

**I: What kind of support or donations?**

R: I lack things and children need a lot of things, government funds can help the child, if he gets sick the children aren't taken to hospital so they only need support and when he is older, I would want to take him to a boarding school.

**I: You had mentioned something about hospital, do you usually take him to a hospital?**

R: Most of the time, I haven't taken him but it's only the epilepsy condition that's an issue, he hasn't been sick from other illnesses--

**I: And we are talking about--**

R: I have never taken him.

**I: You have never taken him? Not once?**

R: I have never taken him

**I: When you said you gave birth to him, where did you give birth to him, was it at the hospital?**

R: The first day I gave birth to him at the hospital, he was born here at G General Hospital. I was there for a week and got released and I never took him back.

**I: And when you were there, were you told the child has epilepsy, did the doctors tell you?**

R: No.

**I: Did you know on your own or who told you?**

R: It's the sickness that's referred to by that name, so I don't know where I heard from [Laughs].

**I: You had told me the moment he was born--**

R: When he is born, the doctors cannot tell you that the child has epilepsy, they don't want you to take the child from the hospital. So for me I did not want to stay in the hospital because the illness doesn't need an injection. We believe if they stay there for long and an injection is administered, the illness worsens. So we take them home to be read a Quran.

**I: Did the doctor tell you so?**

R: No, it's us who believe so, so we were released. I don't know about epilepsy being treated because children are born at that moment, I don't know.

**I: You told me you knew the child had epilepsy when you gave birth but the doctor never mentioned and you took him home and the he was read a Quran?**

R: Yes.

**I: After that, you have never taken him back to the hospital due to epilepsy related illness?**

R: No.

**I: Is there any medicine he is using right now?**

R: There is medicine he is using.

**I: Which medicine is he using?**

R: I took him to a City Council Health Facility where I got the drugs prescription.

**I: Where is the facility located?**

R: At the chief's place.

**I: Which chief's place?**

R: Not that one.

The City council.

**I: Which city council is it in Korogocho?**

R: The one near Soko ya Mawe.

**I: Health Facility K? because it is the only one near that.**

R: Yes, that one. I took him, he looked at it and prescribed drugs. He told me if I am able, I take him to Hospital M.

**I: The doctor told you so?**

R: Yes, he prescribed the drugs and told me to buy at any place selling drugs. I looked at what he had written on the paper. I usually buy a few drugs from here and he takes 1 a day.

**I: He takes?**

R: He takes one pill a day.

**I: The few ones you said you buy, where were they prescribed from? Is it from the hospital?**

R: Yes, it's the one that was prescribed from the hospital.

**I: At what age did you begin getting the prescribed medicine? When was it when you took him to the Health Facility K and the particular drugs were prescribed?**

R: The child?

**I: Yes, how old was the child?**

R: It was this year.

**I: This year?**

R: Yes, I never took him in the past, this illness has worsened nowadays. In the past he would get attacked once in 5 or 6 months, nowadays it has worsened, he gets attacked daily. When he takes the drugs the attacks reduce, if in a day or two he misses on the drug, he gets attacked. That's why I give him daily but he never used to take it in the past.

**I: You went to Health Facility K, you were told you can take him to Hospital M, did you take him to Hospital M?**

R: I have never taken him.

**I: You didn't take him, so you went and bought drugs from a place that sells drugs?**

R: Yes.

**I: Is there any other place you have gone to?**

R: No.

**I: It's only Health Facility K?**

R: Yes.

**I: Okay. Do you think information on where to seek care and treatment for epilepsy is readily available in your community? Is visiting the doctor for care and going for checkups easily accessible in the community?**

R: I don't know.

**I: You said you accessed treatment this year, so what are your thoughts, do you think the services are accessible?**

R: Using drugs?

**I: Yes, the use of drugs, going to hospital?**

R: Yes, he can access the service. When he uses the drugs, he doesn't get the attack often but when he is not using, he worsens. I wasn't able to go to Hospital M due to transport issues and when I go there the child does not want to queue or stay for long, the child becomes stubborn and unrest, cries and sleeps down when we prolong for an hour and wants to leave so I am unable to take him--

**I: You said the issue is transport, crying in the queue when you prolong for one hour and wants to leave, what does he want or where does he want to go?**

R: He doesn't want to be where many people are, doesn't want to sit in one place, he wants to be all over the place but I can't let him walk all over in the hospital. He cries when he is

around many people because he doesn't like it. I also don't know well where Hospital M is and I don't have the transport.

**I: You said you don't know where Hospital M is?**

R: I don't know; I have never been there. A vehicle can take me there but the money for transport is the issue, so I have to buy him a few drugs.

**I: Have you seen or do you know any child or any person in your community who has epilepsy?**

R: Where will I stay?

**I: Yes.**

R: They are there but I can't know, some children don't have the condition.

**I: But there are those you know who have the condition?**

R: Yes.

**I: What challenges do those who have it face while seeking care and treatment for epilepsy?**

R: I don't know. I haven't been around them.

**I: You haven't been around them?**

R: Yes, I haven't, there are those children who have it but I don't know their challenges.

**I: Do people know where to seek treatment and care for epilepsy in the community? If I had someone who needs treatment for epilepsy, would someone from the community know where to seek the treatment or any place he would go to and find help?**

R: People?

**I: Yes, people from the community.**

R: Some go to Hospital M others go to Hospital E.

**I: You feel there are those who know where to go, as some go to Hospital M and Hospital E?**

R: Yes.

**I: You have mentioned financial issues that prevented you from accessing service from Hospital M?**

R: Yes.

**I: How was the availability of equipment used to treat epilepsy when you took the child to Hospital K? what observations did you make about the equipment used in treatment of epilepsy?**

R: Drugs?

**I: Yes, when you went to Hospital K, when he was being diagnosed, were some tests done?**

R: He was only observed, there were no tests done. I told him what I know and he prescribed the drugs. He told me tests would be done if I took the child to Hospital M.

**I: So, when you took the child to Hospital K, he wasn't tested. You were told he would be tested at Hospital M if taken there?**

R: Yes.

**I: Okay. What can be done to make the public more aware about the epilepsy disease and its risk factors? Public can be the people you live around in your community. We had talked about the causes of epilepsy, what can be done to make more people and the community at large aware of everything around epilepsy?**

R: People are aware because people with epilepsy are many so they have such before, they do know a certain child has epilepsy.

**I: What can be done for those who don't know to be able to understand such a condition? You said there are those neighbors who don't want to be around your epileptic child, what can be done for such neighbors to be able to understand epilepsy conditions for them to treat the child well?**

R: People know the child has the condition but if their children don't have the condition, they disregard those with it. Everybody knows the condition they don't have to be told but they disregard.

**I: As much as they are aware, is there anything that can be done for them to be more aware for them to be able to accept the other children? There is nothing that you think can be done?**

R: There is none.

**I: As we come to the end of our conversation, how can people living with epilepsy be supported towards care and living a quality life? How do you think your child can be supported towards living a good life because I am sure you would wish your child to live a good life, right?**

R: Yes.

**I: What can be done or how can he be supported?**

R: If I get support, I can take him to Hospital M for him to be tested so that we get to know his illnesses and know if it can or cannot be treated, if it cannot be treated, he can then live with it.

**I: What support do you mean when you say if he got support to go to Hospital M?**

R: Nowadays everywhere you go you need money. If I get transport because the child cannot walk, he uses a motorcycle here in the community. I will also need money to buy the prescribed drugs. So, I am requesting for government support. I have a card, but I have never received any support.

**I: Which card?**

R: It resembles an ID card but it's for the sick children which we were told when you have it you get some funds from the government; I have had the card close to 2 years but I have never received the support.

**I: How did you get the card?**

R: Some people take it with the help of a hospital card that shows the child has the illness, it's taken at Westlands. I took the card because you can't get any support without the card.

**I: So where did your child get the card from?**

R: I got it at Westlands. The card is supposed to support the child if they are studying or if you want to take him to hospital, but at the moment the card does not support us as it's supposed to.

**I: Where are you supposed to take the card after getting it from Westlands?**

R: When you get the card, it's supposed to support you in accessing all things as in hospital you don't need to pay, they are quickly allowed to school for studies, they get some funds from the government but for now the card does not support us.

**I: Have you ever taken him to school or hospital with the card and he was denied the services?**

R: I have never used the card because it doesn't support us, I will be asked for money. I did not take my child to a normal study school, I took him to a place where they don't learn, they sit and are given food, a child who is able to study is taken to another school but mine is not able to study so he was told to be there. So, I have never tried to get a school, but during the meeting we attended recently--

**I: Where was that?**

R: At Light and Hope, many people said the card has never been of support to them during the meeting.

**I: Were you told so during the meeting?**

R: Yes, people said so during the meeting. All the women said the card had never been of support to them since they got it.

**I: Is there any other thing that you think can be done or your child can be supported with to help them live a good quality life?**

R: I can only help him to my level best because I have not seen anyone with the condition get well.

**I: What do you mean when you say you will help him to your level best?**

R: When I am with him, I wash him, wash his clothes, feed him and any other because I can't get the sickness out of him. If he can study, I can take him to school, if he gets sick, I take him to hospital. It's how I can help.

**I: Taking him to hospital when he's sick, feeding him, taking care of him--**

R: Yes, washing him, changing pampers, my wish is for the sickness to heal but it's up to God.

**I: Is there anything else you want to add?**

R: There is none.

**I: Our conversation ends here but if you have any question you will ask. I will give my colleague a chance to ask if she has any questions or if you mentioned something and she needs more information that she can clarify with you.**

**I2: Okay thank you. There was a time you said that when you are born with epilepsy you can't be healed but if you aren't born with it, you can heal. In your opinion, why can't the one you are born with be able to heal?**

R: We have seen many people who got it at birth and did not heal but one who got it while he's grown gets well after reading the Quran, but there are those who still don't get well even after reading the Quran. Everything is up to God's plan.

**I2: When you say you have seen most times, the ones born with does not heal but the ones not born with heal, did you see them heal, did you hear or where did you get that from?**

R: I heard and I also saw--

**I2: You heard and saw them being healed in this community?**

R: I have never seen anyone born with it get healed.

**I2: And one who was not born with?**

R: One who was not born got healed.

**I2: What was done for him to get healed?**

R: In our religion, they read the Quran.

**I2: About the Quran, who reads this Quran?**

R: Many people know the Quran.

**I2: So, anyone can read the Quran and they get healed?**

R: It can be read by Sheikh because the Sheikh understands everything being read because the illness has different ways of reading the Quran, you can read the whole Quran or a side of the Quran is read.

**I2: What is the Quran on the side read?**

R: There is no much difference from the Qurans; it's how the illness got the patient.

**I2: All the Quran is read by Imam or sheikh—**

R: It's the Imam, the Sheikh.

**I2: Okay. About the card you said you took from Westlands, is the place for epileptic people or for other people?**

R: It helps those children with epilepsy and the disabled.

**I2: Is it where you were given or it's where you go to get the support to take to hospital?**

R: You take it yourself. If you are looking for the card, you go for it with a card from the hospital indicating the child has epilepsy or you can go with the child and when they look at him, they will know he has the condition

**I2: So, you were given the card at Westlands?**

R: Yes, yesterday I had the card but I haven't brought it today. The card is similar to an ID and it has a photo. I took it from Westlands--

**I2: A place for the disabled and epileptic people?**

R: Yes.

**I2: Thanks. That's all.**

**I: Our conversation ends here; do you have any questions for us?**

R: No.

**I: Thanks for your time.**

[End of audio]