

APPENDIX I

GROUP SESSION A (LEARNERS WITH EPILEPSY)

- Researcher: As I have already indicated, we are here to talk about your life experiences, how you experience epilepsy. Who wants to start, Jimmy, would you like to start? Please explain to us how you feel.
- Jimmy: This disease started when I came back from the initiation school. After coming back from the initiation school, I developed a very painful and regular pain and my neck also became painful. One day I felt very dizzy and I nearly fell when they held me and took me to the hospital. When I came back from the hospital, I felt better and went back to school. But I never fall, actually I suffer from heart problems. Sometimes it beats so fast I'm scared. I usually stretch. At school, when I want to raise my hand to give an answer, the heart starts beating fast and I don't raise it.
- Researcher: Do you have problems with raising your hand?
- Jimmy: No, I don't have a problem with raising my hand. My problem is that I am scared of giving an answer. Then I talk with my heart because I'm scared of raising up my hand. I don't know if what I am actually scared of, is being laughed at. So I just talk inside my heart. After someone has given the answer, I usually find that it's the answer which I had in my heart.
- Researcher: So when you are in class you usually feel like raising up your hand to give an answer but you become scared of doing so. What makes you feel so scared?
- Jimmy: I don't know.
- Researcher: Who else experiences this problem? Who else feels like raising up the hand in class when teachers ask something, but becomes scared? (*Two boys raised up their hands*). Is it you Stanford, and Noah? Tell me, my children. Let's start with Stanford. When you are in class and they ask something, are you scared of raising up your hand? Why?
- Stanford: I don't know. I'm just scared of raising up my hand, but I don't know why. I just don't feel okay.
- Researcher: Okay. Evans, would you also like to share your experiences with us? Yes?
- Noah: My hands start shaking. I don't know why. I remember one day when we were writing the exams, when we were busy writing, all of a sudden, I started shaking and then I fell to the ground, then they took me home. When I arrived at home, I slept. The same night it happened again. When I

went back to school, a certain teacher, whose surname is Xivodze (*he started crying*), told me about it often, and it hurts me, you see. So I left the class crying, and then I went home.

Researcher: Okay. Does that make you uncomfortable in class? Is that what makes you scared of raising up your hand?

Noah: Yes.

Researcher: Okay. Who else experiences this problem? Who else feels uncomfortable in class? Who feels scared?

Natasha: When I raise up my hand I start to shake, and feel scared.

Researcher: What makes you feel scared?

Natasha: I don't know what I am scared of.

Researcher: Are you just shy in class?

Natasha: Yes.

Researcher: Okay. Who else wants to share his/her experiences with us? Should I come to you Mabontle my girl?

Mabontle: Yes.

Researcher: Tell us how you feel in class.

Mabontle: When the teacher calls me to write on the chalkboard, when I arrive there, I start shaking.

Researcher: When you write on the chalkboard?

Mabontle: Yes.

Researcher: What about when you write on the book?

Mabontle: I don't shake.

Researcher: Who else want to talk about how they feel in class? Bongani?

Bongani: When I try to raise up my hand, it starts shaking, and I become scared. One day I fell in class. Then they took me outside the classroom, laid down a cardboard box for me and then I slept. After a while, I went back to the classroom.

Researcher: There's something that Noah mentioned here, that is, he sometimes feels that some teachers are unkind to him. Who else feels that way? Who wants to talk about it? (*They all shook their heads to say no*). What about when you play with your friends? How do you feel?

Noah: Our friends are also unkind to us. When we play with them, they often tell us about it. They say that "it's that thing that falls often", you see, and it hurts us.

Researcher: Okay, but are you able to go on living and playing with them?

Noah: Some of them, but others, no.

Researcher: Who else wants to talk about his/her experiences with friends, when you are playing? Bongani?

Bongani: Some of my friends are kind to me. One day when I fell down, they held me, but others when I go closer to them, they tell me about it. They say: "This one who falls down scares us."

Researcher: Okay. Who else wants to talk about it, about friends when you play? Jimmy, which sport do you play, soccer?

Jimmy: No.

Researcher: Which sport do you play?

Jimmy: I usually go around taking people photos.

Researcher: Okay. How do you experience your friends? How do they treat you?

Jimmy: Fine. My life is not so different from others.

Researcher: Okay. Is the problem only in the classroom?

Jimmy: What trouble me a lot are my eyes. They disturb me.

Researcher: Okay. Who else wants to speak? Willy? Which language do you speak? You haven't spoken since we arrived here. How do you feel?

Wayne: I feel fine.

Researcher: When you are with your friends?

Wayne: They treat me well when we are busy playing.

Researcher: At school?

Wayne: Even at school, they treat me well.

Researcher: Rosa, who are your friends? Do you have friends at school? How many friends do you have?

Rosa: I don't know. *(Rosa is the youngest of all the subjects. She is six years old and a sister to Mabontle).*

Researcher: You don't know my girl, but are you able to play well with them?

Rosa: Yes.

Researcher: Okay. Who would like to talk about his/her friends? Okay, Noah.

Noah: My friend is Irvin Phala. He treats me well.

Researcher: Okay. Is he the one whom you trust?

Noah: Yes.

Researcher: Okay. Zola, you haven't spoken. Tell me how you play my girl.

Zola: We don't play well when we are at school. They accuse us of stealing ballpens meanwhile we didn't steal. *(She began to cry)*

Researcher: Okay my girl. It's okay neh, it's okay to cry but please control yourself So that we can finish neh, my child. What about friends at home, do they also accuse you? *(Zola's eyes had been tearful since the beginning of the session)*

Zola: No, they don't accuse me. They treat me well.

Researcher: Your friends at home treat you well?

Zola: Yes.

Researcher: Okay, my child. So are you aware that there are people who love you? Even if some people ill-treat you, in this world, there are some people who will ill-treat you and others who love you. You must all know that in this world, whether you are sick or healthy, there are two types of people. There are those who love you and others who are unkind. The world is like that. Now let's talk about the way in which people at home treat you. Mabontle, my girl.

Mabontle: My friends at home treat me well, but they always gossip about me.

Researcher: They always gossip about you. What about at home? Do you have sisters?

Mabontle: Yes.

Researcher: How do they treat you at home?

Mabontle: They treat me very well.

Researcher: Who else wants to talk about home? Jimmy? You shared with us your experiences at school. After school you go home. What happens at home?

Jimmy: It's just fine.

Researcher: Do they treat you well?

Jimmy: Yes.

Researcher: Okay. Who else? How do you experience home? Bongani.

Bongani: They treat me well at home as well. When I fall down, they carry me to the house and lay me to sleep.

Researcher: Okay. Someone hasn't spoken yet. Golden, don't you want to speak? Don't you envy others when they are talking? Natasha, tell me how you experience this disease.

Natasha: *(Puts her hand in her mouth and speaks shyly and the researcher asked her to remove it)* I feel good. When my mother shouts at me, and I shout back, then she comes and hits me, then I go to my friends and they stay with me.

Researcher: Who else wants to speak? Today we must say everything we have in our minds. Now I want us to talk about what hurts us most. What is it that hurts you most, in having this disease? What disturbed your soul? Who wants to speak, Stanford? Do you remember that Zola indicated that they accuse her of doing things she didn't do, neh? Who wants to talk now? The most hurting thing about this disease.

Jimmy: Since I developed this disease in 1999, I've been falling sick, now and then. My whole body became sore. I was helped by joining the Dutch Reformed Church in the year 2000. Now I am a bit better.

Researcher: Okay. Who wants to say something else before we leave? Make sure you don't leave without saying something that you should have said. Only to

regret later. Lizzy, what do you want to say?

Zola: My ears often bleed (*She begins to cry*) and my eyes are also painful.

Researcher: Doctors will take care of that. Don't cry my child neh. I told you that all the people who are here, do you see how many they are, this disease trouble them as well. Do your parents take you to the doctor when your ears start bleeding?

Zola: Yes.

Researcher: Okay, we will also call parents and talk to them. This is not the end of everything. From here, we are going to call teachers and parents and have a discussion with them as well. Who wants to talk about something? We want to close (*There was silence*). Okay, today you have realized that you are not alone, neh. Previously, you only knew yourself and schoolmates as the only people with this disease, now there are three schools. Only three schools, but look at how many you are. If we can invite the whole district, can you imagine, we can even fill up the hall. Now, from today onwards, know that you know that there are other people who suffer from this illness, how do you feel? Who wants to start? Who wants to talk?

Jimmy: Fine.

Researcher: Explain in which sense?

Jimmy: It feels good to know that we are not the only ones. Many people have it.

Researcher: Is there any person who wants to say something? (*Silence*)

Jimmy: I want to ask something. Are all sicknesses the same?

Researcher: I don't understand.

Jimmy: I mean are all people, even those who do not fall, people suffering from various illnesses, present here?

Researcher: No. Here we only have people with that "sickness of falling". This sickness bothers us because it cannot be cured, but it can be controlled.

Jimmy: But I have never fallen down.

Researcher: Okay, you never fell?

Jimmy: No.

Researcher: Okay. Not all people who suffer from epilepsy fall down. Some people are just not aware of what goes on around them for a while (absences) without falling. This disease does not affect us in the same way.

Jimmy: One boy told me, when I came back from the initiation school. I met him in church.

Hazel: Now listen carefully. I want you to tell me what you wish to become when you finish school. What do you want to become in life? What do you want, John?

Jimmy: A doctor.

Hazel: You want to become a doctor?

Mabontle: I also want to become a doctor.

Hazel: Please do not imitate each other neh. Each and everyone of you should say what is in his/her heart (mind). Zola?

Zola: I want to become a policewoman.

Hazel: Do you want to be a policewoman, Zola?

Lebo: I want to be a doctor.

Hazel: Do you want to be a doctor? What about Stanford? Bongani?

Bongani: A mistress (lady teacher).

Hazel: Do you want to be a teacher? What about you?

Stanford: A teacher.

Hazel: Why do you want to become a teacher?

Stanford: I just like it.

Hazel: You just like it? What about you?

Noah: I want to become a doctor.

Hazel: Why?

Noah: I just like it.

Hazel: You?
Natasha: A mistress.

Hazel: Rosa? What do you want to become, my child?

Rosa: *(She kept quiet)*

Hazel: Okay, think about it. Golden?

Golden: A doctor.

Hazel: You want to become a doctor. Wayne?

Wayne: A doctor.

Hazel: I want to ask you a final question about the disease that you have. What is your wish? What do you want to see happening?

Jimmy: I want it to be cured. It blocks my mind.

Hazel: You want it to be cured because it blocks your mind? What about you?

Mabontle: I want to be able to feel better.

Hazel: To feel better, what will this enable you to do?

Mabontle: So that I can be able to stand next to the chalkboard.

Hazel: So that you can be able to stand next to the chalkboard, good. Zola?

Zola: I want my ears to be cured. I want to go and learn at a school which is far away from home.

Hazel: Oh, you want to go to a school which is far away from here? Why do you want to attend at a school far away from home?

Zola: It is not pleasant here. There are "tsotsis"(thugs).

Hazel: Here?

Zola: Yes.

Hazel: Are there troublesome people at Dan village? Okay my child. What about you Stanford? Don't you want anything?

Stanford: *(He kept quiet)*

Hazel: Don't you want anything? Bongani?

Bongani: I want this disease to be cured.

Hazel: You want it to be cured. What will this enable you to do?

Bongani: So that I can learn well.

Hazel: So that you can learn well, neh. What about you Noah?

Noah: I want it to be cured so I can learn and play well.

Hazel: So you can play well, neh, that's fine.

Natasha: I want to attend a school in Pietersburg.

Researcher: What type of a school would you like to attend in Pietersburg?

Natasha: They call it Mamahlo.

Researcher: Mamahlo?

Natasha: Yes.

Researcher: Why do you want to change from your present school to the one in Pietersburg?

Natasha: No, no, no (I cannot continue schooling here).

Researcher: You want to change your school. You no longer want to attend the current one?

Natasha: Yes.

Researcher: What about you?

Lebo: I want to learn.

Researcher: You want to learn. Do you feel happy at your present school?

Lebo: Yes.

Researcher: What about you , Rosa? *(At this point, the researcher tried to speak to her in Xitsonga)* Rosa, you have never spoken. What is wrong?

Mabontle: She doesn't understand Xitsonga

Researcher: *(Switched over back to Sepedi)* Please speak my child. What important thing do you want in your life?

Rosa: *(Remained silent)*

Researcher: Thank you, Rosa. Golden?

Golden: I want this disease to be cured so that I can learn freely.

Researcher: You want it to be cured so that you can learn freely neh. After school, what do you want to become?

Golden: A doctor.

Researcher: A doctor, it's okay. Wayne? Don't you want anything my child?

Wayne: No.

Researcher: Okay, thank you very much. This is not the last time to be together. I told you that this was our first meeting. Now that we have met, we know each other. We are going to meet again and do something else together. From now onwards, you know that you are not the only one with this disease and that there are people who love you, like Hazel and myself. You must know that we love you. We will visit you to fat your respective schools. I would like you to fill in these papers before you leave. Thank you.

APPENDIX II

GROUP SESSION B (PARENTS)

Researcher: *(After the introductions and the discussion of ground rules)* Sikheto, could you kindly tell us how you feel about this disease. By the way, what's your child's name?

Sikheto: Golden.

Researcher: Oh yes, Golden.

Sikheto: Golden's condition makes my heart sore (hurts me). Firstly, it only attacks him at night. During the day it doesn't come, and when it starts, he starts by kicking the right foot, and starts screaming. So one should hold the toes and stretch them. Then it pretends as if it is subsiding. It doesn't stop, it doesn't stop. It continues like that until it's quiet a bit, then it resumes, continues until he becomes stiff, and his arms and legs shrink. He remains stiff like that, then eyes begin to change, and his mouth changes shape. One cannot stretch his fingers, you see. After a very long time, his body parts begin to loosen up. Then he produces this sound: "tlhaka, tlhaka, tlhaka". Then he becomes silent. Then he starts producing a snoring like sound. Then it goes away. Until the next attack. It can come many times, usually from 10:00 pm up to 3:00 am, attacking him like that, coming and going away, in that manner, but it usually attacks him towards the end of the month. Towards month end, it comes. It comes in that manner. It sometimes comes once, sometimes twice, and the attacks follow each other immediately. It can attack him today and tomorrow. When it stops then, it can take a month before the next attack.

Researcher: How do you feel when it happens like this?

Sikheto: It hurts so much, "my mother" (mam). My wife can't even come closer to him because I'm scared that she will cry and that will damage my child, you see. *(It is a common belief in the African communities of the Limpopo Province that when a child is sick, and a parent cries, the child will become a moron forever after recovery from the illness)*. I am the only one who handles him. That is why I am even here, I am the one who came to attend because she can't handle him. She is scared, I'm scared that she will cry for him when it's happening, you see. *(Sikheto was the only man in this session, the rest were women)* It really hurts, very much so, because one finds that he doesn't know how to help him, you see. That's why it's me who came here, because I am the one who is able to hold him, I'm the one who tries everything, in an attempt to help him until I'm so unable to help him, you see.

Researcher: Thank you "my father"(sir). I will bring more discussion questions, everybody must please feel free to talk. Mam, by the way what's your child's name?

Yolanda: Lebo.

Researcher: Oh yes, I remember Lebo from Xidzumbe, neh?

Yolanda: Yes, she attends school at Xidzumbe.

Researcher: Okay. How does her condition make you feel? It's good to share our feelings first, before we continue with the rest of our discussion.

Yolanda: My heart is sore to see Lebo in that state. At first, when she started falling, I remember one day (*she began to cry*) when I was coming home, (*She then sobbed seriously*).

Researcher: Okay, I will come back to you.

Thoko: My heart is sore because this disease attacked her when she was only three days old at the hospital (*She also started crying. At this point, the older parents intervened and stopped them from crying because it is taboo to cry for your child when he/she is sick*).

Researcher: Okay, I know that it hurts. It does hurt, to all of us. That's why I told you in the beginning that it is good to meet like this, and share our experiences and cry together. It helps us to feel better.

Norah: I am Zola's parent. Zola Nkuna.

Researcher: Oh yes, I remember Zola, with a voice that's a little bit big, from Xidzumbe.

Norah: Yes. When she was born, she was not fine, her legs and arms appeared to be weak. She lived like that until she reached the age of three years, unable to walk. I frequently took her to hospital, when Dr Xihoko was still around. I also took her to church where they help children with physiotherapy. She spent three years, unable to walk and to sit. They even made a certain sponge to enable her to sit up, so that she could rest from sleeping. As time went by, I have been praying that "God, please help me that my child should be like other children even if she is not well in her mind, but she should be able to walk, because it hurts if she can't walk." I continued praying like that, that "please God help me", until she was able to stand a bit and stagger. Then she reached a point where she was able to walk but in her mind, it seemed as if there is something missing. At some

instances, one can find her standing on the "lapa verandah", dancing. She also does not listen. When one speaks to her, sometimes even if she is close to you, and you call her, you must touch her and shake her so that she can hear you. Sometimes she stands on the "lapa verandah", claps hands and dances and also looks at the wall in a certain funny way as if her eyes see something. When I ask her what she sees there, she says she does not see anything. Sometimes she wakes up at night and starts laughing, she continues laughing in that manner. It hurts me so much because when she is busy laughing like that and I ask her what she sees, she says she sees something very interesting but when I look around, I do not see anything. So when I look at her, my soul becomes sore. There is no single day that passes without her doing this. Even if she doesn't clap her hands and dance before she goes to school, she does that when she comes back. Even her ears, sometimes they bleed. When I take her to the hospital, the doctor says that it appears that something is missing.

Researcher: Okay. We will talk about it after a while. All of us here, have a problem which manifests itself in various ways. That's why I brought these papers to give you, to enable you to understand that when you see some of these things happening, it is not a bad omen that is particularly happening to you. I hope you remember when I told Jimmy mother that it is not a must that the child should collapse when he has epilepsy. He can do something you don't understand. Even in class, he can suddenly keep quiet, looking at the teacher. It occurs in various ways. Look at those papers. If you cannot read or understand English, please ask someone who understands English to explain that to you. The paper shows you various ways in which epilepsy occurs. *(The researcher had given them a hand-out on epilepsy)*. Okay. Tintswalo? Who is your child?

Tintswalo: I am a mother to Noah.

Researcher: Noah. We were with him during the last session.

Tintswalo: I can say that as far as Evans is concerned, my heart is sore when he experiences such things. It started when he was still young, until now. When it happens in that manner, I feel a lot of pain in my heart, to such an extent that even prayer goes away from me, and I tell myself that maybe this God didn't want me to be in this world because nothing goes well with me. Can you imagine, bringing up children on my own in poverty, without help from anyone, fighting for everything alone. So it hurts so much, even now, after he came to visit you, the seizures attacked him the day following that one. He spent two weeks without going to school. Even now he is not fit to go back to school. So I feel a lot of pain in my heart. It's just that prayer sometimes is able to make me strong. I'm unable to cry when I see him in that state. I just tell God that anything he sees suitable for me is fine because "I did not take a hoe and plough to deserve such a

harvest" (I did not ask for it). So I ask you to please plead with the school principal, so that he can discuss with the teachers that they can be able to see them (children with epilepsy) as people like others, because sometimes there are conflicts, and then the principal comes to us and says that we'll talk to the teachers who committed these mistakes, that they should not repeat them.

Researcher: You mentioned that there are some conflicts. Which conflicts do you sometimes come across?

Tintswalo: He once had a problem with a teacher who told him that "by the way, people with your condition are mad." Then he became angry and said that he realised that if he could stay in class, he would fight with him. Then he took his books and came back home. Then a male teacher and a female teacher came to our home and said that we saw Evans leaving, we don't know what the reason could be. Then I asked him in front of them. Then he explained that "I was offended by a particular teacher who said this and that and it makes me angry. I will even leave school if things continue like this. Then they spoke to him and said that "we are aware that you are angry but please remain trying to cool down, we will go and talk to that particular teacher. Secondly, we understand that it is not your fault. Only God knows, he can remove this disease when he wants to, then you will be like other people." Then before they left, they prayed for him, thereafter, they left. The following day I pleaded with him and he returned to school.

Researcher: Where is he now, at the hospital or at home?

Tintswalo: He is at home.

Researcher: Is he taking treatment?

Tintswalo: Yes, he is taking treatment.

Researcher: Thank you Mam. Vanayena, how do you feel about this?

Vanayena: I feel very sad. I feel pain because it is not only Rudolph who is attached, we also have another child who is attacked, whom Rudolph comes after. I thought the younger one will have a good life, but he has also been attacked by this disease. I feel very sad, I can't take it. When he has been attacked by a seizure, I don't know "what to take or what to leave" (I don't know what to do). Two kids! It hurts me because recently, Rudolph collapsed, so I don't know "what to take or what to leave" because there are two kids.

Researcher: I remember he didn't come last week.

Vanayena: Yes. He fell and the tongue cracked and went up. Even now as I am talking about it, I experience headache, I feel numb. The way things are in my family, I wish God could feel pity for us, seriously so.

Researcher: Where is he now, because last week they said he was in hospital?

Vanayena: He is now at school. He is at school.

Researcher: Oh, did he go back to school?

Vanayena: Yes.

Researcher: What did they do here (at the neck), did they stitch him?

Vanayena: Yes, they stitched him. He still has the threads.

Researcher: Had he fallen on top of a sharp object?

Vanayena: No, on a flat surface like this one. The tongue went up, he couldn't eat, he couldn't do anything.

Researcher: So he is now back at home.

Vanayena: Yes, he is even back at school.

Researcher: Is he able to eat now?

Vanayena: Yes.

Researcher: Okay, thank you. Judy?

Judy: Ish, hey, my heart is sore. Yes, it is very painful because that disease is too heavy, because wherever the child is, one must always guard her, whether she is standing or sitting down, I must always guard her. Firstly, he was born normal, he was without a problem until he started school. When she reached Standard Two, that's when it started. She was then attacked by the disease, but it took a year without clearly showing that it was epilepsy. When it started, he just said: "I want to fall, I want to fall, please hold me." Then I would hold him and assist him to sit down. The whole year. During the second year, he started falling down, you see. That's when it became clear that okay, it is that disease. So now, even now, it happens, but because he takes "pills", sometimes a month can go by. During the following month, it can attack him twice or three times a day, you see. So that is the fact, hey, it hurts!

Researcher: Yes, it hurts.

Judy: Yes, in a child? It hurts. One as a parent doesn't know what to do. I can't remove it from him and say let it be me, the old one, who is sick.

Researcher: Thank you Mam. "Aus" (sister) Nancy. By the way, do you speak Sepedi or Xitsonga?

Nancy: I speak Sepedi.

Researcher: Okay. Eh. How do you feel when a child is in that condition? whose mother are you?

Nancy: I am a mother to Stanford.

Researcher: Okay, Stanford.

Nancy: Yes. My heart is sore because it happens like this meanwhile I am working. I suffer. When I come back from work, they tell me that your child was doing this and that in your absence, and it hurts me because this problem doesn't occur during week-ends when I'm home. Actually, the problem that I see in my child is that when he is asleep, whether it's summer or winter, he sweats and dampens his blankets. The blankets become wet, heavily so. I share a room with him, so that I can remove his blankets, when I realise that the blankets are becoming wet, so that he can get fresh air, then later on, I cover him again. Whether it is cold or hot, it's the same to him. Also the problem of waking up rapidly, screaming as if he wants to run away, then I hold him. That's the problem that I witness. In most cases, the problem that I do not witness is what they say, that sometimes when he is playing, he speaks alone. They say that one can believe that he is playing with someone, meanwhile he is playing alone. When his sister peeps at him, thinking that he is playing with someone, she only finds that he is playing alone. When she asks: "With whom are you speaking", he just says :'Did you hear me talking?" Then he continues like that.

Researcher: Does he say: "Did you hear me talking?"

Nancy: Yes.

Researcher: Does that suggest that he is not aware that he is talking? We will talk about this later.

- Nancy: Yes. He just asks: " Did you hear me talking? then she says "yes, I heard you talking. When I come back from work, she explains to me that: "Mother, this child has a tendency of speaking alone when he is playing alone. When I ask him that 'with whom are you talking?', he says that he is not talking". Yes, he has a tendency of speaking alone and this problem of falling down, it occurred twice at school last year. They called me when I came back from work and explained to me that the child fell down. He fell at school, he just started shaking and then tightened his teeth, his teeth rubbing against each other. They put a ballpen in his mouth, then they helped him to sleep. That's how they explained to me. But since then, it never happened again. They told me that he should stop eating food with sugar. I shouldn't give him sweets and juice. I should cancel such things. I should also monitor his tea sugar, in order to reduce the strength of the disease.
- Researcher: Did you hear that she mentioned food now, neh? We will talk about it.
- Nancy: Actually, the main problem that I'm having is that I am a working mother. They just explain to me. In most cases I am told by his sister. The only time that I witness this problem is when we are sleeping, because we share a room. This tendency of waking up, he wakes up in a fearful way, rapidly, and then I hold him and ask him what is wrong. Then he just continues to sleep. He never tells me what is wrong. He just continues with his sleep.
- Researcher: Okay. Mabontle's mother. Do you understand a little bit of Xitsonga? Did you hear Vanayena when she said that she has two children with epilepsy. I remember Mabontle and Rosa. (*To Vanayena*) This lady also has two children with epilepsy. Each was born after the other and they are still young, so she has a similar problem with you.
- Mary: I am a mother to Mabontle and Rosa. My heart is very sore because with Mabontle, it started when she was one year old, when she was still young. It just attacked her, and it usually attacks her at night. When it attacks her at night, she shivers and then the whole body becomes very hot (feverish), thereafter she becomes stiff, thereafter she produces this sound: "m,m,m", then saliva drips out of her mouth, then her tummy becomes upset and she farts. Thereafter she releases a lot of urine, hot urine, then a lot of sweat comes out. Then it subsides. It occurred again when she was three years old and then it stopped. It comes back after every two years. It happened again now that she is at school, twice. Then they brought her home. It happens in the same manner. After bringing

out a lot of saliva, she farts, urinates and then it subsides. With Rosa, it attacks her at night but she also bites her tongue, becomes stiff, in the same manner that it happens to her sister. When it subsides, she must urinate and farts, then it subsides.

- Researcher: So it occurs to them the same way.
- Mary: The same way. They are siblings, one was born after the other.
- Researcher: I remember them. Mabontle told me that “Rosa is my younger sister”.
- Mary: I have heard that the young one did not say anything. She just kept quiet. She has just started school this year. Mabontle is doing Standard Two. With the younger one, it occurred twice, but she is still young. I once used a "spuit" (*This refers to inserting a spray into the anus in order to clean the stomach with the belief that the “dirt” which is causing the child’s illness will come out*) . I "spuited" her, then she produced something very little, I continued "spuiting" her until she produced something that looked like eggs, dry eggs. Since then, it didn't happen again.
- Researcher: So is Rosa a little bit better?
- Mary: Yes, since it happened to her once last year, this year it hasn't occurred.
- Researcher: She was quiet. She was the youngest among all the children who were here. Maybe she was scared because all the other children were older than her. She is only six years old. She is young. Thank you Mam.
- Patience: I am Wayne's mother.
- Researcher: Oh, yes. Patience, how do you feel?
- Patience: My heart is very sore. It started attacking him last year. I was told that he had fainted at school, but I didn't take it serious. I witnessed it for the first time last month. I was asleep at night when he started complaining about a headache. He didn't sleep well that night, complaining. In the morning I bathed him and took him to the clinic. As we were walking together to the clinic, he became dizzy. Then I carried him on my back and proceeded to the clinic. As we were still waiting for his file to be found, he fell from the chair, he fell to the floor and urinated, kicking his feet and stretched his arms like this (*She demonstrated*). When I saw him in that state,

eh, they instructed me to carry him to the ward. They gave him an injection so that it could stop. Then they went to look for his file. They told me that I would accompany him to the hospital. They phoned the ambulance, then it arrived and we drove to the hospital. He was unconscious, he couldn't even walk. At the hospital they put him in a bed. They admitted him to the ward. My heart was very sore and I was on the verge of tears (*Her eyes were now filled with tears*).

Researcher: As a parent, it is normal to feel that way. Even myself, I was on the verge of tears last week when those children were here. I just controlled my emotions to avoid feelings of helplessness on their part. So I decided to be strong, because if they could have seen tears on my face, they would feel hopeless. I was also trying hard to be strong, but it hurts. (*To Caroline*) Okay, I know that Jimmy doesn't fall down, could you briefly explain the disease that he is having. We will talk about it later.

Caroline: He just stopped talking and his eyes became wide open and fixed in one place. Then I realised in his eyes that he had changed, but I didn't understand whether it was a sign of an impending mental disturbance or what. Then I took him to the hospital. There they examined him but couldn't find anything wrong in his body (*She began to sob*). Then they told me that I should bring him one morning on another day, so that we could take him to a certain clinic, there at the hospital (*She paused and cried bitterly*).

Researcher: Okay, Mama, we will discuss this later on. Remember I said to you that this is not easy, but I would also like to remind you that crying is healthy. It helps us to feel better. Even when we share our experiences in this manner, it helps us to feel better. In Xitsonga we say "I ku phofula" (is to vent out). You take out what is inside you. We share our feelings with others. So this disease comes in various ways. Let's look at the papers, the first one is called absence. In this case, the child doesn't fall down, as you heard Mary explaining. Her child was here last week. The mind becomes temporarily blank. It can happen that I'm speaking to a child now, ask him a question, then he gives me an answer which is totally irrelevant to the question I asked him, or, say he is eating, he can suddenly stop eating and takes a ball, goes to the street to play, unconsciously. Sometimes it happens as if the child is mentally disturbed. After some time, "the mind comes back". Even in class, which I will discuss more with teachers, the child can suddenly sit still, open his eyes and remain focused on one spot. Sometimes the eyes may turn red and one wonders what this is about. Sometimes one can call her saying "Mercy, Mercy", she will just keep quiet

and look at you, she is not even aware of your presence, she can't hear you. After a while, "the mind comes back" and then she remembers that okay, "I'm in class". That's one type. Another type is the one that appears as if it is a stroke. It starts from one side of the brain. I'm not sure if they explained to you at the clinic that this disease actually emanates from the brain.

Nancy: Another problem that Stanford experiences, even at school I told them, is that sometimes after playing, he says that it is painful here (*pointing at the hips*). He usually complains about the hips. Sometimes he complains about dizziness and says that "my head is turning around. Even at school, when they teach him, he doesn't become serious, he is slow to understand, his mind is slow, and he is unable to ask because he doesn't want to be rushed. If one does that, he just keeps quiet. I told them at school. Even when they are teaching, when the teaching takes place very fast, and when they give him a task to write, after writing, he won't submit his book. When others submit their work, he doesn't because he was in a frightened when he wrote, you see.

Researcher: Did you all hear what she said?

All: Yes.

Researcher: Yes, the child sometimes complain about problems in the head. In class, if teachers appear to be rushing them to such an extent that he becomes frightened, he suddenly becomes scared and when they ask questions in class, he won't answer them. Do you remember that I told you that most of the children who were here, your children, explained that when they are in class, they are scared.

Mary: Just like Mabontle. She once suffered from teeth problems. I took her to Letaba to get a tooth removed, just one, and they said that for the other one she must visit the clinic. Then they gave me a letter, which said that she must be examined by the doctor because her teeth problems appear to be related to her eyes. She can't get her teeth removed before her eyes are examined. When I took her to the doctor, he said that he didn't see anything wrong. At her school, they call me often explaining that there are certain letters which she cannot read when written on the board. One day she is able to copy all of them, another day she can't see properly. Her ability to read from the board is unstable. They call me often at her school. One day she can see properly, the next day she can't. She also suffers from blood dripping out of her nose. I don't understand what is going on.

- Tintswalo: My child, in most cases, complains about headache and if the headache is severe, even his eyes become red. When the headache is mild, the eyes also clear up.
- Vanayena: I believe that because my son sometimes suffer from this arm (*pointing at the right*), and also, when the seizure is about to attack him, the neck bends like this (*He demonstrated*).
- Researcher: Let's resume our discussion on that type. She says that the child starts with this side, appearing as if it is a stroke. It is the second type of this disease.
- Thoko: When Natasha falls down, when she wakes up, she appears confused. At school, she says that she has a problem. When they call her to write on the chalkboard, when she arrives there, because she is scared, she no longer read what is written there. Then she writes incorrect things.
- Researcher: Let's proceed with the second type of this disease before we all forget. This type starts from one side of the brain. So when you see the child's arm going like this (*She demonstrated*), it has started from the side of the brain which controls that side of the hand.
- Tintswalo: Yes. It has many ways in which it manifests itself.
- Researcher: Many.
- Tintswalo: My son now does things which he didn't do before, such as vomiting, and many other unusual things. It varies.
- Researcher: Yes. This is the third type that I was talking about, where the entire brain is attacked at once. The child usually falls down, vomits, bites his tongue, and kicks. The whole body is affected and the child can get hurt in the process. This is the third type. Please don't forget that to find a person who can read and understand English, to read and explain it to you in mother tongue. That's what I wanted to help you understand, that it occurs in various ways.
- Mary: May I please ask a question?
- Researcher: Yes.
- Mary: It appears as if these children have inherited this disease from me, the parent. When they start doing those things, my mother tells me that I also did those things, but they took me to Baragwanath

Hospital in Johannesburg, where I grew up. At Baragwanath, there were some doctors from overseas. I'm told those doctors drained a lot of blood from here (*pointing at the back of her head*) up to the spinal cord. They pumped out dirty blood. The blood filled up a bucket. Thereafter, they said that I should stop growing my hair long and looking at myself in the mirror. Then that was the end of the seizures. I believe that maybe these children inherited from me, but with me, they only drained blood, from here up to here (*pointing at the back of the head and the spinal cord*). Dirty blood, I'm told, it was dirty blood. Then they stopped me from looking at the mirror. That was the end of the seizures. My children are now having those things.

Researcher: When I was discussing with a certain doctor, who said that he stopped a child from watching TV, and the seizures stopped. He explained that this disease can be triggered by various factors. When a child is angered or tired for an example, it starts. Even music, certain tones can start it.

Tintswalo: I believe that there are many things involved. Sometimes the child might not respond to medication. I went to the health centre to complain that the pills that they gave me are of no help. They gave me a different type but I still do not see any change. In my opinion, he is not getting any better. My son also works very hard, when he feels like. He even carries bags of cement at his own will.

Researcher: Okay, but you should bear in mind that fatigue can start it.

Yolanda: I just want to ask something. Can this disease be cured?

Researcher: According to doctors, it cannot be cured but it can be controlled. They also say that it depends on the type and intensity. If it is mild and occurs at a very young age, after the period of five years, it can go away. It doesn't proceed any further. However, if the seizures are too persistent even during the school-going age, it is unlikely that it can be cured, but it can be controlled, by medication and avoiding the trigger, if identified.

Hazel: There is a certain child whom I know who had epilepsy at a very tender age. His parents took him to Doctor Sue, when she was still alive. They gave him medication and after two years, the disease disappeared. The sad part is that the child is not progressing well at school. He gets tired easily, he is not supposed to work very hard. The disease is gone and he is healthy, but has learning problems. Even during adulthood, it can go away. I know two people who are now cured and happily married. One of them works at the hospital.

(Hazel is a preacher and has started her own church. At the end of the session, she indicated that these people were healed through prayer).

Yolanda:

One day I came back from work and found that he was admitted at the hospital. The seizures started at school, and they took her to the clinic. At the clinic the nurses told me that they transferred him to the hospital because he spent five hours in an unconscious state and it is not normal. They phoned the ambulance. The doctor told them that he wanted to talk to me "straight" because I am the mother. They sent my mother back, saying that "go and get the real mother to this child. She came to fetch me from Letaba Estates. I went to the hospital. At the hospital they told me that it's long that this disease has been hiding away from you, so you were not aware that your child has it. I remember one day when he was beaten by a certain child, he fell down. I wanted to beat him up for engaging in a fight, but a certain man stopped me, saying that "wait a minute, it's long that this child has been in this state." Then I discovered that he had wet the place where he was sleeping.

Then the doctor told me that, *(She paused)*, before that, he used to complain of a headache, a back-ache and painful legs. I did not take him into serious consideration. Then the doctor told me that there is a problem. The child is still young. Please learn to communicate with him in a polite way. Don't shout at him, even when you are at home. Another problem is that the husbands that we get nowadays *(She paused)*. When I am not around, he ill-treats my children. Then I told him that "let's separate because my child is stubborn. When he calls him saying "Lebo, Lebo", he just turns around and looks at him like this *(in a disrespectful way)*. He wanted to beat him up saying that it means he can hear that he is being called, he is just ignoring him. Then I said to him: "Please don't ill-treat my child", because even myself, it sometimes reaches a point where I can't tell him (the child) anything, he talks to me in an impolite way. When he does that, I just talk to him politely.

The doctor pleaded with me that "please, never leave this child alone, one day he might fall down alone." Then he asked me: "Do you make open fire?" Then I said 'yes". He then said to me that "one day he might fall into the fire in your absence". This is another problem. There shouldn't be fire at home. The doctor also stopped me from allowing him to make fire. That I have tried. When I realise that I will not be around, I cook a lot of food but because he likes fire, I sometimes find that he made fire in my absence and tells me that "I don't like the vegetables that you have cooked for me, I wanted to cook some gravy". This is a problem

because I am unable to stay with him at home because my family background is poor. My mother is not getting any pension fund and there is nowhere I can ask for mielie-meal. The children's paternal uncle always tells me that he has nothing when I go to him for help, therefore, I must do everything for them. I am both a mother and a father to them. They once called me at his school, he was cold. He did not have shoes, he did not have a jersey. In my opinion, my background becomes better when I go to work temporarily at the orange farms. When the temporary job is over, I go around asking for help from people. I say to them: "May I please do your washing", then they give me something little, then I am able to keep my children alive (*Her tone changes*). Things are tough. Sometimes I'm supposed to take him to the doctor, only to find that I don't have money (*She began to cry*).

Researcher: Okay. Let's talk more about this after the session. Please don't leave.

Thoko: There is something I want to know about this disease. I have a cousin who has it, and was operated. (*She began to sob*). So I want to know if my child is also fit for an operation? (*She continued to sob*).

Researcher: In most cases, they perform surgery when they are convinced that the child doesn't respond to all types of medication. Is it long that the child was suffering from the disease?

Thoko: She was only three days old when it started. (*She continued to sob bitterly*).

Researcher: Okay. I think because the child is still young, they will try everything they can to help her first, before they consider an operation because it can be problematic. They try all types of medication first. Surgery is the last resort.

(Thoko and Yolanda were now sobbing bitterly. The older mothers intervened and rebuked them for crying. They told them that it was going to cause permanent damage to their children. As already indicated, in the African tribes of the Limpopo Province, it is taboo to cry when one's child is sick. It is believed that even when the child is cured from the disease, he/she will become a moron, and remain like that for the rest of his/her life. The session was a bit disturbed at this point. The researcher allowed some time to the older parents to talk to the two crying mothers. They explained how bad it would be for the children. The two mothers listened and tried to control themselves. At this point, Sikheto started speaking,

but the older mothers continued to talk to Thoko and Yolanda. The researcher intervened and redirected the session back to a discussion).

Sikheto: With my son, when it attacks him twice a week, when it goes away, his thinking is out of order. You will find that when I talk to him, his answer is not related to what I am asking him. He gives a very irrelevant answer. Also, when he has been beaten by another child and he cries a lot, it 's a must that the seizures will come at night. It attacks him at night, if he cries a lot. He doesn't want to be angered. After he has recovered from a seizure, he has a lot of physical strength. He likes fighting. I remember one day I stopped a fight between him and his older brother. I said to him "Don't do this. This one is older than you and he will beat you up, he is more powerful than you. Stop the tendency of fighting with him". Then he started crying, then I consoled him. When we went to bed at night, the seizures came, because he had cried a lot, you see. He is very cheeky, he is really cheeky.

Researcher: Are these your experiences as well? (*Referring to the whole group*). Do you think they are short-tempered?

Mary: They react violently to minor provocations, and when one tries to correct them, they think you don't love them. But when I give them money, trying to show them that I love them, they become very happy.

Hazel: Actually, these children would like to be like other children. They didn't expect to have the problems that they are having. It disturbs them that they have this disease. They always ask themselves questions such as: "What will my future be like?" If the child is grown up, he will say to himself: "My friends are at the university. Everything looks great with them. Nothing goes well with me". They do want good things. They also ask themselves: "Will I ever get married? Will I have children? Will I be able to work? What will happen to me?" The child has a lot of questions. He is like other children. You as parents should accept them. Have a special place for them in your hearts especially when you talk to them. You must always remember that you are talking to your child, the one you love. Love is the most important thing that you must show them as parents. You will be able to live with them. Have a special place for that child in your heart. Try to remind these children that "my child, you are not like other children, so accept yourself and live in this way, I will also do what I can to help you." If I can't give you some of the things you need, don't be angry, because you are reducing your days of living, you are killing yourself. The

disease will not get better. Tell them also, to listen to you. "When I say this my child, please listen to me, I'm trying to help you". He shouldn't behave as if you are troubling him. You are there to help him. assure him of this. Recognise their birthdays and do something for them. You as parents, must not think that you have been cursed. You didn't do anything wrong in front of God. A lot of parents with special children ask themselves that: "Why did God give me such a child?" God doesn't discriminate, just like death, it doesn't discriminate. You didn't do anything wrong. Let's accept it.

Researcher: I also told the children to accept themselves. I told them that even people who appear to be happy, do have problems. Thank you , parents. Is there anybody who would like to say something before we close?

Yolanda: I just want to emphasize that my heart is sore, my mothers. I am a poor woman and I bring my children up in very difficult circumstances. I go around working for them. It's painful when I sometimes come home only to be told that Lebo collapsed and he has been taken away by an ambulance. It's hard. It always waits for me to go to work, then he collapses. He has marks all over his body and legs. When he falls down, he always gets injured, then the ambulance must come and transport him to the hospital. The ambulance has to take him to the hospital. There is no one whom I can ask to look after my son. There is no-one. I don't have a support system. He always asks me this question: "Mother, why don't you buy me school uniform, so and so's parents bought them school uniform". Then I call him and say: "My son, you must differentiate among situations. Are you aware that Ronny has a mother and a father?" The he says "yes". Then I say: 'Are you aware that I am just alone? I concentrate on buying food so that you don't become hungry at school, so that you can concentrate when you are learning". After I have explained this to him, he understands, but when he goes there and finds them drinking tea, he comes back to me and asks: "Why don't you buy us bread?" I try in various ways to support him. My mother is just like me. It's hard. This disease should have attacked somebody else. I am poor.

When the doctor tells me not to leave him alone, I don't understand. Even now, they believe that I do not leave him alone, they don't know that I go to Letaba Estates every day, but now my work starts at 2h00 pm and ends at 10h00 pm, and again at 6h00 am and ends at 2h00 pm. When he comes back from school, we arrive home at the same time. Staying at home will not work because I separated with the man with whom I was in love because of ill-treating my son. When he (the child) gets angry, he breathes

heavily and turns his eyes up and stares blankly. He behaves in funny ways, his arm shivers at the same time as his leg. So I realised that my son will die at a young age. I love my son. In my whole life I will never get more children. I gave birth to all my three children through an operation, then I sterilized. This is the reason why I take good care of my children. When I look at my children, I regard them as my brothers and sisters.

Researcher: There is something I like about Sister Yolanda. I don't know if you are all aware of it. The love one has for her child, no one or no man can remove it. I am tempted to say that this is how a woman should be like. There shouldn't be anyone between you and the love for your child. Don't regret that you have stopped seeing that man. I think you are a brave woman. Thank you very much. Let's get the last word, from anyone.

Hazel: The last word is that we are here to help you. To give you support. Thank you for using your time to come here. Some parents do not care about their children. They are tired and decide to ignore it. So we would like to thank you very much for having considered this seriously and used your time to come here. We hope it will be like this even in the future when you have problems. Communicate with your children's teachers, they will inform us and we will visit you. Thank you.

Researcher: Suppose you have a problem in your mind, which you forgot to mention today, we are always available. Hazel is found here (at Tivumbeni Multi-Purpose Centre), and I am found at the District Office. If you feel like coming, just come. We will visit your children at their respective schools. They need us to accompany them in their growing up. They need to understand that they are loved, they are human beings. One last thing that I would like to say, is that this disease can also be in the "blood" of a particular family (*In Xitsonga, the concept "blood" is also used to refer to "genes"*). There is the possibility that your child can have it because one of your ancestors had it. It is hereditary.

Sikheto: My mother also had it. Because it was a long time ago, they consulted a traditional healer, a Sesotho-speaking old woman. She stopped her from drinking alcohol and killing a chicken. She was stopped from seeing blood, hence she had to stop killing a chicken. She was also stopped from making fire. These were the three things that she was banned from doing. In her family, the chicken was supposed to be killed far away from her and be washed thoroughly, placed in a pot and on fire. My mother could then go and cook it. She was not supposed to see any blood and she was

not supposed to drink beer, you see. It is about two months for a traditional healer to help my mother. Because my mother was an understanding person, she also stopped us from killing a chicken next to her, and that disease stopped right away until she died in 1984, without having any more of the seizures. Now that you have reminded me that it is hereditary, and my son has it, I now remember that by the way, my mother also had it.

Researcher: Yes. It happens that you might be having the disease, but your children and grandchildren do not experience it, only to attack your children's grandchildren. In English, they call it a "gene". In other words, in that case, the parents are carriers of the gene. Thank you very much for coming.

All: Thank you.

APPENDIX III

GROUP SESSION C (TEACHERS)

Researcher: *(After Greetings and introductions)* What are your experiences with these learners? What are the problems of these learners in your schools and in your classrooms? Who would like to start? Or should I do it the conventional way, meaning moving from one chair to the next make *(They all laugh)*. Who is comfortable with starting? How do you experience them?

Masungwini: I am Masungwini from Kurhula School. Actually, this problem always affects us in the, eh, especially in the classroom situation where you are busy teaching, or even in the sports field, when we are doing some sporting activities because most of the time when these children, eh, experience this, you find that the process of teaching in that particular classroom, whatever activity you are doing, you have to stop and then start concentrating on how to help the children in any way that you can. It's more dramatic when it's the first time to experience it, to see it happening in a child whom you didn't know he is having that particular problem. The concentration on the child will not be the same as the one who is not having the problem, because obviously, you will leave the class to go and find a place where it can be easy for you to help the child. This is a very bad problem because sometimes we find that we are supposed to call the parents to come to school and some of the kids are living far away from the school. Sometimes it is better when you find that the child is having brothers and sisters in that particular school. However, it is very painful really, because the way it happens, it is also painful to us as teachers even though we are not experiencing that thing. Some of them, the way they react, if you are not strong enough, you cannot stand for it. There is a lot of fear there. They are not doing things the same way. Some of them, whom we know that they experience this problem, when it happens or when the time comes, we try to take her to a good place, especially like an office where there is enough space for that person to recover, to try and make him or her relax and then to the rest, especially teachers, it is a problem.

It is difficult to teach someone like that because sometimes you feel that how can this child become alright. How can he, eh, what is it that we must do? What is it that we must do as teachers to make sure that the child at the end of the day, no longer experience this kind of a problem. That is why we even sometimes call the

parents from home. Some of the parents do come, others do not even mind. They don't worry at all. And then you find that some of these kids are known very well to us at school. Some of them are, I don't know, maybe it is because they know what is it that they, eh, the disease that they are experiencing, you find that they become so, (*He switched over to Xitsonga*), they seek too much attention. Some of them are bully because they know that there is nothing you can do because he knows that you cannot punish him. He thinks "they know what my situation is". Some of them don't want to concentrate in class. They are not learning at all. So I don't understand, the problem maybe is because of this disease. It makes them to be more bully, or it makes them more ignorant. Sometimes I do not understand it. Some of them are, when you look at them, they are, I don't know how to put it. It is a child who, how can I put it? He is a child who, when one looks at him, he appears to be ignorant. He doesn't care about anything. Even when you try to guide him, to tell him something, aah, it seems as if he can't hear you sometimes.

Some of them are really bully to such an extent that if one doesn't know about their condition, he might end up treating them badly, because of such things, and at the end of the day I do believe that as teachers, all teachers, if we do understand the problem, if we can know that this child is not consciously behaving the way he does, looking ignorant, being cheeky and stubborn. Maybe we can also treat them equally, the same as other children. Sometimes they feel as if they are not equal in the classroom, they are undermined, they are not regarded with esteem because of the fact that they have this kind of disease. So it would be good if we as educators can manage to help. If we can be able to let them know, experience, see that even if they are sick, they are equal to the other learners. Sometimes there is that problem, where one does not know how to succeed in helping the child to realise that "no, I also belong to this class, I'm like other children, it's just that sometimes I experience something different for two minutes, five minutes, ten minutes and so on"

Researcher: Okay. I heard you mentioning that you need to try and indicate to them that that they are equal to others. When a child misbehaves in class, he has to be rebuked. They are cheeky, they are emotional, all these things. How do you experience disciplining them?

Musa: I am Musa attached to Malamula Primary School. In accordance with my view, if you realize that this learner is affected with this disease you should sometimes exclude that particular learner from punishment and try to counsel him aside, sometimes, try to show that particular learner that as

you are here at school, you should concentrate on whatever the teacher is teaching you so as to develop the whole, so as to pass at the end of the year, because if you can discipline the child in the midst of others, sometimes he or she will react somehow, and sometimes you fail to handle that type of a situation where maybe she will collapse, maybe doing some sorts of behaviours that you will not be able to handle. So I should think maybe to counsel him or her aside is good, according to my view.

Researcher: Okay. Do you think they are easy to handle?

Masungwini: No, actually the way they, eh, the majority of them are not easy to handle, but some of them are easy to handle. According to my understanding, those who are easy to handle are girls. Boys are always more, eh, they are always difficult, yes. Solving problems is always difficult with boys, but girls are better. You can always try to solve problems with them, but boys are more difficult because some of them think that they are not equal to others. They already know, maybe they know from home that "I'm like this, then when I arrive at school, they must treat me like this because my mother also treats me like this", especially boys. They are more, those are the ones who are more difficult to handle.

Researcher: Okay, thank you. How do you experience them? I haven't heard from this school (*referring to Banana*). How do you experience having these learners in your school?

Emily: I am Emily from Xidzombe Lower Primary School. So far in my class, there is one epileptic child, and I have never experienced anything from him. I just discussed with the parent. She told me that her child is suffering from this disease. So far I have no skills. I don't know, I know nothing about the disease so far and even if he can be attacked, I don't know how to help him. I really need the skills of helping him. I have never experienced that in my teaching field since I have started.

Researcher: Okay. Maggie, how do you experience them?

Maggie: I am Maggie from Xidzombe School. In my class I do not have anyone with that type of sickness but because I was attacked from the time I was in the lower primary school till I was at tertiary, now I am alright. Mmm, I realized something about those who are having this type of sickness. To realize that you got this disease, sometimes it causes you to be, you know, to act badly. Sometimes you hate somebody and try to take things from other children because you know that there is no one who is going to beat you because you are sick. Even sometimes you don't want to write the assignment I can say class- or homework. You find that when the teacher is coming to class, you start to react somehow so that he can call you to

order, then you start to act as if you have been attacked. Yes.

Researcher: This is interesting. What you are saying is that children sometimes use it to get attention?

Maggie: Yes. With me, in 1985, our principal told us to walk to Ledzee. Because it was too hot that day and I didn't like to take a walk, I just started to act as if I have been attacked by the seizures. *(All laughed)*

Researcher: So you were faking it?

Maggie: Yes, I was faking it. I was just doing it, not that I was attacked at that time. Even today, our children at school, they act as if they are attacked when they don't want to write or they see that you have given them classwork and they don't understand that classwork. I can say that we as teachers must show them love, the same as other children, otherwise they are going to take advantage and to tell their parents that "Yeesh, mommy, my mam really loves me, she doesn't love that one". And the parents of the other children, those whose children do not have the sickness, will not be happy about that. We must show them love and always see to it that they got the food at home, because when you are hungry, that sickness is going to attack you continuously because one who has it must always have power. That is the problem. That's why we want this project to see to it that our children got food at home so that when they come to school, they must be well-fed. Even us, we are going to help them with food from the feeding scheme, but you find that the feeding schemes sometimes run out of money, but if parents can give them food at home, at least it will be better. When they are hungry, things are going to be bad at school.

Researcher: Okay. Thank you. We actually discussed with parents that diet plays a very important role in controlling the disease. However, there are also triggers. By triggers we mean something that starts the disease. Factors such as anger, stress, fatigue and also flickering lights such as a television screen can trigger the seizures. Once the trigger is identified, it becomes easy to control the disease.

Maggie: This is a problem because children like watching TV. You know at five o'clock, they are there. They like watching TV.

Researcher: One mother actually said that she wonders how easy it would be for her because her son is a TV fanatic. Okay, Mam, how do you experience these kids?

Dorris: My name is Dorris, attached to Kurhula School. I'm going to say whatever I'm going to say in mother-tongue because I want you to understand this clearly. *(She switched over to Xitsonga)* Actually, with the child whom I

have witnessed experiencing this, she first becomes dizzy, then at the end it appears as if she wants to sleep, then she falls down and starts kicking her legs. You find that sometimes I couldn't notice it because I was busy teaching, until she falls down. Then I also feel hurt and sometimes scared. Because of the fear, one delays to attend to the child. When I run around trying to help her, you find that I am alone in class. There is no other person who can help me. I have to remove her clothes so that she gets enough air and then find something to put in her mouth so that she doesn't bite her tongue. I am alone, there is no one to help me. It's hard as a teacher to have that particular person. So I don't know how we can help such children and after that, you find that , that particular child becomes embarrassed. She can no longer cope when you continue teaching. You find that she is no longer happy, she no longer enjoys anything, so you don't know how best to help her. That is why you find that we call them slow learners. It's not that they are really slow. It is because the child feels that she is not like other children and because of her fear, she is unable to concentrate when you are teaching. She is busy thinking about herself that "what kind of a person am I?", things like that. Those are the things I have realised.

Researcher: Do you realise that this keeps on coming up. The fact that they are afraid. All of those children who were here last week said so. One of them said when I try to raise up my hand in class to give an answer, my hand ends up somewhere in the middle, it shakes and after somebody has given the answer, then I realise that it is the one that I had in mind. It is the correct answer. They spoke last week. Sometimes they feel that you embarrass them by the things you say. They say you are rude to them. *(All laughed)*

Victor: My name is Victor attached to Malamula School. In my class I do have such a learner but I did not experience it. I got the information about the learner from the parent, but what I have realized from the learner is that he has lack of concentration in class. Sometimes you can ask him a very very simple question, only to say that he does not know that answer. You may find that the learner knows that answer, but you find that he gives you the wrong answer. It's the question of concentration. Yes, it is one of the problems, but I think we as educators should treat these learners equally, like other learners because maybe if we pass some provoking remarks to these learners, we are demoralising them. They feel as if they are not welcome. We should also try to tell others, their classmates to be in their boots so that they (learners with epilepsy) should feel comfortable. In that way, they will improve their concentration in the classroom. These kind of learners sometimes feel as if they are not accepted you know. They feel they are rejected so we need to help them and I think the Department should also contribute by workshopping educators on how to deal with learners who are suffering from epilepsy. I think it is how we can help these learners.

- Researcher: Thank you. Do you want to say something (*Addressing Masungwini*)
- Masingwini: Yes. Actually, when we look, it seems as if the majority of these learners are from poor families. The way, even the way they are treated at home, I don't know, but it seems as if their parents discriminate because they know that this one cannot do anything, he is useless. "How can I buy him school uniform?" The majority of them are big. You find that maybe he is fifteen years old but he is still in Grade 6 or in Grade 5, and then at the end of the day, some of them you find that because he is big, and he is in a lower grade, it seems as if they have started drinking and smoking. We believe that drinking and smoking also contribute to this problem. Then, as we have already said, the ration (food) at home. Some of them when they collapse and then you ask : "what is happening?" He or she will tell you that "I didn't eat at home, there was no food at home. Even at school, we know now. When there is no food from the feeding scheme people, when they don't have enough money for that month, we know that after eating, we (teachers) must make sure that we call so and so, then we give them the remaining food. It seems as if some of the drugs they are taking need them to eat first. These are some of the things that influence their epilepsy. It also seems as if some families don't care. They don't follow the instruction that "every month I must go and collect the drugs". Aaah, they don't worry at all. Some of these boys are , I remember one at our school, he is really cheeky. He is so mean that you can say bad things about him, as you have already said that these kids say we always say bad things about them. When you talk to him, especially if it is during break, it is difficult for him to concentrate on what you told him to do. Suppose you call him with his hands in his pocket, he will come to you with his hands still in his pockets (*All laugh*). Then when you tell him to show respect, to remove the hands from the pockets, aaah, it seems as if he is not listening. Even in class, he is just numb there. Then, ah, it is really difficult for us to solve that problem. (*All laugh*)
- Musa: I have two learners in my class. Amongst these two, one is easily provoked or irritated when someone has done bad things. The other one, sometimes when you call him to order, he keeps on repeating the same mistake always but as a teacher, I used to call that particular learner and counsel him, trying to show him the good things he must do, but he keeps on repeating the same mistakes, always, always. In my opinion, dealing with these kind of learners means long term suffering, because they repeat the same thing or rather, they are ignorant, as my friend has already said. They are very ignorant, according to me. Even when you give them some assignments or homework, you find that he or she doesn't write, and you should discipline them the way you discipline others and because she knows that well, "I'm sick, I'm seriously sick", She maybe takes an advantage that "ah, they won't do anything to me, they won't punish me,

they will spare me anyway", you see. So that is why sometimes it is a problem, they don't perform well, taking an advantage that "they won't do anything to me", but we try as teachers to guide them, sometimes using the Bible to guide them. I remember one time, I even prayed for one learner when we were at the assembly. Sometimes they used to collapse, so we used to pray. Sometimes after prayer, well, he recovered for a while. Seemingly, this disease affects the mind.

Researcher: Yes. As I have already indicated, it is the disease of the central nervous system. It emanates from the brain.

Musa: And when they are irritated, they cry, so as a teacher, I need to sometimes call that particular learner and console him. If somebody maybe took his pen, if sometimes I do have it somewhere, I just give that particular learner so that he can feel comfortable. Trying to help the learner is another mechanism that I use.

Researcher: Thank you. Another comment? Who would like to say something? Okay, I will come to you later on, Sir.

Maggie: Another thing that I have noticed with my learner is that he has eye problems. Sometimes he does not see correctly the numbers, even the letters on the board. His school attendance is very poor. Most of the time he would be present today, tomorrow he is absent. But all in all, he is good, he is intelligent. I just wanted to comment on the eye problems.

Researcher: Researcher: It all emanates from the brain. As you know, the brain controls the functioning of the eyes as well. Okay, Sir, do you want to say something?

Masungwini: Yes. I don't know if it can be possible, especially for you as facilitators, to visit schools where you will be able to talk to all the teachers, talk to all of us as teachers, because you know that teachers are not the same. We are here today, we will go back home, okay, maybe we tell them what we have learnt but some of us teachers are difficult to teach, or to convince. I don't understand. They take things for granted, but I do believe that if you do have enough time, it's only three schools, just come one day for thirty minutes, if you have enough time.

Researcher: It is our mission to visit schools.

Masungwini: Ya, it would be better when you talk to all of us as teachers because I do believe even those who are not aware, they will understand because sometimes we rebuke them by referring to their disease.

Researcher: They told us last week. *(To Hazel)* Do you remember?

- Masungwini: That's what we do to them. I have also experienced this. I know what is happening. I know, That's why I even spoke of liquor and cigarettes. Maybe some of these kids get, eh, what is this, pension or what, the money they get from the state. What do they call it?
- Researcher: Disability Grant?
- Masungwini: Ya, those grants. Then it is easy for him to buy cigarettes and beer. That's the problem.
- Researcher: I see, and a person with epilepsy should stay away from alcohol.
- Masungwini: Yes. Liquor and drugs affect the nervous system. *(Masungwini is a lifeskills teacher at Gavaza)*
- Researcher: Yes, and we emphasised that to parents. We told them that these kids should stay away from alcohol.
- Dorris: Okay, mine is just a question. We find that most of the learners who are experiencing this disease come from poor families. I don't know if you have something in mind to help these type of families, because you find that they really do not have food at home to give to these learners. When we ask then, you will find that they had nothing in the morning and even during and after school, in their homes, they won't have anything to eat.
- Researcher: We didn't have anything in mind. It is something that just came up now. We can take it from here. Actually some parents did mention that they sometimes lack food. We didn't have anything in mind. We can discuss afterwards what we need to do about it. Thanks for bringing that up.
- Hazel: Actually, there are many sophisticated issues concerning that. When the parents came here, they were expecting help because at the end they talked about that grant, which we are going to consider.
- Researcher: We are going to note it and then look for channels like social workers. We will follow those channels and see what comes out.
- Hazel: It can be very good, very good.
- Researcher: Maybe we can even try to connect them to doctors who can voluntarily help them in times of need.
- Dorris: Yes. Sometimes you find that a parent is having two kids with epilepsy and it is a problem, you know.

- Researcher: If we can. There could be doctors who could assist.
- Hazel: It is serious.
- Researcher: It is fine. Is there any other comment before this thing switches off?
- Musa: I personally need assistance from you as facilitators. How can we solve the problem that you find that sometimes they provoke others, timeously? Some of them beat others and others steal other learner's properties and all those kinds of things, always. Sometimes you find that they are even cases themselves. I don't know where to get help in such cases.
- Hazel: What is also very important is that these learners must also be counselled. It is very important. The same applies with the child who is disabled in the family. You can say whatever, but because of this overprotection by the parents, the child always needs first class treatment.
- Researcher: Special attention.
- Hazel: Yes. The child at the end is so spoilt in such a way that he expects it even when he is in a school situation. They go to school with the same attitude and then the child says whatever he wants to say to the other learners, even to the teacher because he is spoilt. So in that case, I think the child needs counselling. These children should know that they are just like other children. The only difference is that they have been attacked by this illness. Just like the disabled. They are just like other people but the only thing is that they have got some disabilities, so they need counselling. It is very serious. They need counselling.
- Musa: Furthermore, even some parents do contribute to the situation, to make the situation worse. You find that if that particular learner has done something wrong, they even come to school sometimes saying "Who is teacher so and so who smacked my child? My child is ill", you know, those kinds of things. You find that they even have a bad approach. I have just given you an example. I won't say much of it.
- Researcher: I think we understand what you are trying to say. It is that attitude that "I will confront them".
- Musa: Yes, "I will show them that I'm so and so, I will show them, they will know me, ya, my child is sick and they know that ". You find that their approach is bad even in front of that learner, listening to them trying to protect him. You find that that particular learner is not even controllable at the end of the day. It is sometimes disturbing. It is a problem when you try to discipline those kind of learners.

- Researcher: These are interesting realities.
- Musa: Yes, hey, parents are not co-operative.
- Hazel: I do have the same experience because I taught disabled learners, so I know how troublemakers they are in the classroom. The worst part of it as a teacher, you have learners from different family backgrounds. So it is very difficult as an educator to have learners from different backgrounds. One learner is from a spoiling family, the other one is from a disciplined family, another one is from a "don't care" family and so on, and then they carry it to the classroom situation. You find that at the end the educator is the one who is confronted with a serious problem and it is also discouraging. I have got that experience. You become discouraged sometimes if you don't get guidance from someone who has knowledge about the condition or about the sickness, not so? So you need counselling. You also need techniques on how to approach such problems in the classroom situation, more especially remedial education, how to treat them and how to help them. This is very important. They discourage you. Even when you work with such a child, it discourages you unless you have skills, unless you have a special heart for that condition. Then you won't have a problem. People differ, we have got individual differences.
- Researcher: Yes. Some here have already indicated that they need us to visit schools and talk to all teachers.
- Hazel: Yes. That will be good. We are going to arrange date and time which is going to suit all the educators there and we will come and address them because there is this White Paper 6. They (learners with special educational needs) will all be there in the mainstream schools so it is very important to have techniques on how to work with them. We have this place as a resource centre to cater for educators concerning such learners in your schools. Are we clear ladies and gentlemen? *(All laughed)* You will have all these learners. They are no longer shuffled to Letaba School. At Letaba they are no longer wanted, they have to go to mainstream schools, which are called normal schools. This means you will have them in your classes and you will never send them back home. They have to be there. It's from the government *(All laughed)*. Whether you like it or not, the child (with special needs) will be there.
- Researcher: That's why they are busy building wheel chair ramps in all government institutions.
- Hazel: All over.
- Researcher: Thank you, unless if there is some one who would like to give us the last comment.

- Hazel: In conclusion, I can say that we are available to assist you whenever you have problems. It's an obvious case that the child with epilepsy has got serious learning problems.
- Researcher: Yes, also behavioural problems.
- Hazel: Yes, also behavioural problems and you must know how to handle them, how to treat them, even how to encourage other learners to be positive towards that child.
- Researcher: Thank you.
- Musa: Sometimes there's another thing that can make us to fail in our duties. This thing of overcrowding. Our classes are overcrowded, very overcrowded. Sometimes we are unable to see the learner with this particular problem (epilepsy) and even to help him in that situation. If we can get normal classes, I should think each and every individual can be reached with ease, but hey, our classes!
- Hazel: I'm aware. You know, at Sebone, some of the classes have more than hundred, even hundred and fifty learners.
- Researcher: In one class?
- Hazel and Musa: Yes.
- Hazel: Yes. I know, I have witnessed that and it is very strange. You can't handle learners of hundred and fifty in one class, even hundred, even sixty is too much.
- Musa: Also disciplining that class, hey! It is a problem.
- Hazel: Yes. That is why it is in our minds and it is in our proposal that you must have one special class. I have already proposed this to the area manager.
- Researcher: For the slow learners?
- Hazel: Yes, for the slow learners. Those special learners are no longer wanted in the special schools. They have to go back to the mainstream schools. Thank you so much for that idea.
- Researcher: Thanks a lot.

APPENDIX IV

GROUP SESSION D (CLASSMATES)

Researcher: *(After the introductions, the explanation of the purpose of the session and the discussion of the ground rules).* I hope we are now clear about what we are here for, neh. Please feel free to say anything that is in your mind, neh? How do you experience learning with them? Who would like to start? *(They all looked at each other in a shy manner)* Don't be shy, neh. *(Ntsako raised up is hand)* Okay, my child, first remind us your name and tell us who is your classmate who is living with epilepsy.

Ntsako: My name is Ntsako and I learn with Golden. When we are busy writing or when we are busy doing something else, when they say we must go and submit books, he falls down. Some leave him there, others push him, saying that he is irritating and others help him. Some cry when he has fallen down while others spit at him saying that he is stubborn.

Researcher: By the way which school are you representing?

Ntsako: Xidzumbe.

Researcher: Okay. How do you feel when it happens?

Ntsako: I feel pain in my heart when he falls down. I just take him to the school principal. The principal takes him home.

Researcher: Okay. Who would like to speak next? We won't do it like it was done when you were still in Grade 1 where the teachers moved in rows, neh. We give anybody who feels ready to speak a chance to do so.

Daisy: My name is Daisy. I attend with Zola.

Researcher: Okay, I know Zola from Xidzumbe.

Daisy: She usually falls down when we are outside, when we are playing during the ten o'clock break. When we are busy playing, she usually falls down. We usually play with her "swirhekedyana" and "khazi". *(These are traditional games characterized by skipping)* When we are busy playing, she can't get enough air, then she shakes. I also start shaking, but I manage to rush and hold her before she can fall down. then I take her to the office where they talk to her and tell her to go home. Then I feel a lot of pain in

my heart when she falls because I never experienced such things. I wonder why it is happening to her.

Researcher: Okay. What do other learners do?

Daisy: They also help her because they have never seen the things she does before.

Researcher: Okay. Who would like to be next. Don't forget to remind us your name and your classmate's name neh.

Simon: My name is Simon. My classmate is Rudolph.

Researcher: Rudolph from Kurhula neh?

Simon: Yes, from Kurhula. He suffers from a sickness of "falling". He sometimes cannot get enough air when he did not drink his tablets. When he falls down, we feel pain in our hearts but others do not feel the pain because he also troubles other people sometimes.

Researcher: Does he trouble others?

Simon: Yes.

Researcher: Those are some of the things I would like us to discuss today. What does he do?

Simon: To be honest with you, he is cheeky. If he can come to school without having taken his pills, eh, actually he seldom faints, but he hits people.

Researcher: Okay.

Simon: When he has fainted, they help him by taking him outside. When the fainting is over, they take him home. When he comes back to school without having taken his pills, you find that it happens again.

Researcher: When he troubles people what do you do? I don't mean you as an individual. I mean learners at your school. What do they do?

Simon: Hey, he is a difficult person. Once he starts they can't control him.

Researcher: Does he beat people with his hands or he even uses objects?

Simon: He uses his hands and whatever objects he lays his hands on. He uses anything.

Researcher: What does this do to you and your classmates? Do you reach a point where you don't feel pity for him?

Simon: I can't say it reaches that point with me. I do feel pity for him.

Researcher: What sort of things do people say about him when they are cross with him?

Simon: Some boys just hit him back.

Researcher: Okay. Who would like to speak next? I hope you are now aware that talking is not embarrassing. We are just chatting.

Donald: I learn with Noah.

Researcher: What's your name?

Donald: I am Donald. I attend with Noah. When he writes for a very long time, he starts shaking, produces saliva and then he falls down. Some laugh at him but he socializes well with people at school. He doesn't do anything bad to them.

Researcher: Okay. What about you as a classmate? Are you only a classmate or are you also his good friend?

Donald: I sit next to him.

Researcher: How do you feel when he falls down? What does this do to your soul?

Donald: It hurts me.

Researcher: Busi, (*She looks very shy*), don't be shy neh. "Busis" are not shy people. Look at me, I'm not shy.

Busi: My name is Busi Kurhula. I attend with Bongani. When we are busy writing, Bongani falls down and urinates. This usually happens when she did not take her medication. Then we take her to the office where they take her home.

Researcher: When she urinates, don't other learners laugh at her? What do you (learners) do?

Busi: Some laugh at her while others treat her well.

Researcher: How do you feel when she experiences these things?

Busi: My heart becomes sore.

Researcher: Then what do you do?

Busi: I just take her to the principal.

Researcher: Okay. Who else would like to speak?

Nyiko: My name is Nyiko. I attend with Zola. When we are busy writing at school, she sometimes falls down. Then some people laugh at her but we hold her. Sometimes she falls down on a cement floor. We become hurt. Others enjoy it when she has fallen down.

Researcher: When some are enjoying and laughing at her, do others try to stop them and tell them that it's not a joke? What happens?

Nyiko: We do tell them that it is not a joke.

Researcher: What do they say?

Nyiko: I'm usually the first one who starts telling them that it is not a joke. Then they stop laughing.

Researcher: Thank you. Do you want to speak? Don't forget to mention your name and your classmate's name, neh.

Matladi: My name is Matladi. I attend with Mabontle. When she fights with other people, we tell her that "let's go". Then she starts shaking, begins to cry and then she falls down. We take her to the staff room, then they take her home.

Researcher: Why does she fight with others? Is she also cheeky?

Matladi: She is not cheeky. They provoke her.

Researcher: So when someone provokes her, she starts shaking?

Matladi: Yes, and then she defends herself and says she wants to hit her.

Researcher: So how do you feel?

Matladi: It hurts me. It even disturbs my mind.

Researcher: When she falls down, do they laugh at her?

Matladi: No, they don't laugh at her. They just hold her and say let's go.

Researcher: Okay. Who else wants to speak? Remember, we should all say something. Who wants to be next? Thembi?

Thembi: Yes. My name is Thembi. I stay at Gunyulu villlage and I attend with Bongani. Everyday when she did not take her medication, she urinates and falls down. People laugh at her, but it hurts me. Then I take her to the principal.

Researcher: Okay, do you want to say something, Eddie? Tell us.

Eddie: Yes, but I'm still searching my mind for his surname.

Researcher: What's his first name? I know all of them.

Eddie: Lebo.

Ntsako: He is Lebo Khosa.

Eddie: When we are at school, Lebo also falls down. Then we take him to the principal, who takes him home.

Researcher: How do your classmates react? Don't they laugh at him?

Eddie: No

Research: Okay. Let's now talk about classroom activities. It appears to me that their performance is not satisfactory. What happens in class? Do they participate? Do they write their homework? *(At this point, they all became excited to speak)* Okay, let me start with those who have not yet spoken. I will come to the rest of you later on.

Mpho: They don't like writing classwork. They enjoy playing outside and throwing stones at others. I'm scared of them.

Researcher: Are you scared of them?

Mpho: Yes.

Researcher: What's your name?

Mpho: Mpho..

Researcher: Mpho, who is your classmate?

Mpho: I learn with Mabontle.

Researcher: Okay.

Modise: My name is Modise from Malamula. There's no one with epilepsy in my class. *(He attends with Jimmy)*

Fannie: My name is Fannie. I attend with Lebo. He hits other children. One day he fought with someone who bet him (Fannie) up. Then he began to cry and then he slept. After a while, he fell down and we held him. Others ran to the office to call mam (the teacher). Then she took him to the office.

Researcher: You mentioned that he hits others. Do you think he is bully or they provoke him?

Fannie: He is bully.

Researcher: Is he bully?

Fannie: Yes.

Researcher: Okay. Let's now talk about performance in the classroom. How do they perform in class?

Ntsako: Golden performs very well. he learns properly but he doesn't write some of the homework. He does write others' homework. He writes Mam Rivisi's work only. He seldom writes Mam Shisana's work.

Researcher: What do you think is the reason for not writing Mam Shisana's work?

Ntshembo: He plays soccer a lot. He likes playing. He has never failed, not once. He doesn't fail, he write most of the things correctly but some of the days, he misbehaves intentionally. He hides his book and says that it is lost. When we look for it, we find it and then he says: "Eh, I'm surprised. I did not know that I put it under the desk". When the principal asks him, he says that "I had forgotten where I put it. Even pens, he seldom brings them to class. He is capable of lending a friend a pen while he doesn't have anything to write with. Then he doesn't write, he just sits.

Researcher: What do you think is the reason for him to write Mam Rivisi's work? Is he afraid of her?

Ntshembo: Yes. He is scared of her.

Researcher: What does she do to him?

Ntshembo: She does not hit him at all. She just tells him that "Golden, write your

work otherwise I will hit you". So Mam Shisana does not hit any child. She just leaves him alone, and tells him to bring it the following day. When he didn't do his homework, she just gives him the book and tells him to write. Even the reading book. He sometimes takes the reading book and hides it, or lends it to someone who was not there the previous day. When we are about to start reading, he gives it to someone who was not there the previous day. Even when we have to read out our homework, he takes someone else's homework book and leaves his. He exchanges books when he realizes that someone wrote better things. He reads someone's work, while that someone reads his.

Researcher: Okay. What about others?

Donald: Evans does not write some of the homework. He likes teachers but there is one teacher, Mr Chauke, whom he undermines. He undermines him so much that he doesn't even write his homework. When he tells him, he becomes rude. He once fought with Mr Chauke.

Researcher: Okay. What about his attendance? Does he attend school properly?

Donald: Yes, but he has stopped coming to school recently.

Researcher: Has he stopped?

Donald: Yes.

Researcher: Since when?

Donald: Last month.

Researcher: Do you know the reason?

Donald: No, but what I know is that nowadays it attacks him often. He falls often nowadays.

Researcher: Okay.

Simon: Rudolph does write his schoolwork but hey, he doesn't pass. It's difficult for him. He does try hard, he is just incapable of passing. He tries his best.

Researcher: In your opinion, he is willing to pass, he is just unable?

Simon: Yes, he is unable.

Researcher: What about attendance?

Simon: He does attend school.

Busi: Bongani does write her homework but she doesn't pass. She comes to school everyday. She doesn't play truant.

Researcher: Is she unable to pass?

Busi: Yes.

Thembi: Bongani does write her homework, but it is difficult for her to write. Most of the time when she writes, she writes incorrect things. When they give her homework, she chooses which ones to write and leaves the others.

Researcher: Okay.

Daisy: Zola does come to school regularly and writes her homework, but some of the things, specially if she has been given the work by Mr Kubheka, they are difficult for her because everyday when we have to go to Mr Kubheka's class, she refuses to go there. When we go there, she starts shaking. When we arrive at the door, she appears as if she is about to fall down.

Researcher: Do you mean at the teacher's office?

Daisy: No. There are three classes. We exchange them. If there is no Maths or English, we are taught by Mr Kubheka. You find that he is the only teacher and he beats children at school. So you find that Zola shakes and she doesn't write his homework. If only she could write homework, because she is the worst in our class. We all finish writing in class but she alone doesn't. Even Mam Rivisi and Mam Shisana's work is difficult for her, but Mam Shisana's work is better for her because she talks to her nicely. She doesn't beat her. Mam Rivisi beats her. She doesn't speak to her, she just beats her and then she shakes and suddenly falls down.

Researcher: Is she afraid of her, in your opinion?

Daisy: Yes, she is afraid of her. When we write, even when we read, when she holds a reading book, she shakes when we are in her class and Mr Kubheka's class, and she often collapses.

Researcher: Does she start shaking as soon as you get into her class?

Daisy: Yes, and we tell her that she should wait a bit, go outside and cool down first, is then that she can get into class and learn because if she doesn't get herself together, she will collapse in the classroom, the we all cannot continue with our work. We won't write happily and we won't write the

correct things. We have to wait until she has cooled down. It is then that we can continue writing, and then she can also write what we are told to write.

Researcher: Okay.

Fannie: Zola also tries hard but some of the things are difficult for her, things taught by Mam Shisana and Mam Rivisi. They are difficult for her, but she performs a little bit better with Mr Kubheka's work. It's just that he beats her when she writes wrong things, but she never failed a grade.

Researcher: Oh, she never failed a grade.

Fannie: Yes.

Researcher: What about children at Malamula? Mabontle and others?

Matladi: Mabontle does write her work but I am not sure about her performance because I only started attending at the current school recently. I don't know much about repeating grades.

Researcher: Did you come his year?

Mabontle: Yes, I came this year.

Researcher: Okay. Thank you. Who would like to say something? Something that you think we left out concerning your classmates? Remember I said that we want to try and help them and find ways of living in harmony with them.

Daisy: Golden is my relative. when we are at home most of the time, when there is a "death anniversary" (*It is a norm in the Vatsonga communities of the Limpopo Province to have such a function usually after a year, when a family member has died. They call it "nhluvulo", meaning "undressing". This refers to changing from mourning clothes (which they usually wear for a period of one year after death), into ordinary clothes. This marks the end of the mourning period*), even when there is a funeral, before burial, he is usually attacked. When they go to the graveyard to dig the grave, he follows them. When he is there, he slips, nearly falling into the grave, and then they hold him. When he arrives back home, he also falls down. At that time, he has no strength and also lacks appetite for the whole week.

Researcher: Okay. Is Golden your relative?

Daisy: Yes.

Researcher: Golden is your relative but Zola is your classmate?

Daisy: Yes.

Researcher: Okay. Don't they stop him from going to the graveyard?

Daisy: They do try to stop him but it worries him. He lets them leave, then he runs after them using a different route and meets them on the way. Then they stop and give him a lift. Some of them do not know that he has this kind of a disease, so they let him accompany them. Even when the coffin arrives at home, he immediately collapses. He is usually the first one to collapse. When he falls down, all of us at home including his mother, feel pain in our hearts. We also begin to shake as if we can fall down just like him, the way it frightens us.

Researcher: Okay. What else can you say? Who attends with Jimmy? What can you tell us?

Modise: He does write his homework but he doesn't attend school regularly and he disappears during break.

Researcher: He never comes back to class?

Modise: Yes.

Researcher: What else do you want to say? (*There was silence*) Nothing? Okay. In your opinion what could be the cause of this disease? What do people say is the cause? Who would like to start?

Daisy: Golden's mother says that her mother (Golden's grandmother) also had this disease and she was also possessed by the gods. It is possible that Vukosi has been possessed by "those who are underground" (ancestors) because her grandmother had this disease.

Researcher: Okay. His maternal grandmother also had this disease and she was also possessed by the gods?

Daisy: Yes.

Researcher: Okay. What about the others? Do you just wonder where it comes from? Haven't you heard people talking about the cause?

Simon: I would like to say something, but it is difficult for me. I'm afraid.

Researcher: Say it, don't be scared. Okay, from this point onwards, we are no longer mentioning names, okay? Let's just talk about the causes of the disease in general. Remember, no other person is going to listen to this tape. I'm the

only one who will listen to it. Even your teachers and principals will not know what you said here today, so do not fear.

Simon: When we were still very young, I used to stay next to Rudolph's home. When he was still young, he was not healthy in his mind. He once provoked a certain old man who was riding on a bicycle. That old man was a wizard.

Researcher: Was he a wizard?

Simon: Yes. Then they (Rudolph and friends) provoked that old man. Then he said to them: "I will get you", and he left. The following morning we saw Leonard being carried by a wheelbarrow, being covered by a cloth and being taken to the hospital. He was unable to do anything. Actually, they thought he was dead.

Researcher: Okay. So at home do they believe that it's because he provoked that old man who then bewitched him, that made him to be sick?

Simon: Yes.

Researcher: Where did the old man stay, at Kurhula or from another village?

Simon: He came from Buweni village, but he is dead now.

Researcher: Okay. What do others think is the cause?

Fannie: In my opinion, it has been caused by Mam Mathonsi. When she came to school, she used to beat her everyday when she was late. It was a must that when she enters the classroom, Mam Marivate would beat her.

Researcher: Are you talking about Zola?

Fannie: Yes. When she arrived at home one day after having been beaten, she began to shiver, then it started. Since then, she fell often.

Researcher: Okay. Didn't she have the disease before then?

Fannie: No.

Daisy: Since Sub A, Zola had this disease of falling. Even Mam Mabasa, when Zola came to school, because she knew that she had a sickness of falling, she used to ask her: "Did you bring your pills along?" Then she would say "yes". Then Mam would ask her: "Did you drink them? If you didn't drink them, go and fetch them now and because it is now time to learn". Then she would drink them. Since Sub A, she has been having it, until now, she

still has it. And then she is also afraid of the sjambok. When she sees a sjambok, her body shivers.

Researcher: Even if it is not meant for her?

Daisy: Yes. Even when they want to beat the whole class. She begins to shiver and immediately sleeps. When they try to wake her up, it becomes difficult for her to wake up.

Okay: Who else?

Ntsako: With Golden, I think it comes from the heredity of his family because they say that even his grandmother, and even his mother, had it. He also did not like dressing up. No matter what they said, he would not put on a T-shirt. He would just wear a pair of shorts and play in it, even when we were playing in a dirty place. Even when his parents said: "Golden, you are playing in grass, it's itchy. Come and wear long trousers", he refused. Even when they send him to do something, like there are chickens at his home. When they send him to go and fetch food for the chickens, some of which is rotten and full of worms, he doesn't wear a T-shirt. He just takes a wheelbarrow and even touches those things by his hands and put it in a wheelbarrow.

Researcher: Doesn't he take care of himself, according to you?

Ntsako: Yes.

Researcher: Okay. What else do you want to say:

Daisy: If there is someone with whom one doesn't attend but has epilepsy, is one allowed to say something about that person?

Researcher: Yes, you can say something.

Yvonne: There is someone whose name is Johanna. She also suffers from this sickness of falling. When we are busy playing at home and her parents ask her to do something, she refuses. She appears as if she is not normal. When they send her to do something, she does something totally different. When they send her to go and buy bread for an example, she buys something else. When they send her to go and buy some chicken, she spends the change on her way back. When they rebuke her, she shivers and ends up falling down. Then they are unable to wake her up. The mother says she also had the disease in the past therefore, she is scared of waking her up. Then she calls neighbours to come and help her because she also feels as if she can also fall down. When she (Khensani) wakes up, her mind is out of order. When her mind comes back, she longs for things

which are far away. She doesn't know what to do. She even wants to take a knife and stab herself. Then they rush and hold her, take the knife and put it far away from her. Then she gets into the house and undresses and does some crazy things. Then her mother just leaves the home and says "I will come back when she has finished what she is doing because this is a problem to me". Then we tell her that it hurts us also because we have never experienced these things ourselves.

Researcher: Don't you know what could be the cause of her disease?

Daisy: No.

Researcher: In your opinion, how should we live with these people? You have said that they are cheeky.

Daisy: I think we should help them.

Researcher: Okay, you should help them, neh. What do you think you should do when they provoke you?

Daisy: I think we should just look at them, to show them that what they are doing is not acceptable, or we should tell them that such and such a behaviour is bad. When we tell her she will listen but if her "ears do not work properly" (if she doesn't listen), she will just keep quiet and repeat the unacceptable behaviour. Then we will just ignore her, but if we find someone beating her in the streets, we will help her. We will plead with that person that "please do not beat her, she has a sickness of falling".

Simon: I think we should always walk alongside them so that when he is about to fall down, we can quickly hold him and take him to the office so that they can attend to him and take him home.

Researcher: Thank you. What do you wish for them?

Ntsako: I wish they could be healed. I also wish that Vukosi could stop being cheeky. He is very cheeky, but people do not beat him, they just leave him. When he beats them up, they just go and tell the principal. The principal also doesn't beat him. He just tells him that such and such a behaviour is not right. Even when he didn't do his homework, teachers seldom beat him. They just talk to him.

Researcher: What about others? What do you wish for Tibello?

Daisy: Vukosi doesn't listen. When his mother asks him to do something, he behaves in a funny way and sometimes undresses. Sometimes he eats Jabu (his brother's) food and hides his own food. He is worse when his mother

is around.

Researcher: Okay. What do you wish for them?

Donald: My wish is that they should help them at the clinic so that they can be like us.

Researcher: Do you want them to be like you?

Donald: Yes.

Researcher: Okay. Is there anyone who would like to say something before I switch off the tape recorder? Are you all satisfied with what you have said? Don't you have something to add? *(There was silence)* Okay, thank you very much.

APPENDIX V

Name: A. S. Ahmed

Age: 45

Marital status: Married with 2 children

Profession: Neurologist

Qualifications: LLM-RCP. LLM-RCS. MB Bch. (IRE.) F C P (SA) Neurol

PR: 2000598

Work Experience: 15 years

Work Institutions: Baragwanath Hospital (1987-1990)

Private Practice: 1990 to date

Address: P. O. Box 50

Pietersburg

0700

Tel: (015) 291 2353/4

APPENDIX VI

Name: Jan Chabalala

Age: 41

Marital status: Married with 4 children

Profession: Psychiatrist

Qualifications: MBCH. B. (MEDUNSA) FCPsych (SA) MMed (Psych) WITS

PR: 2204118

Work Experience: 16 years

Work Institutions: - Baragwanath Hospital (1986-1990)

- Nkhensani Hospital (1990 to date)

- Evuxakeni Hospital (1990 to date)

Private Practice: 1998 to date

Address: P. O. Box 369

Giyani

0826

Tel: (015) 295 4606

Fax: (015) 295 7839

Cell: 083 442 1652

APPENDIX VII

Name: Garish Masungi Mohlaba

Age: 36

Marital status: Married with 3 children

Profession: Medical Practitioner

Qualifications: MBCH. B. (MEDUNSA)

PR: 1422278

Work Experience: 12 years

Work Institutions: - Letaba (1990)

Private Practice: 1991 to date

Address: P. O. Box 5112

Tzaneen

0850

E-Mail: Garish@medi.co.za

Tel: (015) 303 0844 (W)

(015) 307 4531 (H)

Fax: (015) 303 0135

Cell: 082 554 9269

APPENDIX VIII

Name: Johan Viljoen

Age: 48

Marital status: Married with 6 children

Profession: Neurosurgeon

Qualifications: M.B., Ch. B., (M. Med.) Neurchir. (U.O.V.S.)

PR: 2400901

Work Experience: 11 years

Private Practice: 1989 to date

Address: P. O. Box 2804

Pietersburg

0700

Tel: (015) 291 2086

Fax: (015) 291 5142