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REQUEST FOR INFORMED CONSENT

14 November 2003

Dear Sir/Madam

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV&AIDS. For this purpose, I have selected your community as participant to the study. The findings of the study will be used to inform other communities in future capacity building initiatives.

I herewith kindly request your assistance in this regard, as you are the expert in the ways that your community functions and copes with this challenge. The study will take place during the period November 2003 to June 2005.

For the purpose of the study, I kindly request you to participate in three to four workshops and discussions, which will be audio-recorded. These discussions will later be followed up by individual interviews with identified community members who are currently coping with HIV&AIDS. Here I once again ask for your assistance. All information provided by you will be treated confidentially and anonymously. You are also free to withdraw from the project at any stage if you wish to do so.

If you are willing to assist me, please complete the form attached and return it to me.

Kind regards

Ronél Ferreira

CONSENT FORM

Having read the letter attached, I declare that I am fully aware of the nature and purpose of the study conducted by Ronél Ferreira. I understand that all information will be treated anonymously and as strictly confidential. I am further aware of the fact that I may withdraw from the study at any stage during the process if I wish to do so.

I hereby consent to participate in the workshops and discussions to be held during the next few months.

Signature

Date

11 November 2003

Mr S Snayer

District Director: Port Elizabeth

Department of Education: Province of the Eastern Cape

Private Bag X3915

NORTH END

6056

Dear Mr Snayer

REQUEST TO CONDUCT RESEARCH AT

PRIMARY SCHOOL

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV/AIDS, by relying on the local resources available to them. For this purpose, I have selected an informal settlement community in the Port Elizabeth region (namely) as participant in the study. The study will take place during the period November 2003 to June 2005 and the findings will be used to inform other communities in future capacity building initiatives.

For the purpose of the study, I kindly request the permission of the Department of Education to conduct workshops and discussions with selected staff members (10) of Cebelihle Primary School in Govan Mbeki, on existing resources in the community as well as current ways of coping with HIV/AIDS. These discussions will serve as first phase of the study and later be followed up by individual interviews with identified community members who are


currently coping with HIV/AIDS. During these discussions the selected educators will be requested to arrange meetings with community members and act as translators when necessary, for which they will be remunerated. Workshops and discussions will take place after hours in order not to interfere with the educators' work.

All information provided will be treated confidentially and anonymously. Any person will also be free to withdraw from the project at any stage should he/she wish to do so.

Please complete the form attached with regard to permission by the Department of Education and return it to me by mail or fax (fax number 012-4205511).

Kind regards

Ronél Ferreira

 083 258 774

11 November 2003

Mr SM M

The Principal: Primary School

Street

Township

PORT ELIZABETH

6001

Dear Mr M

REQUEST TO CONDUCT RESEARCH AT PRIMARY SCHOOL

I am a PhD student at the University of Pretoria and am currently conducting a research project on the manner in which informal settlement communities are coping with HIV/AIDS, by relying on the local resources available to them. For this purpose, I have selected your community as participant in the study. The study will take place during the period November 2003 to June 2005 and the findings will be used to inform other communities in future capacity building initiatives.

For the purpose of the study, I kindly request your permission to conduct workshops and discussions with the staff of your school. These discussions will later be followed up by individual interviews with identified community members who are currently coping with HIV/AIDS. Information provided will be treated confidentially and anonymously. Any person will also be free to withdraw from the project at any stage should he/she wish to do so.

If you are willing to assist me, please complete the form attached and return it to me.

Kind regards

Ronél Ferreira

PERMISSION TO CONDUCT RESEARCH AT PRIMARY SCHOOL

Dear Ms Ronél Ferreira

Having read the letter attached, I hereby grant / do not grant you permission to do research at Primary School, by conducting workshops and facilitating discussions with some of the staff members at my school.

Signature

Date

FIELD VISIT 1 – 14 NOVEMBER 2003

FOCUS GROUP 1

11 x EDUCATOR-PARTICIPANTS

TOPIC GUIDE:

- ⌘ Community's perceptions on HIV&AIDS.
- ⌘ Challenges faced by the community.
- ⌘ Community's current way of coping with HIV&AIDS and the related challenges.
- ⌘ Assets and resources available to community members which might be relied upon in coping with HIV&AIDS.

KEY OF ABBREVIATIONS
R: Researcher
EP: Educator-participant

R: We had such lovely discussions over lunch, now we would like to continue. Could you please tell us about this community's perceptions about HIV&AIDS. What do community members know? How do they feel about HIV&AIDS? What are they wondering about? What do they want to know? How do they cope with the pandemic? Please talk about questions like these.

EP9: Okay ... what I know is, **if you have information**, let's say you have an *advanced* – **you must know what you are going to talk about, the information**, because **sometimes people in the community will ask questions and you must know that you are going to answer all those questions**. And if you don't know, if you don't know a question – you must tell them: "*No I don't know this*", otherwise you will be caught out and find out. And you **must be patient and you must be organized**. You

Need to be informed

Other community members in need of advice

must be flexible, because most of them are very touchable, you see. If they are very touchable, sometimes they don't want to talk about this. They don't know that you know that they know ... even my brother he is HIV positive and his girlfriend and by the time they heard the news, he was so surprised and so worried, but after that he don't want to talk about that – he forgot about that. We told ourselves life must go on ... and they don't want to talk about it all the time, because by the time you are talking about this all the time, you get scared, it is as if you are scared then, you see, and if, the way that you are going to support them is the way they must take care of themselves. Because if you know the diet, you can tell them: "I like you to eat this". But if you support them in a group situation, let's say here at school, I can't just give the child let's say food, spinach or eh special food, here at school they are eating bread and milk, sometimes bread and jam. But I can't just give them special food, because there will be stigma. They will ask: "Why are they eating special foods?" We want to give them the support, but how are we going to give them the support?

R: The children specifically?

EP7: Yes, the children specifically. And even in the community, even in the community, if you can go to give them food parcel, they ask: "Why those houses?"

EP2: You see, the other people will eventually find out and ask: "Why are you just giving those people this? Why aren't you giving other people also? Why are doing this?"

R: It seems as if you are concerned and don't want to label children and families by treating them differently?

Support requires patience, being organised and flexibility

Vulnerability of people living with HIV&AIDS

Aviod discussions

Initial reaction to finding out about HIV status= do not want to disclose/discuss due to fear

Support others to:
-taking care of themselves
-diet
-providing food
-providing knowledge

Stigma

Willingness to support

Don't know how to support

Support ito food
Stigma

Stigma/labeling

- EP9: Yes, yes. **We want to support them**, but **we don't know the way to support others**.
 Support
 -willing to help
 -don't know how
- EP4: I want to say that, let's say my brother or my sister is HIV positive, we as a family **don't have to give him or her something different**. We must eat the same thing at the same time, knowing that it is okay for his or her condition and **not something different from us**.
 Support people living with HIV&AIDS by:
 -not isolating
 -accepting status (within family)
- EP3: I like to differ from that, because even if you've got diabetic, even if you've got cancer, the menu, even in hospital, **are different because you are ill**. You know the situation, you can not put yourself at risk. Even those HIV people, if I know that someone in my house, say my husband is HIV positive and I'm not HIV, **I have to cater for him**. Even the children that is HIV, **you have to cater for them**. Unless the problem is where there is a **denial**. As long as they are **not going to disclose it**, they are **going to suffer**, because I cannot suffer giving my child the diabetic food because I'm diabetic.
 Support ito:
 -special menu/diet
 Special treatment (within family) of people living with HIV&AIDS
 Denial
 Non-disclosure
 Results in vulnerability
- EP10: It's like my child. This evening he is with my mother and my mother is a diabetic. So we cater for her, because the porridge she is suppose to eat, must give him energy, and the supplements.
- EP2: Yes, and she must take extra vitamins.
- EP10: So, **it must be totally different**, not ... eh, unless you are making a full meal for the whole family, **otherwise you must go an extra mile for the HIV people**. Because **they must get the supplements and all the vitamins** they can get, because you want them to survive. If you are going to give them whatever, whatever, you are **not prolonging their lives**.
 Support ito:
 -special treatment
 -special food
 -supplements and vitamins
 Misconception
- R: I'm hearing two things now. I'm hearing when it is in the family where there is already disclosure, there can be differences because the family knows, but on the other hand when it's, for example, in the school, or in

the community, you would like to be there for the people, but you don't want to label them to be different.

EP10: But I think even here at school, my idea that I want to share with my colleagues here, is that, like if the mother of the child, or the people concerned, can come to us and say: "Okay, my child has AIDS", that people wants the child to be given support. So we must, if we are going to give the support, we must also say to that parent, we must change our attitudes here at school. If we are going to cook, maybe maize, we give them with soap, those little ones, because in a classroom situation they will see that this one is suffering.

Support ito:
-acceptance by wider community
Coping requires change of attitudes

Ability to identify people living with HIV&AIDS

R: They will know?

EP10: They will know that this one is suffering. So we must support them here at school. But the consent must be given to us.

Vulnerable children
School as source of support

EP5: Sorry, can I get in? Okay. If we can say, this whole situation is revolving back to disclosure. And if there is someone, like you have said, some who didn't come out with this, it is difficult to give them help, but those who talk about it, it's easy for anyone to help. To show that the most that got denial, the only thing that we know is what we heard other people talking about them and you see them in clinics, you can see the symptoms of this because we are all educated. You could see the symptoms and know that this one is suffering from this. Even though you cannot tell them, that is the denial situation. Some of them, like a woman in our church, she is dying because we cannot give help to her because each and every time we go there to visit and pray, she doesn't want to talk. So what is the use of praying for something like this, because I'm sure that if she's in denial with us, I'm sure she's in denial with God. If you say: "God help me with this", you must tell what it is you need, like help in what. Then what is happening is, you could see the symptoms. All of the symptoms were there, it's the fever ... Even in the working situation, there are some colleagues. We heard about them,

Non-disclosure
Related to challenge in providing support

Denial
Stigmatisation and gossiping

Ability to identify
Denial
Being aware, but cannot talk about it and cannot support
Support ito:
-home visits
-praying

Denial

Ability to identify /see symptoms

but we cannot go to them, they are **not yet ready to talk** about it. Because they **know their fears**. Even if they can die, we **cannot say that they are dying of this**, because it could be TB. Even if **we are able to help them, we cannot** ... The only people that I see most of them that are talking, are those **who are illiterate**, because I've got a parent in my classroom, **but nobody knows** – it's only myself. There is a child who has been raped, and I could **see the symptoms** to the child, but **I couldn't say anything**, but the parents came to my classroom saying that the symptoms were coming like this and when I asked them: "*When are you taking the child to the clinic?*", they said: "*For what? The child was raped.*" You understand, now it hurts me ... **and they prayed and they prayed and they prayed**, because I said: "*Oh Lord, this is a child. She didn't do nothing, please help her*". As a result now, she is doing very well now. It's like I know now, because that's why **I have to go outside and ask for help for that child**, so that I can help that child. And the second person who **disclosed** to myself, and **nobody knows about it**, is a parent whom I had a child too, **and you could see the parent is very sick, the symptoms** were there. And the parent said: "*Mam, I don't have to hide anything, I've gone through to some of those groups and you could see myself*". And I said to him: "**Pray, because you have strength and I'm sure you are going to be okay**, because I can see that **you have faith and you are strong**. *But what I am going to do, I will take care of your kid*".

Hesitant to discuss due to fears
Result: cannot support
Denial
Hesitant to use HIV&AIDS terminology
Want to help, but cannot
If not literate: talk about it
Confidentiality=important
Ability to identify (see symptoms)

Prayer as way of coping

Support by: seeking outside help

Disclosure to educator
Confidentiality=important
Ability to identify (see symptoms)

Coping:
-prayer
-faith
-inner strength

EP9: Okay, I'm going to talk about myself, about my home. As I told you, my brother is HIV positive and practically **it is not easy if you are staying with that person**, you see. He told us that he is HIV positive, but as I told you that, after that, we are not talking about that, you see. We are not everything, **we are not going to talk about that**. Even if I have HIV, I won't say: "*Why this person is not disclosed?*", because this person did not disclose him or herself. Because I know that if it comes to me, it will not be easy, because **we have fears that they are going to chase me out, you see ... out of their lives**. It is not easy, it is **not easy to talk** about this, but in the **family you have to tell them**. What I am saying is

Difficult to cope with HIV positive relative

Avoid discussions on HIV&AIDS

Avoid disclosure due to fear of rejection
Difficult to discuss topic
Importance of disclosure within family

that people are different, people are differ. **My brother is very angry.** He is a, eh ... what can I say? ... he is not one that will say: "*Don't do this because I am ill*", he will say: "*Hey! Leave me alone! I'm living my life! You see, leave me alone!*" It's not easy. **You want to help, but you can't help because of his anger.** If you are talking to them, if you are talking to him, he will say: "*Leave me alone! I'm living my life*". I will say: "*No, I'm going to die, though we are all going to die*". It is not easy to say: "*Don't do this, do this and this*". And sometimes, and sometimes they are **getting that payment,** they are getting that **grant,** that R780, with that money, **they go out and spend it – in liquor.** They are enjoying themselves with that money.

Feelings of anger if HIV positive
Sometimes don't want help
Willing to support but support is rejected by HIV positive person

Governmental grant=asset
Misuse of grant money=challenge

R: Are you referring to the disability grant?

EP9: Yes, but that R780 is too much. **That is suppose to be enough to buy food, but they are misusing it,** you see. Because they say: "*It's my money and I am going to do with whatever I like to do with it*". And some people now, they **are looking for the HIV person so that they can share the blood, because of that money.** Do you understand now what is really the problem? That is why I say to them it is like a joke, you see, and now they are **sharing the blood,** you see.

Grant as asset

Misuse of disability grant

Purposefully get HIV to qualify for grant

R: So if I understand you correctly, they also want to be infected so that they can get the money too?

EP9: And then when you ask them: "*What did you do with your money?*", they will say: "*Why don't you get HIV – this is my money, I'm HIV ... Why don't you get HIV? This is my money!*"

Misuse of disability grant

R: So they say: "*This is my AIDS, this is my money*"?

EP9: Yes. It's my AIDS, it's my money.

R: This is new information for me, that you can get a disability grant if you have HIV and AIDS.

EP9: And I'm sure the government can change the style and give them a full bursary of money and they will abuse that money too. Misuse disability grant

EP7: The government must help so that they could support themselves, so the government must help that they can get the food.

EP9: It would be better if the government could make food parcels, and that R780 is enough for that. They must not, not to give them money, because they can buy anything they would like to buy. Purpose of grant: basic support and food
Rather give food parcels

EP11: I would also like to add on that. Sometimes the reason for the disclosure is because of the money. They disclose, but then they have not yet accepted it. And then somehow somehow the government will get confused because of the statistics. Because now what happens is, if I'm HIV positive and I go to clinic with my blood and I give blood so that everybody can get the grant. And now the numbers are going up, but it's only one person that is HIV positive. Disclosure: to qualify for disability grant

HIV/AIDS statistics not accurate

R: Why do they want to be tested so many times?

EP11: So they, to get the grant. Grant as asset

R: Now I'm totally confused. One blood?

EP11: Yes, one blood for many people.

R: But don't they ask for an ID or something?

EP11: No, so that's what is happening.

R: So you are actually saying that the statistics is wrong?

- EP11: That is the reason why they disclose. Disclosure, in order to qualify for grant
- EP10: The clinics are not following the procedures correct, because they are suppose to get full detail of that person, and ID number, and they are not doing that. Procedures of testing questioned
- EP11: As a result now, what is happening now with this grant ... sometime in October it was stopped because the numbers exceeded the eh, ... And they see this fresh person, waiting to get the money.
- EP10: But now I just want to say that once I was saying that they are afraid in their homes, to talk about this thing. If you are strong, if you are strong and you are counselled, you are suppose to talk about it so that that person must belong to you. Willing to talk if counselled
Inner strength
- EP9: Aa-a (*shaking head*). I want to correct you. No, no ... I want to correct her on something I said. In my house we don't want to talk about it, because my brother becomes angry, he becomes angry. If he is not angry, we can talk about it, but when you correct him to do this, he will say to me: "Leave me alone! I'll do what I want to do." Others avoid discussions
HIV positive: feelings of anger
- EP10: That is why I'm saying that the whole family must go for counselling so that they can see that I am not at school anymore but my family is supporting me. For if you don't, if you don't talk about something that is eating you in your family - what are you doing? You are suppose to talk about it, even if it is going to hurt somebody in your family, you must talk about it. Family should receive counseling and support
Family=source of support
Discussions favorable
- R: You mustn't try to avoid conflict?
- EP9: Yes. Because, my brother too. Sometimes he becomes angry and he is taking medicines from somebody we don't know. Then we ask him: "What is this medicine for?", and he say: "Somebody said it helped me, it helped me". But then I say to him: "No, what you are going to take is the Anger
Coping:
-Treatment
-Community support

medicine that the doctor say you must take. Not everything that somebody said is helping him. If somebody is giving you the medicine, saying this has helped him, come to us and show it to us – we want to see”. So if you are strong and you are counselled, that’s what they need.

Coping:
-counselling
-inner strength

R: Where do you go for counselling?

EP9: Unlike my brother, unlike my brother ... my brother is a heavy weight. I don't want to be kicked by him ...

R: So every family will be different?

EP2: Even if your brother becomes angry at you and say: “Leave me alone”, that’s also a form of denial, that is something you must talk about.

Anger=denial
Avoid
discussions

EP8: That’s right. And also, you have to change the diet. But if you want to give a special dish for him, he won't eat it. You have to change the way they live.

Need for change
in diet and
lifestyle in order
to cope

R: The lifestyle?

EP8: Yes, the lifestyle.

EP10: Sometimes you have to eat the food, even if you don't want to.

EP1: There is something that I've noticed ... in funerals ... they don't want to talk about this. They don't want to say this person has died because of this or this ... As a result, if maybe someone have just said that he was HIV positive, maybe other people they will also say but now, they don't want to say it at funerals. They will just say it was something from TB or something else, that it's ... It is not easy to talk about this, to say this ...

Avoid
discussions

Participants
avoid use of the
term HIV&AIDS
Stigma

Deny cause of
death due to
stigma

EP10: That means that we must change our community, ja (*nodding head*) ... we must change the communities.

Challenge:
Need for change
of attitude in
wider
community

- EP7: Here at school, we **don't want to say they have it**. I had a parent in my class who died. I called her and she came in. She was very sick, she **said she had, that she had the flu** and that she doesn't want to go to the doctor. I said: "*You must go to the doctor and you have to be tested*". She said: "No, **I have been tested**. *There's nothing wrong, it's just this flu*". She said: "**No, I'm going to be fine**", but she was sick and as a result she died, not having gone to the doctor. But this is the problem, and that, her child is still in her class (indicating educator-participant 2) – she is still alright.
- Denial, related to stigma
Denial
- R: Who is taking care of the child?
- EP7: There are **aunts and uncles that are taking care of her**. They **don't want to go and take the tests**, even if the child is sick now. They **don't want us to get in**, because if we get in, then we see and we can help and advise, then I'm sure **we could make a difference**, but **they don't want us in**. **Because they will not tell us if there is a problem and come forward**.
- Extended family taking care of orphans
Avoid testing
Deny and avoid help & support
Aware of own ability to support
Want to support but not allowed
- EP2: They **don't tell us** ... they **don't disclose** and their health goes down, because **they don't tell anybody that they are HIV positive**. And then they don't eat right, because some of the people they **don't want to disclose** and go for help and **find out more about the disease**, you know. Like, "**What must I eat to boost the immune systems?**", and things like that, that's why they **don't want to disclose**. They just go on for a couple of years.
- Non-disclosure
Secrecy
Need to be informed
Don't want help =denial, leads to non-disclosure
- EP1: There is a teacher here at our school, she is having a child in her class. She could **see that the child was suffering**, she know that this child was sick, until that child was admitted to hospital and then the parents came and said that she was HIV positive. That is why we are saying that **parents don't want to come and tell us what is happening**.
- Ability to identify Vulnerable children
Non-disclosure
- EP5: Another thing is, what I am saying is that the kids **needs counselling**, they need to go for different sessions. Even with us educated people,
- Need for counseling

we seldom see **psychologists** – we believe in general practitioners. When we get ill, we must go to the doctor. **We don't use psychologists.** The **only time that they get the counselling, a little bit**, is when they are **told about the results**. Then, before they are told, they get just a little bit of group counselling. Another things is, with the **doctors** now, they are making use of this **grant**. They are doing what they say is viral load, in order for them to get expensive medicine. You know what frustrates one more, is when it is said that: “*No, the count is too low*”, then even this medication is ... is killing this person. This is number one. Number two is, in some areas it is said that you have to be on a certain stage in order for you to **get that grant**. You just, let's say I've been tested and I'm HIV positive, I won't get that grant, not unless I'm just nearly to be fully blown. Then I will be able to get it.

Stigma attached to psychologists

Limited counselling when told about test results
Group counselling
Assets: doctors, grant

Grant=asset: criteria to qualify for grant

R: In other words, you have to be very sick to be able to get the grant?

EP5: Exactly. You must have a history of you going to the clinic, seeing that you are at this stage, then this stage and then it is quick with the clinic. But if you go to the doctor, ugh ... and that **medication is damn expensive and the unemployment rate is too high – they cannot afford it.**

Need for medication
Cannot afford it due to poverty
Unemployment

R: Where do the people go for counselling? Because *L*, you spoke about counselling for families, but mentioned that there is not a lot of counselling and *E*, you also said that there is a need for counselling.

EP10: Okay, let me help you. If you want to go for counselling, if you are a family, you don't want to listen to people. You take your money and **go for counselling or you go to a clinic**, because before the tests you get the prior counselling and then, **after the test, the whole family is included**. Because that is why I say you are going to be strong if you are going for counselling.

Basic counseling received at clinic when tested and HIV positive
Family benefits

R: So the counselling you are talking about is situated in the clinics and done by the nurses? What about social workers? Do they give counselling?

EP10: If you are using medical aid, or you can go and pay money.

R: Have any of you been trained in counselling?

EP10: No, **not in counselling**.

Educators not trained in counseling

R: Have any one of you received training in HIV&AIDS information?

EP11: **Yes, I have**, at the Department of Education.

One educator trained in HIV&AIDS

R: Based on your training, do you have as special task assigned to you here at school?

EP11: I am suppose to teach the grade 6 and 7.

R: Is it life skills training?

EP11: **Yes**, but it's not just about that. There's more to it, and it's not just training.

Part of life-skills

EP3: Okay, now I want to say something. What I want to say is that as long as there is going to be **denial**, because the **counselling is done before you get the test, prior, before you get your results**. But if you **don't have a denial problem, it is easy for the doctor, your own doctor, to help you**. Because if you can get to our GP's, it is written boldly that if you've got this and this it's this. So you've got the chance to talk to your doctor. How can your doctor smell it? How can the doctor smell that you are HIV? **It is up to you to tell the doctor**: "*Doctor, I've got this problem*". Then the doctor can tell, uhm can make you to do all those things where you find out that you have got HIV. It is **your duty to tell your doctor**.

Denial
Pre-test counselling
Doctors= potential asset (not used due to denial)

Should take personal responsibility
Disclosure favorable
People uninformated about this asset

And even if you don't tell, you are not ready to tell your family, somebody, ehm ... who is going to counsel you? It's yourself, you see. **People doesn't know about this, especially those who are illiterate.** But to come to the **denial** situation, if ... let's go back to what we've said about the parents. If the literate, the people who are **educated, have got a denial problem**, what will happen to those who are not educated? So we cannot say that the parents they don't say anything – it happens even to us, those who can understand this things. So it will be difficult for them, unless we people who understand about this things, **accept them.** Then it is easy for them. You can go to that parents and say: *"Look, I've got this problem. You think I'm educated, we are all educated in this room about HIV. I'm HIV. Talk to me so that I can help you"*. If it **doesn't happen to those who are educated**, what about those who are not educated? **We mustn't take blame to the parents.** And the **parents sometimes can see you, eh ... on your attitude** to what you are talking about. So you must **check even the attitude.** It's like when I talked to her about her brother who is **aggressive.** It's a **symptom of denial that aggressiveness**, because he is **not yet ready.** He has **not yet been counselled**, you see. That's why he is so **aggressive.** One day here at school, there was a lady, a lady who ... That lady, he came to school with another lady who was HIV infected. She called us at staff and that lady, *N*, had a nice body, but she's almost dead now, having that virus. She has got a child, but you cannot say anything about *N*. *N* was **going to be sick for a long time, unless she got counselling and was told about her eating habits.** And when *N* addressed the kids, she asked the kids: *"What can you say about myself?"* And the kids said: *"Nothing. You look beautiful, you are pretty"*. She said: *"There's nothing I don't know about myself. I'm HIV positive"*. And *N*, I'm sure God is going to bless *N* and she is still going to have 20 years. She is still working there and there are many more. If you can switch the **radio**, you can hear about this. But let's come to the **disclosure at the funeral.** You cannot talk about death certificate, because **at any funeral there are not a death certificate**, let's put the death certificate aside. The doctors said, like we've said in the beginning: **"You've got pneumonia, you've got TB"**,

People unformed about this asset (especially those who are illiterate)

Denial

Acceptance= important (relates to fear of rejection)

All people avoid discussing =taboo

Positive attitude= Important

Aggression Denial leads to aggressiveness People not ready/prepared and therefore in need of counselling

Positive outcome of counseling: -guided on diet

HIV positive =living positively

Radio: asset

Denial at funerals: cause of death denied

HIV&AIDS-related illnesses

when you see the symptoms. It's up to the family, and even the family, there are two things that make them not to disclose. It is difficult to disclose on a funeral situation, once the wife is left behind. Because now I have to disclose upon my husband and I'm not yet ready, we are married. Then my husband died and then, on his funeral, I cannot disclose if I'm not ready, because it will too affect me worse. You can disclose about your child, knowing that he is not married so that you can teach other kids, but it's different on how you take it to strangers.

Ability to identify
Non-disclosure
Non disclosure:
-not ready
-afraid of
personal effect

R: That's right.

EP10: That's why I say that the community workers must be well trained – they must talk about this. If the community ... the community is about parents, it's about everybody. If the community is well groomed in this, even in the funerals, you can just say this one died of AIDS, whether it is my husband or whoever, as long as we have courage in this.

Community
needs to be
informed and
attitudes
changed

EP2: The problem now is that the one who stays behind, is going to be labelled by his own people, do you understand?

Stigma related
to disclosure

EP10: No, what I'm saying is that before this happens or whatever, we must as a community educate ourselves about this, then there will be no stigma.

Community
needs to be
educated to
address stigma

R: Where should this education come from?

EP10: Education must come from people who are trained.

Need for
external help
Education as
asset
Need to be
trained by
experts/trained
people
Educators=
asset to train
community

EP4: Coming to that, I think that we as a school, as teachers, it is our responsibility to call the community to train the people.

R: If I listen to what you are saying, you seem to be pretty trained yourselves. I can understand that you are saying that there is a need for some counselling skills, but you are all well informed, you know about

lifestyle supports and all sorts of things – you are already well trained in HIV&AIDS.

EP3: To get back to what I've just said. It was 2002 when I got pregnant. Then I got to the gyno, then I went to the gyno, because when you are pregnant at the 8th month you've got to go for a blood test. But I couldn't remember myself taking blood test during those 8th months. But I do remember myself, when I was close to 8th month, the doctor gave me a list that I must go to 4th floor, and I've told my colleagues this story. Then I took this list, and I like to read, because what I remember, when a teacher in the olden days could give you a letter, you will take it to another one and she will spank you. When I took this, I was so pregnant. Then I took this letter from the doctor and I was going to the 4th floor and something said: Read the letter! **And when I read the letter I saw HIV!** And what strike me was my husband who had the affair. And when I got to the lifts, I stopped there and asked myself: "*To which floor am I going to? 4th floor*". And this thing, I was holding it like this. And you know the doctors write lists like these, and say HIV, so **I think: what are they going to do with this big tummy? And what about myself?** Why didn't he tell me earlier? But now look, when I got into the door, I could see a very thin **nurse** with a small face, a lady with legs that are just like sticks. And I said to myself: "*Is she going to counsel me now?*" And I said to her: "*This, what does this mean?*", and I point to the HIV. So they said: "*No, no. You've already done this. So now you come for the booking, for your bed.*" And the nurse said; "*Do you see myself like this? No, I got sick, that's why I am like this. I don't have HIV, but I'm like this*". And when I talked to S and some of the others, they said: "*No, they know that nurse is like this. She is sick, that's why she looks like that*". So, I just want to **tell you, that it is not easy for the first time.**

Difficulty relating to HIV: Shock in case of the possibility of HIV positive status

Concern due to possible status

Counseling by nurses (=asset)

Dealing with HIV= difficult, results in denial

R: Yes, it is not easy.

EP3: What happened is, when I got home, I was relieved. And they said I must give him this letter, and my husband I was teasing him, and I said:

“Look what you did with that girl that you got? I’m HIV now. I’m HIV.”
 And my husband said: “No, no!” And I said: “That’s what you did!”,
 because I want him to get shocked too, because I got shocked. So it
 was his turn now, whereas I knew about it. And then I could see tears
 and I said: “I told you, I told you!”, and he said he will go to the doctor
 tomorrow and I said to him: “Beware of what you are doing beside me,
 be faithful, because I also nearly died”. So that’s what happened.

Shock, fear and
 sadness when
 confronted with
 the possibility of
 HIV positive
 status

EP9: So now, if you are taking that life cover ... I don’t want to go and do that
 blood test, I’ll rather leave that life cover. I don’t want to do the blood
 test. For the time being now, I’m still fresh. If it is something that will
 take me to the blood test, I will say no. Because I’m still fresh and
 there’s nothing wrong. And even for those people who are sick, even for
 those people who are HIV positive – if they are still fresh and healthy,
 they will say leave me alone I’m still alright. But when they are very sick,
 they can do everything because they are ... uhm ... you can do
 whatever you want to do. You can give them a weak porridge because
 they are sick. But when they are still fresh, when they are still healthy,
 when they are still strong – they don’t care. They can do whatever, they
 can eat whatever. They will only be serious when they are very sick.
 Do you understand what I mean? For those who are strong, the life is
 still there.

Avoid testing
 due to fear of
 being HIV
 positive

Avoid possibility
 of being HIV
 positive
 If feel healthy,
 avoid testing

Others
 supporting sick
 people
 Avoid testing
 when healthy

Inner strength,
 result in hope

R: Please help me understand something. Are you saying that you don’t
 want to go for testing?

EP9: No, no, no! I don’t want to go for testing. I don’t want to know my
 status.

Avoid testing
 Deny possibility
 of being HIV
 positive

EP1: I want to tell you about my brother. This is how it happened now. I was
 phoned by my sister to let me know that my younger brother was sick. I
 asked them: “Did you go to the doctor?”, and they said that my brother
 didn’t want to go to the doctor. I told them they must come and we can
 arrange for a doctor that will be able to help him, for my brother’s sake

Avoid support
 and potential
 treatment

because he was in a bad condition. And then I phoned him and ask him how does he feel and he said: “Sissy, **I don’t want to go to the doctor, but I was forced because now I can see with my condition I need to go**”. He was tested. He told me he was sitting in the passage and ... I was **shivering, I was laughing of fear - because the way I was scared to hear the results**. I was shivering because I thought the results are going to be positive.

Fear results, thus avoid help

Fear possibility of being HIV positive

EP5: And he’s a teacher.

EP1: Yes, he’s a teacher. But fortunately the results were negative. That is why I am saying – **It is not easy, even if you feel that you are sick, to go for the test.**

Avoid testing due to fear of being HIV positive

R: Why do you think one should go for testing, even if you are healthy? Why is it necessary?

EP1: Because sometimes when you think you are healthy, you’ve got this. You must go.

EP9: Most of the ladies know their condition when they are pregnant. **Because they are forced to be tested.** Do you understand what I mean? I don’t want to hear while I’m still alright. I will be forced to go there to be tested.

Tested when forced to do so
Avoid possibility of being HIV positive

EP10: That’s why I want to come back to what we’ve said. **If we educate a community, then no one will be afraid to be tested.**

Educating the community and changing attitudes, as way of coping

EP11: But how are you going to do that?

R: That is a very good question, let’s talk about it.

EP11: We are supposed **to lead by example**, because what will happen is this, and what the **government has already started**, is for teachers to be

Educators=
potential asset
(example)
Government=
asset

tested. We are supposed to be the ones who are first to say I've already done it. And the reason why this thing is going up and up, is because everything is always done late and then I'm already HIV positive. **We have to start by educating people on what are the causes of HIV AIDS? What happens after you find out? We are supposed to be the ones doing that.** Once I was told that, I was watching out and I was telling myself I was failing my community, and after that I tried to talk to them, but the problem is, people are not serious. And what we have been saying about people not disclosing at funerals – **there are no need to disclose that.** Because you see, **even in this place, AIDS is not a disease,** so you won't say that person died of AIDS. **They will say it was TB.** But what you are supposed to do, **is to try and persuade the people to change their lifestyles.** That is the best thing to do.

People need to receive basic HIV/AIDS information in order to cope
Educators can educate

AIDS denied in the community as a disease
HIV&AIDS related illnesses
Deny AIDS
Community needs to change lifestyle to cope

R: Yes, and you can even do if from here. How can you as educators, here at school support the people of the community to cope with HIV&AIDS?

EP10: If we are not suppose to get permission somewhere, if we are not suppose to get permission from somewhere, **we can do this. We can do this.** Like I think **we must contact health workers first to come here,** we must contact health workers to come and help us here at school. From there, the principal or the management of the school are suppose to make means that we can use **our school as a center.**

Belief in their abilities
Motivated to take action
Network with outside experts

Educators and school as potential assets

R: What do you mean by that?

EP10: The management must allow us to use the school to reach this. The community **must not see us as educated people, they must see us as people that want to help the community.**

Change in attitude in community required
Motivated to help

R: Also as friends **who want to help the community,** but also as **people who know someone that is infected with HIV,** with some even being infected themselves.

Inside assets= community members
Motivated to help

- EP10: **Because we are affected here.** Mrs Z is having a child, she has a child in her class. The teachers, the school is having these people, you know, and this is affecting us. **In order to support these people, we want to help the community.** **I think we must all go and do this.** HIV&AIDS =challenge
Want to support/help community
Positive attitude
- R: I like your idea of making your school a center of health. Who else can be involved? It is you, the community members, health ... who else?
- EP11: **ATICC** NGOs=
potential assets
- R: What is ATICC?
- EP10: **AIDS Training** what what what ... I'm not sure. Training by NGOs as potential asset
- R: In other words the NGOs. Who else?
- EP11: **The workshops that the department always invites us to attend,** at the NGOs. Department workshops as asset
- R: Which NGOs are involved in this community?
- EP9: I don't know. We are not sure. **It's only the counsellors.** Counsellors as asset
- EP10: But **I think we can get the people who own shops here as our help.** If you can go and talk to them, because the people's needs – they cannot manage them on their own. Because they have got the money, they can help the community to get to those needs, I think so. Shop owners (community members) helping other community members
- R: What about faith organizations?
- EP3: Even if we are doing this thing, it was said **on the television** that we must **also include the reverends and the priests** and all those people, because this is where most of the people meet like at the churches. Because the problem with the churches is they **hide these things as if they are not** Assets:
-television
-church and ministers
Stigmatisation and avoidance

happening, but they are still there. **Because they don't want to talk about sex.** They **must invite nurses**, like at our church we invite nurses to talk about AIDS. We invite nurses to talk about the diseases, like herpes and all those things. It is very important that the **churches must also be involved.** Coming to what she has said (*indicating educator-participant 11*), before doing anything, we also **need workshops.** Because when we are going to these people, we must be able to answer. We must be able to help, to say this, this and this. This is the way to do this, this is the way to do one and two, or one and three, because this people don't know nothing about this.

Churches: deny and avoid topic

Potential asset:
-nurses
(information provision)
-churches

Need for training
Need to be knowledgeable

R: Do you mean that you as teachers want to present these workshops, or do you want to receive the workshops?

EP3: **We want to receive the workshops first, so that we can give them.**

Need for training to be able to train in turn

R: And who do you think should provide the workshop training for you?

EP3: Okay. If the **ATICC or the department can do it, not to take one teacher from the school, but to take all the teachers**, and at the workshop it will be so nice to talk about these things, because it is going to happen in our schools. They've also been to USAPT.

ATICC/
Department=
outside trainers
All educators need to be trained

R: What is USAPT?

EP3: **USAPT is Union of South African Provincial Teachers.** It is the party for teachers. What is happening, they went to those workshops, now they came back and as a result, the day when they made the report it was like a workshop. As a result now, they said **every teacher should receive these workshops.** It is so nice to deal with this, because they make **everything so clear for me** when we were there, but it was a short time. They said they are going to make more workshops so that we can **go to the communities and apply back what we have learned.**

Union as potential asset

Workshops as potential asset, providing clear guidelines and training

Possibility of applying knowledge in the community

R: Now I would like to know, you have actually spoken a little bit about children and a lot about adults. When you spoke about children, you said that you want to be careful in your classes, you don't want to distinguish these children from the other children, and the other thing you mentioned is that sometimes the parent comes to school, but not always, and then discloses the status. What else can help you identify vulnerable children? In your school, is there a system to identify children who are infected with HIV?

EP3: No, no. What that lady was saying about the food that was taking place, we heard that of another school, that's why she raised that point.

R: Are they growing vegetables?

EP3: What they were doing at that school, they ... those people who have HIV AIDS, they are giving them a special diet. **They are doing everything for them, and as a result they are well.** That's what we heard about them.

School as potential asset

R: And here? I remember when we had lunch, *B* I think it was you that mentioned the child that collapsed from hunger in your class. What about the idea of not only providing nutrition for HIV&AIDS children, but for all children in the school, because most children will benefit from nutritional food?

EP2: **Many children get food, it's just the brown bread.**

School as asset (provide in basic needs)

R: That's why I am saying, brown bread is one kind of nutrition, but how about having a vegetable garden where most of the children can benefit?

EP2: Yes, then they can get something from it.

EP7: Yes. In our country unemployment is such a problem. If **there's no work, there's no money,** there's no food, you get hungry children in the

Unemployment

schools. So if we cannot only distinguish children who have HIV AIDS, or who are orphans ... if we can work with all our children and say **many of our children are vulnerable**, let's not label some. Let's try and help them.

Vulnerable children

EP10: I think **you are a blessing in disguise by coming here and give us talks about this, because I think the management of the school must change its policy from today**. Because here at school, the pupils that are getting the feeding are the grade 1's up the grade 3's, while the whole school are suffering.

Positive about outside help and guidance
View outsiders as experts
Could change school policy – providing food to all children
Motivated to change

EP2: But it's the policy of the department to say only those children should receive food.

EP10: But what about internal?

EP2: Yes, that can maybe happen.

R: What are you saying, *M*?

EP2: I'm saying that the management must help but the departmental policy cannot change, but now she (*indicating educator-participant 10*) is saying that **maybe we can do something internally, here at school**.

School as potential asset: general health of children
Motivated to help

EP1: I was sent to a meeting, and it was said that from next year it will not only be bread they get. As a result we are having a certain lady who is coming here, she is going to see management. She is going to do some facilitation about this issue.

EP11: Not to the management?

EP1: No, she has come to the management first. She will invite others now to join. I'm trying to say is that from next year it's not only going to be bread.

R: I'm hearing two things now. I'm hearing that there's the confines, or the boundaries of what government says and what the school policies are, but I'm also hearing about this other school you spoke about, that says: "*Policy says this, but what can we in the school do?*" And when you said you wanted to get community members involved, they can maybe help in that garden at the other school. If there is so much unemployment in the community, to get the children and the community to work with that garden, for example.

EP2: **Some of these children, they just come to school to get a piece of bread because there's nothing at home.** Because there is nothing at home. Poverty/hunger
School support
in basic needs

EP10: And sometimes they cannot help for **not having money,** **we must use them to help** in the garden. Instead of taking their kids away, we must tell the parents to do work for us. Poverty
Community
members' role
as potential
asset

EP3: I want to get in here. Those **vegetable garden here in the community,** it's only the **seeds that are needed.** **Rain** are coming from Above to make that to grow, you see. So everything that is happening, God is happening by purpose. Because there are **this disease,** and most of the **people don't have money,** and for this virus you must depend on *greens*. Greens are coming from soil, soil that can be done by people who are illiterate. **So what we need to do is to motivate,** because if we can go outside **there is a lot that we can do,** but you can see a lot of grass and weeds. Instead they will see the cabbage, or the spinach, or the vegetables. **The parents need to be motivated.** And the other thing that I want to highlight to you is: do you know what is killing our nation? It's the **confidentiality of this thing,** this *pandemic*, being HIV positive, because ever since it was told that it is confidential, because no one knows about my status and you can see I'm a bit fat and fit, and any man could see a fit person out of myself. But because of confidentiality, knowing my status, I could easily accept your proposal – knowing that I'm HIV positive. Knowing that it is wrong, because what is happening, even in our community, people are so stupid sometimes, because why is Assets:
-community
garden
-rain
Challenge: need
for seeds
Avoid
HIV&AIDS
terminology
Poverty

Role of
educators in
motivating
change in
community
Aware of own
abilities
Community
members as
potential asset

Avoiding topic/
confidentiality
issue

- this thing easy now? **It is easy to go to you and sleep with you.** Why don't you strike in your mind why is it easy now? Even those people who are still okay, it is easy for them to say yes, yes, yes. Yes is like good morning, good morning, good morning. **Knowing that at the end of the day, they will be 10 like this one who will die, knowing that I will not die alone.** That is a thing that is killing our nation, that I am not going to die alone.
- EP10: Okay, on that issue. That is why people who find out that one has AIDS, and accepted my proposal and slept with me, become angry. Because you know your status, you are suppose to say that I'm infected, to say: "*I love you, but let's use condoms. I want you to be responsible*" – that's why **people are killing each other because they don't want to be responsible,** I don't want you to have this eh ...
- EP2: They **say I don't want to sleep with her with a rubber on.**
- EP3: They say: "*Do you eat a sweet with a paper or do you want to eat a banana with the peel on?*" So that's where the problem lies. **Even if you know your status, you have one particular responsibility of condomising.** Even I have to be honest enough to tell you: "*Take it or leave it, I'm HIV positive. If you want me, put a condom on. If you don't to, you don't want me*". **If you could see on the TV** – a man that has got an affair and that women, her parents told her: "*You can't go on like this*". They have got 5 years – the man is HIV positive and the women negative, **because they were honest with each other.**
- EP5: I also want to say that it also **goes back with us to our culture.** In our culture it is said that a **man can't sleep to one person.** And it will be **difficult for myself after twenty years saying to my husband: "Let's use a condom".** The very first thing is: Why? So it is easy for me to be infected. Even if I can be as faithful as possible, it is not so easy.

At-risk sexual behaviour

Spreading the virus on purpose

People don't take responsibility for their status
At-risk sexual behaviour

Not practicing safe sex

Importance of acting responsibly

Television as asset and source of information

Coping by taking responsibility for HIV status

Culture as challenge:
-multiple partners
-avoid condom use
-women submissive to husbands

R: So you are saying that in your culture it is okay for a man to have more than one partner?

EP5: Yes.

R: And you are also saying you can be in a marriage for twenty years and if your husband does not want to use a condom, you'll have to stick to his decision and avoid conflict?

EP10: If the man has come to the point **where he is unfaithful**, you must separate, because **I don't want to die**. I want to see my kids when they grow. You must go separate, you can't just get the disease for nothing.

At-risk sexual
behaviour
Fear of dying

EP3: To add on what she is saying, it is not an issue, it is not an excuse. It is an excuse because it will not happen to ... the married man know he is married. But even if you could see **your husband is not faithful**, it is alright to say: "*No, let's check again*". It's coming back to: why don't you go for the test again? To **those people who are unmarried, they are doing it purposely**, because if you are not married, it is your duty to say: "*Take it or leave it*". To the little ones who are still at school, it is their responsibility to say take it or leave it. It is ABC – its either you Abstain, or you **Condomize** or B, I don't know the B.

At-risk sexual
behaviour

At-risk sexual
behaviour

Safe sex as
prevention
(coping)

R: Be faithful

EP3: Be faithful, yes. So, **it all comes back to us**. I cannot say: "*I know my husband is moving around but okay, I take it*". No, I **must tell him: "No, my life is also in danger"**.

Need to take
responsibility
themselves

R: Are you saying that women should learn to be more assertive?

EP3: Yes.

- EP9: I wonder how many of us here are saying to the young ones: “No, let’s use this”. Because you are not ready at that time to say that, you know. If you say to your husband: “Okay, let’s use a condom”. We always say so, but we are forced not to use it. But you know that he will go out, you are not ready for your marriage to end, you are not ready for a fight and you are not ready that your marriage are going to fall apart. You give him what he wants, because he is your husband.
- Unsafe sex practices:
-related to culture
-avoid conflict
-to maintain marriage
-women submissive
- EP10: But what about the consequences?
- EP9: You will suffer, you will suffer. And you are not yet ready for your marriage to fall apart. How many of us ... how many of us here use the condoms?
- Vulnerability=
related to culture
- EP1: I want to reply by saying: right enough, it is not easy to say you want a condom. But now, if you can see that your husband he is unfaithful, now you have got the right to say that you want it. It is your right!
- Difficult to demand condom use, especially in marriage
Despite right to do so
- EP7: I want to again talk about this denial. I have a friend who is married and has HIV, and the husband doesn’t want to use the condom and now she is HIV. I’m sure the husband is also HIV now. She tells me he does that, he is in denial.
- Difficulty to use condoms:
-difficult to be assertive
-avoid conflict in marriage
Denial
- R: I want you to talk some more about the children. What do we tell our children about HIV&AIDS? Do you know if parents talk to their children about HIV&AIDS? Do parents tell their children if they are HIV positive?
- All: No.
- EP9: Let’s talk about this point. Tell me, why do HIV positive woman become pregnant although they know that they are HIV and then they don’t want to terminate the pregnancy? Although they know it will leave orphans, everyday we are talking about the orphans – a lot of orphans, but they
- At-risk sexual behaviour
Potential increase in orphan numbers
High number of orphans

still become pregnant, although they know that they are HIV positive.
Do you understand what I mean?

R: Yes, I do.

EP9: Why don't they accept to terminate the pregnancy?

EP10: I think the answer there is this – they **want to prove a point**. They want to prove a point. You know what? If you are HIV positive, and you said to that one or even if you didn't say it to him, and you want the other person to know that, even if they see how tired are you, you don't want them to know that I am HIV. I am going to prove a point that I am going to be pregnant and you will see my child, although the consequences will follow.

Prove a point
Denial

R: So it is denial?

EP10: **It's denial, it's denial!**

Denial

EP11: I don't think they get pregnant to prove a point and secondly, it's against the law to terminate a pregnancy. It is not that they want to get pregnant and then to have that child.

EP10: But even then, even if you are not HIV and then you become pregnant, you are tested and you know your status, now is ..., you can terminate the pregnancy because you are not going to care that child. **It is not okay to see when a child is sick**. If you go to this hospitals, **their parents are dead already and now the child is suffering**. But again, because **I'm not responsible or I don't want to be responsible, I get pregnant**. Why? **It's denial**.

Challenge of coping with vulnerable children
Lack of responsible sexual behaviour
Denial

EP5: Again, to what you are saying ... I'm going back again to say **cultures play an important role**, because our **parents don't talk with us about sex first of all**. They don't even tell us what are the consequences. They are

Lack of sex education by parents=related to culture

still continuing with that. Even with us here, right here, we don't even know if our parents had the will or whatever. The only thing that is happening is that we fight when they are dead. We fight about the house, because **nothing is being said to the children, absolutely nothing. You just go out and find out yourselves.**

Avoid discussions on HIV&AIDS and death

R: Do most of the parents not talk to their children about HIV&AIDS or death?

EP10: But **I think there is no need, there is no need.**

No discussion, related to cultural belief

EP3: What is happening now, is that we are taking the blame to our parents. Now the parents are us. I've got a 16 year old, she's (*indicating educator-participant 9*) got a 21 year old. This century is another century, being us as parents. What are we as parents going to do with our children, because most of our parents died long ago.

R: Do you talk about sex with your children?

EP9: **Yes, but not in a formal way.** For instance, I've got 2 children - the one is a 21 year old and the other one is 18. When I am talking about sex, I said to them ... I talk like this: "*If you have many girlfriends...*", you see, I shout! I don't talk to them in a formal way. I say: "*If you have many girlfriends, you will see my dear, you will have HIV – you will have AIDS*". That is the way we are talking to them, we **don't sit down and talk to them in a formal way with detail.** I am talking about myself now.

Lack of formal sex education by parents

Lack of sufficient sex education by parents (related to cultural beliefs)

EP4: My children are still like this and this (*indicating small*), the one is 5 years and the one is 3. So they are still small.

EP9: **If I have condoms, I just go to their rooms and put it in their cupboards. I don't tell them:** "*Here at the condoms*", I just take the condoms and put it. I don't want to know what they are doing when they are busy, you

Reluctance of parents to talk about sex-related matters with children

know. But what I did – I just take the condoms and put it in their cupboards.

Secrecy of sex-related topics

R: So sex education is still limited, it's still a taboo?

EP9: Yes. I can talk with other kids, but not to mine.

R: And what do you do (*addressing educator-participants 1*)?

EP1: I just talk to them when they start showing, then I'll say you must talk with them.

Limited discussions with children

R: What do you tell them?

EP1: I just tell them that: "*If you go with a man, you can get pregnant*".

EP10: They are saying that communication is the best policy for our homes, but we don't do that. But now, a word of advice: Kids are seeing these things on TV, but they are naughty because they want to proof it on their own bodies, and its carelessness. Even if you talk, they just want to do it.

Lack of communication on sex-related issues
Television as source of information about sex (potential asset)

EP2: You know, even here at school we have sex education, but we are not trained on how to answer these children's questions, and I understand there are teachers for that. So I think we need to get some ... maybe learn how to approach these kids at school, because all that we know is that what we hear on things like that.

Sex education presented at school
Lack of trained educators on these topics
Need to be informed, to cope

EP1: I was for training, but you know, you can't even look at them. So I think it's for us to be trained.

One trained educator

EP11: I want to know: In our classes, eh ... in our school, we've got different age groups. We've got the little ones, then around 10 and then the

bigger ones. So, some of the information is catered for the older ones, so you cannot just give it to all of them.

R: Yes, it has to suit the age group.

EP9: And even now, I will give lessons to a specific age group, because these younger children, they like to go to their homes and say *Mrs D* has done this and this and this.

R: In other words you need the parent's consent?

EP10: Yes, you need the consent.

EP3: What I can say, now ... I just want to say, it's like my daughter asked me one day – she was 14 years, now she is 16. She asked me: "*When is the right time to get involved*". And I asked her: "*Where did you hear that?*" And I said, "*Okay, one day I will tell you*" Uh!! One day? One day is too far! And I asked her: "*Why do you ask such question*", and she said: "*I got a form from school that I have to fill in and discuss everything*". And I said to her: "*Show me your form*", and she answered the form and wrote that age 16 is right to get involved. And she answered that herself, you see. And that shows that **even at school they are talking about it**, you see. Even us as **parents, we have to ask them why, so that you can be involved.** **Like we don't talk about these things with our kids** – it's not like this with us, even when we are washing, our kids look away.

Avoid conversation

Sex education by (pot assets):
-school
-parents

Avoid discussion on sex-related topics-related to cultural beliefs

EP3: What we were saying is, **we as blacks**, we said to a vagina is a cow, but how can it be a cow if it's between your thighs? We want to make a child a fool. But they think how a cow with horns put his head between your thighs? So when we, they talk about men they say *puti* – you don't tell him, but when he ask you say all men have got this, because look at the 3 year old when she saw the 8 year old: "*My, my, come and look at this*", and she was pulling it, because she could see that hers was not

Behaviour and (lack of) sex education =embedded in culture

like his. And we didn't say anything about it, but she could see it was not like hers.

Lack of information by parents, influencing sex education

EP10: I think when you come back again, you will see the difference.

Predict change
Motivated to take action

R: Tell us what you mean.

EP10: Because we will be up to the principal to ask what is going to happen? We want to save the community.

Positive attitude to make a difference and change the community

R: You can't leave everything to the principal.

EP9: No, in our school it is like this. The parents, the community, came to our school before and asked the principal if they can plant there and we can have the veggies, everything, you see. But the principal said no. So that's why, so we are going back to the principal now and ask him to accept those parents to come back and plant here at school, because it will help the teachers.

Identify potential asset and make action plans to mobilise it

R: And this must then be for the school and not for themselves?

EP9: No, even for themselves, that will be fine. They will give us ... We, eh, they will donate what they plant, you see. We will get something from them.

School/educators supporting the community

R: But it should be for the school, and then maybe if the parents feel that they are doing something for their children, it will make sense to them.

EP9: No, if we say they can plant for us here at school, they will come and steal. They will come and steal. But if you say they can plant for them and then we'll get something, maybe a quarter, that will work.

Crime (theft) as community challenge

R: I understand what you are saying.

EP9: Then they will not come and steal, because then they will steal their own. Maybe if they will come here and plant for the school, they will steal.

Ownership as way of preventing crime (cope)

R: Okay, I think we need to wrap up this discussion, so that we can go on. Thank you for all the information, we will definitely continue this discussion in January.

EP9: Are we finished now?

R: No, we are not finish for today. We are still going to do some posters. I just wanted to say thank you for the information that you shared. And I think you didn't only share information – I think you got some ideas of what you would like to do. That's excellent!

EP10: If it wasn't for you, we wouldn't get the ideas.

Appreciate outside facilitation Acknowledge role as catalyst

R: We did it together.

FIELD VISIT 2 – 23 JANUARY 2004

FOCUS GROUP 2

11 x EDUCATOR-PARTICIPANTS

TOPIC GUIDE:

- ⓧ Challenges faced by the community.
- ⓧ Assets and resources available in the community.
- ⓧ Potential ways of coping with challenges (such as HIV&AIDS) in the community, by relying on existing assets and local resources.

KEY OF ABBREVIATIONS
R: Researcher
EP: Educator-participant

R: We learned so much from you last time when we were here and it was such a privilege to be here. And you made such nice posters – this is very valuable. When Liesel and I went home we discussed our visit and told one another that you are such a **huge resources to this community** and that you've got so much potential and things within yourselves that you can give to the population. So when we got home I took the video and wrote down everything that everybody said, and then I looked at what you said and then I made some conclusions. So we want to start with that today. We want to tell you about our conclusions and then you must please tell us if its correct and if you agree, if we heard you correctly. Because sometimes people say something and other people don't understand exactly what they mean. They say one thing but others understand something else. That's why we want to tell you what we think

Resources available

you said to us last time and then you can say: “Yes, *it’s okay*” or “No, *that’s not right. That’s not what we meant*”. If you want to, you can also add things to what you said last time. That will be the first part of today and after that we will work on the posters again. So let’s start. Last time we asked you about your concerns regarding HIV&AIDS and what this community think about the pandemic – what are the perceptions regarding HIV&AIDS. We think that you basically told us about several things that are good and then you also identified several things that you are concerned about, your worries. Let’s start with the good things. The first thing that **you identified is resources and institutions in and around this community that is actually helping the people of the community**. You mentioned agricultural things like the vegetable garden one road down and that it only needs seeds, because you get rain often. So agriculture is actually a good thing in this community to help the people overcome problems. Another thing that you said is that the **community members themselves – the aunts and the uncles, grandfathers and grandmothers – is taking care of the children and that they are good resources**.

Resources available in and around the community

Still need to be mobilised

Extended family=resource/asset

EP3: Yes, they help.

R: Another thing that you said is that the **government is helping** indirectly by **presenting workshops and training people**, like the workshop that K attended as part of her life skills training. You also said that the **government helps by giving treatment and grants**, so there are multiple ways in which the government is helping. The next thing you mentioned as being good in the community is **mental health services or counselling that sometimes take place**, even though you said that it is not always taking place and that there is a **need for counselling**, you did say that sometimes there is a **little bit of counselling** and that the counselling is **for mental health and also for nutrition**.

Government as resource

Mental health/ Counseling services

Need for more-not yet mobilized

Counselling for mental health and nutrition

EP6: Yes, they take care of that.

R: Then you said that the schools in the community are very good resources and that the teachers look after the children and that they identify the children with problems, give them food, support them and care for them. So the schools and the teachers are good resources.

EP6: **Yes!** *(several participants agree)*

R: Those were the good things that you identified. Is there something that you remember saying on the things that are good that we didn't mention now? Something like a resource in your community which we might not have picked up? Can you remember something? And if you cannot, it's also fine.

EP3: You've said them all!

EP6: Yes, all is there.

R: Okay! The second thing that we thought you told us that day was that there are also certain barriers, certain things that make it difficult in the community – things like stumbling blocks that lead to it that people can't cope. The first thing that we heard you saying related to cultural ideas and that cultural approach is sometimes a barrier. You mentioned that in your culture people sometimes believe that men have to have many wives and that that can spread HIV&AIDS.

EP: **Ja!** ... and that it is actually a problem for the community.

EP2: And even if, even these people they have many girlfriends or eh boyfriends, you know. Most of the people are poor and more of them are women and they solve their problem by, by eh sleeping around. Ja, by

sleeping around. You know, if she can get a men who is going to support her. And then: “*If this one is not working, okay I’m going to leave this one and get me another one. Or it will be better if I can **have two boyfriends or three boyfriends**, so that I can **get money from here** and here and there”, you see. That’s the problem, that’s the problem! **To sleep around is only because they want to get some money.***

Multiple sexual partners/encounters

Due to poverty

At risk sexual behaviour to get money (combat poverty)

R: They see it as a solution to their problem.

EP10: It’s poverty, hmm ... It’s **poverty**, that’s why! Some other kids, some other girls, only they are ..., some other’s are **young and have a, a old man**, you see, only because they **want money** and then they get the, the **disease from them**, you see! Sugar daddy, sugar daddies!

Poverty= Problem

Young girls sexual intercourse with older men to get money-spreading HIV/AIDS

R: B, did you want to say something?

Deny terminology

EP1: No. She was saying it.

R: But how prevalent is that? How often does it happen? It sounds like it’s girls and men, né? Because you said that some men, even though they’re not married, may have many girlfriends. **So unmarried men will have many girlfriends, married men might have girlfriends outside their marriage and young girls will have sugar daddies.** So if you say, let’s take an example, if there are ten people in a room, how many of these people – boys and girls, men and women – will have many girlfriends and boyfriends? Is it one out of ten or five out of ten? How often does it happen?

Multiple sexual partners/encounters

Young girls sexual intercourse with older men

EP6: **Plenty!** (other participants agree) It depends on that family.

Degree of problem: high/high incidence rate

EP8: It depends on that family and if it does struggle to get money, struggles to get food. So in fact those children go in a way and depend on the uncles and aunts.

Poverty/need for food – results in higher incidence rate

R: Does this have to do with unemployment and poverty, or also with parents who died maybe from HIV&AIDS where the children are orphaned and are then also at risk of sleeping around? (*all participants agree*). So sleeping around is seen as a way of getting money and not be poor?

At risk sexual behaviour in order to combat poverty and get money

EP4: **Yes!** You know what's happening is, if my parents passed away, you see, and now I'm left behind, even if I'm young and maybe my parents died of this, like eh, disease. Then, with sleeping with that, the, the people or the, those men or those guys with money in the community, will take care of this little girl. Because when you take a chance like this and get the result with this and then you know that you are not going to get it anywhere, you see, that is the problem. And because this little girl knows that I won't get it anywhere, it is all about the money. (*all participants: money, yes*).

Avoid terminology

Men abusing young girls

Lack of hope
↓
Involvement

EP6: There is a place here, there is a place with the trucks, big trucks, you know. Most of the girls, most of the girls they like to wear some sexy clothes, né and go get those trucks, some other they're married. My cousin who is driving the trucks, né, he even get a girl there. It's like: "*When I need it I get the girl there*". Because they know, they know they will get the girl in the truck, 'cause there are a lot of trucks, and there are many girls there in the trucks, those big trucks né, who goes to Jo'burgh and around. So this girls they just go there at night and have it there.

Young girls involved in sexual activities with adult men

R: Okay, so this sounds like a reality. And it's a reality that does not only have to do with HIV&AIDS, but it's a reality that does lead to people

dying. What I want to know now is: how does this community cope with these young girls and these men, based on your culture? It seems to me, when you're talking about this, to me as an outsider it seems that you're so used to it. But what will you do about it?

EP9: It's a mess, because if you are try to convince that person next door, they ask: "Are you going to be able to help me? Are you going to buy me the things that the sugar daddy is buying me?" Then if you say no, so they will do this, even though they are sure this is wrong. If we were able to help the problem we should have solved this problem, but how can you help in this needs, cause it's financially, the problem is money. But financially you cannot even help if it's your relative to do that, and you don't like it, but what if she will ask you: "Are you going to give me what she, what he is giving me?" And if the answer is no: "Well, let me continue with it, I know that I'm at risk but I get money".

Reason for involvement: material gain

Other community members not able to address financial needs

Financial needs of community members

R: I can understand that, but what I mean is, women through all the ages and all societies have been doing this because women don't always have power, and what some women do have is the ability to use their bodies, so it's something that has always been there. But if there's a threat of people dying because of that, does that change the way in which you try to deal with the girls or not?

EP3: I think the community is coping with this. The community has all been traumatised by this HIV AIDS. And that made the community to take it. They are apparently, they ... They must sell their body in order to get something. So with the deaths that are occurring, it's nothing, because they say we are all together in the community and so.

Community is coping

Traumatised by HIV/AIDS

Child prostitution= way of coping

R: If I'm hearing you correctly, you are saying that a way of coping is through selling your body, that that is in fact coping?

EP7: Ja. You know, for example, last year in March my sister in law past away because of AIDS, you know. Okay, so I called eh, my family, the young ones, you know, and I told them that we saw her, she suffered a lot. She was sick for a long time. And they said:” ~~Yes, yes, it was so terrible~~”. You know, even we were afraid to wash her, you see. But eh, I don’t know. They seemed as if they will not go that way. Do you understand what I mean? (R: Yes) For that time being it was bad, but after some few months, maybe by October, one, one of my in-laws, she was pregnant! How? Because no safe sex. I told her to use eh, to use condoms so that they can be safe, but I don’t know how she, how she can be pregnant after she knew that one of our sisters has passed away because of AIDS, you know. To me there is, it seems as if they don’t care. They don’t care, even they always like to say: “*I know you’re going to burry me*”, you see. That is way I always say it is like a joke to them. You see, we sympathise with them and when this thing happens in the family we are all traumatised, you know, because we know the results, we know what is going to happen when time come, you see. It all traumatise us in the family. But they don’t care! They do not care! They always say: “*I know you are going to burry me*”. If you write, if you say: “*I have a policy for them*” then they say: “*Yes! My sister take the policy for me*”. So something like that, it’s something like that. It, and it traumatise us, it traumatise us. And to them, it is a joke! It is like a joke, it is like a joke.

Partial disclosing of family member

Ill informed-fear of HIV/AIDS if affected (eg.family member)

At risk sexual behaviour

People don’t realize seriousness of the pandemic

Two reactions= traumatized and don’t care attitude

R: And it’s the young people?

EP7: Yes! It is the young people. It happens in the married wife, in a married couple. because I know after that they will be with others, you see. And, you see, I told you last time that it will bother me that I’m HIV positive but I get pregnant. Who is going to look after that child? And the reason and the option to terminate, to terminate the pregnancy, you know. But they

Multiple partners

Concern about orphans

don't want to. Who is going to look after that kid? Who is going to look after that kid? It means they don't care! They do not care!

Ignorance by general community members

R: Who does look after the children?

EP4: The people who ... all the cousins, anyone, but some other families, but some other families, they don't want to take those children. They're left in the house alone!

Orphans cared for by:
-extended family
-child-headed households

R: But mostly? Are the children usually looked after by family?

EP5: The grandparents.

R: The grandparents?

EP6: Yes! The grandparents. But in other families they're just leave them there. They're left alone.

R: In your community, has there been an increase on orphans? Do you see more orphans?

EP2: Yes! I have a brother who, who is HIV positive and, and his girlfriend ... his girlfriend is pregnant for the fourth time! What is going to happen? And those children are not, are not having problems. But she keeps on! She keeps on! You see!

Partial disclosure family of members status
Increase in orphans

At risk sexual behaviour

EP5: Yes, I don't know! I don't know whether the treatment is making them fertile. I don't know, but they're supposed to use condom.

Educators feel community members not responsible-should be

EP2: Ja, they're supposed to use condom, you, know.

R: It seems that there is a general agreement that there's more orphans. How do you know? How do you see this? What is the evidence that you see more orphans?

Increase in orphans

EP9: Here at school it's easy for us, ~~because some of them they are~~ registered. We always find evidence if you ask them: "Where is your mother?", and then the mother has passed away. So we usually get that in the stats that show with registration. Sometimes they come and you find both parents have passed. ~~if they come with the other parents, for so and so's mother or so and so's father. And through the year they report to us that their mother has passed away. And even some other, those children they don't do well because they are traumatised.~~

Orphans identified :
- at school registration

-tell teacher

-traumatized

R: Do these children receive any kind of counselling or, or special care?

EP3: No! If I can say, we are their psychologists ~~the teachers~~, the teachers, because you are very well to them. We are trying to give them the best, the best life, you see. There's no, I, eh, there's no psychologist that, there's no counsellor that is special, you see. We are their counsellors, we are their psychologists you know. And if you are teacher, if you are a teacher, you are supposed to do it all, you see. You're supposed to do it all!

Lack of counseling to orphaned children

Educators fulfill role as counselors/ Psychologists

R: That's true.

EP2: But sometimes it's difficult times because some children won't tell us. For example, there is a teacher who managed to identify this child, but you are not a psychologist, you're not a doctor but you are trying. Now it was a disclosed one, the child was taken into the hospital to help this child. Sometimes it's difficult because they don't tell us but if you know,

Want to help but doesn't feel equipped enough

Lack of disclosure

it's like, you realise the problem. If you happen to know the child will be sick, you will be accommodating the child.

R: How will you go about to do that?

EP1: By giving support that is accommodating the child in class and you must support that child and be kind.

Want to help by supporting and accommodating children in class

EP2: Ja, kindness, because if she feels a secret you must quickly take care of it. And also, they are easy to cry, you know. They like to cry.

Way of supporting – kindness

R: They are often sad and grieving.

Child experiences sadness

EP7: Eh ... ja, and now you take that trauma, ~~you take that, you take eh, what~~ can I say? It affects you. It affects you as a teacher, you know. It affects you as a teacher, because you are loosing, eh seeing this child everyday. And now it works and now it doesn't work.

Negative effect on educators

R: Who takes care of you?

All: Nobody! Nobody!

Educators in need of care/support to them

R: Do you take care of each other?

EP9: Yes, yes. Sometimes.

Some support one another

R: You are a resource to each other?

Potential resource/asset

EP9: Yes! (All agree) Like if I, if I have noticed, if I notice in my class this one, that there is a child with withdrawal symptoms. I will go to my colleague

Educators approach each other for help and support

and eh, try to help this child and afterwards, I will see this is how we helped each other. And we are giving care to each other.

R: It is sad to see an adult grieve, but it must be heartbreaking to see a child.

EP3: Mmm! The one child passed away. It was very bad, very bad!

R: What will you do if you find out about a child that has been left on his own, you mentioned it earlier that sometimes the parents will die and just leave their children in the house. What do you do then?

EP3: What we did né! It's like *Mrs N*, eh ... last year, her, she had a child who was alone who was left alone at home. What we did, what the teacher did is, she gave him a bread, a loaf of bread everyday. ~~But what we did, we went to the home~~ and she was, eh ... that one, the big one *M* was staying next to the squad. We went there with the police squad and found that it was locked, because this boy was staying in the house. Fortunately she was staying with the sister, and the sister was staying with her boyfriend.

Supporting orphaned children left alone in the house:
-provide food
-home visits

Family and friends taking care

R: How old was this boy?

EP3: He was thirteen, fourteen.

R: And the sister?

EP3: The sister was, was ... eh 18, already at matric. Now we found out what was happening with the sister. We found out that this sister doesn't want to escort him. It was only the boyfriend who was at least having a good

Other community members helping

time. So we said: "*It is, it is not going to help you, its not going to help you to rely on the boyfriend if the sister doesn't want to be with him*".

← Educators identifying and helping

EP6: She doesn't give a damn!

EP3: Therefore we found out about the possibility to stay here in Soweto with that grandfather. The grandfather fortunately knew this boy and he take that boy with him. So that boy stays there now. Everyday therefore we find a loaf of bread on my, on top of the poverty and we give that boy, we give that boy everyday.

← Extended family as potential asset

← Child-headed household

← School supports with food

R: Did you pay for it out of your own pocket?

EP3: No, the school nutrition gave that.

R: Continuously?

EP3: Ja! But the boy's got appetite.

R: So in fact you realised that this child was in need of assistance?

EP6: What we also did is, we took university forms and we apply for a bursary.

← Educator support

R: You said that you can see when a child is vulnerable, how do you see that? Say you have 40 children in front of you, how do you which one needs attention?

← Identifying with children

EP6: Oh, it's easy! It's very easy. First thing is, if you look at the performance of the, the kids in the class. then you do everything that you can to improve, to improve those and the others and then maybe there's one, for example this one boy who cannot. Then you take him aside and be

← Educator identifying children due to bad performance

... or be left with him and try to get every information from him. Its then that she, he starts to open, and speaks openly and tell you everything.

Relationship of trust

R: And then?

EP3: And sometimes they're afraid, tired, everyday ... Everyday they are sleeping in the class, so sometimes you speak and you can see they're far away from you, especially with the young ones. (*other participants agree*)

Symptoms:
-fear
-tiredness
-concentration problems

EP5: And even in the daily news you see it, you like to, you like them to talk, you know. And then even in the mornings you see it and then you know, okay, that's the reason.

classroom activities

EP3: Sometimes, eh, you know sometimes you find that a child is, like especially the, that one with the grandfather, then all of a sudden that child, it seems, you find out that she is not like she was before.

-changes in child

R: So you have to be very observant.

Educator=
observant

EP3: Yes, you must look at the behaviour of the child. ~~You must ask about the home:~~ "With whom did you stay?" He will tell you with the father. "So where is your mother staying?" So then you find out that also there is no hope.

Observing change in behaviour=
inquiry

R: Do you ever become so tired that you don't even want to know?

All: No, no!

Educators positive about their involvement/
truly caring

EP10: Because those things that happen, always in the day, you see, when you could see that there's something wrong, you got a problem that

particular moment or when you are dealing with the whole class some of the children who is usually here at school, it's the emotional disturbance of the kids. Because they easily cry and when a child is emotionally disturbed you could see she, she or he can not concentrate – she cries. And when you call that kid : “Come. What's wrong?” it's then that you start to hear the problem. And for us, for us it's difficult to know when did this things started. Because when you call the parent, the parent doesn't come to school or anyone who can assist you, so that you can help this child. We are helping these kids out of our own potential.

Emotional problems:
-Sadness
-Concentration problems
-Vulnerable
-Inquire about feelings
-Attempt to help parents sometimes not co-operative

R: You are. Z, did you want to say something?

Educator helping/ supporting children with what they have to deal with

EP4: The parents are the one's who say: “We are sick”. (other participants agree) “We are sick!”

No external help

E3: For example today there was a parent here, N's father. One time she gives them two, eh, kids but unfortunately this one passed ~~last year~~. Now this children came one day, ~~one was crying~~. I asked, and then I asked them: “What is wrong?” “I stay with my mother, I stay my mother”, she cried. It was then, it is then that I found out that they are staying with their mother instead of their father. So how we managed to know is, she cried and I knew something was wrong. Uhm ... the other one is, they are new, now yesterday in my classroom and the child's new in this town and there's no parent. The aunt – a young girl, young aunt, because I was so shocked that the aunt was even coming, she asked me if I didn't notice that the child was crying and I said to her: “*They are still new, you see*”, I will get used in them. She said: “*When we go back from school, when we go back home yesterday she was a crying and she could see her eyes when there is something wrong with the kid*”. And when she asked the kid and the kid she said somebody was bothering her, eh, eh, within the classroom. And she disclosed to me and I said: “*Thanks, for*

Educators support-inquire

Disclosure

me to know, because if you didn't tell me this, I should have not known about this. And the child would suffer and you would have tell me that the child, he would not want to go to school". And I said: "You know what, now what happened, I would try and be a parent for that child", because sometimes if that child can get love from me because her mother has passed away last year, late last year, so he left, he was left alone, together with the younger one who's two years old. So whoever take care of the private needs? The young auntie took care of her. So those children, I said to her I was so glad she came to school and talked to me, because this thing is going to affect this child and in a way, in his learning progress, you see. Now what I'm going to do as a teacher? and I've told her, because she told me: "We are not working, my husband is doing chores like he did gardening". And I won't leave her, because she told me she must bring some people money. And I said to her: "Because you can't be here it's a new problem now, and be able to buy that kid this. So on Monday, don't worry. I will try by all my means that, so that she will feel comfortable and she can not feel that my mother is not here. If my mother was here I should have had this. So, to, to, to rub away that, that loneliness". Like what I will do on Monday I will call that child and I will tell her that: "Now I'm your mother", and I will take the whole class because that's what I used to tell them: "I'm your mother, if you've got a problem come to me. Here at school I'm your mother when you are here".

Educator support:
-fulfill parenting role/substitute parent

Extended family=
caregivers

Negative effect on children

Unemployment

Financial support

Loneliness /sadness

Educator=
parenting role=
support children

R: I am hearing two things. On the one hand, I hear that there are some people who are neglectful and do not care whether they live or die, but on the other hand I hear many caring stories from each one of you. I'm hearing about caring aunts, and caring grandfathers, and I think that's extremely special, because that's probably how the two things are balanced.

Negative about life

Educators=
caring

Extended family=
care

EP10: To pick up on that question of what can the community do or what are the community doing about these people that is giving money everywhere to those young kids. You see, what is happening is that they are not afraid of death, what I can see, because, let's look like this example. There are, there are seven girls who in this house but four of them they went to Gauteng and when they come back they guide the three girls. But only two, the other one got pregnant, the other one she's pretty? I don't know anything what she is doing, here at the next doors, you see. But what surprises me, they know the situation of this girls, you see, those lads, the neighbours, they know about the situation and they know about the status. But they keep on How can you have an affair with somebody that you know that is having this thing? You see. That's where I can see that they're not afraid or the ... the thing is, for that matter I'm going to die and I'm not going to die alone. When then later me and M was left by, by, alone, what happened? Three of them passed away the same day, same day. They all, they all, is because when you got me then you are going to buy me a *dop*. There is something like the tap.

At risk sexual behaviour

Avoid terminology

Don't fear death transfer virus

R: This is too quick for me! What are they going to do?

EP3: If you're going to buy me a tap, then she'll be equal.

R: Oh, a drink?

EP3: Ja! You can have this one. This man doesn't mind or this man is not jealous of her having a affair with this one, you see. It's going around, she and the other one – this man. She was from this house.

Multiple sexual partners

R: I'm sorry, but I still don't understand. You are going to buy me a *dop*?

EP3: Ja!

R: To drink?

EP3: Ja!

R: But what does that have to do with the three of them dying at the same day?

EP3: What we're saying is that they are moving around. They are, they are staying like this (*indicating with hands*). Their houses are so close, you see. They are in the same area, but I know your status and now it's easy for me that I can sleep with you and you know you got it, you see. So the dad, when the dad comes, he doesn't say: "*I'll go that side and that side*". It happen just there, you see, that carelessness, because if I know that you, your status and I know that I love you, you see? Why don't I use a condom? That's why I said we die alone, die alone.

Multiple sexual partners

Transferring HIV

At risk sexual behaviour

EP6: But the one day, the previous one, the girl passed my house. We talk to each other but I managed to hear him. What she was saying is that she is HIV positive and she said she is not going to tell anybody cause she is not going to die alone. Those others they will get it.

Transferring HIV on purpose

EP9: And because of this grant, and because of this grant, they deposit, it's 780 per month, ne? 780.

R: The disability grant?

EP1: Ja, the disability grant, it's 780 per month. And because of that, everybody wants that money. They want this money, they don't care. They want it 'cause they are going to get money now, you see. They are going to get it.

Transfer HIV to get AIDS grant

R: Let me re-cap this. So they're going to get money. If you're a young girl or you're not working, you're going to sell your body for a sugar daddy and then you get money. And if you get AIDS, you will get more money, so you're actually not worried because you're going to have money for the rest of your life, is that what you are saying?

Unemployment

Child prostitution get AIDS to get grant

Misspent grant

EP3: Yes! And even with that money, they don't buy uh... food or education. They just enjoy themselves with that money. That is why...

R: What were you going to say, E?

EP6: I think a condom is not the solution, because they don't care about it.

R: But they don't care about death either.

EP11: That's because they need education. If you educate them ... workshop them.

Need for community to be involved

R: What do we need to educate?

Community needs to be educated-safe sex

EP11: Condom use. It's all about education. If you don't talk about condom, that mean there's no education. By saying use a condom, that educate that essence, to use condom so that you can get safe, you see. By saying, what I'm saying is, if you want to do it, there's no problem, do it. But do it, knowing that it kills! But if you want to do it to be safer that is an order on the education, so I don't think the government is not doing something about this, because it is something that has been done by the government. The radios, the clinic, the peer group, the families, you see. Even, even what we said last time, that I take condoms from anywhere and I put it on my children so that they could see that this is the condom

Government= Asset

Assets

that they were supposed to use. If I want to be involved with sex, let me use condom. This is education, what is, she was looking what education is. But what they are doing the government and all, is doing a good thing by trying. But what the government is trying to address, is to let them live longer. They must use that money so they can buy food, mattresses, and things like that.

Promote safe sex

Government=asset

R: Are you saying the government shouldn't necessarily provide money?

EP11: Not money, yes! Not money to buy liquor.

Providing food-basic living things/grant instead of money

EP3: Ja! They must rather use vouchers, ja!

Disability grant's format should change

EP2: Or maybe it will be better if they can get food parcels ... food parcels and education, you know. Because what they are going to do with vouchers they are going to sell the vouchers to others. That's our tragedy, that's our tragedy. Even if they can get food parcel ... even if you get to the bus, it's our tragedy. If you want, you can take even a flower and, and send it next door. The problem is to buy to us. Because the problem are that if you buy they'll even rob you. We lie easily, to buy stolen things, you see. Because they are cheaper, we buy it. We don't want to go to shop. So I don't think it's that problem.

Need for food parcels and education

Crime

R: Is that part of your culture?

EP8: Ja! It's cultural behaviour.

Cultural barrier

EP5: There was only shacks here, no, no houses, no big houses. But, they built, eh ... the government built the houses, they built houses. What they did, they sell houses and go to, go to shacks, go to shacks. So what

Government and houses=assets

Poverty-poor living conditions

must the government do now, what else? Because they don't want to be ashamed.

R: I ant to come back to the cultural aspect. Last time when you discussed culture, you said that it is difficult to get the parents involved at the school, because it sounded like culturally they weren't as involved as you would like them to be. But today you are mentioning quite a lot of parent involvement, even if it's a grandparent or an aunt who are involved in the school. Can you maybe explain that to us? Maybe I misunderstood last time?

EP6: The parents that doesn't come to school are the parents of those kids, that they're the parents. We didn't say they're coming to school all of them. No, they're coming to school some of them, you see. That's why we are saying, that's why we take our problem to ourselves for those people that have parents that doesn't come to school, you see. This is the 50/50, you understand? This is the 50/50. Then for those who are having no parents its where we could see the guardians, the aunts are coming and trying to help you.

Some parents=asset – potential

Extended family= caregivers= potential assets

EP2: The parents who have the problems doesn't come. If for instance she is sick, she won't help. It's when she dies, then the other one or the neighbour will come and tell you of the problem. But while she's alive she won't tell you nothing about it.

Neighbours support

Fail to disclose

R: That was one of the other barriers you discussed last time – denial because of stigma. (*participants agree*) Let's go over the barriers you mentioned last time quickly – I think we've discussed all of them again. You mentioned cultural aspects, denial, the whole thing about education or counselling about the HIV status, financial barriers, the HIV grants, the issue of stigmatisation and the treatment of people to themselves

Denial-stigma

Barriers

and by others. I think we've discussed all these barriers. Something that has changed since last time we came here is that last year the government had not yet decided to give anti-retroviral treatment and now it is available. How does the community handle it? What is everybody saying, now that the treatment is available?

Barriers

EP3: Not yet! All gets medical aids, TB treatment. And it's when they get it, when they admitted it, those, you see, those, HIV related illnesses, ja, then you're going to get treatment. Otherwise they just stay at home, with no treatment, no medical aid! Even if you go to hospital and get discharged, some of them didn't want to go to, like public hospi, hospital like the whites, because no one wanted to be seen there in the department. They know the department, go to this department. So if somebody in that area could see you in the department, that's a denial, he could notice that and get there. So they are not going there.

Lack of treatment except on admission-for related illnesses

Hesitant to go to hospital

Stigma- avoid disclosure

Denial

R: It sounds like the community is still in denial, even though people can now get treatment?

Stigmatization

EP3: Ja! Ja, because they are going to get that stigma.

EP9: Sometimes the problem is with our brothers and sisters, they wait until late, because sometimes by denial they wouldn't get those, eh ... medicines. Because they would wait until somebody defines that. Because by going to directly eh, ... the clinic, that's where they're going to get help.

Avoid disclosing due to denial

Clinic=asset

Stigma relates to way of transferal

R: So the stigma is not related to the dying, but has to do with how you were infected, do I understand you correctly?

EP7: And they've got that position, forgetting that it's not like that, because sometimes you can get HIV without ..., by drug or blood transfusion, you see.

R: Or mother to child. Or being married to a person but not knowing how that person was before you got married.

All: Yes, yes.

R: Okay, let us move on to the next aspect. I think we've also mentioned a lot of it already. The third main thing that you spoke about last time when we were here is that there is a lot of needs in the community. You spoke about the need for a change in attitude by the community members in general, not to stigmatise others, not having more than one sexual partner, not sleeping around etcetera. The second thing you mentioned was the need for education ~~we discussed that earlier on, and the third one is a need for external help, in other words other people coming in and helping you by providing help, like food parcels.~~ (*participants: Ja! Ja!*)

Needs:

-change in attitude

-change in sexual behaviour

-need for education

-need for external help

EP6: Ja, because sometimes like, like myself. The problem that I've talk about, you see. You have to go ... You want to give help, you want to give help, because you could see this person ~~has no one to help her~~. Even if it's financial, just a little bit. Not that much solution, you see, just to like buy food parcel or give her something, like fruit. So that he can get that plan, you understand, ~~or do something~~. When you go there and you could see that uh-uh, there's nothing I can do, you see. When you go there without giving hope to that person, you understand, because that person has lost hope, everything, you see. But if you could do something then it's when you know that when, like, like ... when we talked to this woman, she's very sick, she's lost, she's lost, but I could

Educators want to help

Educators able to identify need

Financial support

Assistance in qualifying for grant

Want to provide hope

Want to help

see a denial. ~~Because she is talking about other things,~~ running away from what is happening, what she's seeing. Then when the dad, he talk about that, when you are, when you seek, but we didn't mention this, you, you look lots of money, you see. And the result now, I haven't got much for begging. And she was begging and she's now haven't got enough. So what we did when we went there as women union, you see, we go there for prayers. And when I got there, it's like okay, the, the daughter was cutting a little orange, you see, but we were going there without a parcel of fruit, but for prayers. Prayers must be supported by something, you see. Yet we know we are praying for God, but what else are we coming with? So what we did then is we said to, to the women what about having a collection? A collection and I said forgive myself let us have a collection. And I took my last money in the bank, so that even if just by being here I got something to give to you, you understand?

Denial

Women union=asset

Prayers=way of coping

Want to do more/give

Provide in material needs

R: So it has to be functional?

Positive about help they give

EP7: Ja, and we felt happy when we did that! Just a little bit. When, when we go to this houses, what you need to do is to adjust a little bit so that, so that, during that, they're still needed. They love you.

Benefit= appreciated

R: Is this women's group you talk about based in the church?

Church=asset

EP6: It's from the church side, ja. She was, she was asked and then she could see. But there are other groups that come, that do various things, like support groups. Ja, supporting groups, for ploughing, vegetables, that stuff and supporting the people who are sick. But they don't know they've disclosed.

Support groups

Support=home visits

R: Is it home-based visits?

EP6: Eh, ja, because you cannot go to a person like that one who have a denial and say: “*We’ll come to you to give this and this*”, you see. “*Why do you give me this?*”

Denial leads to/implies no help

R: So how do you approach it?

EP7: In May or June we know this. Then we ask: “*What are you doing to our kids?*”, you see. Because you could see what comes up there, so what I can do is to try and help by this way, you see. So the better way to do it is like this, but it will be difficult for someone who is not educated, who is not interested sometimes.

Educators want to help

EP2: They’ll ask you: “*Who was the child? Who was here last year?*” and then he’s dropped out. He was in *Mrs N’s* class, class. This boy came to ask for a, uhm, a, a transfer. I asked him why?, because he left early. So I though it’s a chance to save him, but I could see there’s something like a neglect. I’m trying to, to say the teachers also come early to assist. You know I told this boy: “*Boy I don’t know who gave you a transfer. Because I don’t know why you were supposed to come here?*” I took my car and went eh to *A’s* place, with *A*. I found out he stays only with his granny, his old grandmother, you know. You know we get to sit here in a big house, but it’s pathetic. I asked from the mother: “*Why is A coming to the session? Why, where is he going, because he was our learner.*” We know he’s falling, eh, on supplements. “*Where is he going? He’s a kid!*” The grandmother told me: “*Madam, this boy, his father passed away last year. His mother is sickly, you know. In a, very sick, and suffering from HIV. He was infected due to HIV and also this boy is sick. Right now he doesn’t have the school shoes*” But he took, she took all the medicine and showed me, you know. You know, I found that this grandmother doesn’t have money to come and register at school. That is why now they take him away. I don’t know how it will go, because they was

Educators identify needy

Educators help wherever possible

Extended family= caregivers

Individual infected

Poverty

- saving. What I did is I told the mother: "Come over and talk, about the question of money especially", because they wanted to see him focus. ← Educator wants to help
- EP1: It's something, you see. It's nice to have, because if they put you as if they didn't care, it's hard. You should be glad that people care. But because of the symptoms that you see, this child is doing the wrong thing. Then you must say: "Let we go and check what is happening". ← Educator able to identify
- EP6: You know what, I don't blame those parents or people who are, who, who doesn't want to disclose their status, because, because even a, even those professional, professional supporters, they don't want to disclose, they don't want to disclose. They just keep quiet, you know. ← Avoid disclosing
But, but you know what, although we are not going to be able to give something to each or to give something, we give like eh, emotional support, you know. You give them support, you give them support, but they don't want to disclose their status. ← Educators want to support
- R: In other words not disclosing is also a way of coping? ← Non disclosure= Coping
- EP9: Mmm! Mmm! Ja. You see, how can we blame others, as even the professionals they don't want to disclose? It's not that, it's only because they are, it's not that they are, it's not that they, because of the ... being illiterate! It's only because they don't want to, because professionals even they don't want to. ← General phenomenon (not restricted to illiterate)
- R: You've actually raised the issue of generating solutions to cope many times today, and this is just another example, because what I hear is that you teaches at a school, assisting and supporting and teaching learners ← Community= generating ways of coping
but sometimes giving emotional support and the women's groups are also giving support, and the community members, the grandparents and

the aunts and the uncles, so that's the whole idea of generating ways to cope, it's already happening in the community.

EP9: But we want to do more, we want to do more. ~~Like we said last time, that we wish to have a garden here in our school.~~ A big garden with a lot of vegetables there and we want a garden because to help eh, to plant vegetables, everything so that everybody can get some. As you know, that we have children that are HIV positive, it will be easy for us if we have a garden here, you see.

Educators want to do more eg. veg garden (generating ideas to cope better)

↓
Get better solutions to challenges

R: And even children who are not HIV positive – children who are under nourished or malnourished.

EP3: Ja, it will be easy for us to do that. We are doing it because there is poverty.

← Poverty

R: You know what? Sometimes I get so angry at the media, because it tells about all the bad things that are happening. That is why we couldn't stop talking about you after our last visit. Because here you are, you are magnificent people doing all of this. You are telling us about all the things that you are doing and I am just astounded!

EP1: But the government doesn't want to come to the ground and understand. But the government is doing the AIDS things, they're trying, and we want to do more!

← Looking for outside help and government= asset

← Educators want to do more to help

R: I'm not saying it's the government. I'm saying it's television and radio that tell the people all the terrible stories, like rape and so on.

EP6: For instance, last year there was the district at Q where the children liked to have, to go there, those schools all around. Then what we did as a school is we signed papers and sold chips.

EP8: Even for us the teachers it was good. Now, what we did as a school, ne, is we go out to the clinic, the clinics, so that they, the nurses can come to the school to inject the children for the infections, to help them! At least we are trying our best. We are trying our best, you know. ~~Those who~~ were suddenly committed like *M*, who did it, the child who are, he, he is in her class. The, the nurses of the clinic could come to *M* to monitor if the child is drinking the treatment, is taking the treatment, because the parents didn't care!

Educator/school helping create solution

Clinic/nurses= Asset

Educators believe in their attempts

Clinic and school=outside

Parental neglect

R: So you help in monitoring the medication program?

EP8: Ja, the teacher has to take a form to say that you'll see to it and *M* had to write a letter and send that child with another one so that we could see that he did go to the clinic for check-ups, and that child ended up to receive treatment. But the parents are there, the parents. But if that parents, if it was said that it's a toyi-toyi, they are the first ones to come!

Educator identifying problem and come up with solution

R: What are you saying, *B*?

EP1: It's our tradition. It's our tradition, to do so, to help.

R: You know, I'm thinking that we have identified cultural aspects as a barrier, but I actually think we should also put it as a resource, because some of the things you are doing relate to you culture, for example all your kindness and the care you provide.

Cultural= both barrier and resource eg. Care and kindness

All: Ja! Ja.

- EP6: And you know, and you know what? You white people ne, you don't care about the others. Look like in the houses, you don't know who is staying next door to you. You don't care! You just mind your own business. You don't know what is happening next door. To us, you know what is happening in the area, you know your area. Because we care, we know each and every house.
- Community= huge asset/support one another
- R: Your culture is the foundation of your coping
- Culture as foundation of coping
- EP4: Yes! Yes! Yes! (*several participants responding*) Look, what is happening now is the parent told me. And here it is community and she said: *Mrs G*, I've got a child who I want to register, I, I am able to register. And I said: "What's wrong with him?" He was a drop-out, he fight and the, the reason was, he hasn't got shoes to come to school. That was the excuse of the kid, you see, but it was really that he got no shoes to wear. You see it was the neighbours who phoned me, the parents went away. The father go this way, the mother goes this way. So they were left behind with the granny, grandmother. The grandmother then divided the kids, she doesn't like this one. She like the... those, she like the others that are from the hostels. Then, this, this were the neighbour, asked: "*Why you don't take care of her?*". She said, eh she said: "*No! I don't like this one because he is, I just don't like him, that is why I don't take care.*"
- Educators identify potential problems
- Neighbours/ community members care=asset
- Extended family take care
- EP4: You see, then the pa... the neighbours ... The neighbour asked can they come to school? And I asked: "*Are you going to be able to take care of him?*" She said: "Yes! I will be able to, I will do everything for that kid." As a result, I go to the deputy, I talk to the deputy, and I went to the deputy and I said to the deputy: "*Deputy, that is the problem*", and I realise it so much, that neighbour wasn't just a neighbour, he's a real neighbour, because he could see the need of this kid! You see. And
- Neighbours/ community members care=asset
- Educators making plans to cope with problems
- Neighbours identify problems and make plans

what is that to us? I think, I told this kid to come to my home to take a lunch, every morning! I ... I, even will pay school fees for this child, and he said: "I will do everything for he, him". And we said, what we are saying are we promised to do for the child and as the teachers, *M.* together with myself, we promised to take care of him.

Taking care and helping financially – educator and neighbours

Educators believe in themselves-positive

R: Last time when we were here, you kept on saying you want to receive training, but now, while you are talking, I am thinking you should give training to others.

Educators experiences= resource

EP9: It's experience, 'cause, eh, the reason why we know this is, it is happening around us.

R: And you are making it happen! Okay, I think we should end here. It's been a long week for all of you and it's after four already.

FIELD VISIT 6 – 29 OCTOBER 2004

FOCUS GROUP 3

9 x EDUCATOR-PARTICIPANTS

TOPIC GUIDE:

- ⌘ Reports on the progress of the three community-based projects.
- ⌘ Educator-participants' experiences of their involvement in initiating the projects.
- ⌘ Outcomes of the activist interventionist research strategy.
- ⌘ Educator-participants' experiences of the activities and processes employed during phases one to five.

KEY OF ABBREVIATIONS	
R:	Researcher
EP:	Educator-participant

R: Today we're here for two reasons. The one reason is that we would like to hear from you what happened since our previous visit, the one on the 19th of August. We would like to know what you are doing in the community garden, how you did it, what you do with the clothes and basically everything that you are doing. The second question we would like to ask you is: if you think back over the last year and about our visits, what do you think worked, what was good, but also what do you think we might have done differently. Let's start with the three projects. What are you doing at present? How far are you in the process and if you plan to do some more things, what do you plan? Who would like to start?

EP1: Let me start. First of all, as we have promised, we met with the principal and we asked for a place where we should start our garden. That is why

we used that place. And then I phoned, of course I met my friend who told me that I have to contact *clinic Z*.

R: Which friend is that?

EP1: She is working as somebody who's dealing with community people, especially those that have poverty. She is one of those ladies who are having that project of feeding some people. It's a project, some ANC things. Now that lady has told me that I have to contact *clinic Z*, as there's a certain lady there who's going to give me some seeds. I phoned *clinic Z* and got hold of that lady and she promised to come and give us some seeds. She came really, it was late that day and it was a closing day. She came with a lot of seeds and I called the parents to come. In fact *Mrs N* is having something to do with active schools. So there are parents who are cleaning the schools as we are sitting here, who used to come and clean our school here, assisting us in every aspect that we do here at school.

R: So active schools is another project?

EP1: Ja, it's the other project. So we said then, we have to make use of those parents, those that are taking part in assisting the schools. Those are the parents that are going to benefit in the garden and we told the parents that we are also going to ask from them whatever we want, because we're going to organise some seeds and some crops for them. Now we got the seeds and then I shared it for them. Then I phoned the municipality, the PE, Mandela Metropole. I phoned a certain guy at the municipality, in fact I was eh, I've written all these things, it's there. I phoned this guy, I was interested now in equipment because we wanted to have some tools, we don't have tools here at school. And then that man said he's going to send someone here at school, really the two, one gentleman and a lady came, and I told them about the policy that we have, that we are earning in this and this and then they were very excited in the sense that they said they would give us a tractor. But because

now the panels have already flooded there, therefore we cannot be able to be given a tractor, what they are going to give us is only the seeds. Then they said I must write a letter then asking for the seeds. I wrote the letter, I don't think it was even two weeks, they came with a big van here with the seeds. It was only the onion and cabbage. They gave us lots of seeds and then I called the parents, they shared among themselves. The seeds that you see there are the products of us assisting those parents. They didn't buy for themselves. So we've managed to have that done. As a result, now we don't have a problem. What we said to those parents, we said if teachers want the crops that are grown there they must buy them, but for us, those that are wearing these HIV nametags, we are going to go, if we want to, to ask, because we know we are helping the entire community. So we have a chance for those across there, to ask for the parents whom I think we are doing it for them.

Believe in own ability

R: In other words you can get vegetables from the parents to put in the food packages?

EP1: Yes, but for other teachers they buy, because we know people are going to make use of those parents, to ask for their names. Although we are having an aim in those things, therefore we said let them, the teachers, buy those things in order for them also to get some money.

EP7: Ja, to get something back.

EP3: To add more on that, not all of us with these tags, only the support group can get it, because we as the support group, T, N, we know which days we always give those parents the bags. We told them to come on Wednesdays to come and collect the veg. It is not all of us who ask those parents for the veg, only the support group, because we have already sat down with them, we already sat down with them, we told them everything and then we told them that we are going to support them with vegetables but all of them know which day they are going to collect the veg.

Support group

EP7: Okay, what is happening is, that as we all agreed that when we meet that garden, we did make a promise that we are not going to label, like as if it's a HIV garden. No we didn't label it, that's why we use parents and the parents don't know that behind whatever they are doing we are going to see eh, there is a aim, the aim is that on Wednesdays we ask for a supply of vegetables. And they know that these vegetables, we are going to take it to those houses that have a HIV and AIDS people who are suffering, who cannot do anything for themselves, that's what they know, that we are taking the vegetables so that we can help those people who cannot do things for themselves, that's why we showed them the nametags. They know very well, if you've got a nametag, they know that we've got those houses that we have to help them. So they work so nicely because they know that even themselves, they are helping on the other side, you see.

R: What about the other days? Can they sell the vegetables then?

EP3: Ja, for the teachers, for the entire teachers. We encourage them to sell the veg so that they can have money to buy paraffin. It's sort of a project that they have to benefit also for themselves.

R: Do you have something like a soup kitchen or some place where you can take some of that vegetables and make soup?

EP6: At the moment we haven't got a soup kitchen, that's why we give those parents some veg. But I'm sure on our year plan for next year ~~we are going to have a soup kitchen~~ because we could see there is a need for it, for the children.

Potential project

EP3: And the parents are coming, are free now to disclose, they come in numbers to come and disclose their status since they have seen that we are, here at *school G*, there is a group of HIV and AIDS, they come and

← More disclosure

Information
sharing

disclose to us then. I usually refer them to Z, who is information sharing team. And I also refer them to the support group. So it's really working.

EP2: Yes, as an information team we had a meeting here at school, it was a parent's meeting. In our agenda we said let's include the HIV and AIDS, it is then that we managed to announce to parents that there are teachers who are trained here, and there are those projects that are here at school. Therefore any parent who's having a problem at home must come. It is then that they came to inform *Mrs N* and then they are referred to the support group, so that is how we connect.

EP4: Every parent meeting that we have here at school, HIV and AIDS is on the programme for information.

R: Please explain what that means?

EP4: When we are having meetings, we have to put on the agenda anything about HIV and AIDS, so that we can keep them updated. Because sometimes on this meeting there are parents who are not, who were not on the previous meeting you see, and we wanted them to know that HIV is here to stay, so that they can be capacitated too, so that they can know where to get help. You see that's why we have to include in each and every parent's meeting, because they are not only suffering, even their children, they've got children at home you see, even if though their parents are their parents, that's why we are doing it.

Goal=
empowering
community
members

R: That makes sense.

EP4: And even on, to add more on that, on August, early September, I and *Mrs N* we went to Old Mutual. Last week on 23rd, we had a banquet at Great Centenary Hall and then we went out early on September asking for the sponsors. We went to Old Mutual asking them to buy a table for R1000, when we addressed everything, trying to explain what we are hoping for, why we are doing the banquet, we want to upgrade our media

centre, we want to have some field and a hall so that our parents can do their sewing and hand work there in the hall. They said to us: “No, we are not going to give you R1000, what we are going to give you is we are going to give you between R30 000 and R40 000 as long as you are doing good work”. I told them that we’ve got a garden, that the parents are working there, if you want to say, we add HIV AIDS and the community. They said okay, and we told them that even that garden is not even, we want the field to be levelled and we need a hall. They said to us: “Okay, what you must do, draw a plan”, and they gave us the form so that the principal can fill those forms and they said we must draw a plan and a business plan and a quotation of those things that we want to do. Now we’ve got a problem, we are stuck about quotations. But they said: “No, we are going to give you between R30 000 and R40 000”. We are still busy with that.

Income generating activities

R: I don’t understand?

EP1: We have to bring two or three quotations so that they can see which one is reasonable. And to add on that, the reason why Old Mutual was so excited is to see that we have here the HIV and AIDS programme. Otherwise, if they didn’t mention that, he should not have been asked, because they said they are going to come, to take photos for the vegetable garden and they could see that we are wearing this (*indicating nametag*), because we were not afraid wearing these nametags, even anyone who can maybe ask, we don’t mind, because we know what we are struggling for.

Participants positive about HIV/AIDS/proud

EP4: And they asked us if we are there as a committee, I said: “*There is a committee, we are, there is an existing committee, we are the committee with the parents who are working there in the garden*”. We want them to give us more because we’ve got a need, for instance some parents want to do bead work, we haven’t got those beads to give to them, we haven’t got the resources, we haven’t got money to buy those things, that is why

we want help. We haven't got a hall, we need to have a hall so that the parents can use that hall in sewing, in building.

R: What is so wonderful is that last year when we were here for the first time, you also said this. You said you didn't have resources, November last year, and now you say we did this, we are going to Old Mutual, they are going to give us money, we are going to draw up a business plan. All the ideas are there and you are putting actions behind them and running with it. It's magnificent!

EP4: Yes, and then, then we took that business plan from deputy, do you remember that plan, the policy, we took that policy plan to Old Mutual so that they can see that there is something that we are doing.

EP3: Now let's move on to the support group.

EP8: Before that, we, the vegetable garden team, I think you said we can also phone ACVV, then they said that there are meetings that they used to have in this area, so they are going to tell me or to give me their programme when to come at *township X*. I'm still waiting then for the fax from them. I want to join those meetings because they said it's then that I'm going to be advised and to be told where to go if I want something. Otherwise, with them, they cannot, there's nothing that they can give us but they are just going to advise where to go to get some help. So I'm still waiting for them.

R: Tell us more about the parents that you involved. You started with the ones that work here at school, is it still only those or have other parents joined? And how many parents are involved in the community garden presently?

EP9: There are so many parents, but we have told ourselves that we'll make use of parents with kids here at school, only parents with kids here at school, that is what we are trying to do with all the parents. As a result I

think we are going to have numbers of children, because they are coming here, even those that ..., there were two parents who came here, they came to me to say Deputy, what strategy do you use, because we hear about the garden. Now, there were two parents who came here to ask permission to be part of the school and I told them unless you have kids here in our school. Then they said: "*We don't have kids*", so I said to them: "*It's unfortunate of you, otherwise, but we consider those that are having kids here*".

R: You need to have criteria.

EP2: Yes, but you know even our outside appearance, now you can see, the parents, even the men, you know men are stubborn, but they are trying to assist us.

Change in attitude (culture)

R: What do the men do? How do you see the change in what the men are doing?

EP2: You know, they always come to school and clean the plants. They came and cleaned the plants and then they cleaned the doors. They were the volunteers, they volunteered themselves.

Men involved

EP6: What is happening, again thanks for that vegetable garden, because we used to have animals moving around the school, but seeing that the parents are having the garden here at school, are having plots, they are taking care of the school too, you see. The gate is always locked, there is no burglary since we did that, no vandalism, nothing. Everybody have an eye to the school because he or she knows that: "*I've got a garden there and I have to look after my vegetable*". So they are having a duty in a way to take care of the school. They are very responsible, it's a community school.

Community take responsibility

Community school

R: I remember that you said last year, that the parents thought that the teachers are different from them and now it seems that you are more of a team, the parents and the teachers?

EP3: We are a great team. We didn't know that in a school we can work together, parents and teachers like this. You see this is so great, but let us move to the support group.

Parents and educators collaborate

R: Tell us about the support group.

EP3: Okay, let's move to the support group so that we can touch on all the groups. They are on information, she is on the garden, ja (*indicating fellow educator-participants*). So after a meeting there was a great improvement, after the meeting where the information team had talks with the parents. We received some parents, we had two parents previously you see who disclosed, except the kid that we know that they are sick. You see, it was like that with the parents that they used to disclose their kids, you see, knowing that they are in our classrooms. But it was worse now, we had a step forward because they did come forward and it's a very touching moment. It needs somebody who has a heart. It touches us a lot in the sense that we have to pray all the time. We did get those parents, they did come to school, one of them you could see that she was very sick and she didn't disclose for a long time. She got pregnant, after getting pregnant, she didn't know that, but she could see the symptoms but she didn't know she's HIV and when I asked her, on our talks she delayed herself because if she had told the nurses that: "*Can't you please take my blood so that you can check if I'm HIV or not?*", because she did go to the doctor and the doctor said you must go to the clinic and ask for a HIV test and if they tell you that you are positive you must terminate the pregnancy. But she didn't do it because she wasn't ready at that time. So she got through that and she got sick. What happened is that when she was in hospital, after giving birth. You see, they were told everything, after giving birth, and she could see a file and it's written there "*HIV*" because the nurses couldn't tell her, because

More disclosures

Prayer=central

Doctor=advice

Clinic=resource

she wasn't ready and she didn't say that take my blood so that you can check so and so. It is up to you to tell them, you see that's what I told her because she was complaining to me, so that I can see for myself. And I said the nurses cannot tell you because sometimes you are not ready, it's your duty to tell. The only thing that the nurses could do is when they tell them the whole people who were pregnant to tell them: *"We are doing it like this and that. We did take blood but we don't check your status, it's up to you to come to us so that we can check your status"*. She got sick. And when the doctor came to her and asked: *"Did they tell you the result?"*, because you could see she was very sick, then the doctor asked her, if the doctor said: *"Did they tell you your status?"*, she started crying and the doctor moved back and didn't tell her. She was discharged and she wanted to see her child because she didn't have a chance to see her child. Then after that meeting here at school, he came to school, then I was called, she was crying the whole time I was talking to her. But it was during school hours, I couldn't call C and the others you see, and the principal called me.

R: What do you usually do? Do all three of you talk to the parents together?

EP3: Ja, it used to be the three of us.

R: In a private office?

EP3: In the private office, but that day the principal asked myself to go there, because it was during school hours and I asked them not to disturb me and I talked to her and I showed her what we received from you and what I've learnt from the books and what I know. She was crying the whole time and she stopped working, she hasn't got an income, she doesn't know what to do with the child and I tried to convince her. After that I told her that what you can do now, if you're ready, you can go back to the clinic and talk to one of the nurses and ask them now your status, it's after that that we can do whatever we can do. Fortunate enough, she got a friend who is HIV positive and who is helping her, like trying to

Friend/ HIV positive and friend supports her

convince her I'm HIV, but look, nobody knows that I'm HIV but I can tell you now because I know your status you see, but she was crying all the time. But what made me so excited is the following day when she came, she didn't even have a tear on her eyes and she said: "*I came here to thank you. I didn't know that I could get help, even the nurses at the hospital prayed for me and said why did you take so long? And I told them it's only when I got information at the school, it's only now that I'm ready*". They prepared a grant for her, they gave her a cream, and I told her that you have to get a cream you see, because you told me that you haven't got money, so you have to go to the clinic you see, because there are some things that you cannot do, that you have to refer them, they gave her a cream and that cream is doing very well, I don't want to lie but when she came to school the other day and I said: "*You look nice, can you see yourself?*", and she was so excited, full of smiles, I was so glad.

Prayer
 School prepare for disclosure
 Grant
 Financial need
 Clinic=resource
 School/ teachers refer

And she stopped breast feeding the child, but she didn't even at first because she was sick. She is getting food here at school and she is so excited and the child likes that nutritional food because she's not breast feeding, now we haven't got money to buy food, now she's getting food from school, she's getting vegetables. I told her the way to eat you see, and I also told her to ask the clinic nurses to tell her more about what she is suffering from so that they can add more on what we have told her you see. So I'm so excited. Now the other one, I'm going to my other case now.

School provides for needy

R: First tell us about the parcels you give to people?

EP7: In the parcel, we got those food parcels from Cadbury, there is a lady who is working at Cadbury.

Networking

R: How did you get to contact her?

EP7: She is on the support group at my church. She had a sister who passed away who was HIV positive, that's why she decided to be on a support group in her work at Cadbury. So what they did at Cadbury, they gave them food parcels so that they can give to people whom they know that they are HIV positive. So that lady contacted me, and she told me that: *"I've got these soups and all these things"*. And I said: *"Can't you give it to me because I've got some houses that I used to visit and some people that can get the food?"* And she was so excited and I went to collect them, that is the food that you are seeing here. And the clothes, we collected some clothes. We could see that they need clothes even for their kids you see, that's why we asked the school to donate some clothes, even the principal has got some clothes parcel, he is going to bring it, even other teachers, they are so excited to contribute the old clothes. And then it's the vegetables. They are coming on Wednesday because they have to eat greens.

Arranged parcels

R: Do you include African potato?

EP7: Not yet, African potato is what we are telling them, meanwhile we don't have it. This it's Becko, fortunate enough it's a Vitamin B – they are getting it from the clinic, all of them. And if they are running short of that Becko, we've got medical aid, we are going to supply them with Becko, we did bring even some Becko that we have, so that if they are running short of Becko, because they are getting it in a clinic.

Supplement

R: Is the medical aid bringing the vitamins to the school?

EP7: Ja, we want to help, and Becko is not that much expensive, but it's expensive to them because they are not working. We're trying to show them that we are here to help.

EP3: I'm coming to that one now. There is a parent who had a daughter, and the daughter is HIV positive from 2000, her husband is so furious he doesn't want to see the daughter and the husband is asking when is she

going to die. He's a step father, the mother is not working, she has to hide food for her daughter because she's not working. She has to take food from her cupboard but he husband mustn't see it.

R: Are they staying together?

EP3: No they are not staying together, the mother, eh, what she did, she went to ask for a plot, she is staying by herself, she is 22 years old, she has got two kids, the other one is safe but the other one is – but she said she is not infected at all because she did use AZT while she was pregnant, she is a brave child because she could speak and she is not afraid, she talked to us, she has got two beautiful girls. She is getting the grant, the other one is one, she is getting the grant, so we are also helping her with food. We are helping the mother so that she can take food for her, she did come to school to take their share, they are staying far away. Disclosed

EP9: But we still have a problem, you know. We are trying to organise for her, but still we are having a problem now, because of the abuse of the grant, the disability grant, the government is very strict now. When we phoned the ATICC they told us that the CD count must be below 200 because of the abuse of the disability grant. But we are trying to get hold of a grant, but we did get for that one, because at the clinic they did everything for her, but she is taking treatment. Abuse of disability grant
School assisting in getting a grant

R: You are really helping them. I want to hear from the information team now and then we can go back to the cases. Tell us about what the information team did, and about that evening that you planned, when you invited the parents and when HIV and AIDS was on the agenda. What did you discuss? What did you tell the parents?

EP6: You know Ronél, because these parents are coming to school timeously and meeting with the support group, usually if they are having a problem, since we assigned N to report to when they are having problems. So we only do capture some problems and the problems are not too much now

because they are coping well, you know they are doing well with these support groups. So instead of coming to us now, at information, we are referring them straight to the support group because some of them are very ill.

Coping well

R: It sounds as if the need for caring is currently more than the need for information and prevention, is that correct?

EP6: Ja, we only give information to their kids, how to take care of them, but the good thing of it is the thing done by the support group because really they must be supported by Ford, by Biko, supported by everything.

Information to individuals

Networking

R: Do you think the information group should continue?

EP6: Ja, it must carry on because most of the time they get the information from the parents meeting.

EP8: We are working hand in hand with them.

EP3: Yes, because even we as the support group, we have to take part of the information, we are doing also the information, it's a sort of a glove.

Collaborative approach

EP2: I was going to say the same thing that *T* has just said, after we have the parents meeting, the parents did come to my class, trying to get more advise from me. Then I refer them to *T* so that she can try to give a little more support to them, because she has got the transport, she visits their homes and take them something, whatever she has she gives to them at their houses.

EP6: You know Ronél, the thing is, if the case is being reported, it's not easy when you visit the parents and they say: "*This one is doing this and this one is doing this*". So the one who goes to that house must do it all. It's not easy to separate.

R: In other words you started doing each other's chores?

EP6: Ja, as long as one is empowered.

Empowering
community
member

EP8: Okay, further on the information. Now we've got the books and we teach kids about some of the facts, because some of the kids are sexually active now, and their ages are 15 to 16 some of them. We teach them how to handle a condom, how to use it, when to use it. But I think there's a shortage of female condoms, because they don't know how to use it and it's different, it's too different to this one because this one is easy, the male one and this one, you take it the whole day, 8 hours with yourself and to these kids, it's not easy.

R: Do you only teach the children in your class or do you teach all the children?

EP8: No, the phase 2 children because they are older than these.

R: Who teaches them?

EP8: No, I do the teaching.

R: And you see all the kids?

EP8: Yes.

R: Boys and girls together?

EP8: Boys and girls together, but sometimes some boys are naughty, they don't want to go there because they know they are sexually active, they know what is going on there. They use sometimes big names that we don't want to share with you, we're just giving them the basic of how a child cares for themselves.

R: Do you find the formal curriculum on Life Skills useful to help the children, to give information? Or do you just give outside information?

EP8: The information that I'm giving them is the information that is in those books, that are supplied by the government, but there are teachers who were trained last year, currently they are not doing it because they are waiting for the curriculum as a learning area.

EP6: But what the department did after those two teachers went to the course, they did supply us with Life Skills books, from Grade 1 to Grade 7, that's why I told the deputy that those teachers must make use of those books because we are using them. Even the lady, *Mrs S*, the lady who is working at the department, who supplied those books used to phone at school and ask if we are using those books, that's why I say to deputy: *"We must make sure that other teachers are using those books because some of the teachers are using those books"*.

R: How many of them?

EP6: It's almost like eh ... 30 percent, especially those teachers who did attend the course, they are using the books.

EP8: There is another problem, sometimes they don't want their kids to learn anything about sex because they're saying they are turning them in other words, so we don't know really because some of the kids, once you start talking about this they want to be excused.

R: How do you deal with that?

EP8: I excuse them, because you will find that the principal is saying that the policy of the department is silent about that, they are silent about the child, the parent must let the child, must allow.

EP6: But in future what we had to do, we had to start with a parent, especially the information, our information committee. They had to start with the parent, like when they are educating the parent about this, they have to tell them that there is a need for their kids to know or they can ask from them: *“How do you feel if we can?”*, but we are going to do it in future, like next year.

EP8: But the parents, before, before we started all these things, before we started talking about the HIV, we called the parents, but you know if you come the parents they don't come all.

R: That was before?

EP8: Ja, but not now, especially now they are seeing we are working together with them and they are getting help, I'm sure they will understand what is taking place.

EP6: Ja, and they can tell them why do we have to do that. Because if we can start now to educate the young ones, that means we will have a greater nation, they will grow up knowing what is wrong and right, and that means even the number of HIV and AIDS infected will decrease. But as long as the parents can understand it, it will be easier to talk to the kids you see.

Positive future perspective

EP2: Okay, the problem sometimes is, the parent is reluctant in front of an educator to say: *“Okay I can be with you in this, I can say this in my house”*, but I had a problem last week, two boys, these boys are not sleeping at home. Seemingly there's an open house where they sleep with these girls and these boys are here at school. So when the parent came, I referred this parent to the teacher who is the class teacher and who heads this course of Life Skills. Then the parent is saying: *“I've got my culture, there's no white man or a book can say to me I can do this or that in my house”*. So some parents are reluctant, though you want to empower them they are reluctant. He or she cannot come to you and

say: “*Okay, I will be with you, I will do this in my house*”, but at the back he knows what he’s going to do.

R: Do the majority of the parents feel like that or the minority?

EP8: Few of the parents are open when they come to me, few of them are open, because they don’t want to acknowledge the fact that their kids are sexually active, they don’t want to see, if eh, they say their children are young, they are not involved in sex, but they will see it later when the problem is there.

EP2: And most of the parents here in this community are backward, you see, they still have those traditional minds, they don’t want to speak out about HIV, though they know HIV is something that exists, you know. It’s only because ... eh, even we educated people, we don’t want to talk about HIV in our houses, in our children’s presence, it will be difficult for uneducated people to talk about it, you see, but we are trying by all means and we are going to try. It will take time for anyone, even for yourself to be convinced. As long as there is reinforcement, we must stick on reinforcement, talking about it, talking and talking, at the end they will understand about it.

Hesitant to talk about HIV with children at home

Perseverance

EP3: Let’s talk more about the 22 year old girl who has two kids. What we want for her is to go back to school next year in January, she said she wants to go back to school because she was doing Grade 9, but the problem is the young child, the young kid is still young, she is still breast feeding, I don’t know what the risk of that is, because she’s HIV positive.

EP6: She did use the AZT, the child is negative, but she’s still using breast milk, because she doesn’t have money to buy milk.

R: What she can do, *M*, is to send her information to us, there are people working at the university and they developed a very easy way to take breast milk and sterilise it so that the mother don’t transfer to the child

when breast feeding, and it's so easy. It's just a little steel pot, and you boil water and put the water into the pot, then you take out an empty jar and you express the milk in that bottle and you put the bottle in the boiled water for a few minutes, and when you can put your finger in the bottle, then that milk is fine for the baby to drink, so if they use that procedure then a person who is HIV positive can give breast milk to the baby, if she follows that procedures correctly.

EP6: Because the one, when we asked some advice from somebody else, she was afraid that the child can bite the mother's nipples and can contract HIV.

R: Blood is not a problem, the milk is the problem. The HI virus is in the milk.

EP6: Because we did tell her that she must stop breast feeding because maybe the child was safe because she did use AZT when she was pregnant. But what is she going to do? She hasn't got food to feed this child, she hasn't got money to buy milk, she depends on the breast feeding.

Give advice



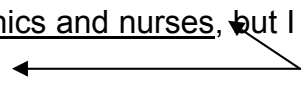
R: Doesn't the clinic provide formula milk?

EP6: Not all of them, but that child did go to the clinic to take treatment and all those things you see, but the only clinic that I know that distributes milk is *hospital D*, but we have to see how to get in touch with them, contact somebody.

EP8: Or even if you've got some more booklets, because sometimes we want to give a booklet to her so that she can read for herself, to get more knowledge but we haven't got those books, the only ones that we've got is for ourselves.

R: Have you thought about contacting some of the NGOs for information and booklets?

EP8: Ja, for booklets and even the pamphlets, because we must have them, because sometimes you are talking to them, but you need something to give, especially those books, they are nice because they've got Xhosa part of each so it's easy for them to understand.

R: What about social workers? We've spoken about clinics and nurses, but I don't hear any of you talk about the social workers?  Assets

EP2: At the clinic they refer them to social workers, it's so nice when you send them to the clinic because they refer them to the social workers.

R: Do you refer them to social workers?

EP2: No, it's the nurses who refer them to social workers. We haven't got a social worker who can work with us. The only social worker, who used to help us, is from ATICC, but that social worker, when we phoned her the week before last, she has been promoted to Johannesburg, but the other one assigned to us have not yet worked with us, we couldn't get hold of her, but we are getting her.

EP3: Ja, they used to help us, even if you phone them they used to bring food parcels, but now since she has stopped working there, we haven't received any food parcels. They used to have those visits, ask for an address and go for a visit, but she is new, we haven't met her.

R: You can also consider contacting Grace Ngwaba at the Department of Social Development, she's a social worker and she said that she will be able to give you information and contact detail.

EP6: I've got something else I want to share with all of us. I was watching TV, it was on Tuesday night, this happened in Uganda. I'm sure where, but

she was asking the girl if, what happened, eh ... there was a little girl who was married in Uganda and she was 16 at that time, then the husband went to work at Johannesburg, when he came back, the husband was HIV but didn't tell the girl, the wife. Then the wife slept with a man for almost a year, there was nothing wrong. Then after a year, this girl wanted to go back to school, didn't know what is happening with her. She then went to school, there at school, because she doesn't know. She was a runner, in athletics, she was playing netball, all the school kids are doing that, then she fainted, they took her to the clinic and the clinic took her blood and then, after two weeks she was called. At that time she was with nobody to support her. She heard the news that she's HIV positive. She kept quiet, from that day to date. When they visited her home, there was nobody, she was staying with her husband and her husband was a furious man, this girl became thin and thin, the neighbours were very far from their house, then at school she told one of her teachers, she said: "I think I must tell you that I'm HIV *positive*" then the teacher said "*You are going to infect other kids, you are supposed to be killed*". The educator told the chief, the chief told the subordinates and they called her and then eh ... They called her, they said: "*With whom did you sleep after you heard your status*", she said: "*Nobody*", they said: "*Where do you sit in the classroom, do you sit next to a boy or next to a girl?*". And she said: "*I'm sitting next to a boy?*". She suffered inside, because eh .. eh, emotionally she was not talking to anybody, and that educator was wrong because he should have known what is happening, but because of the culture, the chief and the subordinate was reluctant to inform the whole vicinity about this. So I wish that if that girl goes back to school she must have one teacher to tell her that: "*My status is like this, that I was supported by some members at school G, so if you are having a problem with me, just refer myself to school G*". It must come from within, within her, it's not something to be forced.

EP4: To the story that Z relates to us, that means, let's take it the way she related the story to us, that means even if that child, she can tell her

teacher, she is not quite sure how her teacher is going to react, let her be ready first and then she can see what kind of a teacher she has. Sometimes if she's a good teacher, maybe sometimes there will be some things, or some topic that will touch on HIV and AIDS and she could see how she is going to react, is when you start trusting somebody else, it's not easy just to get to a school or to get to a situation where you can go and say I'm HIV positive.

R: You say there's an increase of people coming to school. What do you think are the reasons for that?

EP7: Okay, the reason for this is because when the information team tell them about it, when we put them on the programme, we told them that since they know nothing about HIV and AIDS, they can come to school to get help. The only thing that the teachers can give them is to give them help and to show them the right procedures to take and give them the advice, good advice, that's what the information team can do because they know nothing about this.

Increase in disclosure

Reasons: can get help and advice (from school)

R: Yet they know they will not be judged?

EP3: Ja, it's confidential. Mind you, they can tell you about the visits, the people who are staying together, both of them are HIV, you see, you can tell them maybe about our visits.

R: How many families are you supported at the moment?

EP3: At the moment, and I'm talking about the parents, four parents excluding the kids that we used to talk to you about, excluding them, that means they are coming, even now the other parent came to us you see, talking about their children. We said to them: "*You must take time, you come to us when you think they are ready to talk to us, don't force them to come us you see*". They did come to us, say: "*Look I've got someone, I've got my child who's HIV positive you see, may I bring her to you?*" But the

four of them, we have four houses that we are supplying with food, clothes, vegetables you see but they who are coming and even ourselves we don't want them to come in big numbers so that we can control them, it would be so nice if you get them bit by bit so that you can have time for them. Because if they can come in numbers, maybe sometimes they will come just to get vegetables to fool us, because the ones that are coming to us, are the ones that we could see they are weak and they need help.

R: And child-headed households, do you have more houses where there's only children living?

EP1: We have 7 or 8 children here at school.

R: How do you help those households? How do you support the child-headed households?

EP7: You know, what is happening with them is they are the one that we organise for, like with ATICC. ATTIC used to bring food parcels to go to them when they are sick but some parents they come to school, but when you see the child is absent, to disclose the child but the parents vanished, you see. But those we have are getting help, even the others were getting a grant of R130, it changed to the disability.

R: What does ATICC do and what do you do?

EP9: It is, they give food parcel, they are getting food parcel, they are getting information, we are working hand in hand, what to eat, you see, if they are sick they can report at school, we phone ATICC so that he can send a social worker, someone to help them.

Disclosure
↓
Get help and advice and food parcels and social worker

R: And the function of the support group?

EP7: We pray all the time, whatever we are doing is based on prayers because when they stop crying, is when we pray and we've told them: *"You must also pray all the time, you must know that even if no one can love you but God loves you"*.

Prayer=central

R: Yes, and they often need love, they miss to be hugged.

EP3: No, what is happening here at school is and what we've told their parents, because they are young. When we went to those houses, *M* is going to tell you, when we start talking, we know they've disclosed their status. We will tell them that: *"You know what, we are your friends, when we are sitting here, we are sharing everything, if you have a problem you must know that you've got a friend at school"*, you see, we don't go there sort of as a teachers or educators, no, we go to them as friends, even those kids who are here at school, like the other one, they used to come to me, like *T*, she is my friend because I hug them. When they go to stadium I say: *"T, here is something, you must buy fruit for yourself"*, you see you create that atmosphere of trust. I've got someone who loves me, I've got someone whom I can go to and talk you see, but we don't say why we love *T* you, and *T* would say: *I know there's somebody who loves me at school*", you see, that's why we create that atmosphere of trust and love.

Support as friends

Trust and love= important

EP2: Another one is, when we visited the other house there, *B*'s mother told us that: *"My child came to me last week and said my teacher said to me those parents don't love you"*, you see there was a parents day, and that parent was not there, she didn't come to school and the teacher said to them: *"Those children that their mothers did not come to school and were not here, they don't love them"*., You see, in a Xhosa way that can help you. And then that child went home and cried and said: *"Mother my teacher says this and this"*. And then, that sick mother was crying to us, she said: *"I'm so worried I can't go to school, I was sick"*. Then I said: *"Okay, next time we will be your parent of your child, we will go to their classes and tell the teacher you are sick"*. *B*'s mother was very sick and

Take care of children

she was very emotional about it because her child was crying because she did not come to school. And then we promised them we will be their parents, we are going to take care of their children, we will be part of their children, she is quite a caring mother, she was so hurt when the child came and she was very sick. The time when we came there she said I'm so glad that you came but the thing that made me.

EP7: Yes, but sometimes the children don't know and we tell them: "*Because she doesn't know you are sick because you didn't even write a letter to tell that you are sick*". That's what we used to say to those parents who doesn't care, but starting from today, because she wanted to come to school: "*I can go to school and tell her that I've got this and this*" and said: "*There's no need for that because we know as support group we have to give you a support*". What is going to happen, we are going to talk to the teacher and what happened really here at school, I called the teacher concerned and I told the teacher what happened, the teacher was so worried you see, and I said: "*We know what happened but I want to tell you about the mother's child, the mother's child is very sick, sometimes she cannot come to school, but you can give us the report so that we can be the mouth for her when she is sick. So starting from today, you must know that she cares for her child and she is a sick woman, if she's okay she can come to school, but if she's got a problem contact the support group so that it help you deal with the problem.* And what you can do now is to go back to your classroom, to create that atmosphere of trust, go to the classroom and tell that little boy that you know why the mother wasn't there and you excuse yourself because you know that her mother is a caring mother". So she said: "*I'm so worried but I will go to my classroom to create that atmosphere of trust to the child and tell the child I know your mother was sick that's why she wasn't here*".

Supporting by taking over parent responsibilities

R: It seems that you are directly supporting the community and also indirectly the teachers and then you are also spreading the word to the teachers.

Supporting: -community members -colleagues

EP3: Ja, and look Ronél, when we visited those homes, I can see that, I could see that even the affected, the people that live together need support because when we visited that home, the mother who is taking care, the grandmother, she was crying but she was so excited to see that there are teachers who care about them you see. Because even ourselves, we told the mother that: “*You are a great mother, did you know that you are a great mother? You took care of a neighbour who got sick, you take it to your home that means you’ve done a great job and you must keep it up*”. And that mother, you see, was motivated because now she’s taking care of two people, her daughter and the friend of the daughter who’s staying with them.

Affected needs support

Taking care of family and friends

R: Do you ever talk about their status, like tell the mother and the child together “*Child, your mother may die and then this is what’s going to happen with you*”?

EP3: No.

R: Have you discussed the testament or the will for the mother with her?

EP3: Not yet.

EP4: We’ve got a poem in our Grade 5 prescribed book, this poem is about HIV and living together. It goes on and goes on and at the end it says: “*I’m here today but I don’t know about tomorrow, we are here today, we won’t be here tomorrow, I’m sick today and I may be sick but I wish you to be my companion*”. It is sad and in my view you can explain more and more. And while you are explaining, you can see they want to talk and when they talk you know that they understand everything, they know what grief is, they know if the one is not here it is because of this. People know and they will come and support us, we will depend on some others.

EP7: That's why we encourage the living together so that if one of them can pass away, they can take care of each other, it's so nice when you see people living together, living and caring for each other.

R: Tell us, do you give like legal advice, counselling for legal assistance to, for example say: *"If I die this must happen, the child must live with these people, these possessions are going to this child"*?

EP4: Sort of like a will?

R: Yes, does the support group tell them to write a will, to tell the child: *"Listen your mum said, maybe you will stay with this aunt or the grandmother and it is written by your mom in a legal document, so nobody can take you away from what is their property"*.

EP8: But in our culture, it automatically goes that way.

EP9: But we need to advise them. ~~You know some of them are illiterate, they don't know how to write, they don't know how to do anything. We need to advise them~~ and once you advise them, the support group once they are there, in those houses, they need to advise and ask them if after she or he is gone who is going to look after them.

Advise them
with regard to a
will

EP7: With our culture it's like this, if we can say, like the question that she is going to ask is *"Am I going to die tomorrow?"*, that's why she's asking me such a question. Unless we can do that if we have been dealing with these houses for a long time, we must check for the process, after we can see that okay these people understand us and we can, like on our talks, when we sit down and talk say *"Did you know that one day you are going to die"*, but now it's too soon, because now we are giving them strength even though we can see that they are very sick, we say: *"No you are going to be alright, be strong, it doesn't mean when you are sick you're going to die"*. We cannot mix those two things, so if we say: *"Did*


you write anything about your kids?”, they will say that we can see from them that they are going to die.

EP3: Yes, we have to select the words.

EP7: We have to say: *“You are sick, or if you are sick you have to write something so that your children must stay with your aunt”* or something like that.

EP3: But it is wrong when we do that, you cannot use those words when they are sick, it's a process. On our process when we could see that they are working, they are doing their chores okay, it's when we can start saying that now, when they are okay doing the whole thing, not while they are sick.

Sensitive approach



EP4: I was going to say it's one thing to advise them to have something written down, as to who is going to take care of my kids when sometime I die, but it's difficult for us to do that. Each and every time we must always give them hope that they are going to get well, so if we mention something about death they will become very sick and die at an early stage without having prepared themselves for their kids, you see.

Provide hope



R: I believe you have to start with what is tradition, and be respectful and even more so with something such as HIV and AIDS. But I also think we must not be blind to the fact that people die from AIDS and then children are left without a parent and their biggest fear is uncertainty. Children are not dumb, they know that people die, they can see it.

EP7: They do talk about those things, but we must do it at the right time. We are going to do it, if it's a good thing.

R: Yes, wait for the right time and then consider helping them to also keep a birth certificate for the child, all those important documents so that this

child and the aunt know that this is all the formal legal documents of that child.

EP7: At the end we have to teach them about the memory box, but it's a start now, but when we could see that we are working hand in hand with them, it's only then that, on that memory box everything will be there.

Potential asset/
next project

EP9: Ja, even us, if there is somebody who's selling insurance, we do take insurance policies. It's for our children, we are preparing because we don't know when we are going to die, but to us it's different because we are not sick. There's no stigma, otherwise they must know that they must do it. Even themselves, they've got that thing on their mind, that I want to leave my child with my sister, I don't him to stay with my uncle, they have got it, it's to brainstorm it in a way.

R: Okay, I think we can wrap up the first part of today's session. I think we've got a good idea about all three of the projects and it sounds like it's going great! For the second part of today we would like to know: if you look back over the last year, what do you think what worked and what should we have done differently?

EP6: You know what, I want to thank you because we were sitting here doing nothing and then you came to us. The first time you came here I thought it will be a workshop, it will be a once off thing. I said it's not a thing I was thinking, I was looking for, what is this now, these people are coming to us, these people come to us, they want us to talk, talk, talk, talk, talk.

Participants
empowered

EP9: I agree, but I say now we must keep on working, we must keep on sharing.

EP7: You know, like I joined you later but I don't regret that, but I'm with you now, for me being here with you, I've been wanting to help people living with HIV and AIDS but I didn't have a breakthrough. But for me being part of this team, now I got a chance to do whatever I wished for. Inside

Empowered in
the process –
by serving the
community

myself I'm feeling great that there's a lot that I'm doing for the community who are infected or affected with HIV and AIDS, through you.

EP5: You know what, it was something that I was thinking about it, but I didn't know how to start it. I said you, have a light, why I don't use it, I am a candle, why I don't use this light to the community that I'm working in. I was doing nothing, but I was thinking of myself. Brenda Fassie passed away but when Brenda Fassie passed away, everybody was talking about her work, she did everything for the people. Brenda Fassie died but her work is still living, it's still with us. And what am I doing as a person? What I was doing for the community, there was nothing I was doing. I want to thank you because now I feel proud that there is something I'm doing for the community. I am the light here in this community now, when they saw me, when the people see me here in this community they can see *Mrs M* as on HIV team, *Mrs M* she's a real teacher. To be a teacher you are like a minister, you've got a mission, there is something to do, you must do something, like Jesus, Jesus was a teacher. Now what kind of a teacher is going to come just to school and teach the children and then leave. What am I doing for the community? Are you supposed to teach netball for the community? I'm supposed to teach them anything that I know, but now I feel great because in my school there's a garden, in my school there are some people that are coming in and out. In this school there were no people coming in for help, they would just ask for the work of their children and then they go out, and now they were coming for help, they know they will get help. Thank you again.

Feel enabled
and skilled =
Empowered

R: M, when you said that we wanted to talk, talk, talk, talk, talk, what do you think, what should we have done differently, that first day we came?

EP6: You know what, in the first day, I said to *Mrs J*: "*I'm not coming again because they just ask us, what do you know, how do you know?*" I thought we will have pens, and pencils and write and write and write, and look at the board and write and write.

R: You thought you were going to learn?

EP6: Yes, I though I was going to learn from you when you first came here, and then your teaching was different, it is knowledge, we work together, we share the knowledge and it is great and then I said: "*When will we meet again?*", and then when you came again we were so happy. Your project was not boring because we helped.

← Links to methodology

R: So actually you liked the fact that you talked and talked and talked? (*laughing*)?

EP6: Ja, everybody is free to talk, we don't just listen, everybody is free to talk you know, and as you know, I like to talk.

R: So you like the participation?

EP6: Ja, but even, later I was so worried that the time was too short, if you came at 14:00 and left at 16:00, I say I wish we started at 08:00 to 17:00.

R: Do you suggest longer sessions?

EP6: Yes, but not after school, during weekends.

Recommendation – for improvement – longer sessions and weekends

EP3: Yes, after school is difficult, sometimes you came here at 15:00 and we are staying far and then by 17:00 we are panicking, but I need to be with you 5/6 hours.

R: Which day would be best?

EP3: Sunday, because we want to be with you for a long time.

EP9: Now let me speak to that question of the past year. When you came here, I, myself was like a stagnant water because I had a vision, but my vision needed somebody to stimulate it to be out. Like I was angry at

Need facilitation
At first experienced:
-anger towards HIV
-hesitant to discuss

first with this disease, I didn't want even to talk about it because I was affected because somebody in my house is infected. ~~I didn't want anything to say about this disease.~~ But the second week or third time you visited us, something was taken off my shoulders because I learnt to talk about this. I learnt to see what is happening in the world with a real eye. And as we were always gathering every time, I saw that this one can help me, that one can help me, this is a support group for me, I am counselling myself. Then I said also to myself, this thing is a blessing in disguise to me, because now I can talk to my family about this. We can see this as a diabetic, we can see this as a fever which came to our house, it's not a separate disease. Now you want the difference because you came here. Ronél, it was a blessing in disguise, really because there's a light in our community now, through you and because of us there's a light in our community. There was a conflict before between us and the parents, but I think now they believe in us, they know that we want to work with them. They must not chase us away, we want to support them, they must believe in us because of you. Thank you.

Avoid terminology

Discussing

Enabled to identifying assets

Discuss with family

Community= better off due to teachers input

Parents believe in teachers

Community-teachers= Partners

EP2: For me also, at first when I came here I came for advises because I'm one of the people who are affected with this disease. I had not idea how to support my family and like M, I had that thing that I am a teacher, I must do something, but I had that fear of going out alone. I wanted a group so that we must discuss, so that we must have information from other people, to help the community. We had visions but we could not put them in action. So we are very thankful for your help, you helped us a lot. Thank you very much.

Initially came for advise

Needed guidelines and advice

Feared to help

EP1: And now we can care.

R: You've been caring all along, you must just believe in yourself.

EP9: I'm so glad because we've recorded what you are saying, the evidence, this is a legal document. Because first when you came in here, we thought that we are going to be receptive, to get everything from you, but

it was vice versa. You came here really as a lecturer, coming to the students, wanting to get information from them, it was really a good education to us because everything, we didn't know we are capable of doing some things. You get everything from us, we didn't know that we've got such a knowledge, like a pot full of knowledge. You came to us, saying to us that: You've got something, give us that something". We didn't know, you know what happened, on the bible, I just want to quote: "Moses didn't know that he had something in his hand until God said to Moses, look at your hand, what do you have in your hand?" He said: "I have religious stick" and then God said: "Use that stick". We didn't know that we had a wooden spoon (referring to a symbol used during PRA activities) and we have to use a wooden spoon. Firstly you are a big wooden spoon. Yes, we are wooden spoons but you are a big wooded spoon who can steer teachers to do something, you steered us, we steered the parents. So it's a sort of a circle, you see. Again, you are an eye opener, you opened our eyes. All along we thought that we've got good, that our side is very good, until you came and took out us and showed us what it is that was in our eyes, that membrane, you took a membrane out of our eyes so that we can do something for our nation. You helped because, eh ... I didn't know that, I'm sure everyone here knows her strong point or her weak point. I couldn't see my strong points. Yes, I didn't know what I'm capable of doing, but you did make sure that I know what I can do, because if you didn't come, I wouldn't have known that I can do something for the community that I'm working for, for the people in my church, and they trust in me. What I learnt here is what I'm doing in my church. You've shown us that we are able, we are capable of doing things but we don't use that capability of doing that, but since you came here, look at the garden, there was land that was not used, it had nobody to work on but since you came we've got a farm out of that land, we've got a *plaas – is nie 'n tuin, is 'n plaas, groot plaas ook.* Today we are proud of teachers that can help our nation. You know what, when you first came to this school, when we wanted to have the motto of our badge, we said we must be the light of this nation. We have to be the light of this community because we knew that this community

Empowered and feel enabled

Mobilised to go into action

Expected expert advise

Feel skilled and proud

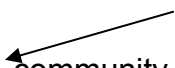
Feel they are leading and helping the community

has got illiterate parents, and we wanted to be a light, but today I can stand here and say school G has progressed on that, and school G is the light of community X, because where parents can get help there is a light. And it's true that, you can forgive me please, it is true that when you educate a woman, you educate a nation, when you educate a man, you educate an individual.

R: When we came here, we saw all these beautiful woman and there was one man. And you started talking, telling us what is going on, and that you thought that you were not doing anything. That first time we drove out here and we thought to ourselves: "*But they are doing so much!*". We thought maybe we shouldn't even be here because you were already doing so much and then we thought: Okay, maybe what we were supposed to be doing here is to tell you that you are doing so much because it didn't seem as if you knew that.

EP8: You know what, we are no longer educators now, we are community workers, because we are here to work in this community.

Acknowledge
important role in
community



R: Okay, I think that wraps it up for today.

Mapping activities



Getting to know one another



Starting with a clean sheet



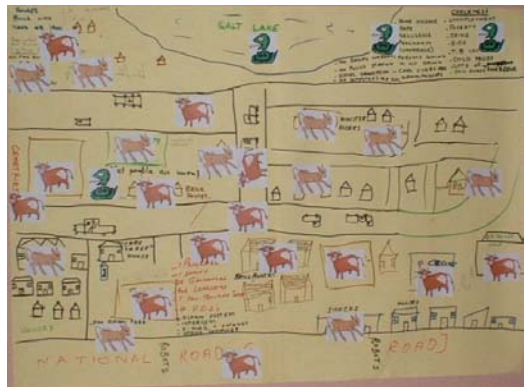
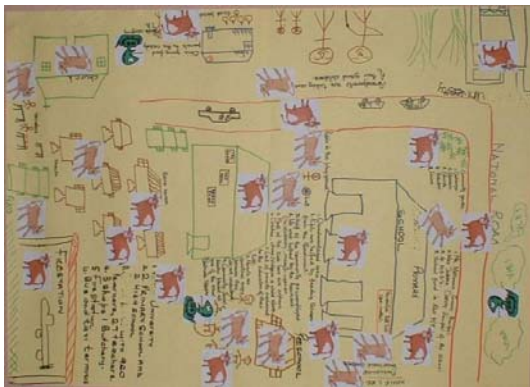
Mapping the community



Mapping the community by means of photographs



Identifying challenges (snakes), assets (cows) and potential assets (calves)



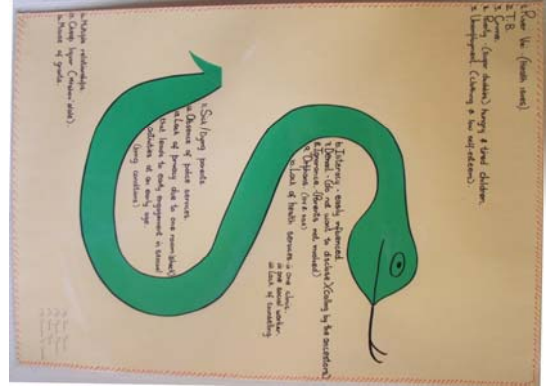
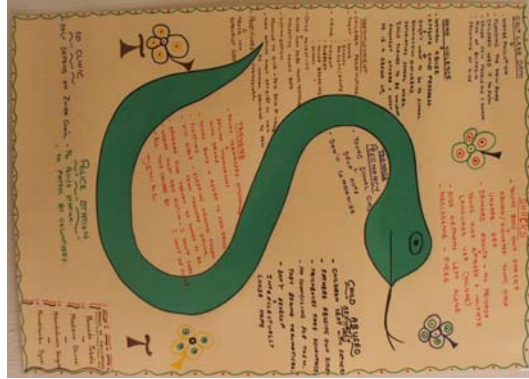
The community mapped



Mapping community challenges



Mapping assets and potential assets to cope with challenges



Community challenges mapped



Community assets mapped



The educator-participants



Planning the three school-based projects

INFORMATION SHARING

PLAN OF ACTION

- *TO REACH OUT TO THE whole community.
- *TO INVITE THE experts ^{doctors, councillors, church ministers etc.} + ATTIC
- *TO USE MEDIA CENTRE (for making for info & videos)
- * Use Flexi Time for learners to give them information.
- * POSTERS + Flyers.

PLAN OF ACTION { SUPPORT GROUP }

1. VISIT ALL ALREADY DISCLOSED
 - GIVE SUPPORT
 - PRAY
 - GIVE RELEVANT SOURCES I.E. ATTIC - ALREADY IN USE
 - SOCIAL WORKER
 - HOSPITAL/HOSPICE
2. ENCOURAGE GOOD DIET I.E. VEGES
 - VEGETABLE GARDEN
3. FORM SUPPORT GROUP - PARENTS AFFECTED
 - INFECTED PARENTS
4. ENCOURAGE CLINIC VISITS I.E. MEDICATION
5. ORGANISE CARE-GIVERS WHERE POSSIBLE.
 - CLEANLINESS
 - TAKING OF MEDICINE

Action plans



From barren land to a vegetable garden



A team called Masizakheni



The participants:
Self-confident, proud and enthusiastic



DEDICATION:
INVOLVEMENT IN
HIV/AIDS INITIATIVE AT
XXX PRIMARY SCHOOL



XXXXX
8 June 2004

“ I am very much dedicated to the HIV and AIDS information and support group. I am affected because one of my family members is infected with the virus. It has been my wish and hope to give help to the sick, because I have the heart to do so. I once had a learner in my class who was infected. The parents disclosed it to me in a late stage. I feel great because I spent most of my time visiting that sick child at hospital and home. I am looking forward to help and share what I know and understand about HIV and AIDS with the community, so that everybody understand exactly more about it and take precautions.”



The Community



Informal housing



Informal housing



Informal housing



Informal housing



Communal water point



Informal housing



Informal housing



Salt lake adjoining community



Informal housing



Informal housing

Assets and potential assets



University



Welding shop



Bottle exchange



Vegetable shop



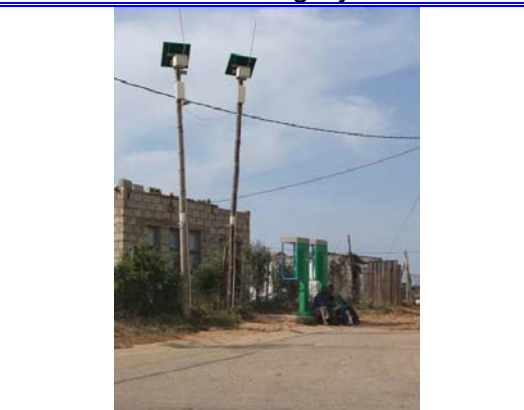
Supermarket



Dr's Surgery



Supermarket



Telephones



High school



Vegetable shop



Primary School



Principle of primary school (Interview 3)



Clinic (neighbouring community)



Government office
(neighbouring community)



Hospital



Hospital ward (not used)



Communal water point



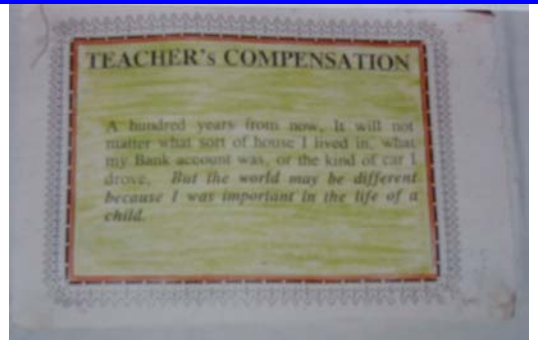
Hospice



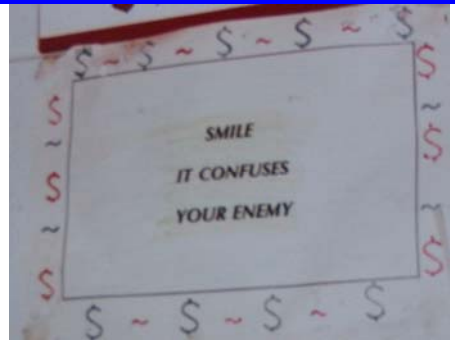
Community care centre (neighbouring community)



Traditional healer



Slogan in teachers' staff room



Slogan in teachers' staff room



Classroom at primary school



School media centre



Inside media centre at primary school



Computers in media centre at primary school



Pre-school in community



Parents from the community that tend the garden

FIELD VISIT 3 – 18 FEBRUARY 2004
INDIVIDUAL INTERVIEW 1
CHURCH MINISTER

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which role is the church currently fulfilling in supporting the community – both in general and with regard to coping with HIV&AIDS?
- ⌘ Which potential role might churches/religious institutions fulfil in future?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: I'm busy with a research study in *community X*, asking the following question: *How is the community coping with HIV and AIDS and the challenges that are associated with the pandemic?* My basic assumption is that the community is coping. I understand that it is sometimes difficult and that the community also experience great needs, but I believe that they are coping. What I would like to find out from you is: *What does this community do to cope?* In other words: *What do community members use? Do they, for example, rely on other people to help them? Or maybe on NGOs, clinics, churches, ministers? What is your perception?*

P: Okay, I think **in our community it's not easy for the people to come out and say in the public: "I'm HIV positive."**

Non-disclosure

R: Is it still difficult to disclose?

P: Ja, it's still a problem. But I'll tell you about the experience which I had, I think it was last year, whereby I was doing my PhD with the University of Fort Hare. In one of our practical subjects we had been asked by the lecturer to go and make a counselling to the people who are living with HIV in, in, in *township N*. So I think it was a man and also the wife, and I think we were three students. One eh ... it was a small lady and the other one was old, the middle aged, and mine was an old man who was about 52. Ja, then I think it was **through the ministers** and **also the nurses who were assisting**, because I was there as the minister and **a certain white lady, was also assisting them by tablets**. Ja ... **through the hope which we gave them, then they could cope**, because we **were visiting them now and again**, now and again, and **we explained** to them that they mustn't eh ... worry, that **they can cope with the situation**. But the problem is **you have to accept it** ... that you are HIV positive and you can also live a longer life if you take, eh **use the medication** and you **take a right diet**. So that, that was the, I think it was my first time to account men who are living with AIDS. But since I was going there, Wednesdays, sometimes Fridays, I could see the change.

Asset: Minister

Asset: Nurses

Medical treatment

Hope as a way of coping

Home visits as support to others

Asset: knowledge/ advice from others

Belief in ability to cope

Accepting status

Medical treatment

Diet/nutrition as a coping strategy

R: Tell us about the change?

P: I mean now, that kind of the attitude whereby you don't need to see people, eh ... you **don't want to talk** eh ... but they became friendly with, eh, to me and then we started talking, then we started to, to eh, to pass the jokes, then **that tension was, was lost**. Then I could see now when I go there, sometimes they say: "*Why you didn't come last Friday?*" You see, eh they were expecting me now at a certain time to **visit them and to talk with them**. So it was the eh ... **they could cope**, but unfortunately at the end of the year, I received the news that the husband passed away.

Avoid discussion

Healthy relationships in supporting others

Home visits as support to others

Supported to cope by community members

R: Was the husband the one that was HIV positive?

P: And also the wife, but the wife was not ill. He was HIV positive, the husband. He did have it bad.

R: I see.

Belief in ability to cope

P: Ja, so that was the, my first time. So I think, **I think they can cope.** It was due to the medic..., it was the **medication** of the **clinic**, I think the sister of the clinic next to *township N* was **counselling** them and **giving them tablets.**

Treatment
Assets related to health: clinic, nurses
Counselling
Treatment

R: I'm hearing a lot of things. You are saying that the medication helped and that the right diet helped. And you are further saying that the support you and the nurses gave them and the regular visits you paid made it easier for them to talk about their status and accept it, that you assisted them in accepting their status, and that that also helped them to cope. Were there any other people or means of support to them, like family members? Or were it only you and the nurses?

P: Ja, they, eh ... they **didn't have a family here** in Port Elizabeth because the guy was coming from Port Alfred. So he was not very long staying in that area. But concerning that they **didn't disclose that to the neighbours**, so they only ... they could only **see when we visited with the home that there is a problem**, but **they never disclosed their status.**

Lack of social support

Avoid disclosure due to lack of support

Stigmatisation
Identify others
Non disclosure

R: Never to the neighbours, throughout the process?

P: Never, throughout the process.

R: So they only trusted you and the nurse?

P: Ja, and there was also **another minister of the Salvation Army** ... he, she **also helped them.** **It was three of us.** **Sometimes it was my turn,** **sometimes it was the turn of the Salvation Army,** eh minister and the

Trusting relationship as basis for support & disclosure
Asset: minister
Care and support in coping

- nurse. **Sometimes we arrived at the same time** because we were checking, now and again, what is the situation. Care and support
- R: And you said that they experienced a lot of acceptance from your side and that you conveyed the message that *"It's okay and you must have faith and accept it and carry on"*. That's the kind of message that you gave them?
- P: Yeah, I **said that they must accept it**. Eh ... **in order for them to be strong**, you have to accept that I have the status ... treat it as if you have the diabetes or high blood or something of that nature. Then you can carry on with your life, eh ... you **keep eh in touch with the counsellors and the, and the nurses**, then you **carry on with your life**. **Your life will be normal** because I gave them the typical example of that lady who was diagnosed in 1989, but even today eh ... she's still strong. Accepting status
Inner strength
Assets:
counsellors,
nurses
Living a normal
life
- R: She's still living.
- P: Living and not sick. And I said that the, **the best way of dealing with it is to accept it** and to say: *"Well, I have HIV, I, I'm HIV positive, I cannot die because of that."* So, **so they listened to us**. Accepting status
Counselling by
minister
- R: And after the husband passed away, did you still went to see them, or did you stop then?
- P: No, I couldn't because it was eh, eh ... I, I finished studying last year. So even this year I thought that it was just the opening, I couldn't make it, just to go now, not visiting because I am a student, but just for my interest to see what is taking place. Ja.
- R: Tell me about this community, here in Port Elizabeth. Are there a lot of community members infected with HIV?

- P: No, there are a lot of people, but you won't hear them saying that they are. You could only know when you see that this person is eh ... becoming sick and very thin and then you'd start realising when you see the symptoms, but they won't say that we are HIV positive. High HIV infection rate
Non-disclosure
Ability to identify
Non-disclosure
- R: Also in your church – they still don't disclose?
- P: I don't know any in my church but the latest one ..., although I was not told, I buried just two weeks ago. He was very thin, ja very thin, very very thin, and to me, I said that maybe she is HIV positive, but it was never been discussed or disclosed to me, that she had the status. Only last Saturday when we had a funeral, one of our congregation whereby the sister of that gentleman felt that my brother was killed by AIDS, he was HIV positive, he does have AIDS. So only last week on funeral, I hear eh ... people disclosing that: "This is because of AIDS." Ability to identify
Non-disclosure
Disclosure: at funeral
- R: Do you provide support to such families?
- P: We can, we can provide if we have eh ... well, the information. Potential asset: support by church
- R: But you only received that at the funeral?
- P: Only on the funeral.
- R: What about the family that stays behind?
- P: The family ... It was, it was this weekend that we heard of that, so it's now when we are going to make a follow up. Support by church
- R: Will you support them?
- P: Ja, because my wife was working with the people who are HIV. Eh eh ... she was very interested in this HIV eh courses, then she did went to the, eh that International Aids Conference in Durban. She was there and she Asset: minister's wife

had a lot of books, then she had one while she was here, eh here in this area, eh ... **social worker**. Then they used to ask her, eh if she's present, to **assist the people** who are living with HIV and AIDS.

Potential asset
ito support by
social worker

R: Your wife?

P: My wife.

R: What did they do to assist people?

P: **Giving the counsel**, the counselling. **She did a lot of courses** which deals with this business of counselling.

Counselling

Asset:
knowledge

R: Do I understand you correctly that it was your wife and the social worker in the area that provided counselling to the people, but that they are not willing to disclose, resulting in you not knowing when community members are infected with HIV?

P: Uhm ... ja. **They disclose to the social worker only because eh ... some of them they want a grant. They only disclose to them** because there's no way of getting a grant without being recommended by the social worker. Ja, sometimes the social worker, eh, **she used to ask also my wife** – but the previous one, this one is new.

Disclosure to
social worker in
order to obtain
grant

Disclosure to
selected
audience

Potential asset:
minister's wife

R: And the social worker then helps them to apply for the grant or refer them for the grant?

P: Yes.

R: Does it often occur that community members approach the social worker and disclose their status because they want a grant?

P: Ja, I think it's like that because **people now are for the grant**, they are coming now and again, although sometimes I don't know eh ... what they ..., because **the social worker cannot tell me that they came**.

Asset: Grant

Confidentiality

R: Do you think it will be possible for me to have a conversation with the social worker?

P: With the social worker?

R: Yes.

P: When are you going to have that? When are you going to come?

R: I'm here for the whole week, I'm leaving on Sunday and then I'll be returning in March again.

P: Okay, so the whole week you are here?

R: Yes, I might meet with her on Friday or Saturday.

P: What I will do, I'll get your telephone number and I will make an appointment with her and also with the **auxiliary worker over here, they are working with these people who are HIV positive**. Then I will phone you and say: "*Okay, come on such and such a time.*" I will arrange it for you.

Asset: church
auxiliary worker

R: Thank you, that will be very helpful. I would like to ask you another question. We know that there are many HIV and AIDS cases present in South African communities – that is the reality we face. In your opinion, which sources or resources do members of this community use to cope with HIV and AIDS – in other words to cope with their sorrow and the challenges they face?

- P: I think the better sources for them to use is the **social workers** and the, the **ministers** and the **psychiatrists**. These are the people who can help. Assets: social workers, ministers, psychiatrists
- R: Are there psychiatrists present in this community?
- P: No, I'm not sure of that, because I did not see any office of the psychiatrist, but I've seen them in *community K*.
- R: You've mentioned that community members rely on the social worker and sometimes the ministers, as support base. Could you please elaborate?
- P: For **support base**, ja, but for the **medication** I'm not sure if they have the support or no support, because our **clinics** they **don't have the supplies**. That is such a **problem**, not everything is in our clinics. Some of them they are suffering **because they don't get help**. Support by social workers
Treatment
Potential asset: clinics
Challenge: lack of medical supplies
- R: And what happens when a parent dies, what happens to the children?
- P: Usually with us **as the black people**, the **family take the children**. I don't know, most of the people they, they have families. **So when the parents pass away, the family they take the children**. Asset: culture
Asset: family
Family = caregivers to children
- R: And they look after them?
- P: Ja, but once upon a time I had that idea ... if we have, I, I thought that, that the **orphanages they are the best places of keeping the children**, but it's **unfortunate they are rare**. So now, because now **people they take children because they are related** eh ... to the person who passed away, but **they don't give them the good treatment sometimes**. Orphanages to cope with children
Lack of orphanages
Relatives as caregivers to children
Need for proper treatment of children
- R: Tell me about that. What do you mean by that?

- P: They don't ... You see people, they **don't want to take responsibility**. If you have your own children **you don't want more children** than what you have. For instance, if my sister passed away, I have two children and she, she has four or five. Then **I have to take that responsibility**, ja, it will be seven children. Then you'll find that some, eh some of the people eh ... no, they **can't cope** with that. Extended family = caregivers, despite their hesitancy
Extended family = caregivers of children
Challenge of not coping
- R: Do they then neglect the children or what do they do?
- P: **Sometimes**. Possibility of neglected children
- R: In your experience, is it most often the brothers and sisters of deceased relatives who take care of the children, like the uncle and the aunt? Or is it more often the grandparents?
- P: Usually **it used to be the grandparents**, but sometimes if there are no **grandparents the sisters and brothers**, they are taking the children. Grandparents, uncles and aunts as caregivers
- R: But they sometimes experience difficulty in coping with all the children?
- P: Yes, **they encounter new problems**. Challenge of caring for orphaned children
- R: Who supports them? Are there other people supporting these families?
- P: Yes, a little bit. Because you see, one of the problems, **if maybe I pass away because of the HIV, I don't say to the people that my brother passed away because of HIV**, you see. Then **it's not easy for other people to give the support**, but it could have been easier if they said: "*Okay, it's because of this.*" Then I have this burden on my shoulders. Non-disclosure
Lack of support due to non-disclosure
- R: Why do people avoid disclosing their status?
- P: I would say that it's because **HIV is always associated to sex**. Then if you are HIV positive, it has got that **bad flesh**, that maybe **you didn't behave** Non-disclosure due to stigmatisation, moral judgement

in a good manner. Eh, you have AIDS because you didn't ever behave, your behaviour was bad.

moral judgement, at-risk sexual behaviour

R: So people almost fear that others might say they were promiscuous or that they weren't behaving morally appropriate? Is that what you're saying?

P: Ja, you'll become the laughing stock in the community. Ja, because they don't want that, they don't want that.

Stigmatisation

R: Tell me, what kind of support services do you offer in your church to community members, or to church members?

P: Uhm ... can you just repeat that?

R: What kind of support do you offer for your church members? What do you do? For example, do you visit people when they are sick or what does the church do to help the members of the church who need support?

P: Oh that. I think that is the only thing which we do, is to make the home visits, and if we see eh ... maybe there are that kind of a family, they don't have, they have nothing, then we will recommend in our church council that we give the support which we can give, maybe something to help, to eat.

Home visits by church members
Poverty

Support by churches
Material support (food)

R: Are you referring to people who are unemployed and in financial need? Are those the ones you support by visiting them at home and providing them with food? Is that what you mean?

P: Ja, them, and secondly those who are, maybe the old ladies who cannot be able to clean the house at a certain time, eh ... the women they assist them to clean up the house if the granny's staying alone.

Elderly support with household task (church)

R: Who is involved in providing these services? Only you, or do you have a team of church members helping you?

P: Not a team as such, it will ... that will be difficult. Maybe today I, I, when we see the programme, we conduct eh ... I say: "Man, can't you help me eh ... with her?" Then, at a certain stage they do eh ... work themselves, because I, I, I don't touch all areas. I'm working *area X* and also *area Z*, so I can't be able to be there all the time. So the, the leaders of the groups ... eh, we call it *Manyanos*, the women's gathering, they do it.

Limited time to support
Asset: church support groups

R: What does that mean?

P: *Manyano* is a unit. Ja, I can say ... I, we have a sort of organisation whereby all women they belong. Those who are wearing the new church uniform, they belong to *Manyano*. Always on Thursdays they are coming together as a pray gr..., eh a prayer group and the youth they're coming together on Tuesday to a prayer group, and men they are coming on Saturdays.

Prayer=central
Assets: prayer support group at church

R: *Manyano*. It's a lovely word. And they pray together?

P: Ja, together. So if man eh ... is, is sick or it, there's been a problem, then there are ... that men's *Manyano*, they are visiting the man. And if you belong to the youth, eh ... then that *Manyano* of youth they are visiting all the people who belong to that *Manyano*. And also the women is like that.

Supporting other community members
Home visits by church groups

R: What kind of challenges do you deal with? Is it only people being sick and unemployed or do you also deal with things like abuse?

P: We deal with the bereaved mostly. The abused, eh ... is not, not here, the abused is not .., we don't have eh ... most of the people. The abused, we don't deal most of the time with that.

Challenge: bereaved people

R: The social worker will deal with it?

P: Ja, I think they disclose to the social worker.

R: So you basically deal with illness, bereavement and unemployment?

P: Ja, or, or if people they have, eh ... they are up in any area, if something else is happening, eh then **we give the support to them.**

Support by church

R: Whenever needed?

P: Yes.

R: And if I understand you correctly, you yourself are like the co-ordinating body. You will hear about a problem, find out what is going on and then divert the case to the specific church group that will provide the support. Is that correct?

P: Ja, ja. So as a minister I'm working with all *Manyanos*. If we have a problem, say for instance eh of a woman who is sick or eh ... expelled from the job or the firm has been closed, then I don't only ask women. I ask also the members of the **church council, even the youth, that we go and have a service there.**

Support by church: home service

R: So you decide which one is appropriate and then you ask whoever is available?

P: Ja, if maybe from, from the youth or from the women, eh it was .., I got a report of that nature, then I just organise other *Manyanos* - men, youth and all, the whole congregation. So say, okay, eh ... if we got that on Sunday, we say on Monday eh ... **at six o'clock we are going to have a service there.** Then if, if the youth, eh ... they have to render the services on Tuesday, they are coming together. Then the women they are coming together on Thursdays. Ja, so they visit eh women, eh ...

Support by church: home service

that is their programme. And the men, the, they're coming together on Saturdays, eh ... they continue with their programmes.

R: You are certainly providing various services – it's the praying of the *Manyanos* every week, the home visits and the services that you provide to people that need support.

P: **If people are sick, ja.** But in, in a normal situation, I'm not with them eh ... on Tuesday and Thursday and Saturday. But if one of their members, **if there's a problem which needs the minister, then I go.**

Church supporting sick people

Minister=provide support

R: And apart from having a service you then also ask the church council to support with food, and you might ask other members of the church to help with tasks like cleaning the house or paying home visits.

P: Ja, eh ... sometimes eh, eh, eh ... without going to the church council **I just know the people in the congregation** and say: "*Well, can you borrow us, can you buy for us certain things?*" The people whom you know, but eh: "*I have this family and there's nothing in the family, then can you help us with that?*" And **I'll go to somebody else in the congregation and say:** "*Can you support us with that, eh because the situation here is very critical.*" So I, I could see people who can manage.

Asset: minister's knowledge

Community members supporting one another (material needs) Minister as facilitator of support

R: Because you know your people?

P: Yeah, because we have got professionals, eh ... we have got the people who are not professionals but will manage everything, so we just consult sometimes.

R: So you as the church minister have knowledge about the resources in the church – who you can ask for help?

Asset: minister's knowledge

P: **Yes.**

R: And I assume that you will be able to provide the same kind of service to people being infected with and affected by HIV and AIDS, if they were willing to disclose?

P: Yes, if they are willing to disclose. I think at a certain stage there was a gentleman who, who came here after the service. Unfortunately I was not in and then eh, he does not belong to our church and he disclosed in the church. Then the, the, eh the brother, who was there, they, they collected some money. Within no time, more than eh ... R50 he got it, because he was eh..., he was going down and he felt eh .. that I must get into church so to disclose my status. So they supported that man.

Disclosure
Supporting other
community
members, even
if unfamiliar
(money)
Disclosure clue
to state of dying
Supporting
fellow
community
members

R: They supported him. Are you perhaps aware of any HIV and AIDS support groups that operate in this area?

P: Oh, the person who can tell you about that is the one whom I'm going to ask, eh, the social worker and that auxiliary worker who are assisting them. He does work, eh she does work with the support groups.

Assets: social
worker, auxiliary
worker

R: I will ask her about it then. Thank you for all the information that you've provided me with. Is there anything else you can think of?

P: Not, not at this stage.

FIELD VISIT 3 – 18 FEBRUARY 2004
INDIVIDUAL INTERVIEW 2 (INTERPRETED INTERVIEW)
CAREGIVERS (AUNTS) OF CHILDREN INFECTED WITH HIV

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How are you coping with the children in your care?
- ⌘ What are the main challenges you have to cope with in looking after the children in your care?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

KEY OF ABBREVIATIONS	
R:	Researcher
P1:	Participant 1
P2:	Participant 2
I:	Interpreter

R: *(directed at interpreter)* Please tell these two ladies that I am aware of the fact that they look after the children of relatives who have passed away and that I also know that the children they care for are infected with HIV. Please request them to tell me about their background. Who are they? How did it come about that they are caring for the children? How are they related to the children?

P1: I am the aunt of the child. She's the daughter of my sister. The mother started, got sick in 2000. After that the younger boy, who lived with the elder one, the younger boy got sick.

R: How old is the younger one?

P1: Okay, the other one he was 5 years. The other one who ... the younger brother who passed away he was five years old. The, the first one who passed away is their mother, then the younger brother of the one who's here at school passed away, following her mother, he was ... he was five years old. Then her, their father got sick. So the father passed away last year. He went to Ladysmith in ... in Natal. After their father passed away when he was in Ladysmith, the daughter, L, got sick. It was last year. It was last year. Ever since the, the, the child is not feeling well.

R: When did the mother pass away?

P1: In 2000 the mother passed away.

R: Do I understand correct that when the mother passed away, the father took care of L?

P1: Yes, their father took care of them.

R: And then he passed away last year and now you are taking care of L?

P1: Yes, we are two sisters. We are taking care of the daughter L.

R: How old is L?

P1: She is eight years old.

R: Tell me about the time when L started getting sick?

P1: L started last year to get sick. She started here at school and got that sickness. We took her to the doctor and the doctor find out that she was HIV. The doctor took L and he ... because she was sick, he took the

Asset: Doctor
Child infected with HIV

blood from her to see what was wrong. Then they called us to tell us that L she was HIV positive.

R: Did the mother or the father disclose their HIV status at any stage?

P1: No, the father and the mother didn't tell anyone. They were hiding that they eh, they were HIV. They started to eh, we started to ... it was that time when I took the little boy to hospital. They took the blood test and told us that the younger boy is HIV positive, it's when I suspected that the father and the mother were HIV positive. It's when the father disclosed that.

R: To whom did he disclose?

P1: He told the family, his wife's family that he was HIV positive. He asked a permission to go to Ladysmith so that he can die there, not here in Port Elizabeth.

R: And now the two sisters are taking care of the children. How are you doing it?

P1: L is staying with my sister, who's at work now. I accompany L when she's coming to school, up to the gate. When she's from school I took her and when my sister is from work she took her so she can take care of her. So we are doing turns in taking care of L.

R: Do you and your sister stay close by, close to one another?

P1: We are staying like eh ... in sort of eh ... we're nearer to each other.

R: How did you decide that both of you will take care of L?

P1: When my sister is in the job, doing her ... eh at work, I am taking care of L, taking her to school and then after school, taking her from school and

taking care of her. Then when my sister is coming from work she will take care of L. **So we are taking turns to take care of her.**

R: Do you and your sister also have children of your own?

P1: Yes, we've got kids, but mine eh, are older than L. My sister has got a child who's the same age as L, the other one is in high school. They are two, the other one is in high school, the other one is the same age as L.

R: Thank you. Could you (*addressing participant 2*) tell us your story, please.

P2: T was staying with my mother in *community m*. My mother is **87 years old** now. T is my sister's child. Her mother passed away in 2000, in April in 2000.

R: The mother of T?

P2: The mother of T, the real mother, biological mother.

R: In April 2000 and then she went to stay with your mother?

P2: Ja, at Motherwell. The reason why I took her from my mother in Motherwell, we found out that **she was raped**. Since my **mother was old**, **I decided to take her with me.**

R: When was that?

P2: In 2002. So I take her with me **so that I can take her to clinic**. The reason why I noticed her to take her to clinic, I found out she has got **sores all over the body**. So at clinic they took blood so that they can test it and they found out that she was HIV positive.

R: Please continue.

P2: The person eh, the perpetrator who did that to her was taken to the police station. She wasn't taken to jail, she was taken to police station. When I was trying to find out what happened to him I found out that they took him away from the police station. When I asked them: Why do you take him out of the police station while the case is not over?, Mr Jonas, the policeman, told me that the case is over. And I had to sit down and take care of *T*'s health. I used to take her to the doctor, sometimes she got convulsions. Now I'm still staying like that. The reason why I disclosed to the teacher, I disclosed to the teacher so that if he found that *T* is confused or *T* got convulsions she can know, so that the teacher cannot get shocked when these things happened, so that *T* can get also help from the teacher. The teacher told me that she'll look after the kid, after the child, the teacher promised that she will look for the correct medicine that can help *T*. It's when the teacher could tell it, she could know that when *T*'s not at school, she is at the clinic. That's why I reported it.

R: Do you have other children of your own?

P2: Yes, yes. There are two.

R: How old are they?

P2: The other one is 18 years old, the other one is 11 years old. *T* will be 11 years old.

R: Do you have a husband or a friend staying with you, or is it only you and the three kids?

P2: I don't have a husband. My husband passed away, it was last year.

R: So it's you and the three children at home?

P2: Yes.

R: (*addressing participant 1*) Do you and your sister stay with any other relatives or husbands?

P1: Yes, my sister has got a husband and myself I've got a husband.

R: I just want to confirm, your sister is staying with her husband and the two children and then it's you and your husband and the two children?

P1: That's right.

R: (*addressing both participants*) Both of you are facing a lot of challenges because you have taken children of relatives into your care, children who are also sick. What do you find difficult?

P1: There are some times where I got eh, where I got **loss of money**, where I **couldn't get money to buy her things that she needs**. Sometimes she wants fruit but **I couldn't have money to buy her fruit**. Sometimes the money, the **grant money it has not yet arrived**. But the **social worker has promised** me that, that they are going to try by all their means so **that we can get money in time, so that she can get help**.

R: (*addressing participant 2*) And you?

P2: With me, after my husband passed away I found out my **health has changed**. I had to go to the doctor and the **doctor diagnosed** me with high blood. And I said, eh I found out that the, the, the trauma of my husband passing away, I've mixed it with the sickness of T. On the other hand **I have no money** because **my husband wasn't working**. Even if I'm trying by what I'm **getting from the neighbours**, they are trying to help me, so I took the high blood treatment, so that I can eh, eh get pension.

R: How do your neighbours help you?

P2: Sometimes **they give me food** so that I can cook for us, they would **give me flour** so that I can make bread for us. Sometimes they'd give me

Community members (neighbours) supporting one another

Food Money

Care and support

even money so that the child can buy something here at school to eat. It's with her ... the neighbours are taking good care of her. The neighbours are giving me whatever they've got, food or even they sometimes buy shoes for her.

R: (addressing participant 1) Do you agree with that? Do your neighbours support you?

P1: No neighbour is helping me. We are helping us by ourselves, by trying by all means to get whatever is good for the child. My husband is doing some jobs and my sister's husband is doing some jobs, so that they can have something. But they are getting paid on fortnight. Sometimes during that first week we get short of something. Because L is like this, when she wants something, like even if she wants something to eat, she wants that thing now.

R: (addressing participant 1) How much is the grant that you receive?

P1: We have not yet received the grant, but the social worker said we're going to get R700.

R: (addressing participant 2) If I understood you correctly, you are also still awaiting a grant?

P2: Yes, I'm still going to the social worker so that we can do something like that.

R: Are you going to contact the social worker?

P2: Yes, I am busy with, eh in contact with the social worker. I'm supposed to go to court to make an affidavit on Thursday. I to date didn't attend it because I left the child behind, because I didn't know I had to go with her. Now I've given a date for 28th of June to go to court to make an

affidavit so that the child is my sister's child, so that they can prepare grant for her.

R: What kind of a grant will they prepare?

P2: They said for **foster care**, not for *T* being sick.

Asset: Foster care grant

R: (*addressing participant 1*) And the grant that you refer to, is that the disability grant or for foster care?

P1: Ja, it's **the disability grant**.

Asset: Disability grant

R: Tell me about the difficulties you experience. Did you go to the social worker or what did you do?

P1: We went to **hospital D**. We talked to the **social worker** about the child who's not, eh **who's sick**. We've told them that the child ..., we told them that the child has been infected with HIV AIDS. We were given a social worker to attend us, *G* is her name, and she made all this possible for us. She took us to court. *G* was very shocked on Monday to learn that we have **not yet received the grant**, because we've last got a grant, grant on the 23rd of October last year.

Asset: hospital & social worker

Vulnerability of children

Challenge: obtaining/accessing grant

R: How did you hear about applying for the grant? Is it common knowledge?

P1: I went to **hospital D**, that's where I got the **information**. Because that lady *G*, the **social worker** who were working on that case, she told me that she, **she can qualify for the grant**.

Informants (assets) about grant: hospital & social worker

Ways of coping

R: Both of you are supporting these children. I would like to know: How do you do it? What do you have that help you cope – within yourself but also in other people? You mentioned the neighbours, you mentioned the

grants and the social workers, but what else? Who else help you and how?

P1: What happens is that, eh when I notice that she's going to get sick or she's get a symptom of getting sick, I ran quickly to the doctor so that she can get help.

Asset: doctor/family

R: So the doctor is somebody who helps?

P1: Ja. If she get sick at night I take her straight to the doctor, but during the day, during the day I take her to the clinic, took her to the clinic.

Asset: doctor/clinic

R: Are we talking about the clinic just opposite the national road?

P1: We are using *clinic D*.

I: (*addressing researcher*) You know the police station you went to, there is a clinic down there in that area.

Asset: clinic in neighbouring community

R: And the doctor, where's the doctor?

I: There are nurses there, no doctors.

Asset: nurses

R: But when you say you take her to the doctor, where do you go?

P1: I am using my money to take her to the doctor at K. There's a doctor there opposite the traffic department, I take her to that doctor. So I am using the money out of my pocket to take her to the doctor. The doctor charges R55.

Asset: doctor in neighbouring community

R: Who or what else help you?

P2: I used to take T to Dr P here at Z. We are paying when we take her there, R90.

Asset: doctor

R: Where is this doctor?

P2: Here at Z. It's a surgery.

R: Here in the community?

I: **Not this community, just across the national road**, there it's Z area.

Challenge:
community
limited Doctors

P2: So we used to take T to the **doctor**. Sometimes we used to take her to **hospital D** because they said, they told us that each and every month we have to take her to *hospital D*, so that she can get **medication**.

Asset: doctor in
neighbouring
community

Assets: doctor
hospital

Treatment

R: Who told you that?

P2: It's the **doctor** who took care of her at *hospital D*. So he said that we must bring her every month, so that she can get medication.

Informant:
doctor

R: I want to know more. Who and what help you cope with the challenge of caring for these children?

P1: The reason why I cope with this is that I **saw my sister got sick in front of me**. I was worried because I didn't know what she was suffering from, **she was saying she didn't know why she was sick**, but when I heard that she was HIV positive, it's when **I accepted it**. I took it that it might happen to me and I would ..., if it might happen to me I would accept it. **When I saw it on their kids it was worse**, but I, but I, **I accepted it. So that's why I'm coping**.

Challenge:
coping dying
loved ones

Denial / non
disclosure

Acceptance of
others living with
HIV/AIDS

Acceptance as
coping
mechanism

R: (addressing participant 2) And you?

Challenge:
coping with
vulnerable
children

P2: The reason why I cope, it's because I **know that it's my sister's child and my sister's child is my own child**. What I want to do is for her not to feel that she has lost her mother, she must know that her mother is still alive,

Strong family
bond as basis of
coping

which is myself. So that I can take her as my own child. So that's why I'm coping, **I'm taking her as my own child.**

Maintaining legacy as coping mechanism

R: So what I hear – and please tell me if I'm wrong – I hear that both of you want to help your family. I hear that there are people helping you, you and your sister helping one another (*addressing participant 1*) and the neighbours helping you (*addressing participant 2*). I hear that you do have some money available – although it's very little and that you need more money. I hear that there are doctors, clinics and social services that you use. What else are you relying on in this community? Are there any other things in this community that help you? What about churches or traditional healers, for example?

P1: On Sunday I just go to church and come back again. **I don't go traditional healers.**

Traditional healers not regarded as assets

P2: On Sunday I used to take T to the church, but **not to consult traditional healers.**

R: Does the church in any way support you or don't the people at the church know about the children's status?

Churches not supporting community members

P1: **The churches know nothing.**

Non-disclosure

P2: **I didn't tell the church.**

Non-disclosure

R: Who knows about the details?

P1: **It's the family only** and the **teachers here at school**, the teachers who work with these kids. Not all the teachers know, **only the teachers who are teaching these kids.**

Selected disclosure : Family Educator

Selected disclosure

R: May I ask why you are so secretive about it? Why don't you tell the church?

- P1: We as blacks we are not like you, we laugh at each other when we disclose of that. Even the kids next door, if they can, they could know that this child is suffering from this thing, they'll laugh at her and insult her about the, the, the HIV status.
- Cultural challenges
 - Non-disclosure due to stigmatisation
 - Stigmatisation
- R: Why would they laugh?
- I: It's like that to our culture. That's why many people don't tell the status. If you can notice it, you will remember even in Gauteng, Lulu, that lady who disclosed that, then they stoned her to death. Even the other lady, who was the activist, they raped her and killed her because she disclosed her status. So it's like that with us. I'm sure the reason why those ladies were killed, it's their previous boyfriends whom they know that, oh now they are disclosing, now what about myself, you see? It's like that in our culture. It's difficult sometimes, it's the other things that make ... Because what is happening in our culture, we mind the thing of next door. You don't mind your own business, you want to know what's happening next door, not minding your own business, that's the problem with our culture. You want to know: *oh, there is an ambulance next door, I wonder what she's suffering from.* Then if you said: "I've got TB", when there is an argument or the children are fighting, they'll say: "she's like that because she's got TB", you see. That's the way we grow up.
- Stigma related to culture
 - Non disclosure
 - Fear of death and being harmed
 - Role of culture in stigma
 - Culture as asset: involvement of neighbours
 - Challenge ito of stigmatisation
 - Culture is embedded
- R: Why don't you tell the minister?
- P2: The reason why I don't disclose is even the neighbours will talk. Sometimes the neighbour will be reluctant for her child to play with mine or she want to, to, to send her to somewhere but she won't be able to do that, so that the child can feel that I'm alone and I'm not accepted and that will contribute to her health.
- Non disclosure due to fear of being stigmatised, rejected
 - Fear of rejection/ Isolation
- I: You know what, it's because..., it's happening even to us educated people, you see. You don't want your child to play with that one, thinking
- Perception to be/outsider

- that **because he's HIV your child will also be positive**, HIV positive. It's that manner that she's talking about (*referring to participant 2*).
Stigmatisation
Inaccurate HIV/AIDS knowledge
myths
- R: The information that you have about HIV and AIDS, where do you get your information?
- P2: **We know nothing about it.** ←
Lack of information regarding HIV/AIDS
- P1: I saw it on my sister's child in 1997. **She was very sick in my house, so she died. We know nothing about the HIV and AIDS.**
Challenge: coping with death of relatives
Lack of knowledge
- R: (*addressing participant 1*) What did the doctor tell you, when you took L to the doctor?
- P1: The doctor called me that time during the results and he told me that you mustn't be shocked when I'm going to give you this news and tell you the news, it was like that. **The doctor doesn't give me, didn't give me any education about this.**
Challenge: Lack of HIV/AIDS training/counselling
- R: Any counselling?
- P1: No counselling. ←
Lack of counselling
- R: Do the children know about their status?
- P1: We told L that she is sick. She knows that, we've told her that. When she came back from school **she told us that the other child insulted her.** The child here at school, in fact the child said: "**You look like a HIV person, child**". So it's when we told the child: "Yes, you are sick."
Stigmatisation—insults and discrimination
- R: How did she react?
- P1: We told her not to take care of that because she's not that sick.

R: Did you tell her to keep quiet and not to tell other people?

P1: We said she mustn't take care of that because the children at school are naughty.

Avoiding disclosure

R: (addressing participant 2) And T, does she know?

P2: I didn't tell her nothing. But she could see that she got sick but she doesn't know why, or what is she suffering from. It's because we are afraid to tell her, because my sister ... eh ... we've told my sister's child that she was HIV positive, because he got scared. That's why he deteriorated and got sick. So thereafter we told her that she was going to get sick little bit more, because she's a little bit older.

Vulnerability = denial, avoid disclosure, fear

R: I want to return to your discussion on the things that are good in the community that helps you cope. Do you receive any help from school?

I: It's the help that we were talking about the other day. Like the one case where the child was infected here at school and they said: "You look like a HIV child." Then she went back home and tell the aunt that someone at school swear at her. Then the aunt told her that you musn't worry about this people. Yes, you know you're sick, but you musn't worry about it that the truth are noted at school. That gave me an impression that we must talk to our kids here at school, you see, so that they musn't laugh at each other.

Asset: school

Stigmatisation

School as source of support

R: I want to return to what you said, that the hospitals are helping and also the social services and neighbours, and that the people in the community are assisting one another, helping one another. What about the school and the teachers? Do they help in any way?

P1: The principal called me here at school, together with the present teacher. They said they are going to phone for me the social worker. They really phoned the social worker. The social worker came to me the following

Asset: School
Principal
Educators
Social worker

- day, having the **food parcel** for us. She told me that she's going to do that three times, three times a day. She would give me groceries **until we get the grant.**
- Food support
- R: How did the principal know to call you?
- P1: **In the classroom L got sleepy and the teacher called me.** We came to school and we told the principal, we **disclosed to the principal** and then we **disclosed to the teacher** so that when, you see, she's with her in the **classroom she can take care of her.**
- Potential asset: grant
- Educators identifying problems
- Selected disclosure
- Disclose in order to receive help & support
- R: (*addressing participant 2*) And you?
- P2: I didn't tell the principal. **I just told the class teacher** which is **my friend**, so that when she could see that the concentration, there's no concentration in the classroom, *T* has got a problem at that time.
- Selected disclosure to friends & educators
- I: But what happened was that, I had to meet the principal. So **I told the principal, so that we could get help.**
- Disclose in order to get help
- R: Do you think that the school supports you?
- P2: They help me at school because the **teachers here got ... take care of T.** Even here at **school they look** at her. Even once we did go to *hospital D*, the **teachers did go to hospital** when he was, when she was admitted last year.
- Asset: School-teachers as care & support
- R: Are there any support other than the neighbours, or the school or the sisters in the community?
- P1: No.
- P2: No.

R: No support groups? Might it be because the people don't know about the details?

P2: Ja.

P1: Yes, maybe.

R: And you, do you support one another?

I: They don't know each other.

R: But will you be able to support one another?

P2: Yes, I think so.

Potential asset=
caregivers
supporting one
another (not
mobilised yet)

P1: We can help each other.

R: You might learn from one another and be there and care for one another.

I: Yes, they can help each other. Like maybe with getting the grant, you see, all those things. Even telling each other what to use when she gets sick, because it can help, you see.

Potential asset:
shared
knowledge &
experience
between
caregivers

R: Have you perhaps heard about *Sister E*?

P1: I know about *Sister E*.

P2: I don't know about her.

R: (*addressing participant 1*) What do you know about her?

Poverty

P1: She's helping the poor people. If you go there and put your problems down on the table, she can be able to help you.

Potential asset:
Sister E (not
fully mobilized
yet)

R: *(directed at participant 1)* Have you ever visited her?

P1: I did go once. She gave me **food parcel** and a dress. Asset: Sister E
food provision

R: I would like to continue with our discussion on social workers. Are you aware of any social workers in this community other than the one at *hospital D*?

P1: There is a **social worker in this community**, but she's only working in *school G*, and she's very busy and she's dealing with the ... eh, **not the problems like these**. She's dealing with the children who cannot cope, but not eh these, and she's very much busy. **She's working alone in this whole community, especially helping children from that school**. Asset: social workers
Challenge: limited services in community
Challenge: social worker overworked

R: You are very special people, because you look after other people's children. What makes you special, what good characteristics do you have?

P2: *(laughing)* **We love these kids**, because it's our chil..., **it's our sisters' kids. We love them**. Asset: Strong familial bonds & love

R: And you've got the support of the family?

P2: Yes, we've **got that support of the family**. Asset: Family as support system

R: Thank you very much. Is there anything that you would like to know?

P2: Sometimes when *T* is sick, when she's not okay, how can I get help? Can I take her to the psychologist or who?

R: A psychologist is a good start, because she was raped as well.

I: I **will talk to the principal** because the **psychologist here is very much busy, even if you've got a referral letter**. I will ask the principal to take Asset: principal
Challenge: limited psychological services

these kids, because they need counselling. But even if we've got the social worker, that would also help a lot.

Need for counselling to vulnerable children

R: (addressing both participants) Is it in order with you that S (indicating interpreter) tells the principal?

P1: Yes.

Asset: Educator

P2: It's good like that.

R: One last question: Do you think there's anything else in this community that is already here, but are not being used but that can be used?

P1: We are planting vegetables at another school, a high school here and I'm part of it.

Potential Asset: Vegetable garden in the community

R: Tell me about that?

P1: We go as a community, go there and plant for ourselves, at the next school, it's a high school.

R: How did you get involved in this project?

P1: There was a meeting, and they said that if you want to have a garden, you can go there. So when you're walking through the National road, they are using that land there for planting the vegetables.

Asset: agriculture

R: Tell me more, where did you get the seeds to plant?

P1: They are coming from the office from the ACVV. They're helping a lot because they are working with that social worker to take care of the kids who are, who have problems, the poor kids.

Asset: ACVV & social worker

Vulnerability of children

R: So that is another thing that helps you cope, as you can now provide for your own food.

P1: Yes, and it, that plot is not far from the ... eh, from my house.

R: Thank you ladies.

FIELD VISIT 3 – 19 FEBRUARY 2004
INDIVIDUAL INTERVIEW 3
SCHOOL PRINCIPAL

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which challenges are faced by the community?
- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How does your school and staff support community members in coping with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: *Mr M*, you are aware of my research and that I am trying to determine how this community is coping with HIV and AIDS. Could you please share your perspective on this with us? In your opinion, who and what does this community rely on to cope? I know, for example, about you and the teachers at your school that care and identify children that need support, calling in the parents, helping wherever you can, but what else?

Poverty

P: I wonder whether I'm going to say they cope or they don't cope, I'm not very sure. But I have gone to some families in relation, in particular with those that are having kids infected. What I've discovered is that the neighbourhood is sometimes a burden to them. The neighbourhood in the sense that quite more of them are ... those infected or affected families are mostly below the poverty line type of families. And because

Asset: school (provide food)

Community challenge
Lack of being informed
Neighbourhood (Community members)

Identify those living with HIV&AIDS

Identify needs

Support by neighbours/community

of that, you would have to give something to eat for the kids, they would be observed here at school, because the community do not observe or do not see that, do not understand that probably, at times do not understand that there is somebody that is positive, but at times observe the loss of weight of that particular individual and become concerned, saying probably it's because of the meal and all the likes, and then they take responsibility to be giving some food into the next door neighbour. So the neighbours can also help.

Another thing that I think is very important is the media. The media seems to be playing a predominant role, into spreading the news for the people to understand that HIV AIDS is indeed a reality and that is among people. And another point is that I don't want to seem to be praising ourselves, we are not praising ourselves but we speak about HIV AIDS in a number of meetings that we have. For an example, on the 27th, that is Friday next week, we called parents to speak to them as to, to speak about only few things. We don't have a big meeting, we don't have a long meeting, we've got only two items, that purports the academic excellence, to speak about what do we expect from them and again we speak about the social responsibility that we are going to do, not only to the kids that are positive, but to the affected and infected parents as well, because what we have started ... we are starting to get hold of the NGOs so that they can be given some clothes and the meals and with the meal again it can make a difference to one's life. Then again seeming to be boasting, one mother has requested that we submit the names of those that are most suffering here at school. We have collected the name of the kids to the mother, though she's having a link with a rich white man, because he's working for Life Line and that is the person that is very concerned about the plight of the poor people in relation to HIV AIDS.

Okay, why is the community coping? They are coping because that they have faith. One, amongst other things, that I think they believe in is that God cannot just give it or give up, either than that. Now there's nothing more I can speak about in relation to coping, that's why they cope.

R: You mentioned that the media is playing a role. What kind of media are we talking about in this community?

P: We sometimes have **flyers** around here, we sometimes, more often than not, have the **radio and TV, speaking volumes about HIV AIDS** and, here at school **we invite social workers to come and speak about the epidemic and it's spread to the community**. It's like multiplication of information. **We always say one parent that receives information must multiply it to ten other parents**, other families, you know. That is the type of eh media that I'm talking about. And there are **too many meetings** as well here, particularly it's predominantly **African National Congress** area and in a number of meetings that I have attended, they will **always speak about the sketch of the HIV AIDS**. **I've been also addressing the communities of this area, wearing a different cap. I've got two caps**, not this one. I'm also a member of the **Communist Party** which is an organisation that is concerned with the suffering of our people across the colour lines. When **given a chance to come and speak to the communities**, we don't also **leave out to speak about the ways and means in which ... that they live without being employed. We speak of what we call eh, the co-ops. When few families around could collect some money, maybe R20, R20, and so on and so on, they start to buy paraffin, they sell, they get the profit, they multiply, they buy more paraffin and they buy bed, tables and so on and so on, basically part of the co-ops and that also plays a role. We speak about the value of the eating, the reason, you know the failure of the government as well, to be limiting to help every family with food – we would understand therefore that this is a capitalistic country, it cannot help a family to eat and the interest of the capitalist country is the profit and not the people, that's what we believe as communist as well. But we are saying the **government is also making a difference but it is not enough for people to manage to eat**.**

Media as asset: flyers, radio, TV (informative)

School network with social workers – to provide information

Community members as source of information

Asset: political parties & meetings

Principal as informant

Political meetings informative

Asset: government

Challenge: poverty and hunger

R: If I understand you correctly, the political involvement might in other words also fulfil a supportive role in the community?

P: Exactly, exactly. You know, in a **family shack dwelling area**, because this was 100% shack dwelling area until brick houses were built, **but it's a semi-shack dwelling now**, because there are still shacks around here, there **are the people that always have a hope** and whenever a meeting is being called, they come out in big numbers because they always expect for, you know, the work that is going to be delivered on the day. So the **meetings are well attended**. Maybe I would have to be blamed, they stand in the corners, but sometimes there are no halls, you will get them standing even outside and attending to the meetings.

R: What is the role of traditional healers in this community? Do they play a role in helping the community cope?

P: I would not know, but I would suspect when people are confused, when people are not very sure of whether there is HIV or AIDS, **they would go to the sangomas to go and get some help**. And I would not be able to say they are really playing a role because it's only from the experience that you can say indeed they play a role. Other than that, there are also false prophets, that they think that they can make a difference. Do you know what I'm saying? One needs a lot of money for say HIV AIDS, knowing that it's a highest illness in the country now that kills, that **false prophets say they can be in a position to cure it**. So I don't know whether they play a predominant role, but I suspect they don't have a role to play for people.

R: Faith in God seems to play a bigger role in this community?

P: Yes. This area is predominantly church going people, it's predominantly a church going community and a predominant church going community always has faith and hope that God will provide. Do you get what I'm trying to say? They have a **hope** that one day this disease will come to an end, and that is part of faith, you know.

Hope as coping mechanism

R: Does the church provide a lot of support? Do they, for example, have support groups that can go out and support people or are you not aware of any such activities? Or is it only when people disclose that they are supported?

P: I, we, there's a stigma and people seldom disclose in this community.

R: Why?

P: Because of the stigma. But some disclose naively, they don't disclose what they want to disclose and apparently when both parents pass away, probably the guardian manages to say to the community I've got this child that is HIV positive and both parents have died because of related sicknesses. But the disclosure is very rare to happen. I've got one child here who is affected, not infected – the mother was buried during December holiday, and that was never disclosed. The mother used to come and assist here at school. That's one example of a family that never disclosed. But on the day of the family I attended that funeral, on the day of the funeral the friend was a speaker, we normally have a lot of speakers in our funerals. The friend was a speaker, the friend stood up to say: "It was two/three years ago when my friend disclosed to me that she's positive, and today I'm proud to say that she was living her life good and that she lived her life for three more years". And then apparently, it, probably it's an assumption that the woman has died of HIV AIDS related sickness, that the husband is also HIV positive, because when he came into my school sometime this week, he was carrying a very bad face with sores and to me, by indication it might be that. But what I'm trying to say is disclosure is very rare, it's only naïve people that are disclosing. And what is very bad is, they don't have confidence. That's what is lacking, that I've observed. They will tell this child is positive and open about it but there was no pre- and post-counselling, so people were not even exposed to counselling. Both parents have passed without disclosing and then the mother or the guardian that remains does not know what about counselling, what about

the importance of being confidential, but some kids are seemingly are taking strain. Yesterday there was one child here, you might have seen her, she was sitting there. She normally comes there every break period.

Principal providing food (poverty)

I have this food about everyday for her, she is confidently coming to this office, sitting there every break. But I've spoken to ATICC, they've already given her some support and all the other children that need it too.

Asset: NGO (ATICC) (food support)

R: ATICC seems to be an important resource in this area?

P: Ja, ATICC it becomes a very serious resource and mostly next year it's going to be even much more important. It was not focussed in this area until this year. Then I attended a workshop, when I told them of the plight of the communities of the area and now they have already attended to three kids here at school and they promised next year they have decided to be more involved, in good time so that they can do almost everything to make a difference to the children.

ATICC/NGO'S as asset

Asset: principle as networker

Support by ATICC to vulnerable children

R: What is ATICC's role? How can they help this community?

P: They conduct workshops. They make pre- and post-counselling. They also provide clothing and food, especially for the families that have need. that's what they do. And they are working hand in glove with a number of NGOs and organisations. they are housed at Vista house, which is a municipality area in town and they've got a very good man by the name of *H*, a good man, he knows his work.

ATICC/NGO'S as informative workshops
Counselling
Providing in basic needs (clothing & food) poverty
networking

R: Please tell us about the NGOs that are involved in the community?

P: The very obvious one are probably Holland link, that is ACVV. ACVV plays a role meeting the needs of the communities of the area. That is one predominant NGO that plays a role in the area, and it also creates jobs to some parents, bead making, basket making and also providing some manufacturing work like making tracksuit of schools and employ

Assets: ACVV, ATTIC (combat poverty and allow for job provision)

the communities that cannot afford it. **That is ACVV, that plays a very serious role in the area.** ACVV as important asset

R: Who is the contact person there?

P: I know of an **auxiliary social worker**, *B*. Her office is there in *AP*, she's operating from there. Then there's also the white ladies, the very old white ladies that sometimes visit here, it's very unfortunate, but it's deep too Afrikaner names. Asset: social worker

R: The reason why I ask is that I have been trying to contact them, the ACVV, but without success.

P: **I can try and get hold of *B***, then you can be able to get hold of **ACVV**, because they are playing a very predominant role. Then there's also something that takes place at **clinic *Z***, which is led by a man called *M*, who is also an **auxiliary social worker**, that looks very seriously into the plight of the most suffering people of the area. The *M* I heard is the same one that's **there at the clinic**, near the university. It's there by the mission, you just pass their, and this *M* he's a very good man, he does the best work. Asset: principles networking ability
Asset: clinic/social worker
Asset: clinic, principle's knowledge

R: Thank you, I will also try to contact him. Challenge: community members sometimes ignorant

P: But having said this, it is indeed very painful, **the ignorance some of the parents are still having**. It is very painful, the ignorant, the educated people are still having over the problem. It is very painful but we do get **some workshops that are done via the course of the Department of Education**. We seldom see officials of the Department of Education, to become part of such workshops, because some people are by nature corrupt, when they don't see any supervisor, they even make workshops half way – do you get what I'm saying? And it is indeed painful to me, not to hear in various principals meetings the manager of the area. For me, the great concern of the Department is teaching and learning which is Asset: department of Education (workshops/information)

Asset:
department of
Education
(teaching and
learning)

good. But you cannot take teaching and learning in isolation with a social problem of the communities. You can't, what I mean is it's like, we cannot at this school be an island within South Africa. And this year we have declared that we are going to make a difference, and not in the classroom alone, but in the communities. In the next five to ten years they must always remember that there have been the teachers in the year 2004 that have been very concerned with the plight of the communities in which we find ourselves in. The very unfortunate part of it initially, is that teachers as well can be part of the problem.

School as asset
/resource in
community

Assets:
educators

What I'm trying to instil and it's happening gradually, it's that all have got to understand that we are the part of the community. Most hours of the day we are here and we are going to be here most of the more than 20 years we are going to stay within this area, and therefore you become a part of that community, by virtue of also your employment. I hope and I wish when you shall be coming down to school in future, we must continuously know of the importance of the value of the community and the norms and value of the community in which people are finding themselves. The norms and the values of this area might not be same as the norms and the values of the area where I stay and for us to be able to work very well in the environment, is to be able to understand the norms and values of the community.

School regarded
as part of the
community

School as asset

Asset: school's
insight into the
community

R: Please tell us more about the school's declaration that you mentioned?

P: You see, one of the important things to me is that by nature all people are different, each one is unique. We've got different ways in which we present ourselves to the learners. But it is important the manner in which we handle the HIV cases. They need to be loved, the manner in which you speak to the kids becomes very much important. Because not all kids are homogeneous in the class, some are infected and affected and they easily get traumatised. And whoever is HIV positive, is easily being stressed and stress complicates. So this is one other important thing as to how do you handle your children. Some people they are character

School as
supporting
and loving to
those living with
HIV&AIDS

vulnerability of
children

into shouts, but how do we manage ourselves and **how do we handle the kids? I'm known here to be a spoiling father at the school.** I don't know how many times kids have been turned away in this area by the teachers, because what I do, I go with them, they go around with me, and I handle them like they my children. **So I'm said to be a very spoiling father** because in order to be able for the learners to be able to learn, **show them love to them.** And shouting, shouting your anger, you are not sending the message by shouting. You talk in a proper manner, you talk. You don't have to shout to show anger, you don't have to shout, you say it calmly. You talk very nicely, then you make a difference.

Principals and teachers-basic respect & love to all children

Asset: Loving teaching approach

R: Please continue.

P: You seem to be very willing to work. I think the school's strategy as well, maybe does not necessarily speak very much on our programme. But what I'm going to say is, it must be good at times. You blow it out in a breath, you tell them it's a **confidential**, then you work with the willing parents to come out and to expose what you have managed to unlock as the hidden people. But that we will need their agreement to that type of an arrangement. When you call the press you say the plight of the almost poor, these are the kids of the infected and these are the parents that are affected. My view of that is, **I know the press can break you, but it can also build you.** My interest here is to make the point that a **good Samaritan** can as well see how can they assist this type of families. There are people waiting outside there to assist with the families that are impoverished, that are positive, but they cannot be able to assist them when they don't see them. And the people in the area must also understand this indeed exist within this area of operation.

Asset: school's respect of confidentiality

Potential asset: Media school role in helping to identify how to support them
Outside help-poverty

R: Why is HIV&AIDS stigmatised to such high levels? Is it about morals? Is it about shame? Is it a cultural thing? What is your view?

P: It's so difficult to understand. It is indeed very difficult to understand. We would have to move from the case in which a **woman in Soweto**

Non-disclosure due to fear of death

disclosed and then was killed. And supposedly to be the turning curve in the plight of the HIV positive people. If you compare the lady that was killed and the young Johnson, that guy Johnson, who died a hero but that lady died a villain. It's in the sense that Johnson, as young as he is, went around the world and told the people indeed that this exists. The only thing that I would suspect why people are hiding this is because they are probably afraid, some individuals interpret to be positive as you are positive because you are corrupt, maybe you are linked with a prostitute or maybe you've been going with truck drivers. You know these are the type of attachments to one who is positive, and that's not looking into whatever else. So the moral issue becomes a big problem here, that people are now fearing because you are being isolated immediately you disclose. And more often than not, most people stand to move away from you, because you are positive, and not positive enough to understand that you can live longer, as long as you know yourself, because people can live short lives because they don't know themselves. They don't have safe sex and they can live their normal life, the virus is still hiding somewhere within one's human body, you know. So I think the one that is positive is supposed to be worried to be very healthy, and to be very fortunate to know the status than to die by sudden death, because you did not know that you are positive. Because when the virus goes down you go, when it goes below 200 you go.

R: Is there anything else that you can think of, that might add to my understanding of this community's way of coping?

P: What I want to say to you is that I wish you to apply whatever you learn here. I believe that the one who is educated but does not manage to apply it in real life, in daily life, that person is illiterate. You cannot be known to be highly schooled but then not apply the knowledge that you got from the institution. I wish that you can be successful and I'm 100% sure you will be successful, by the way. Your approach to it is very obviously, by hook or by crook you have to go through. But the only thing that is needed, after you have acquired, you have to apply in a real

life situation because some people are studying and when it comes to real life operation you don't see them anywhere.

R: Thank you. *Mr M.* It is my wish that this study will make a difference in this community.

P: You know it's indeed very unfortunate, researchers can sometimes make a lot of damage. And even now there's a big wall in between ourselves in this country, some people they can live in a luxury life, not understanding what's happening in the other communities within your own country. But all the positive people shall never fail.

R: That's what you said the other day.

P: I'm telling you, **positive people shall never ever fail**. I continually tell teachers, I continually tell parents, I've come up with a project now. After the 27th they are going to clean the school, that's going to happen. **They are going to be given computer lessons at the Technikon**, for 80 teachers and parents.

Asset: principles
positive attitude,
negotiation
powers

R: That's wonderful!

P: Yes, that's an incentive to pay for them to come and clean the school and for the school to be in a active programme. We will be able to **access resources**, paint will be available immediately, **this is what I've got in one of the NGOs**. And then I'm also **working with people from Netherlands**. What I'm trying to say is, there are quite a number of incentives for the teachers in the community, and **I am going to keep on trying, I want to go and unlock other opportunities for the community in which I find myself in.**

Principle as
asset:
-networker
-initiatives
-positive attitude

R: You are constantly on the look-out for opportunities.

P: Yes. So imagine, they are going to be transported from here to Technikon free, and the company will pay for them to go to that

Assets: external
funding
agencies

workshop. And the kids at this school is going to be the centre of arts and culture, because **there are people that are funding the school**, they want to convert one of the classrooms to be an art class. They are doing visual arts, they've got a number of activities they do and we'll have a workshop with one lady. **Then our kids are going to get to a national competition of drama** and they are going to be transported from here to Technikon to be trained seriously on art, and to be able to learn at the early age as to how to write their own scripts. These are the **opportunities that I'm trying**, so that we can look at the kids that are going to, at the end go to Grade 12 and to the universities, they might, they must have something to do. That's what I'm also trying to do.

R: It certainly is a lot of opportunities.

P: And it's **because of positiveness**. You know, my teacher, *Dr H* said to us: "*If you are positive and you want to, you can go and break the wall*", which was a greatest exaggeration. I normally say to the kids: "*There I put R50 on the wall, go fetch it. Because if you are positive, you can go, you will think as to how do I go there. Then you go around and look for a ladder, you go up the ladder, you get that R50*", it's a matter of being positive and not to say things cannot happen. That's what we do. **So if you are positive you can be able to do anything, that's true.** Yes, *Dr H*, he was a good man, he also ... he used to say: "man is my brother not by blood but because we share the same burdens". He was a clever man.

R: *Mr M*, thank you very much.

FIELD VISIT 3 – 19 FEBRUARY 2004
INDIVIDUAL INTERVIEW 4
CATHOLIC SISTER AT COMMUNITY CARE CENTRE

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which services are provided by the community care centre in the selected community?
- ⌘ Which role is the community care centre fulfilling in supporting the community in coping with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Please tell us about this community, the challenges it faces and the ways in which it is coping with challenges such as HIV&AIDS. Secondly, please tell us about the services that the community care centre provides in the community, in assisting members of the community in coping with HIV&AIDS.

P: In my opinion, one of the biggest problems is poverty. You know, some people still say it doesn't exist but the reality is that it is mind-boggling, you know. That is the reality and we cannot get the poverty to go away. Now eh ... this morning for instance, there's a woman in there with me, she's 29, 30, and her mother is very sick, and her mother would be in her mid-fifties and this woman had a partner who committed suicide. But it was going very bad with them, to the effect that they had nothing in the

Challenge:
poverty

Challenge:
Illnesses

Suicide/loss of
hope

house to eat. And he had, you know he had TB and there was no possibility, no way that he could get work. He used to come out and walk around and walk in the suburbs and collected the people's cans and that kind of things, you know. And he did that every week, you know, but anyway, he just couldn't keep facing the poverty. Now she's left with six children, you know. Now there's no school fees, there's no school shoes, there's no eh ... none of the school requirements. And sometimes they come here, having nothing. So that is the reality, and the school fees and all that. Now, what we do with the people one to one and I even found myself saying to M yesterday; "It's just wonderful we have such a passion for the people", you know, that we like talking to them and we are liking that. We say: "Poverty can attack you, yes that's true, but the ability that you have within yourself is more important." And they don't believe in death and I will definitely say that that is the one thing keeping people together here, saying that it's okay. And they can still laugh and they can still be nice to each other, they can still make space in the seating accommodation out there. I admire them even for that. The idea that they all trash together and somebody comes and they can see that woman is pregnant, she's having a baby or she's very sick, they'd still make space for her and give her their place. Now I see myself, that is a great policy for any person to have. It sounds stupid, you know, but that they have this, where as we are a bit more fortunate, you know. And I have to be honest here, this is the kind of extra that you can approach life with, they are making the most of what they have in that way.

Now, you know, I think the thing that we can give the people here is our time, our love and our care. And that I think is a challenge for every one of us to do, you know. And uhm ... you know it's then, when people realise, I actually have to ... just say I am HIV and you are not, and then you make me realise it's okay. Yes, I do have this illness but basically we have the same strength, you know. And whatever that is, I don't know, but it's kind of building a relationship with each individual and when we do it with one it just spreads. Now just take for instance, we

had a woman here two/three years ago, and she was very hypertensive and she was living with a **man who was very abusive**, you know, and he said to her I want to have a big family. He wanted to prove to his neighbours that he was a real man. He used to say that to her. So she had baby after baby after baby, you know. So anyway, **at the age of 32 she got a stroke**. So I said to her: “*You leave the last baby to him to see to and you go for a walk.*” And she said: “*No, I can’t do this.*” I said: “*Okay, if you cannot do that don’t come to me next week*”, I said to her: “*You deserve that time*”, I mean I knew she didn’t want to **lose her friendship** with me and the **relationship** that we had over the years. I said: “*You give him the baby and let him realise what it is about*”, I mean a crying baby with **no food** for the baby, you know. So anyway, I said: “*Come back next week and tell me you have walked five times in seven days.*” She came back and told me she left him with the baby, the baby cried every evening of the week for its mother and she went for a walk and she felt so good when she came back. Anyway, **she began a walking club**, and now she has a walking club together, you know.

Challenge: abuse/violence

coping with illness
community care centre
Outsides serve to inform, guide, counsel and provide friendship
Challenge: poverty

Community members supporting one another (sense of community)

R: That sounds amazing.

P: Yes, it is amazing. Now **that woman had nothing** and that **man was not able to work**, he had a car accident, you know. Anyway, that was another story. But that was just one private affair but it **still did not fill that empty tummies of the children**. But they had a mother that was more patient with them. She had now achieved a partner that knew I cannot have another baby. She knew that he would now understand that they had a family and **that they had nothing to feed another baby**, there’s no more babies in that house now. That child now has gone to school. And it was great for him to get that experience and it was great that she, you know, that she really in a sense would say **her friendship with me that we kind of value**, that she wasn’t prepared to sacrifice this, you know. Anyway, now her blood pressure has gone down and she’s better, doing the vegetables and all. She never comes here anymore. That was a good one. But look, the thing is that we’d all love to believe there are no

Poverty – unemployment

Support by professionals/volunteers

poverty and I suppose in a rich country like South Africa, you know really we are part of the outcome of apartheid, we know we are. And I think you know, they have learned to say I need this or I need that, but now we don't create a system of hand-outs here. So what I think it is, the **system of apartheid** is that just because I have a different colour skin I don't have the same rights and that is really being mean to people. And that is what we are trying to correct, but that is a huge struggle. For example, before I was speaking to a psychologist, we were all supposed to be able to speak to a psychologist. Like I remember at my sister's home one day she said to me: "I feel so sorry for these people, especially the babies that have to grow up." And I mean we all know that, these people often suffered and have babies that grow up and suffer. And the people here, you know, **they grew up here, they're living here, they were so inferior and it is so imbedded in them.** It is imbedded in the people, you know. And I thoroughly agree with the philosophy **that people have it in them to help themselves and cope with HIV** and all this, but the reality that we are working with here is that **it's a world of pushing the limits.** It's a war that should be pursued, you know, that we fight against it and that one day it's true, it **will be true that I have it in me to fight this.**

Focus on empowering community members

Negative outcome of apartheid

Belief community can cope/able to cope

Life=challenging

R: Do you attend to the people of area X, do they also come here?

P: **We attend to all.** Yes, very much so.

Community centre as potential asset

R: And do the people approach you or how does it work? Do they just come here? What is the procedure?

P: The people, **some people actually know they can get help here. They can get like nutrition and attention here and they tell each other.** We also stress amongst the people that anybody and everybody is welcome, because we believe if you need help you can come here and they always come, day by day, and sit in the long queues and wait for help.

Community centre
-support
-medical assistance
-nutrition

Community members share information= strong communal feeling

R: How many people on average per day? More or less?

P: It's such a difficult question to answer ... I would say ... It varies, but it's a lot of people and families everyday. The queue is very long ... **All the people that want to come and need help, they just come.** And then there's also **the school**, you see, that's the thing, the school also has a section. And when people come to me that has children that's not in a school, I see such families everyday, I'd say, I then tell them to go the **teachers**. You know, if the person says maybe the children isn't in a school.

R: You refer them to the teachers?

P: Yes, the teachers.

R: How many staff members are assisting you here?

P: We're thirteen all together helping at the **clinic**. Uhm, I'll ask *M* to check the statistics and tell you, because that would give you a rough idea of how many we see per year. It is mind-boggling, you know. **And that includes those for HIV and AIDS**, the infected and the affected. It is a factor you know, because mentally the people who are not infected they are affected. They are affected and literally they become as infectious, you know, because all they can think about is the infected.

R: The whole community is affected.

P: Yes, absolutely. Absolutely. And then to see the **poor little children**, you know just looking at them and their **dying mothers**. You should see them when they stare at their mothers. They know that she's sick, you know, but ... it's just so sad.

R: Do you have a lot of people disclosing to you?

- P: I, ... Yes, a lot of them do. **I would recognise it anyway**, because of what they say to me, when I ask them: *How are you feeling?*” and they will remember when they came before that, and then we will talk and then eventually they will say that they’re HIV positive. **They would tell me in various ways. Some don’t, but a lot of them they do.**
- R: I ask this, as non-disclosure seems to be one of the challenges faced by this community.
- P: Ja, well, we have a lot of **stigma**. It’s like, seeing that my mother won’t allow me to cook, they won’t eat when I cook, you know. **They won’t sit beside me, those kind of things, they won’t touch me.**
- R: A lot of myths.
- P: Ja, and the thing is that, how will I say, they know that **they will be isolated from the community**, they **even look funny**. I had one lady like that and I really took care of her, but anyway she suddenly became special, you know. So anyway, another one came to me after a while and she asked about this lady and I said to her: *“I don’t know that she has AIDS”*, you know. *“It’s a pity if she has AIDS, but she can get treatment”*, but **she didn’t want to disclose**. I don’t think we will ever be able to get into the mind of a person who’s got AIDS, you know, because it’s like a person who has cancer, **they need the treatment**, you know.
- R: Do you assist community members who are HIV positive or living with AIDS with grant applications? Do you give them guidance on how to access governmental grants?
- P: Yes, I do, and then **we also try to help where we can**. I find myself give them help. I’m often going **out there, trying to get donations from the private sector for me to buy the food supplements**, which is sometimes expensive.

Ability to identify people living with HIV&AIDS

Disclosure to trusting volunteer/ Sr E

Stigmatisation based on myths and misconceptions

Avoid disclosure due to:

Fear of isolation/ rejection and being different

Non-disclosure

Need for treatment to cope

Community centre:
-advice
-getting donations
-medication
-assisting with grant application

R: *Sister E*, thank you so much for your valuable time and the video on the centre that we could watch. I'm sure that I will get the necessary detail about your centre in this brochure and if I have any other questions, I will ask *M*. Thank you for making the time to see us.

P: You're welcome.

R: Thank you! Your centre is a great asset in this community.

P: Thanks, Ronél. **I try to help where I can.** ← But I think, just by **being there for them and loving them** ← and believing in them they are already helped. **We don't care whether or not they're positive or whatever.** ← The mere way that they believe makes it easier, however difficult it is. And another important thing is **acceptance**, ← you can't do anything without accepting your situation and give it your best way, which is whatever.

Sr E as assets
in coping:
-presence
-willing to help
-loving and
-accepting

R: I get the idea that the faith of the people of the community is one way of them coping with HIV – it seems as if the community is religious and rely on their belief systems in difficult times.

P: Ja, **they do believe in a higher power, that there is a higher power helping them.**

Faith central to coping

R: What is the role of traditional healers in the community?

P: They are **important to some**, and some will go there if they get the chance.

Traditional healers role is limited

R: Thank you once again for all the information.

P: You're welcome.

FIELD VISIT 3 – 19 FEBRUARY 2004
INDIVIDUAL INTERVIEW 5 (INTERPRETED INTERVIEW)
FAMILY OF A PERSON LIVING WITH HIV&AIDS

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How are you coping with a family member who is living with HIV&AIDS?
- ⌘ What are the main challenges you have to cope with related to the fact that a relative is living with HIV&AIDS?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

KEY OF ABBREVIATIONS
R: Researcher
PS: Participant sister
PM: Participant mother
IF: Interpreter and family friend

R: *T (indicating interpreter)* told me that your son has been diagnosed with AIDS. Could you please tell us about the time when he found out about his status. How did it happen? How did you feel? What did you experience during that time?

PS: She (*indicating participant mother*) was **in shock** and **it was a burden**. Now when we had the problem, we had to sit down and tell her that. Before we talked to our, to our brother, we talk first to the woman, my mother ... and my mother understands and then after that we talked to our brother. And we all **understood that HIV is not a thing that you can**

Initial reaction of family: shock & being burdened

Hospital as asset: counselling

Family as caregivers

die of now, you can live longer, because we can see it even through my mother. Because even she is diabetic, but she is living good.

R: Where did you get this information, your knowledge on HIV and AIDS?

PS: The problem was that my mother was sick, she's a diabetic. Then the hospital said that they will take him, and counsel him because he was very sick. And you have to understand now, my mother is sick, I must look after her. And it's then when I felt that I must go to learn ... this thing, home care. Then after that I came to become ... a home care in home nursing. A home care home nurse ... has to care.

R: That's true. How did your brother find out about his status? How did he decide to go for a blood test?

PS: He felt sick, ne. At the time he wanted to close the door and after 30 minutes he was asked to, to, to open the door, and then now he started out saying something ... but he was coughing and fighting here at the house. Then we as a family we sat down, but it's not us who saw that this man is sick, it's my other younger sister and she phoned. My sister then she phoned and then said no, something is wrong, because we could see what he was doing now is not the same thing he used to do, he was not like that before. Then his friend talked him into going.

R: So Z new first. Did he first tell her and then he you and then you told your mother?

PS: Yes.

R: How was it for the family during that time?

PM: It was a difficult time to everyone ... to everyone. First I said: "Not in this house, not in this house!" I could not accept something like this in my house. But we accepted it, we must accept it and that one (indicating

participant sister), we are so happy in this house because it happened to us, but what is difficult is because **we are going to look after him** but we didn't know what is wrong with him, but we thanked him because he **opened up and then we looked after him**.

Acceptance of relatives

Family as care & support

R: It is challenging to deal with something like this. Please tell us about the challenges you have to cope with. What is difficult?

PS: My brother he is a generous man, the second thing ... **he didn't want to go to hospital**, the third thing is, he said to everyone, **he didn't want to eat right**. We had to sit down **and fight with him**, but in a right way. We talked to him, you see, but in the right way. ~~And then the minute he decided to go to **hospital**, *hospital E* because we talked to him and he decided to go there, it's not us who send him here. The hospital gave him a date and said that he must go back there. It was last year when he was admitted, then we used to be with him, **he has got that courage to want to go to hospital** because **he could see that he was very sick**.~~

Reactions to being infected: anger and denial deny treatment

Hospital as asset to people living with HIV&AIDS

Courage of people living with HIV&AIDS

R: Was his health deteriorating at that stage?

Awareness of own illness

PS: During that time, yes. It was early last year. Maybe February.

R: Did he take medication then? Did he start with medication at that stage?

PS: **That's right**.

Asset: treatment

PS: Ja, ja.

R: Please continue. What happened then?

PS: Yes, after, after Z took him to hospital, then the **doctor** arranged that he's supposed to be admitted and treated in that **hospital** that I told you, the hospital. So it's when **he got the treatment there**. He, he, he wasn't an

Asset: Doctor

Hospital

Treatment

outside patient, they had to treat him inside hospital so that he can be very much better than he was.

R: How did you, as his family, cope during this time? How did you deal with it?

PS: I do cope because in everything you do **you must pray, if you pray and you believe then God will hear you**. But now, there were times whereby **it was difficult for us because** when we go to that place he don't eat the food, he only **share to all the people** and now we found out that even it's that food you sent him. Sometimes you, you, you **give him money** because he likes money, he would say "*I want money*". You buy for him, he says he's going to buy oranges because they mos said he must eat fruit and all that, the **nurses at the clinic said** that. Then he would **share to all the people**, maybe he only has this R10. I told myself that if I gave him this R10, I will come next week Monday, he will have this, those fruits, but when I come in he has nothing, he only has food, because **he share with other people**. Now you feel that: "*Hey man, this man, why you're doing this?*", but you can't shout him, because **he shouts you first** and say: "*Where's the fruit and all that and all that?*", you see. You **must tolerate**, you see, **you must deal with that**.

Faith and prayer as way of coping

Challenge of coping with relative living with HIV&AIDS

Care and support into money

Feelings of collectivism

Asset: nurses at clinic (information provision)

Communal belief/collectivism

Feelings of people living with HIV&AIDS Anger due to status

Challenge of coping with the feeling of a relative living with HIV&AIDS

R: Who helps you to deal with it?

IF: What was happening there at the **hospital** ~~is ... because I know what happened there~~ (*laughing*). He could see that the other people are very more sick than himself, then he should feel pity for them, not for himself. As a result what happened there, they ... usually when somebody had to wash for the whole day, he would take that somebody because the nurses got tired, asking this gentleman to wash but **her brother used to take that gentleman or that somebody**, that patient and **wash him himself because he wanted those to get healed**, you see. That is the type of person he is. So sometimes, what we are trying to say, they gave ... he, he gave them a difficult time, because sometimes, it's **far away to go visit**.

Asset: hospital

Community members supporting one another

Challenge to visit relatives in hospital

him, so **they had to leave some money** so that he can stay for four days or for two days or something, but **he would share that money amongst others**. You see, at the end he's left with nothing.

PS: Ja, **even food, he would share everything**. So it becomes **difficult for us to cope with him** because sometimes you will take this and **this is your last money, it's the last food** ... you prepared the food and you know that this **food is healthier** for, because you know mos this **hospital**, the government is doing nothing but they are there. Even the nutrition that they got is ... it's better here in our house than to go there, you see, but they are there so that they can get **good treatment** that they are not going to get here, you see. But we bought for him the **vitamin supplements** so that when he's there he must also take the supplements.

R: Who is helping you with money to buy these things? Is it only you and your mother and your sister?

PS: Yeah, it's **me, my mother and my sister Z**, and even this one *S (indicating interpreter and friend)* ... **she supports us**.

PM: Ja, **she supports us a lot, this one** (*indicating interpreter and friend*).

R: So it's the family, the sisters, the mother and the friend, helping with food and money and emotional support. And you mentioned that the hospitals and clinics help.

IF: **The family is very much supportive**. I remember one time, because he didn't want to go to this hospital, they asked me to come so that I can talk to him, so that he can go to hospital because they **could see that he, he, he was sick**, because he get cold and was coughing as we had said. **So I talked to him** and I promised him that **I will visit you** and you know your mother loves you, she's going to miss you, she's going to visit you and you know your family. You see, he is **healthy because of this family support**, because the family means a lot, especially his mother.

Financial support by family

Community members share financial resources (support one another)

Support one another, (food)

Family members find it difficult to cope

Poverty

Diet is important

Assets: government, hospital

Family members support and provide: financially food supplement

Family and friends as care and support

Family as primary care and support

Ability to identify people who are ill

Friends as sources of care and support

- IF: (addressing participant mother) You spoil him. **She (indicating participant mother) loves** him like a younger one. Family as source of love
- R: Tell us about that. Family as source of love
- IF: **She loves him.** She doesn't want anyone to touch him.
- PM: He's the only son, and he's somebody that never would get cross. He liked to, to, to laugh with everybody.
- R: Has this changed?
- PM: It's **changed yeah, because he's sick now.** Changes in people living with HIV&AIDS
- R: How difficult is that for you? Difficult to deal with HIV status of family member (son)
- PM: **It's very difficult as a mother.**
- IF: It's really difficult, because sometimes she would phone Z at work and say: "Z, **your brother doesn't want to eat, your brother doesn't want to drink the ... his pills**". **So Z had to come here and talk to the brother,** but he's a good listener, because when somebody talk to him he would listen. Resisting care and support
Family as source of care, support and advice
- R: How old is he?
- PM: 45, 46.
- R: Who else support you?
- PS: Nobody.
- R: Nobody else?

- PS: There is a lady here who is a nurse, she's the other one who supports us. Asset: nurse
- R: How does she support you?
- PS: She comes here and talk to my mother and all that. Nurse: as asset home visits and counseling
- IF: She gives them support instead of counselling because knowing that she's a diabetic (*indicating mother*), you see. So that she can accept that more than she accepted it.
- R: What about the church? Do the people at the church know that he's HIV positive?
- PS: Yes, we shared with our church friends. We disclosed it. Disclosure to church friends
- R: Did you discuss it openly?
- PS: Ah-ah, no. We only shared with our friends. Selected disclosure:
-friends only
-church friends
- R: Only with your friends? And at church?
- PS: Ah-ah, no. Only our friends.
- IF: There are some people at the church who knows ... the friends. They (*indicating participant mother and sister*) don't hide this thing. That's why they get help easy because they talk about it and their brother, even that one talk about it. Disclosure leads to care and support
- PM: That one talks to everyone.
- IF: And he doesn't have a problem to disclose it. disclosure
- R: Do the people at church that knows about it also support you?

- PS: Ja, they also support me. **The friends support us there in church**, ja. Asset: church as care and support
- R: And your other friends?
- PS: It was to me ... the time I heard about it ... I'm working shifts, even now I'm working shifts. When I come in, I heard this rumour. Then at work I have to hold up at work because I'm a care person, then I, **I didn't work like the way that I used to work**, and then my friend asked me what was wrong - the coloured. I said: "*No, I have a problem of this and this and we are hurt about this and this*". Then she called the other girls at work who's coloured people, she called the other girls and **everyone was saying: "Sorry people, sorry people, sorry" to me**. Even last year we had something here, I didn't know that they noticed my brother, my brother was here. Then they told me that ... they told me that my brother is looking very, very nice. We share with ... you share with us, **now we pray for you**. I just thanked them. You know, because they are younger than me but **they helped me**. Becoming aware of status of brother: influence on work initial difficulty in coping hurt
Colleagues/community supporting one another in handling the news of infected relative
Prayer as way of supporting others
Colleagues as source of support
- R: So the people at you work know too?
- PS: Ja, because **we shared it**, because this **man share also with the people**. Disclosure to family's colleagues leads to support
- R: Are there any people that had contact with you before your brother disclosed but are now avoiding you? No rejection based on disclosure
- PS: **No**, because I support people also. If somebody, if my friend has something I support her and other people. That's why I had **lots of support when I had this problem**. Community members as source of support to people with a relative living with HIV&AIDS
- R: Does your brother receive a governmental grant?
- PS: Ja, the **doctor** gave him the **grant on investigation**. But the doctor cut it down, they cut it to ... he was there for three months, and then he come Assets: grant and doctor

there and had to eat the food outside, though in the clinic he had it for three months.

Asset Clinic

IF: What happened is that last year when he was admitted there, he's supposed to stay for six months, they used to stay there for six months. So what happened to him, three months was inside, there by **hospital E**, then the three months he was **treated as an out patient**, taking his treatment here in ... **at the clinic**, not far away from here. Then, what happened is **they prepared a grant for him**. When he went out of hospital, the grant was already approved.

Assets in coping with HIV&AIDS: Hospital, Treatment, clinic, grant

R: So the hospital assisted with that?

Hospital as aid helping to access grants

IF: Ja, ja, ja. They do **organise for them**, for the people who are admitted there.

R: Why do you think some people don't want to disclose their status?

PS: Sometimes the **people like to gossip**, ne, **about your health, in our culture**. It's when a, a, a person don't say, because it's because of you ... ya, talking about their health and all that. You don't come and help. The only thing, if you come ... if a person come to my place, the only thing is, **he's going to gossip about my brother**. We heard about that thing ne, but we don't like to fight with the people, they are like that. There's **a lady here, who, who talk about my brother**, that he's coming here, he's not coming to *hospital E*, because he's about to die. And it's like that. **That's why people don't want to talk about their health, you see**. To other families, **in other families, they not even wanted to come inside, because of this disease ... in our culture**. I will give an example now here in my area. In this corner there are **two guys who died already of AIDS**, and in this street, in two houses, there's a girl from uhm, from Jo'burg, **she died yesterday because of AIDS**, and **they don't want to share with the people because the people are going to gossip**.

Lack of disclosure related to stigmatisation (gossip)

Challenge stigmatisation based on culture

Non-disclosure: avoid gossip

Isolation due to status relating to culture

HIV-related deaths

Non-disclosure due to gossip

- IF: That's why they also **did suffer because of the disclosure**, but they didn't take care of that, knowing that **they supported their brother**, as you have heard, if you have heard it correctly. They were talking as if their brother is going to die now, so they're going to buy food and be with them on the funeral. In our culture and we understand it, **it's really our culture**, and it's the **gossip we never had**. If they should have taken that gossip and take it as an issue, they should have suffered also, but because they **don't care**, knowing that the person who has got this HIV virus has no problem, and they, they, they are **sad as a family** also haven't got a problem with that. So it's difficult for an outsider even if he can talk to whenever he wants to do that, you see, but some, the families are not always the same, **some when they hear those things, they got hurt, got fights**.
- R: (*addressing interpreter*) But you, as a friend, seemed to have been very positive?
- IF: Ja, ja, ja. **I was very much positive**.
- R: You almost stood up against the gossip. You didn't push them away?
- IF: Ja, ja.
- R: What has changed over the past two years? What is different? For example, are you making special meals now?
- PS: It didn't change, because we have, we used to **eat veg and all that, fruit** and all that, because of my mother.
- R: Because she is diabetic.
- PS: Yeah, and we **don't use too much oil**, because of my mother. Now my brother, he, he didn't have a problem with that. You know he didn't take
- Disclosure leads to negative experience
- Family as source of support
- Culture relating to stigma
In order to cope - ignore gossip - don't care attitude
- Sadness experienced by relatives
- Pain and conflict caused by gossip
- Friend as source of support- being positive
- Healthy eating habits as components of coping

oil, he looked after himself. Instead he ate all, like ... even ... we were giving him supplements ... that is good for what he is suffering from.

Supplements provided by family in taking care and supporting

R: Is there anything else that has changed? Or did life just go on?

PS: The life just go on, but we had a problem with him, you see, because I don't know whether it's in his mind, he likes money too much you see. He must have money every time, when I asked: "What are you going to do with this money?", he would say: "I'm going to buy the fruit" but every time we buy a fruit here. He always eat fruit, even if you don't have fruit. Today we don't have the fruit but tomorrow we are going to have, because we know that they must eat fruit, we must eat fruit also.

Coping with relatives status

Difficulty in coping with relative living with HIV&AIDS

Financial needs

Practice it

Family informed about healthy eating habits

IF: So it's like what you've heard yesterday about that woman who said that the daughter needs it, when she needs something she really craving for that thing, it's the same case.

R: Is there anything in your personal life that has changed?

PS: Nothing's changed to me, ne, but the problem is this, I give him the money all the time and ... but if he has money he gives me money now and after 5 minutes he wants his money back. Now there's nothing changed to me. If he wants his money I would, I give him his money back, you see, because he's my brother and I want to support him, you see. The only thing I can do ... if I go to town and buy fruit for him, he will sit there and say: I want money, you see. The only thing I must do for him, for me, you know I can't change because if I change I will hurt him, you see. The only thing I must do, I must give him the money if I have money. Even Z, Z can't even pass him, then: "Can't you give me R5, I want to buy cold drink?", you see. She can't change, if she has money she must give him.

Financial support by family members

Family supporting one another

Financial demands

Family share what they have (money) as a way of support

R: Would you have done that a few years ago too?

- PS: **No.** ← Higher levels of financial support due to HIV status
- R: It seems that you are even more supportive now than what you used to be. You have always been supportive but now you are doing even more? → Enhanced levels of support due to HIV status
- IF: **Ja.** You know what he is trying to do, the way I see it, he is trying to, to, to draw their attention. He wants to see if they care for him, you see, by doing that, asking, knowing that: **"If you don't want to give me I will see that you don't love me"**. It's the way they are saying things. But it's not like that. **Sometimes you don't have money** really, you see, but you need to have it, but on that particular day, money is not always there. But to them, especially men, they like to do that, you see, to see to it **if you do care about me**. Like his doing to, to, to his mother. He likes to ask money, knowing the mother is a pensioner, you see. But his **mother is very much supportive, if she has got something she use to give him.** And she'll even **love him and stay with him**. So it's changed. Now he's acting like a baby, you see. **Acting like a baby, who wanted to be cared for** ← Financial needs
 ← Manipulating behaviour by relatives living with HIV&AIDS
 ← Manipulating based on HIV status
 ← Family as source of support (provide money, love)
 ← Need of support by people living with HIV&AIDS. Need for care and attention
- R: (*addressing participant mother*) What is your experience? Has your son changed? → Family providing in needs
- PM: Mmm, ja. **I give him things, give him nice things.** And he likes to buy things like drinks and another things like apples. He likes to be ... but I always **feel sorry for him**, but there's nothing wrong now. ← Family members feeling sympathy with HIV positive relatives
- R: Tell us about feeling sorry for him.
- PM: Even before ... as a mother, you know. **I want to give him that warmth.**
- R: That love. ← Family is a source of love
- PM: **That love, yes.** ← You can even love because that one ... You know mos the babies like to cry, and he's like that.

R: Has he always been like that, or is it only now?

PS: It's now, it's only now. **It's the behaviour, now that has change**, because the ... there are the .. Z's daughters, ne, now it doesn't mean he doesn't love them, you see. He loves them but he has got that thing inside, that I don't know how to say **He gets cross**.

Changes due to HIV status
-need for love
-anger
-behaviour

R: Is it aggression, or a bit of anger maybe?

PS: **Ja, and letting that anger out**, but not in uhm ... in that manner, you see, but there is this thing that, I need to make him see that it's not a good thing to do, you see. So there's this **changing of the behaviour**.

R: What does he say about his illness? Does he talk about it?

Initial feeling of infected person
Shock

PS: Ja. Last time he said he, he was **in shock** the time that the doctor told him. **Everyone was in shock**, if me ... but I didn't want to see, so that he could see that I'm in shock because he does talk openly, you see and we were sitting here, listening to him.

Shock experienced by all family members

Reaction to HIV positive status:
-aggression
-gets cross easily

IF: Yes, responding to him. He ... usually **he has that aggression, gets cross quickly**, you see. So that's what they noticed about him. He, **he, he don't want anyone to touch him sometimes, you see**.

HIV infected people Avoids contact/isolates himself

R: It wasn't like that before?

Changes due to HIV Status

PS: Ja, ja. **It wasn't like that before**.

R: What is the most difficult about illness? What is your biggest challenge?

Family as a source of empathy

PS: The only thing is I ... is that **I don't want him to get sick again** because I always think about the people we **all see on TV** and all that because I can't ease that pain, you see. **I pray that he must not be in pain**, even if he is getting cough or what what, I want him to, you know, **die quickly**, I

Asset: TV

Prayer as way of coping

Avoid pain and suffering (family members)

don't want him to suffer because I feel this thing. Yes **I'm supporting him** but even to me it's painful, you see

Family
-support but
hurting

R: Did he receive some information on HIV and AIDS from the clinic and the hospital? Did they give him some information?

PS: I don't know because **I thought that a person there in the clinic** counselled him, because he didn't hide this thing. **And people like to** hide it. **Many people**, before he got his results some person provided ... **counselled him**, because the people don't want to open when they tell you. You are going to treat a person thinking that it's something else when it's HIV AIDS, but that one, with everyone here, we heard it, **he told us all**. But now we are, **we must pull our socks** because this one is our only brother and **we need him**, you see. When ... I told you mos ... I **talked to this woman at work**, and **then we talked and then we prayed**. We said: "*No, we must close the door and pray and say thank you God*", you see. Z was not here at that time, she only knew as she was coming from the school. Then I said no ... But after that we went to the kitchen, you see mos that, it was Z's daughter. Even then they said we are so grateful about that, because **now we know how, how to treat him**.

Counseling at
clinic: asset

Avoid disclosure

HIV&AIDS
counseling

Disclosure

Family as
source of
support

Family needs
each other

Colleagues as
source of
support

Prayer as way
of coping

Disclosure leads
to knowledge/
insight on how
to treat a person

R: I get the idea – and please tell me if I'm wrong – that in your culture you support one another to a great extent. You really support and help one another and you're there for one another. But I'm starting to get the idea that it's all about women. It's the women that pray and it's the women that support. What is the role of the men?

PS: **There's no role of men.**

Women central
of care and
support in the
culture

R: So it's actually the women in your culture supporting men and other women?

IF: Ja, ja. **So they are having that overload.**

R: What is the role of men then?

All: *(Laughing)*

PS: *(laughing)* Nothing ... Even if it's ... it's like, it's a mother, if it's a married couple they've got a daughter or a son, then the, the, **the husband will tell his wife that: "You must take me away of this, you can deal with it", you see.** It's like that to, to ... **in our culture**, you see, **the man doesn't want to take responsibility for others.**

Women as strength
↓
Culture related
↑
Women as responsible for supporting others

PM: Yeah, example *T (indicating the interpreter and family friend)* supported him too much, this one *(laughing)*.

Friends as source of support

R: Tell us about that?

PS: *T (indicating interpreter and family friend)* used to go to that place and now he said to me when maybe *T*, she, she don't come there for a week. He just said: "Oh, **she must come back, must come back, she must come, oh!**"

Friend as source of support

IF: *(laughing)* He wants me to come and visit him because what he told them is that: "Oh, *it's T who'd take me here, now she doesn't want to come and visit me*". So **I had to go there and visit him.** Oh, he's such a nice guy.

Friend supports (crisis at hospital)

R: *(addressing participant mother)* What is the most difficult for you, about his illness?

PM: Sometimes he is **not even drinking water** and sometimes he ... he is **suffering.**

HIV positive:
-influence on eating
-pain

R: He's in pain?

PM: **Yes.**

- R: It's difficult for you to see him suffer, to see him experience pain? Difficult for family to see suffering and pain
- PM: Ja ... ja. Challenging to cope with relative living with HIV&AIDS
- PS: And then after that the problem that he has with money, it was difficult, and even there it was difficult. Financial demands
- R: So if I hear you correctly, you find it hard to see him suffer, and also to deal with his demands that you should give him money?
- PS: Mmm, ja.
- IF: What they are trying to say is that, you know when you are craving with something that you know it's gonna give you eh eh ... So when he, he is eating fruit, he's got that relief that I got what I want, you see. It doesn't mean that he's after money. He wants this money to buy things so that he can fulfil that need of wanting the ... that particular thing, you see. Needs to fulfil
- And now the problem, I saw the other thing that causes it, it's because he was working. Now he, he, he doesn't earn anything now, you see. Unemployment due to illness
- You know mos when you're used to get your, your salary or your wage at the end of the week, now you got sick, you are not, you, you, you are no longer getting that money. Bad working conditions
- So you, you, you want to ... you see, because you know that if I was working, I was about to do all this by myself, but now, you know, he's used to getting money because he was working. But now he stopped working because of the illness.
- R: When did he stop working?
- IF: Last year, when he started getting, uhm getting sick. When he started getting sick, when he was admitted at hospital then he never come to work again, because ... the other thing that contributed on his health is the chemicals that he was working with. They contributed a lot, because he was coughing, getting cold because of the chemicals, and also the water there. It was bad for his lungs.

R: It damaged his lungs?

PS: Ja, and **one of the lungs collapsed.**

Health problems due to bad working conditions

PM: Last night he **complained.**

R: Please tell us more?

Family as source of information, give advice

IF: Ja, because those are the symptoms. **You know mos it can cause the .. eh eh eh .. that damage,** but it takes a long time to do that. But what **I suggest him that he must go to the doctor,** you see, so that he can help, the sooner the better, you see. Because it has got something to do with his eyes as well, you see, but I **will suggest that he must go to the doctor** that he can complain that now the eyes ... he has got a problem. He needs to report this.

family as source of advice

PM: Ja, he is slowly loosing his sight, **he's getting blind.**

Health problems

PS: When someone dies, ne, if someone passes away, ne and he was living with you, you, you won't even hear the news and all that. They **don't talk about it, don't talk.** **But he talks about it the whole time,** I don't know why is it. **I think maybe he's afraid,** ne. You now, he makes it a point that whenever, if it's raining or what, he's **going to these funerals, because that person was with him there in hospital.**

Avoid discussions about death

Family: Continuous discussions HIV positive person-fear

HIV positive people support one another

R: How do you feel when you hear of somebody that has died of AIDS?

Feeling sorry for HIV positive people

PS: I **feel sorry for him,** because ... and even if, even if his voice is not right, he's talking too loud to people, hey ... **shouting to people.**

HIV positive: anger

R: It's again that anger?

Family avoid telling HIV positive member about deaths

IF: Ja, ja. That's what Z was saying to me, that they **don't want to tell him when somebody passed away,** because they've noticed that when

someone, whether it's a friend or someone whom they've slept together there by the hospital, when he'd passed away, he, he, he's got that feeling that: "*Maybe I'm the next one to go.*" He's that scared, you see. So sometimes they **don't want to tell him**, but it happens that he could hear it somewhere. Ja, he's going around, moving around, you see.

Family avoid telling HIV positive member about deaths due to fear

R: Thank you very much, ladies and good luck. I know it's a long and challenging road. But I think your positive attitude and your faith and your friends and family that are supporting you are helping you.

PS: Ja, we just keep on **praying**.

Prayer as central component of coping

R: And it's like you said, if you look after yourself, it's like living with TB or being a diabetic.

PS: But **what is important is to live longer**, as long as he's living and as long as he's alive, that's good.

Hope

R: Thank you once again for sharing your story and feelings with us. We know that it is a sensitive and difficult topic to talk about and appreciate it that we could talk to you.

FIELD VISIT 3 – 20 FEBRUARY 2004
INDIVIDUAL INTERVIEW 6
SOCIAL WORKER AT PROVINCIAL HOSPITAL

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How is the social worker at the provincial hospital currently supporting community members infected with HIV or living with AIDS?
- ⌘ Which procedures are followed when community members infected with HIV or living with AIDS want to access social services at the provincial hospital?
- ⌘ Which health services are provided in the area supporting community members living with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Could you please tell me about the procedures a person infected with HIV or who has AIDS should follow when reporting to you and, secondly, about the different services you offer to these patients.

P: The person is referred to us by the **doctors**, usually to get advice on how to get the grant. And then you tell the person that he must bring his folder and also the letter saying that he's HIV positive.

Assets:
Doctors-referral
Medical social
worker at
hospital: advice
on financial
grant

R: In other words, people infected with HIV should bring you their letters?

P: That's right. Some of them they have got a letter from the **clinic or private doctor**, but with others it's written on the folder, you know, that you are HIV positive. Then you must phone the **Department of Welfare**, on the

Assets:
-clinic
-doctor

first floor, to **apply for a grant**. In other words you must see to the registration first.

Asset:
Department of
Welfare
provides grant

R: So registration needs to take place first and is done on the first level?

P: To the Department of Welfare, yes.

R: Can patients come here to the hospital for registration at the Department of Welfare or do they need to go to the office in *N*?

P: No, you must not mix issues. Department of Welfare works with Department of Pensions, so they are one body, but the Department of Pensions are working with the Department of Welfare. So if you apply for a grant, you must go to the Department of Pension, it's still the same building, and they are there for social security. So you go for social security, then you go to see ..., there's a person you see that then recommends the grant. You take that form, that is the medical form, which is signed by the doctor who approved it, you take it to the pension office where they draw up the application, so that you can get your first payment after a certain time. And then once it goes to the Provincial Office in *B* you get a letter after some time to say your application has been approved, telling you to go to this particular pay point on this particular day to get your grant.

Definite
structured
procedures to
follow in
applying for a
grant

R: Do you perhaps know what is the CD-4 count and the viral load criteria for the disability grant in this province?

P: No, **you must go to the doctor to get the grant**.

Asset: doctor
assist in
receiving grant

R: The doctor?

P: **Ja, the social worker does not recommend a grant.**

R: I understand that, but what I would like to know is: What is the CD-4 count and viral load criteria to qualify for the disability grant in this province?

P: The doctor can tell you that.

Asset: Doctor provides information on HIV/AIDS

R: Thank you, I will ask a doctor. I would like to continue with our discussion on the social services you provide here at the hospital. Do you see people coming from *area X*, do they also come to this hospital?

P: They come if they are sick, but they must start from their clinic, you know the primary health care. That goes together with the hospital.

R: So they first go to the clinic and then they come here.

P: Yes, if there's a need, if the clinic requires assistance.

R: Is the clinic in *area X*, are you referring to *clinic M*?

P: *M clinic*, yes.

R: Is that where *Sister E*'s centre is or is there another clinic?

Assets:
Clinic
Hospital
Community centre
Resources

P: No, the clinic is next door.

R: Now I'm getting the picture.

P: Yes, that centre is the community centre and the clinic is the clinic.

R: Is the clinic run by an organisation?

P: No, the clinic falls under the Metropole. Their head office is in town.

R: I suppose here at the hospital you also do pre-counselling and post-counselling?

P: Yes, this is done.

Hospital provides pre and post counselling

R: Do you deal with a lot of HIV infections?

Poverty

P: Yes, that's the problem we have with poverty. Hence you get a grant. Because if there was employment, other people would continue working or get a job because the major problem is not necessarily that they get sick quickly. You find that some of them are really fit. But if you are poor and you get HIV, get infected by AIDS, you are going to get a grant. But you must talk to the lady at the clinic to find out about the grant.

Unemployment

Grant

R: I will definitely do so. I also wanted to ask you: Are you situated only here at the hospital?

P: Yes, we are called medical social workers

Medical social workers at hospital

R: So you don't go out into the community?

P: Yes, we are for hospital, you know, this section. But we have a lot from outside coming here.

R: The reason that I ask you this is that it seems that there are not many social workers working in area X, going into the community?

P: You see, social workers work according to certain areas. That's why even those patients who come here, you know, come here because of ignorance. We must then explain to them: "your office is this side, that's where you must go". But the Department of Welfare will tell you about the social services, that's why I would like you to meet with the lady there ... because I work with her and I also respect my people's health.

R: I will try to get a hold of her today or if I cannot, I might meet with her in March when I return. But I will phone her in the mean time and tell her that you referred me to her and that I will be contacting her.

P: Yes, because we work together.

R: I will definitely phone her and tell her that you referred me to her.

P: Okay ... And another place you must go is in the City Metropole, it's called ATICC. ←

NGO's ATICC

R: Yes, we are going there this afternoon.

P: I think that there you can get all the information, because the clinics work with us, you know. They work together ... the whole Department, in other words they network with us. They're ... It's just like different departments in the hospital and they all work together for the benefit of the patient.

Networking in wider community and on Departmental level

R: Thank you very much. Is there anything else that you can tell us about the services you provide?

Poverty

P: You know, as I have said the **problem is poverty**. We have poverty. If only, you know, there can be job creation, there will be less people **demanding for the departmental grants**. That is my take ... and you can imagine if everybody is going to get a grant who is going to work. So I'm for job creation, not for hand-out. **The job creation is very important** ... very, very important, you know. Hence here **I have my project**, that one of HIV and AIDS (*Participant shows researcher and field worker a few salt and pepper sets decorated with bead work*). **It's for ladies who are HIV**. You can also buy some of these, so that you can say you've made a contribution to them. I've got ladies who are HIV positive who make it, and then once it is sold they get the payment.

High demand for grants

Medical social worker=initiator of financial income/job creation

R: That's wonderful. How much is one?

P: The bottles are R20 each. I say to them, you know: "*Rather than wasting time at home or twining and whining about your status or drinking, why don't you do something so that you get pocket money?*" Because, you know, it helps a lot if you don't get a grant, you know to get something, having made it with their own hands.

Medical social worker=encouraging/motivates people to work

R: In which area do you run this project?

P: What happens, the ladies come here and I've got a room here in which they work.

R: So they're from all over and then they come here and work?

P: That's right. And again, because of poverty, you know, a person works and then when the grant comes, disappears ... you won't see them here again. And because it's not a funded project, it just depends on people like you coming to buy. You find that some of them are not committed but there are those who are enjoying it.

Poverty

Lack of work ethos

R: Yes, because you are creating an opportunity for them.

P: For them, ja ... and mostly I'm supported by whites from overseas, who becomes involved with the project and buy.

Support on Macro-level-international

R: Do you market the salt and pepper pots on the internet or how do you go about getting in contact with people from overseas?

P: You find that what we do is we take these bottles of theirs and just show them to some of the staff people here. We don't go to internet or what ... because we don't have the facilities of internet.

Lack of facilities

R: I understand. Thank you once again for all the information and your valuable time. May we perhaps have a look at your project, where the ladies are working?

P: Yes, I will take you there now.

FIELD VISIT 3 – 20 FEBRUARY 2004
INDIVIDUAL INTERVIEW 7
ATICC EMPLOYEE

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ Which services are currently provided by ATICC in the selected community?
- ⌘ Which role is ATICC currently fulfilling in supporting the community in coping with HIV&AIDS?
- ⌘ Which potential role might ATICC fulfil in future?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant
PIH:	Person infected with HIV

R: Please tell us about ATICC'S involvement and the services that you offer in *area X*.

P: To be honest with you, it's an area that ... well, what shall I say? We concentrated there, but because it's only two of us operating there, it's ... uhm ...

R: Two is very little.

P: Yes, when you mention that area ... there's **always something that I've neglected with that area**. I've just been there about a week ago for a staff meeting with one of the schools, because one of the **principals attended a workshop** and then the person who was facilitating it mentioned that we offer what we call the *Back to School campaign*.

Limited involvement in area

Principals= network request workshops

That's where we provide them with uniform and shoes. We go to companies and raise funds and then target the orphans, vulnerable and the destitute ... or whatever. So the principal got to know about this. So he phoned and we had to respond without assessing the room because we transferred it. So we simply brought the stuff, but when we got there we realised that the room doesn't qualify at all but it's because we were there. And it's an area that I wouldn't visit at all, but I went there that time.

Provide uniform and shoes

Fundraising networking with external companies assist vulnerable individuals

Principal requested help

Area neglected (help by ATTIC)

R: I can understand that, and also that you try to reach as many people as possible.

P: So we ... Actually, we are a centre that was started in 1989. I can give you a background ... a copy of where we started.

R: Please, that would be of great help.

P: Ja, uhm ... It was started by the then Department of Health and then there were four of these centres if I'm not mistaken, that is Cape Town, Johannesburg, Botswana and then the local one. So the Cape was fortunate in that they had Cape Town and this one. And around 1991 it was a centre, one in Queenstown and one in Umtata. So when we started operating in 89, we covered the entire Eastern Cape through the then former Transkei and Ciskei. We couldn't go in there, but there were other people covering it. Then after 1994 the province was divided into five regions – that is region A up to E. So we're actually region A, which is worse than the others.

R: Of the Eastern Cape.

P: Yes, we're the Western part of the Eastern Cape, but that has changed now. We no longer refer to region A, we've got the Metropole now. And we do training, but not only training. We also do counselling ... We train the community here – training for nurses, business people ... and then

Provide HIV training(counseling)

there's training for the **community**. And where people cannot speak English, we've got to do **training in Xhosa**. There's training for **traditional healers**, because if you want something, we realise that from time to time, **before people come into the centre or any health facility** for that matter, **they will go to a traditional healer**. So whether we like it or not we've got to bring them aboard. And at times we realise that you find the same people ... they're **concerned about their health** and when you train them, they cannot be part and parcel of the problem, for instance, you know, the means that they use for sterilising and so on. So if ten people is living in a household and if one of those people is HIV positive, then the healer must not be responsible for spreading the virus. So we train them that they mustn't use one blade, they know about it. **They know that they cannot treat it**, they know that they cannot get rid of the HIV virus but they can be able to stop the running stomach if that person has diarrhoea. They've got their own muti to deal with that and formula's that they use ... In Xhosa we say *futha, gapa, si*, that means you steam it – the person – and then you induce vomiting and then use enema.

Training (various languages)
-Professionals
-Community
-Traditional healers

Traditional healer=resource in community/ then centre/ health facility

Training (traditional healers)
-basic health issues

-Provide basic HIV knowledge

R: So they use an enema?

P: Yes, that's the formula that the traditional healers use, but they know that if you're HIV positive it can result to something else. So from time to time **they consult us**. If they know that things ... that they cannot handle it, they phone me. And then I would **refer the person to hospital** and then I **make arrangements** and phone the nearest clinic and they then deal with it. They keep condoms, they keep the information that we have got. So provincially, if we want to do something, we call on them. We've got a file specifically for them. They've got their leadership, although from time to time it changes (*person enters*). This is actually *G (introducing person)*. Eh ... I don't want to say anything, she can tell you her story ...

-Available for consultation

-Referral service to hospital

-Network with local clinics arrange help/assistance

PIH: Hi, I am G. I also work here at ATICC and I am somebody who is HIV positive and living with AIDS.

R: It's an honour to meet you. And it is wonderful that you seem to have overcome the challenge of disclosing that seems to be such a big problem in this area. So you say you work here?

PIH: Ja, I support people and help them to disclose. And we are a few people here that support each other.

ATTIC:
-support HIV positive individuals
-encourage and guide them to disclose
-HIV positive supports one another

R: That's great! And you're certainly the right person to do something like this.

PIH: Ja.

R: Thank you for introducing yourself.

P: Yes, I always say there's life after HIV.

Living with HIV

R: There's definitely life after HIV.

P: And she's getting married.

PIH: (giggles) Yes. What else?

P: That's all, thank you.

R: Thank you for sharing with me (*Person G leaves*).

P: She's actually in the leadership of the traditional healers, the present one. We also train them. Most of the time we are saying the same thing ... to deal with diarrhoea is almost the same method that is followed by the medical profession. In their own way they will make eggs and some herbs but when you look at it, it's one and the same thing. At the end of the day they are able to stop diarrhoea and the person will recover. They've got muti that can actually keep other people healthy and strong. So we've got training specifically for that and we bring them together so

ATTIC:
-on the look out for misconceptions
-correct them

that we don't find people thinking that they can cure this and whatever, so if there's someone in the township claiming that they can get rid of the HIV virus, I phone them and ask: "Are you aware of this?", and then they will sort it out and come here. **We will then bring that person on board and we educate that person.**

-educative role

R: How do you get them to come to the training? Do you advertise or do you phone them? Or is it by word of mouth?

P: Well, uhm ... Well, as I have mentioned we are also marketing this place. We eh ..., we have got partners, like the SABC is one of our partners. Usually DJ's would fight about me being on board on their programmes. For instance, last Thursday **I was on the air** from twelve midnight right up until half past one, it was a programme on condom use. Others were phoning in as far as from North West, I had no idea that they were watching.

ATTIC:
networks on
national level
eg. SABC and
Radio

R: So it was like an awareness campaign?

P: Ja, we **had built up to a national event**. South Africa selected the Western Cape for a competition, so we had a national event, so it built up to that event, **when we were launching**. There were many teachers and great ones, even now they're downstairs.

Awareness
campaign
(national level)

Advertising

R: We saw all the people when we entered the building.

P: Yes, there's a group maybe sitting outside, maybe next to the flowers ... Did you see them?

R: I can't recall. We were in such a hurry, we just quickly passed the people in the foyer.

P: They are the peer educators as well. Now the **peer educators** is something that we've started about three years ago, in the year 2001,

Peer educators

where we train these peer educators to actually target high transition areas. Now what we mean by high transition areas is that it is areas where people are likely to go in and come out with a new partner. If you need a new partner, that's the place to go. So we're actually targeting those places. So we are educating the ladies who are frequenting the men, so they can get into these shibeens and educate the people. They do plays and then the audience becomes involved. They don't stand there lecturing, they do drama and then people are involved.

ATICC as education provider

ATTIC: focuses on at risk sexual behaviour

Way in which they address it=drama, community members get involved

R: It's interactive, almost like entertainment.

P: Yes, people are involved and then from there they sensitise them about STD's, HIV, where to get medication, where to go if you want to know about living positive with the virus, where to go and all those things. So from time to time after they've been to the area, you'd find an informant saying: "Hey, everybody is rushing because of those educators". That's what they are there for. So we've got that problem, so we've been introducing these plays to all these areas. We have introduced it to areas like H, L and therefore M, and they've actually agreed that we can do it. But now the problem is, we'd like to start ATICC in all the areas outside of town. So slowly we're actually involving them, but we've got to approve them until that time. So besides the training and the counselling, we've got health forums along the clinics with community members. If you want something in that clinic you get in touch with the health forums, then you organise with them. They have to have their own special training, as people are going to go around helping. They're involved with the gardening as it is happening there, they're involved with education, they're volunteers within the clinics. Besides that, we train people in some of the work, you know the ones who have gone within the mental health or the clinics and we also train these. Now when we train, when you train people who don't have education at all, they're going to talk and address them in their own language so that they can understand in detail what is involved, what's different between HIV and a person who has developed from this, or what is to say proper AIDS disease – so it's

Providing practical information:
-STD's
-HIV medication
-Living as HIV positive

ATTIC: targets whole area

ATTIC:

-training
-counselling

-health forums

-volunteer workers
-education and help in community

... There's actually a launch on this that is due. For instance, after the partnership you can see outside, **we've started doing the sectoral forums** where we also involve other departments. So we have meetings, if you look here (*indicating a document on the wall*), these are the dates of the **local council meetings** and if you look here, we've got dates on the sectoral forums. It's usually on Thursday, we usually meet at **hospital D.** **So all NGOs are on board there.** And then you've got the businesses, you've got some **companies** involved and then from there, they get their own representatives. You'll also have a **representative from the traditional healers, being a member of his local area**, which is set by the portfolio committee. And then we've got tertiary institutions on board and some of the teachers. So, whatever happens, if there's a new NGO, if it's in the news, that NGO has got to attend to the local one and say: "Hey, I'm from Johannesburg and this is what I do", **so that they can see they don't duplicate.**

Sectoral forums

Networking with local council

NGO's= resource

Networks on National level:
-companies
-traditional healers
-tertiary institutions
-educators

Monitor involvement of NGO's

R: Do you have a list of all the NGOs involved in this area?

P: We've got files.

R: When I return in March, would it be possible for me to have access to that file?

P: Yes, I can prepare it for you.

R: That would be very helpful, thank you.

P: For instance, we have got NGOs that are being supported by Botswana. So I actually have learnt Volkswagen has got a community trust operating within, that is being supported by ... they call it *Catholes homes*, based in Germany. So we have been saying that you are actually funding some of the NGOs, and the department also is trying to, but they don't tell you that's the department. So Volkswagen has actually depended on them, these NGOs have actually received funding or they

National and International networking and supporting
Also Department involved in networking and funding

are going to receive it. So we check on our side which are being supported by the department. And now we've also got our own list of all NGOs.

R: I would appreciate insight into that list, as I am trying to determine what exactly is going on in *area X*.

P: Well I can make a copy of it. You don't have to wait much. From here, where are you going? Because I can actually sit down to share all the information that you want. For instance, you said you want to know what is happening in our files, what do we do. Because we are doing training, some of the files are not with me, I have to borrow them. **The people we are using here are not ours, it's actually people who did the training and now come and do the training.**

Empowering role

R: Is there a specific course like for teachers or is it exactly the same for everybody?

P: I wouldn't say ... eh ... **basic AIDS education is the same** for everybody, but now as I've told you, if **I'm going to the community**, I've got to change and address them in **their own language**. ~~But now when we speak of life skills, we've got **modules specifically for teachers** within education, who should be different to others ... how to approach young children and all those. But now when you deal with others it changes it. When you deal with **traditional healers** as well, you've got to change and approach them according to some of their beliefs, for instance they do things their way. So we have to find out about their ways before we start. So you know that if you want to start at eight, they've got to gather there by half past seven, so they've got to do what we call *inhlompho*. So if you don't know how to deal with them, you will run late in the programme. And you cannot stop them when they do that. There are days when they get off to do certain things, you've got to wait until you're going to hear things. So **allow them to do that**.~~ ~~And when you address them, how shall I say, it's~~

Basic AIDS education=genetic

Community visits and involvement

Mother tongue

Specific training, eg. For teachers

Profession-related/based approach

Guided by cultural needs and habits

like a pyramid. You also have some of the traditional healers to address others **according to their needs**, ~~not according to what you want.~~

Focus on communities needs

R: Not according to ATICC's needs.

P: So you listen to them, how do they approach certain things, and then within that you bring them the information that is relevant.

R: Tell us about the training programme you offer to teachers.

P: The training programme ... Uhm, I would say, the course that is happening here at the present moment, this one (*showing pamphlet*), this is what we do.

R: The basic A?

P: The basic one, yes. Now from here, which is a five day programme..., and then today they are doing counselling, it's a three day basic and then **two day counselling, just to deal with a person living with HIV, how to go about.** And then from this group then they can go on, if there are **nurses** within the group then they'll be able to attend the training that we do that is according to the minimum standards. That is a ten day counselling course. And then there's also the five day counselling programme. But we're also **training lay counsellors**, ~~although they won't be trained so strictly, but they must have the information as to how to deal with a person when they have to.~~ So this one (*indicating pamphlet*) is a basic one.

Basic counselling, training:

-Dealing with a person living with HIV

Training:
-nurses
-lay counsellors

R: Do everybody start with this basic one?

P: Yes, everybody starts with it, even teachers who are now being trained by the Department, using other people. All have got to start here first.

R: May I please have this pamphlet?

P: I've actually prepared this for you.

R: That's great, thank you! You say that you have health forums at the clinic, is that at all clinics?

Health forums at all clinics

P: All clinics

R: So the clinic in *area X* will also have a health forum?

P: It will have a forum.

R: And the forum is organised by ATICC?

P: Not really. There's nursing management who are responsible for the health forums, but when it comes to training, ATICC provides it.

Responsible: Nursing management

R: So you do the training for them.

P: We do the training.

R: Now I understand.

P: Yes, before people become community workers, they can't be community workers without getting the first basic training. And that's part of the reason why they are there. So all the forums have been trained. So when you train all the forums, in conjunction with the nursing management and the ministers in charge in all the areas, we will do the training together and then have a three day HIV and AIDS basic information programme and then they will slot in whatever they've got with them. For instance, there's a course going on in *W*, in the health centre. We have just spent five days there. But I didn't go there myself, I have to use somebody who actually started this week to do this course, within the home-based care. And then they'll carry on with their training, I

Basic training for community members and forums

Training: nursing management and ministers

think it will be for nine days or so. So the five days one, it was the basic one.

R: If I hear you correctly, ATICC is involved with training across various levels. It trains professional people and community members and lay people, it trains people across the range. And you've got a basic five day package and then also advance levels.

Summary:
Training basic /advanced level=
-Professionals
-community members
-lay people/workers

P: That's right, yes. And you cannot get, for instance, to the ten day course if you have not attended that basic one. We are not accepting you.

R: So the training is the one leg and then the other leg is counselling?

P: Yes, the other leg is the **counselling**, which is the continuation of phase one. Even the training, ... (*searching for document*) ... no, I don't have it here ... The training will start around, if not the 3rd, then the 8th of March there will be training, for the whole Metropole. Now within that training we'll usually train ..., have four courses per year where we train all people. Then they are supposed to know what to do with HIV and AIDS and a lot of those things. For example, if you are going to give birth and it is proved that you are HIV, if people are during the latest stage of their pregnancy and are given the neveropine, they've got to join. You've got to join if you are HIV positive and pregnant. So this one lady is responsible for that. She **attends sessions at hospital D with pregnant mothers and educators and also go in where they are**. Their work is to market, if you are pregnant you need to test to see if you are HIV positive. It's about prevention of the mother to child transmission.

Counselling

Community based sessions= hospitals with -pregnant mothers -educators -community visits

R: Preventing the mother to transmit the virus to the child.

Advocate responsible behaviour

P: **Yes**. I would give you a manual but unfortunately I don't think it has come back, because I'm going to run a course. The ones that we have seen we will actually use them. I'm responsible for the training, I'm actually

Prevention

the master trainer for the board. If the board has got to train other trainers, I've got to train them.

R: Training the trainers.

P: Yes, training those trainers. And then those **trainers will again facilitate and train.** ← Empowering and spreading the word

R: That sounds great.

P: Now you may look at my office and think: "*Hey, what's going on?*" Now there behind you is some of the material, it has to remain there because I've got to take it to my car. It's actually the material that the other trainers are using, they don't have the place to keep it. So the master trainer has got to see to it that everything is made the same. Now if you look in the corner, there's some other material on information for learners. I will love to show you the content of that material some other time.

R: Thank you, we can get it at a later stage.

P: And although it is information that is prepared for learners, the approach is not the same. And what I've realised is that when they train these teachers, those who **attend the courses, they will go back and tell the others and they will tell the others and then it goes like that.** → Trained people share with others

R: Do you perhaps have a brochure on all the work that ATICC does?

P: Yes, I shall prepare it for you and leave it down at the front desk. Then you can pick it up from there. It actually tells you exactly what we do, we also use it to market this place. We've **networked** to put it everywhere in the **Metropole**. It even has our cell phone number on it, to market the place. It's actually a **hotline.** ← Marketing network target whole Metropole hotline

R: Thank you very much. When will I be able to get this from you?

P: I can prepare it today and leave it downstairs by half past four. I'll put it in a package and drop it there.

R: Thank you! Tell me, what is the cost of the courses you offer?

P: Well, it's actually **funded by the government**. ATICC was actually started by the Department of Health, because of the content ... training people to be responsible, and sexually responsible, having information on HIV and AIDS and those things.

Government
funded courses



R: I understand. Thank you very much for your time and all the information. I really appreciate it.

P: Okay, thank you.

FIELD VISIT 3 – 20 FEBRUARY 2004
INDIVIDUAL INTERVIEW 8
EX-EMPLOYEE OF THE SOUTH AFRICAN POLICE DEPARTMENT

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ How are you coping with a family member who is living with HIV&AIDS?
- ⌘ What are the main challenges you have to cope with related to the fact that a relative is living with HIV&AIDS?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Please tell us about your sister – what happened and when did it happen?

P: My sister was diagnosed in 1994. When, after she was diagnosed in 1994 she never told anyone. The only thing that she does everyday, up until 1999, 1999 when she got sick. When she got sick I took her to the doctor. That's where I found out that she was diagnosed in 1994 but up until now she doesn't want me to tell anybody. Nobody except me in our family knows that she's living with this virus. Whether I can say

HIV positive family member

Family as support

Avoid disclosure

everybody now are asking themselves, because if you can see her, you won't even ask, she changed a lot, so breaking off hair, all those things, you see, and now she was like me but now she's darker. But it's not easy for me to tell them that this person is living with AIDS, because she doesn't want everybody, nobody to know that.

R: Why doesn't she want the people to know?

P: I really don't know now, because she already lost her daughter. Uh, what happened was that her daughter passed away last year November - 2003 November. In 2002 she was involved in a car accident. She was visiting a friend when it happened. After that she was admitted at uhm the hospital, East London. I think she was in a coma for a month. After that we found out that she is paralysed, she can't walk again and can't speak well, all those things. Then we tried to take her from that side to PE, at least because in our family the, the, we don't have parents at the moment, so we are trying to help each other. And the most of uh, the family are not working, so we are two who are trying to help in our family.

R: How do you help, what do you do?

P: Uhm ... If I've got money I have to buy for them. If there's a problem I have to try to solve their problem. I, I'm treating them like my children now, especially my sister because when somebody is ill, and the only thing that she thinks about is dying. So she needs someone who can move that out of her mind, but it's too difficult because I can be willing to do that but she's supposed to have faith first, you see. And she must know that to be HIV positive doesn't mean that you, you are dying. But in her case now she's fully blown AIDS, she's not HIV any more. So, I think it was August ne, last year, her daughter was sick in August last year, then they took her to hospital, she was admitted I think in August up until, because she died on the second November. But when I was in hospital on Sunday or Saturday, because she died on Sunday, they uhm, the sisters told me that what is really going on because they were talking

about it, the accident and, and all those feelings. Then I asked them: “*What is really going on?*”, because I thought if that uhm accident because was through her illness. But when the eh, eh, that sister was trying to explain to me, I realised that no, maybe before she got involved in that accident, she was HIV positive, but **she knew nothing about that then**. So, **what makes her not to cope anymore is to hear that really she’s HIV positive too**. So they transferred her to *hospital E*. That’s where she died. So after we bury her sister, your ... her daughter, then after that I sat down with my sister, I said to her: “*We are living an African life, why can’t you tell your son?*”, because she’s got a 21 year old son, “*Why can’t you tell him that?*”, because he wants to know what is wrong, because he is **old enough to see what is going on**. But he wants to hear that from somebody. So I don’t want to be that person to tell him that, I asked her: “*Why can’t you tell him that you are dying because of HIV AIDS?*” She said **she doesn’t want him to find out**. But I told her that they’re suffering now because they want to know what is wrong. Maybe they can, **even they can help you with other things**, because sometimes if **she’s ill, there’s no way for her to wake up, even if she wants to go to toilet, she cannot go from here to the toilet. You see. So who’s going to clean her?** You see. So I told her: “*You must tell your son*”, but up until today **she has not done so**. But if, even if we can go and visit her, you’ll see that at least now she is better.

Unaware of status being HIV positive: devastating (cannot cope)

Able to identify in others

Avoid disclosure

Family=informant/ advisor

Family=potential resource, if they know

Potential to assist with basic chores

Avoid disclosure

R: But she still doesn’t want to disclose?

P: No ... no.

R: Why doesn’t she want to disclose?

P: I really don’t, I don’t know, because, I really don’t know.

R: What about other people in the community, why don’t they disclose?

- P: In this ... Here in Eastern Cape, I will talk about Port Elizabeth, There's some ... **some of the people are disclosing their status because they need help**, they want ... they don't want to die, you see. Because before, if you ... **I hear that you are HIV positive I won't speak to you again!**
- R: Why not?
- P: I really don't know where that came from but it was like that before, up until ...
- R: Is it only in this area, or is it in your culture, or is it all over?
- P: I uhm, I think all over. **We blacks, I will talk about blacks, you see.** It's what happened. **If we hear that you've got this disease nobody will talk to you.**
- R: So then you'll reject the people who are sick?
- P: Yes, yes, yes. But up until, because what is going on, because before, it was few houses who've got this disease around, you see. **So now each and every family now is infected.** So I find that now it's a challenge to to to everybody, whereas some **other people they don't want to disclose their status.** There is that... Last ... I think 2001 there is my neighbour who stays in that house. I, I, **I like to help, you see.** After I found out that my sister is living with the disease, that makes me to go out you see, to **get some help to, to get the knowledge,** you see. What must I do? What am I not supposed to do about it? And really that helped a lot. And there is a friend of mine. **This friend of mine is living with this disease.** She's working for ATICC, but I don't know what ATICC mean. There's a house in *area X*, so she's **doing counselling there.** If you can, if you can see her, she is **very helping,** she is like me, you see. **She's the one who who make me see that really to help this disease.** It's like a challenge, you see, because when you have this disease, you know what are you dealing with, you see. You know what you're supposed to do. You know

Disclosure, in order to get help

Fear death
Stigma=
rejection when they disclose

Culturally related

High HIV infection rate

Avoid disclosure

Community members=
support others

Family=knowledge/seek information

HIV positive friend

Community members:
-counselling
-helping
-information

what you are not supposed to do if you want to live. Because before we thought that if **people are going to die because they don't have money to buy eh, eh medicines and all, all that stuff**, but as I ... I just think medicine is not important. Yes we must use eh, eh medicines, but before you have to, you have to, to, must **learn to love your family**, you must **accept what you have**. And you, you ... I don't know ... How can I say it? The problem is, some other people they think that if you've got this disease, tomorrow or the day after you are going to die. **But what I found out** is that you can have this disease, you can live for more than 20 years.

Medicine: important

More important: loving you family and accepting

Family members seek information

R: Where did you get your information? You said you went out and you wanted information.

P: Uhm ... I like to, to ... **there is a group here at K**. It's people from area X, K, KD, J and the extension W. They formed a, eh eh group, you see. All those people, they met each other at the **clinic**. ~~So they used to go to the clinic and discuss their problems there.~~ But one lady told me that they are, they are not feeling comfortable there, at the, at the clinic because everybody is coming there, you see, **even those that are not living with the, with the ... this disease**. So what they do now is they visit. Today they are coming to my house, tomorrow to your house something like that. Then afterwards I said to this lady: "*I want, I want, I want to go there, I want to share some views with you, can I go there?*" Then she said: "*Okay, I have to go to them and speak to them first and I'll come back to you.*" Really, this lady came back to me and I went there. I found that **those people are, are, are positive**, you see, are positive ... they know what they want, you see. And they are 100% sure that they are going to survive, you see. Then some of them are **not using drugs because they don't have money to to to use drugs**, some of them they are using drugs. Like this friend of mine I was talking about, uhm ... she's married, she's Mrs N. Her husband is a policeman. What happened ... **when she disclosed her status to her husband, her husband left her**. Even now she is on divorce process. That is very terrible.

Support groups in community

Clinic based support groups

Stigma Avoid them

Living positively HIV

Financial needs=medicine

Disclosure leads to rejection/ divorce

Because what I know, in that couple I, I, I just tell her that your husband is on denial, because you can't be ... If you are positive he's supposed to be positive. But she said uhm her husband said he was tested and he's negative. So nobody's got the proof about that. It's what he is saying. So he asked for the divorce. So she has to divorce her husband because of this ...

R: Because she disclosed her status.

P: So it's one of the things that make people not to disclose their status. Some of other people they would, they say that I didn't invite the, the, this disease, you see. So I won't tell anybody, I will just sleep with this one, sleep with that one – even if, you see. That is why this disease spread so fast, because nobody wants to stand up and say: "I do have this, you see, so that we can protect those who are innocent." You get what I'm saying?

R: If you think back of your sister, how is she coping or how are you coping with her being HIV positive?

P: I am coping very well with her. But I am not happy, because what will make me more happy if she can stand up and tell everybody in our family that I've got this. So that they can know that even if there is somebody else in our family, all of them they can come out so that we can, we can try to help each other because I used to tell them that if you've got a problem come to me, I am not good, I'm not perfect, but I am willing to help, I am willing to share what I already know, you see, especially about, about... because really I am concerned about this disease, it is killing our children, our sisters and brothers, our mothers, you see. So I cannot let it go just like that. Uh, Uh... I... Yesterday I went to, to, to area X. There's uhm, uhm sixteen year old daughter who's really sick there. I was so frustrated when I found out that nobody wants to go inside that house. I don't know why because by touching that person, that doesn't mean that you'll get this disease. By cleaning that person, that doesn't mean that

you'll get this disease. By, by touching ... because those people need to be loved, you see.

R: Why do you think are they ignoring her? Why don't they want to enter her house?

P: Some other **people are not, well are not educated about this, you see.** That's why I told you before that we need to go out, you see. We need to call in everybody ... **teachers, reverends, NGOs, everybody must be involved, you see.** It's not only one body's problem, it's everybody's problem. So to fight this everybody **must stand up to help those who can't help themselves,** you see. Even if we don't have money, we can go just there, to, to see that, to **show them that everybody's caring about these people, you see.** They've got brothers and sisters outside who cares about them. That's the only thing I, I, I think that can help people. And we must **try to teach them that even if we don't have money, try to make something for your own living,** you see. You can go and uh ... you can go and get something somewhere else, you see, to try to make yourself healthy. Because what I know, **even if you can get treatment,** if you don't eat well, **I don't think you can, you can make it. If you are not happy about who you are, I don't think you can make** it, you see. You need to be strong. You, **you need to love yourself** first you see, so that the rest will follow. You, I, I cannot say that I, I don't, I, I, I don't believe that I, I, I do have this disease then I will expect the treatment that you are giving me will help me, **I must help myself first, then the rest will follow.**

Lack of information in general community (misinformed)

Potential resources=community based challenge-all need to be informed and involved to help support

Community needs to support

Fulfil in own needs/initiate solutions

Client=important

Acceptance of one self and status=important

Inner strength and love=important

Coping=person based

R: Tell me about that sixteen year old of yesterday. Who... How is she coping?

P: Oh... **Not very well... because she's in denial.** She doesn't want to believe that she is HIV positive. Then I spoke to her and told her: *"You've got something in your body and that thing is in your body, if you don't fight it, it will cost your life, do you want to die?"* She said: "No." Then I

Denial-them not coping

Community members: provide information =support

ask her: *“If you don’t fight this disease, who do you think will fight it for you? But if you want to I will help you.”* Then she asked me how, then I asked her: *“Do you believe in God, and do you went to... do you go to church?”* But I asked her: **“Do you know that God is alive?” I prayed and I prayed, and prayed...** then after that I asked her: *“How do you feel now?”* She said she feels better. Then she asked for water. I bring water for her, then I said to that lady they must uhm, because our water here is not... eh eh, sometimes you find out that the water is infected, after you drink it. Then I asked her to boil her water first before drinking it. Then, **every time if she says she wants water, give her boiled water.** Then I said to this lady: *“Why don’t you stand up?”* and she said: *“Her knees are ... I think she’s feeling weak because she doesn’t want to eat, she doesn’t want anything, if she eats something that thing will come out again”.* Then I said to her: *“It will be like that because you are ... you don’t know what are you dealing with up until you make up your mind”.* Then I asked the lady, because I asked: *“Where is the girl’s parents?”* Then she said: *“The parents are in East London.”* But I told her that this girl needs somebody who’s going to look after her. You see I didn’t want to ask her so many questions, because ... **I must ask her where did she think she got this disease from so that we can call in that boy, maybe we can help even that boy or maybe that boy doesn’t even know that he’s got this disease.** Then I promised her that I will come again on Sunday afternoon. Maybe **I will try to find something for her, like e-pap.** You know e-pap? You don’t know e-pap? It’s a porridge, I think it’s R6.50 at Shoprite Checkers, it’s like a, it’s like a Maltabella, you know Maltabella? It’s something like that, at least you can use it as a drink so that at least you get strong, then after it, it will be easy for her to to to eat everything because even if she drinks something like Amasi, it will come out again. People used to say that, but I don’t believe that, people **used to say that berries are not okay for those who are living with this virus, but I don’t believe** in that. I really don’t believe that. But eh, we are listening to different people, everybody is trying to say what they know. Let me go back to my sister’s case.

Faith in God and prayer=central

Community members= source of information

Basic care

Community members= -support -responsible behaviour propagate

-provide food

Utilising all possible sources

After I found out that my sister is living with this disease, I do have a medical aid. Then I went to my doctor. Then when I went to my doctor I said to my doctor: *“Look doctor, I was diagnosed in 1999 that I’m HIV positive but then I didn’t want to use treatment but now I’m ready, I want to use treatment, I want you to organise something for me.”* Then he said: *“Who tested your blood?”*, then I said *doctor M*. Then he asked: *“Why didn’t he organise something for you?”* Then I said: *“I was not ready then to use the treatment but now I do need treatment.”* Really, he prescribed something for me, antiretrovirals, or something like African potato tablets, and the other tablets, big tablets which you take one a week. So every month I must go to him to get a prescription to go to the pharmacy to get the, the medication. From 2000 up until last year. Then what happened, I was sleeping here at home, somebody phoned and said: *“You are losing your benefit, why don’t you apply for, for chronic because we do have chronic for, we do have treatment for our members. If you can apply, you can go to your doctor he’ll apply chronic for you, we’ll bring your treatment straight to your house every month?”* *“What treatment now, what are you talking about?”*, I asked her. Then the lady said: *“You are HIV positive.”* I said: *“No! Me, I’m HIV positive? No, no, no, no, no, no! I’m not HIV positive.”* Then the lady said to me: *“You are not Mrs XS K?”* I said: *“I am. I am not HIV positive”*. Then the lady dropped the phone. After ten to fifteen minutes, my phone rang again. My doctor’s receptionist asked me: *“What are you doing?”* I said to her: *“About what?”* She said *“You were here and said that you are HIV positive. Now you said you are not HIV positive, you are trying to to to to get my, to to put my doctor in trouble now.”* **Then I realised that I lied.** I said: *“Okay, okay, I will fix that.”* Then the lady phoned again. I had to admit to the lady that I was HIV positive, because now I know that my doctor would have a big problem because of what I said. So I told them that **I was trying to help my sister, I know that what I did was wrong, but I was trying to help my sister.** Then they asked me: *“Do you know that what you’re doing was very wrong?”* I said: *“Yes, but I am willing to say that I was wrong.”* So my medical aid was terminated there and then, I am paying R600 every month for what I’ve done. Otherwise I’ve got sick,

Family members lie to help HIV positive members

because I was so frustrated. I was, I I I was worried about my sister. I was not worried about myself and that I can go to jail and loose everything for what I've done, I was worried about her, because I know that she already started this medication. Maybe after some time now, because I won't afford to buy it every month for her now. So maybe after two or three months after, maybe she got sick. Really, after two months she got sick and she, she nearly died that time. Then, what I've done, I just sat down with her and told her: *"There's nothing now that I can do for you unless you help yourself. The only thing that you can do now, I can see that really it's too late, but maybe it isn't too late at all. Try to accept this thing."* Then after if you get... eh, eh because another thing that she was doing, she was drinking a lot. Then I asked her: *"Why, because you are killing yourself."* *"The problem is I cannot sleep at night"*, she said. Then I tried to to to to open her mind, saying that: *"What makes you not sleep at night, because those people who are living with it, they don't know what is going on, you see. Now you are trusting yourself by killing yourself, at least tell that one that you've got this disease."* Then she said: *"I cannot do that but I will try to accept that I am living with this disease."*

Coping= in person himself

Acceptance=important

Alcohol abuse

Sleeplessness

Avoid disclosure

Really, after that ... I could see that she, she's a fighter, because the nurses were, were were telling me so many things, that she won't make it. Because I asked the nurses that I could see that she, she was loosing her strength, you see because she was loosing too much of water, then I asked them to, to, to ... what do you call it? You call it drip, I don't know if you know it. So they said: *"No, they cannot do that now, it's too late for us, for her to, to, to give that now. As a result, tomorrow, we are discharging her."* I went back to, to the wards again and told her: *"Tomorrow you're going home."* Then I called some members of the family and told them this lady won't make it, we must try and prepare something for her so that when she dies everybody must be involved, because a funeral is too expensive in our days. Everybody was so frustrated, was so frustrated but the miracle that happened, because up

Strength lies within themselves

Family=support

until now she is still alive. Whereas if you can see her, she's not in a, a, a right situation, you see.

R: Is she taking medication at the moment?

P: No, except eh, eh Biko... It's difficult here to get uhm medication but she is got now eh, because **my doctor** tried to help her **to get a pension**. So she's earning pension so that she can, she can ... (*paused, phone ringing*) Can I answer? Sorry.

Resource
Pension= financial resource (potential)

R: You were saying that your sister is not taking medication but your doctor is helping her to get the pension?

P: Ja, she already, she's **earning pension every month**. So that if she's sick at least she will have money to go to the doctors, ~~she can buy food~~, you see, **healthy food** for her and try to look after herself, because me alone, I cannot afford to do that.

Receive grant
Diet=healthy food=important

R: Tell us about the time after your husband died. Last time when we spoke, you mentioned that first you didn't cope but that you started to cope later on. Please tell us about that time?

P: Uhm ... what happened, **my husband died**, ~~it was on the ... it was Tuesday, on the 5th of January 1998. My husband was working at ..(unclear) police station. That day he was working the second to ten ... two to ten. Then, before ... Before, I think in 1995, in 1996, we were separated. He moved out of the house. I've got two sons. **So he was having an affair**... So he moved out of the house, okay, for two years. Then, in 1997, I think it was on the 23rd of June, he came back, we tried to discuss our problems and start and rebuilt our marriage again. Then everything, from that day everything went smooth. On that day he came home, I think it was five past five because I was watching Days of our lives. Then he said to me I must cook early. When he's doing two to ten I must cook early because at that time I was not having an oven to warm~~

Coping with the death of a spouse
At risk sexual behaviour

his food, so I like to cook around nine o'clock because I know that half past ten he would be at home. So he said to me I must cook early that time, that day, he will come at home at least eight o'clock. Then after Days I started preparing my food. Half passed eight I went to bed. After that... Maybe I just gone to sleep, I don't know but I woke up at about five to twelve. When I look, I saw nobody is here. I realised that he was not home. I thought: "*Where is he now?*" I thought to myself that oh, maybe he decided to go back, you see, to what he was doing before. When I tried to sleep I hear that there is someone who is knocking at my front door. I peeped through the window, I saw that there are so many cars, police cars outside. What's going on, maybe there is an accident or what, I think. Then I came in, I turned to open the door, I found that it's Reverend, pastor, eh ... police chaplain. They came in and asked if I am alone. I said: "*No I'm not alone, I'm with my kids.*" Then they asked me: "*Where is your husband?*" I said: "*He went to work but never came back, I don't know.*" They start eh ... they said eh: "*Because your husband was involved in an accident.*" Then I stand up and asked: "*Can I go to my room and wear my clothes and come back?*" They said: "*No, wait.*" Then somebody bring water for me, give me water to drink. At least now, I uhm ... after that time I see my blood was trying to ... eh, eh, you see. Then one lady asked us to, to, to, **to pray, really we prayed.** ← When we were busy praying, I read that ... I, I **listened to one lady** who was saying that they are feeling sorry for me, you see, at my age, that I can loose my husband that way. I thought that I couldn't know what happened after that because the following day I was in hospital. Then I was uhm ... summoned on the next day again. So we went to the police station where I said that my husband was shot last night. It was him and his colleague. Eh ... there's a woman who was fighting with her husband. Then the woman was, uhm went to the police station to try to ask the police to help her, because she was looking for her clothes at her home and the husband was refusing to let her take her clothes. Then my husband said to this lady: "*No, this case is not our case. Go to the social workers or to the lawyer*", you see. Then the lady went out and phoned 10111. When the lady phoned 10111, then it was radio control who sent

Prayer=Ist
resource=
Central

Community
members and
colleagues=
support

my husband there. Then my husband said to this radio control: “No, control, this woman was at the station a bit earlier, then I tried to explain to this lady that this is a, a marriage problem, so she can go to the social workers or to her lawyer.” Then the control said to my husband: “Please help because this lady wants to go to work on the following day, so she needs clothes.” Really my husband and his colleague went to that house, but they never came out alive. My husband was shot while he was sitting on the chair, trying to help.

So what happened, uhm ... **I tried to, to, to, to make myself strong**, you see ... tried to cope with that up until we buried him. After we bury him, two weeks after, because I was admitted on the 29th of January, up until towards month-end of February, I was lying on the bed, early in the morning, I wanted to go to toilet but I couldn't stand up. Then **I called my younger brother because after the funeral I asked my younger brother to come stay with me.** Then I called him and said: “I want to go to toilet.” Then he said: “Why don't you wake up and go to toilet?” I then told him that: “I cannot stand up, don't know why.” He said: “You are lying”. When I tried to stand up I just couldn't. After that, he called one of my neighbours, they took me to hospital. After that, then I was admitted. Uhm ... it was very painful, it was very, very, very bad. **I thought then that I'm dying**, I will never walk again, I will never see my children again. The doctors were trying to help me, every.. everybody was trying to help me, but eh eh ... I think then I was not able to help myself. Up until, up until one time one woman came to me... my children were there, it was Sunday afternoon. This lady said to me: “These are your children?” I said: “Yes.” “Do you think about them?”, she asked. I said: “Too much, but **there's nothing that I can do**, I can see now that I am living for my children.” Then the lady said to me: “**There's nothing that I can say to you except to tell you that you need to be strong, not for yourself**”, and then **that's when she left.** In that Sunday evening I couldn't sleep, I really couldn't sleep. **I was thinking that**, really, if I can die now what is going to happen to my children because I don't have parents, there's no one that I eh eh ... no one in my family members who can look after my children

Coping lies with being strong inside yourself

Family support one another in difficult times to cope

Last hope

Inner strength=way of coping

Decision to get well

the way I want. **So I realised that, the only thing that I can do was to fight now**, to stand up so that I can look after my children. Since that day, even my doctor couldn't believe, because he used to send somebody to, to, to, to train me and do all the stuff, but I told him that I don't need that anymore, when I'm ready to stand up I would stand up. Three days after, I woke up early in the morning because I used to ... the nurses were used to wash me because I couldn't even wash myself. So that day I woke up early, five o'clock in the morning, I went to the toilet. When my doctor came in on that morning, I was busy preparing my bed and I told him: "*Today I want to go home.*" He said to me, because I was, I've got three operations. He told me: "*You are not well, the operations are still wet and all those things.*" I said: "*No, I need to go home now.*" Really, the following day he said: "*Okay, I will discharge you the following day.*" Then they discharged me, they gave me goals and all those things, I came back home. **It was my brother who was caring for my children. I never went back to my doctor** except the day of moving out of hospital.

Will to be cured and to live

Family members looking after children

From that day I felt that **I have the courage**, living is about challenges. It's about **accepting your, your, your problems and dealing with your problems in an open mind**. So since then that's how I got back on my feet.

Courage

Acceptance=1st step in coping

R: And if I understand you correctly that is the way that people in this community cope. It's with their faith (Yes) and with other people supporting them (Yes) and other people helping them (Yes) and maybe a healthy diet (Yes). Is there anything that I'm leaving out?

Summary:
Cope:
1.Faith
2.Community members support/help
3.Healthy diet

P: Yes, uh and sharing, you see, and **sharing**. **I think sharing ... to, to accept your, your, your problem is the most important thing, you see. It's the main thing, because if you don't have faith, nothing will come right - you must believe that.** What I believe in is that **if you want to live, you will live, if you want to achieve something, you'll achieve that, you see.** So it's what I used to tell people that don't rely on drugs, because even I don't believe in drugs. You see, I don't believe in drugs, but I don't say that if

Community members sharing

Accepting=important

Faith=important

Positive attitude and belief/faith

somebody wants to use drugs they cannot use it, you see, but before ...
learn to accept it, have faith, have somebody, one person so that if you ...
 ... because sometimes ... we are living, now people ... **most of us are**
not dying because of this disease, it's because of, they've got a lot of
 stress, **they don't have people to share their problems** with, because they
 are ... there are those who **feel afraid of that people who are laughing** at
 them, you see. But in fact I used to tell them I don't mind, if you tell, you,
 you, you tell **me your problem** then I went to my neighbour and, and uhm
 talk about that problem of yours to my neighbour ... it's my own problem,
 not yours, you see, because **the minute you, you, you take out your**
problem you'll be very relieved, you see. So if, because by telling me
 your problem, that means you **trust me**, you see, that's why ... that's
 what make you share your problem with me. So if I go up and down and
 talk about it to other people it's not your problem, **it's my problem. I will**
answer to God, on my day, you see. Don't mind that. The **most**
 important thing is, is, is ... you know that by taking it out of you, at least
 you will be relieved, because most of the people now are, are, are dying
 because of stress, you see, because they **don't have people to share**
their problems. That is the most important thing, and you must believe.
 You must **believe in God**, you see. You must believe in God, because if
 you want God to help you, I know that you will get that help, you must,
 you must ... Now is the time for us to demand, you see, if we demand,
 everybody's got ... I'm talking about myself, I want to live twenty years
 more for my children. I demand that to God everyday, every now and
 again because he knows that I want to live, not for me, for my kids, so he
 can't let me down. He can't let me down. That's what we need to do, you
 see. That's what we need to do. But it will take time to other people to
 understand that. That's why I, I, I, I said to you before that **we need**
something like workshops, so that everybody, everybody must be there,
you see, because some other people are just looking for their relatives,
for their family members. Go out and help another person's life, that will
 make something to your, to you too. But some other people they just
 don't want to be forward so that they can be involved to other things, it's

Strengths:

Accept it

Faith

Support system

Stress then

Support=
important

Fear – stigma

Share problems

Tell other
community
members=relief

Relationship of
trust=important

Community
members
sharing in other
problems-taking
burden

Having a
support
system=brings
relief

Religion and
faith in God

Need for
informing
people(all
community
members)

Family=primary
support system

something like that, but I do know that most of the people are going to survive in our five years to come.

R: The sixteen year old girl that you saw yesterday, is it just a friend?

P: No, what happened there is that I saw the problem of eh family members in area X, so when you come to me about your project I listened to you. Then after, if I, I, I, I will see that I can do this, I can help you in this project, you see. Before, I will tell you about myself, about where do I come from, some other people they don't know me before, they just know me now, so they don't know where I'm coming from, you see. So it's what I used to do that, I would tell them that I am coming from a poorest poor, poor, poor family, but you won't believe. You won't believe because I told myself that God helps those who want to help themselves. So I just told myself that I want to be one of those people who help themselves and help others. So it was something like that. So those, since that day, those ladies came to me again and said: We've got a problem that side, people are dying, nobody wants to be involved in these things, you see. Because there are, there are NGOs in our areas, there are social workers but I don't know what is going on, because it's not about helping people at your workplace, help your community, do it for community, you see. Because really we need our communities, you see, especially those children who are from, from, at the age of ten up to twenty-one, you see. They know nothing, so they need people who can show them that there is future outside, but you must, you must try to take things slowly, you see. So they need somebody who can teach them, you see. Somebody, eh ... not a person who's going to, to, to, to shout at them, to be harsh on them, somebody who'll be in that position so that they can really understand what is going on outside. Because most of the people who are dying now is our youth. Our youth are really dying and it's my concern, because we need those children, you see. We need those people to, to, to be our future teachers and doctors or ... But if, if we are not ... we don't want to help them now, where are we going?

Family=support

Coping lies within PLUS God's HELP

Community members help one another

Community members support and look for help

Mobilising assets

Resources

Future perspective=important

People need to be informed

Need for a positive future perspective

Community members help

R: I want to ask you one more question. Tell us about that group that works in the community, the one that you went to, to get your information from. Do they meet regularly and do they go to people's houses or what do they do?

P: What they are doing, every Wednesday they meet, there is a hall here at K, so they meet there to ... if, to, to share their views. Then, if there are, one of them is sick or what, they are **visiting each other at their homes to help each other.**

Home visits
Community based support group

R: So they are like a support group?

P: Ja, it's a support group.

R: Do you know of any other support group in *area X*?

P: No, no. I don't know in *area X*, but in that support group, there are people from *area X* that also goes there, but there is few of them, you see. That's why I said that we need, **we need to go out to this areas,** you see, and, and, and try to, to, to, to explain to them that, that ... Don't feel ashamed of yourself, you see. **Stand up for your rights because to have this disease, it's your own right,** you see. It's your own right and it's something that you can, you can live with. If I don't want to, to, to stand **up for myself, who can stand up for me?** ~~No one,~~ you see. And if I already have it, it won't just go away, you see, it's something that it will be there for the rest of my life, you see. But the only thing that is important, if you know what are you getting.

Need to inform and motivate HIV positive people

Crux of coping lies within yourself

R: And accept it.

P: Yes, that's right.

R: L, thank you very much for your time and for sharing your story with us.

P: It's a pleasure. I must tell you, I was having a **meeting yesterday five o'clock at the police station** ~~with our youth~~. I'm a co-ordinator of the youth in this area. Really, our youth are involved in drugs. Our youth are involved in **rapes, car thefts, house breaking**, all those things, you see. Now I was trying to ... **trying to get some help from NGOs** and our **counsellors** ~~to try to, to, to do something, to do something about our youth~~. But what is happening now, I'll just say, maybe because the, the, our elections are, are, are coming very soon, it's what makes them not to respond, because without our local government we cannot move, you see. We cannot move. They must be involved, each and everything that we are doing, you see. So on Sunday, one policeman killed an eighteen year boy, Sunday morning. That boy was trying to rape his cousin. So that person died on the spot. It was very, it was ... when I hear that, I was feeling very sorry for that boy, but as long as nobody feels what I feel, I'm not sure because we ... we don't think eh ... we are different people here, coming from different places, you see. Some they don't have interest in these children, because I tell them, from our last meeting I just tell them that: ~~Why can't you sit down people and check, what makes our crime rate high?~~ Is it **poverty**, or is, is, is it because those kids doesn't have something to do or what? Because I don't believe that I can make that to my son, then when he has reached eighteen years he will go out and steal your things, you see. There is something wrong somewhere somehow, so we need to check from those things, really what is going on because those children are our children, you see. But uhm ... our meeting was so successful yesterday.

Resource

Youth problems:
-drug abuse
-sexual abuse
-crimes

Potential resources

Crimes

Poverty

R: You've been working hard this week. Thank you for your time!

FIELD VISIT 4 – 4 JUNE 2004
INDIVIDUAL INTERVIEW 9
(interview conducted in Afrikaans)
ACVV EMPLOYEE (CO-ORDINATOR/SOCIAL WORKER)

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ What are the main challenges faced by the selected community?
- ⌘ Which resources and potential resources can be identified in the community, which might be utilised to address the challenges the community face?
- ⌘ Which services are currently provided by the ACVV in the selected community?
- ⌘ Which role is the ACVV currently fulfilling in supporting the community in coping with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Ek is besig met navorsing in *gemeenskap X* en probeer verstaan hoe die gemeenskap MIV&VIGS hanteer, hoe hulle daarmee “cope”. Vertel my asseblief van die dienste wat julle binne die betrokke gemeenskap verskaf en wat jou persepsie is oor die wyse waarop die gemeenskap die eise van die pandemie hanteer.

P: Wel, ons het 'n maatskaplike werker wat binne die gemeenskap werk en na sewe jaar min of meer die gemeenskap dek. Sy het 'n kantoor by die een laerskool, wat die skool gratis gee. In ruil daarvoor ondersteun ons die skool waar ons kan – finansiële of met vaardighede wat ons het waar

Community based social worker at a primary school Support Networking

ons hulle kan ondersteun. Op hierdie stadium van die geveg het ons, ja uhm ..., so ons kantoor is daar, maar ons probeer om uit te brei.

R: Mmm?

P: Ja, ons het aansoek gedoen by die **Lotto, vir 'n sponsor, en ons het dit gekry!** Nou **wil ons 'n hele dienssentrum,** soos wat ons hier het, in *gemeenskap X* **bou.** Ons het nou Maandag 'n vergadering met die argitek gehad, ons wag fisies net vir ons eerste paaiement wat uitbetaal moet word, dan gaan ons begin bou. Behalwe hierdie grond het ons ook **ons eie crèche in gemeenskap X.** Daar is 58 kinders op hierdie stadium wat geregistreer is daar, maar dit is ons, die ACVV se gronde. Dit is nogal redelik groot, en die crèche is ons fase een, die **dienssentrum is ons fase twee** en fase drie gaan meer 'n **gemeenskaps-service centre** basies wees. Ons het ook, wat baie goed is, 'n salarisvergunning gekry vir die koms van 'n **dienssentrumorganiseerder.** En dit is hoekom ons maatskaplike werker ook hier is vanoggend, want ons betrek haar – sy's alreeds betrokke by ons groep wat ons het, en dan sal sy, net soos wat ons dienssentrumorganiseerder dit hier doen, sal sy dit dan daar gaan doen. **Ons wil probeer om al die dienste wat ons hier apart het en kan lewer aan die gemeenskap ook aan daai kant te doen.** Die ding is, dis **ons gemeenskap, ons is verantwoordelik daarvoor.** Daar is **bitter min – volgens my – ander NGO's verteenwoordig daar.** En dit is 'n **baie behoeftige gemeenskap.** So, **Departement Welsyn of Sosiale Ontwikkeling is ook betrokke,** maar meer met gevalle waar dit nie soseer oor bemagtiging van die gemeenskap gaan nie. Dit is meer krisis-ingrypend, jy weet.

Lottery=financial asset
Service centre=potential asset

Creche in Community

Community centre planned =potential asset

Co-ordinator to be employed=potential asset

Planned to extend service provision to community =potential asset
Responsible to support community
Limited NGO involvement in Poverty
Government involvement

R: Ek verstaan.

P: En wat lekker is van hierdie crèche is dat, ons het geen statutêre werk nie. Geen. Ons is **verantwoordelik vir gemeenskapsontwikkeling en-bemagtiging** in *gemeenskap X*. So alles wat ons doen is gefokus of gemeenskapsprojekte en **nie op gevalle-werk nie.** Want jou satutêre

Focus on community development and community empowerment
Not individual cases

werk vat gewoonlik 80% van jou dag se tyd. So, umm, alles wat jy doen is net **gemeenskapsgerig**. So dit maak nogal 'n baie groot verskil. Ons het op hierdie stadium ook 'n **jeuggroep**. Ek dink dit gaan deesdae meer na 'n **vrouegroep**, want ons moet aanvaar ons **kan nooit iemand wegwys nie**. As jy dertig is en jy wil deel word van hierdie groep dan word jy aanvaar. Ons **leer vir hulle handvaardighede**, hulle het vir my so 'n lys gegee; hulle wil naaldwerk doen, hulle wil leer brei, hulle wil leer hekel, hulle wil lapverf. Al daai tipe van goed wil hulle doen, en ons probeer om al daai vaardighede vir hulle aan te leer as, op die ou end van die dag 'n **inkomste-genererende projek**, want hulle kan dit maar gaan verkoop en die inkomste is hulle sin. Ons kom elke Maandag en Woensdag bymekaar vir twee ure. Op 'n Woensdag is dit basies hulle handwerk en op 'n Maandag sal hulle dinge doen soos 'n **opvoedkundige onderwerp wat hulle moet bespreek** of hulle kan hulle **bybelstudiegroep** doen. Dit hang maar af wat die groep se behoefte is. Ons het so een keer in twee maande 'n vergadering met hulle om te beplan vir die volgende twee maande om seker te maak ons spreek aan wat hulle wil doen. Hulle dink dit is baie maklik om in die roetine te val van 'n program vir die volgende twee maande, want hulle kry hulle program vooruit, elke maand, van wat hulle op die Maandag en Woensdag gaan doen. Hulle dink dis baie maklik op die ou end van die dag as jy eers in hierdie roetine van werk is en jy sit die program neer van dis wat ek gedink het julle moet doen vir die res van die maand. So ons probeer sover as moontlik – as hulle vandag sê hulle is nie lus hiervoor nie en hulle wil eerder iets anders doen, dan doen ons dit. So, **ons is redelik oop vir verandering**.

Community-focused

Youth group

Women's group (nobody is turned down) Focus on skills development

Income generating potential

Educational discussions and Bible study

Flexible ito change

R: Waar vind hierdie byeenkomste plaas?

P: Umm, by die **wit kerkie op die hoek**. Ons het hierdie kerkie, dit is een of ander geloof, ek kan nou net nie op die naam kom nie, umm ... Maar ons gebruik dit absoluut gratis. Alles wat ons doen word daar gedoen. Ons **fondsinsameling** as hulle iets maak en dit verkoop, is dit daar, ons jeuggroep word daar aangebied, die naaldwerkers doen dit ook daar – so is dit net meer gerieflik en meer privaat. En dis nie 'n groot saal nie,

Church in community= asset

Fundraising (coping with financial needs)

dis nie eers die helfte van die saal hier binne nie. So dis 'n baie klein saaltjie wat die atmosfeer net half beter maak – dis nou nie hierdie groot skoolsaal nie. So dis op hierdie stadium gratis, wat baie goed is, maar ook baie primitief in terme van daar is elektrisiteit maar ons het sover as moontlik vir hulle 'n kas met al hul goed in voorsien. En dis koud, in die winter is dit verskriklik koud, jy't eintlik 'n mat nodig en daai tipe van ding en dis hoekom ons graag ons eie sentrum wou gehad het. Net om dit meer gemaklik en gerieflik vir hulle te maak. En hulle moet voel dit is 'n mooi omgewing en 'n meer rustige omgewing, wat hulle gaan motiveer om op die ou end uit hul pad te gaan om deel te neem.

Need for proper facilities

Coping ito being motivated

Nee weet jy ek sê altyd as jy gebore word in 'n omgewing en jy leer dis hoe dit is, gaan jy nie noodwendig weet wat jy mis nie. Maar as jy vir hulle indring en sê dis hoe jou omgewing kan wees, sal hulle ook daaruit leer. En op die ou end van die dag is dit ook ons doel. Om vir hulle 'n gemaklike plek te gee daar waar ons alle aktiwiteite vir hulle kan aanbied, waar hulle bemagtig kan word en dat hulle dit dan ook kan verder vat. So dit is die groepe. Toe ek hier begin het, was die groepe minder, daar het so vyf of ses gekom. Ons staan nou op so 15. En spesifiek wat ek nou net gesê het, hoe moet jy byvoorbeeld lewe inblaas? Hoe kan jy, want ek weet nie wat voor my tyd gebeur het nie. Maar dis ongelooflik as jy hulle eers begin motiveer en ook hoor wat hulle behoeftes is en sien hoe hulle deelneem en ook na vore kom, ons is nou besig om handskoene te brei – glo dit of nie, want dit is wat hulle wou gehad het. En geel serpe vir hulle kinders en 'n serp vir die winter. En ons het 'n donasie van wol gekry, so hulle is aan die brei. En ons het 'n naaldwerkinstruktrise wat ook, sy is die heelyd by ons woonstelle, en ook weer eens geld van die Lotto af, wat dit alles moontlik maak. En ons het genoeg fondse om fisies te koop wat hulle nodig het, wat baie lekker is.

Focus on empowerment and sustainability as ways of coping

Motivation and dedication

Donations= assets

R: Dis wonderlik!

- P: En ek sal vir jou sê, hierdie Lotto is baie welkom, maar ons wag nou al baie lank en hulle sê hulle weet nie wanneer ons eerste paaiement gaan kom nie. Maar ek kla nie hardop nie, want hulle het letterlik vir elke maatskaplike program waarvoor ons aansoek gedoen het, het hulle gegee.
- R: Fantasties.
- P: Ja, dis ongelooflik. Dis so lekker, want gewoonlik as jy dink hierdie ding gaan werk moet jy hom ses keer gaan omdraai en kyk of iets anders beter gaan werk of nie dalk goedkoper is nie. Dis so lekker, nou gaan jy in, jy kry wat jy nodig het en jy weet dis wat hulle gaan en kan gebruik. So dit maak nogal 'n reuse verskil. Ek dink as die Lotto besluit nou draai ons krane toe, gaan dit 'n groot aanpassing wees vir baie. So dis basies dit vir vanjaar se groepe. Dan het ons ook ons weekgroep, in dieselfde kerk en dit is 'n groep wat basies laerskool en hoërskool georiënteerd is. En weet jy, die groep groei ook geweldig. Hulle het begin met so 12, 13 kinders, en op hierdie stadium kom daar so 22 tot 23 op na 25. En dit is 'n voorkomings- en opvoedingsgroep, maar basies doen hulle nie fondsinsamelings en sulke tipe van goed nie. Ons doen baie jeugkampe met hulle en sportontwikkeling met daai spesifieke groep. En dis maar basies voorkomingsprogramme, op hierdie stadium is hulle besig spesifiek met die hele HIV, die disease, seksvoorigting, al daai tipe van dinge is hulle besig mee. En ons het nou van die 11de tot die 13de Junie 'n jeugkamp vir hulle. En ons het vir hulle 'n workshop vir Saterdag gereël van iemand uit die gemeenskap wat – Dinsdag het ek hulle ontmoet vir die eerste keer – hulle is besig met 'n HIV-support group, maar D gaan julle meer daarvan kan vertel. Miskien ken julle al die mense, hulle is al gevestig maar hulle wil graag uitbrei, en hulle kom bied fisies die workshop vir die jeug aan vir die hele Saterdag. So ons probeer om sover moontlik van die gemeenskap se hulpbronne gebruik te maak om hulle eie mense te bemagtig, wat beter is as wat ek byvoorbeeld gaan, want dan kan hulle in hulle eie taal bemagtig word wat, ek dink, 'n groot verskil maak op die ou einde van die dag.

National lottery as financial asset

Weekly group

Growth in group

Prevention(HIV) and educational

Youth camps and sport development

Prevention programmes: -HIV&AIDS -sex education

Youth camp Workshop

HIV support groups

Mobilising community resources to empower others (=asset-based approach)

R: Hoe gereeld vergader die groep?

P: Een keer 'n week, ook op 'n Dinsdag, vir so uur en 'n half in die middag, van reg na skool tot so vier uur toe. Partykeer, as hulle dit baie interessant vind, gaan hulle oor die tyd. En vir al hierdie groepe voorsien ons vir hulle broodjies en tee, maar nie vir die jeuggroep nie. By die jeuggroep drink hulle koeldrank en wat ook al, maar almal kry hulle eetdingetjie, soos vir die menses wat op 'n Woensdag daar is, kry basies 'n dish met so gebakte ete, met groente en sulke tipe van dingetjies in. En die kinders by die crèche kry e-pap.

Provide in basic needs:
-food
-food supplements

R: Ek het al baie daarvan gehoor.

P: Ek het al e-pap geëet. Dit werk soos wat hulle sê dit moet, maar ek eet dit nie elke dag nie, want dis nie baie lekker nie. Maar in elk geval, ek het nou al hierdie mense ingetrek om 'n presentation te gee oor hierdie e-pap, en elke week as ek soontoe gaan moet ek daarvan bestel – ek voel al soos 'n rep vir e-pap, want ek moet bel en die aflewering doen en al daai goed.

R: Hoeveel kos dit?

P: Weet jy, dit is R10 vir 'n 25 gram pakkie, en uit een pakkie kan jy 20 kinders voed. Want jy eet mos net so een of twee opgehoopte eetlepels dan meng jy dit met óf water óf melk. En dit bou jou immuunstelsel, dit gee vir jou energie, en sê nou maar jy eet dit agt uur die oggend en tien uur drink jy 'n glas water, dan sit dit fisies uit in jou maag dan voel jy versadig en asof jy nou net 'n maaltyd gehad het. En ek belowe vir jou, ek eet my ontbyt sewe uur in die oggend, en twetse opgehoopte eetlepels is te veel vir my want ek eet dit saam met joghurt en teen twee uur daai middag is ek nog nie honger nie. En e-pap se vitamien en minerale is gecoat – dit het een of ander lagie om sodat dit nie teen mekaar kan werk nie. So jy kry fisies al jou vitamien en daai voedingswaarde wat jy nodig het in. Dit boost dan jou immuunstelsel.

E-pap: nutritious and inexpensive
-combat hunger and malnutrition

En jy maak dit ook nie met gekookte water nie, want uit die aard van die saak brand dit al daai voedingswaarde dood. Maar jy kan lou water, of lou-warm water of lou melk of wat ook al kan jy maar bysit. Vandat die crèche dit nou probeer gaan dit beter met die kinders, maar hulle voel nogsteeds dis te duur, en hulle sê die kinders hou nie daarvan nie want jy kry dit in *strawberry* en *vanilla*, en ja, hulle sê die kinders hou nie daarvan nie, ongeag van die geur. Maar weet jy, as kinders net daai twee eetlepels inkry per dag, hoef hulle geen ander groente of enige iets anders te eet nie. So ons gebruik dit ook vir ons jeuggroep en baie van die bejaarde vrouens wat sukkel met hulle gesondheid en met diabetes gebruik dit ook. Ek sukkel geweldig met my bloedsuiker en as ek daai pap geëet het, het ek nie soveel probleme nie. Dit werk basies vir alles. Dit help met hulle gesondheid ook.

Dan is ons terug by die crèche. Sover as moontlik probeer hulle om elkeen in 'n spesifieke area te wees sodat die hele area bedien kan word. Hulle koste per maand beloop so R60 per kind, baie van die ouers betaal nie want hulle het fisies nie daai R60 nie. En wat vir my goed is van die crèche is hulle wys niemand weg nie want op die ou end van die dag – ongeag of die ouers die geld het of nie – daai kinders het leer nodig. Dis hoekom ons so 328 kinders het. Hul probeer die beste van die behuising maak. Hulle doen aansoek by die munisipaliteit en elkeen, waar ook al, individueel doen dan aansoek. Ons doen vir hulle aansoek by die jeughuis, wat vir ons op hierdie stadium redelik goed ondersteun. So hulle het nogal daai fondse gekry en hulle fondse word uitbetaal aan hulle onder ons leiding. Sê byvoorbeeld hulle moet gaan vir 'n *educational course*, sal ons hulle fisies gaan haal en ons vat hulle soontoe. Maar 'n groot behoefte is kos, want hoe gaan hulle aan al hierdie kinders kos voorsien? Soos ek gesê het, hulle eet agt uur, tien uur, twaalf uur en drie uur. Jy kan vir die ouers vra dat hulle net 'n broodjie insit – maar al die ouers doen dit nie. Daar is baie kinders wat met 'n leë rugsak by die skool aankom. So hulle het 'n baie moeilike taak. Op hierdie stadium is ons, ek kan nie vir jou sê watse vennootskap dit is nie, want hulle vra, en ons moet gee. En dit is nie vir my bemagtig

Crèche in community as asset

Financial need

Crèche accommodating all children

Assist in obtaining funds and external aid

External funding as asset

Poverty and hunger

nie, want ons is op dié stadium besig met *hand-outs* en dit moet gestop word. Die ongeluk van die saak is daar is 'n president geskep. Ek het 'n ongelooflike lelike vergadering nou die dag gehad, ek is nuut, ek kom met al hierdie inligting wat gebruik moet word, want dit is nie hoe dit werk nie, en ek kry dit van alle kante af. Daar is baie wat ons raadpleeg en wat ons soebaat hulle wil deel word en hulle wil op ons lys kom – wat ek met alle mag en krag wil keer. Ons is hier om finansiële ondersteuning vir hulle te gee. Ons vat hulle een keer 'n kwartaal op 'n uitstappie. Al daai administratiewe werk doen ons. En toe laat weet hulle net nou die dag ons moet nog die vervoer betaal ook, toe sê ek vir hulle dis waar ek nou die streep trek. In 'n mate het julle 'n inkomste gehad. Ek is bereid om julle 50% te help maar ek gaan nie die ander 50% betaal nie. En hulle was kinderlik ongelukkig met my. Maar ek het hulle so ver dat hulle aan die einde van die maand gaan hulle betaal, die totaal was R600. Ons sal die R600 betaal maar hulle moet vir ons R300 terugbetaal. Want hulle moet daai verantwoordelikheid leer – ons kan nie net gee nie.

Hand-outs not favourable

Financial support in community
Take community members on outings

Focus should shift to empowerment instead of hand-out

So, die crèche het, die werk wat hulle fisies in die gemeenskap doen is goed, hoe hulle daai kinders oplei, baie keer gaan ons tydens ons besoeke en kyk fisies wat hulle met die kinders doen. En ek moet sê: ek sal een van my kinders soontoe vat want hulle kry die stimulering wat hulle nodig het. Maar net om die hele konsep en persepsie om te draai van ons gee – dit werk nie. So dit gaan 'n baie lang proses wees. Hulle dink op hierdie stadium dat, van ons kantoor se kant af het hulle gevoel iewers moet ons ons losmaak van die crèche, maar dit kan jy ook nie doen nie, want dan doen jy nie meer jou werk nie. Bemagtig hulle dan, dat hulle kan voortgaan op hulle eie. So dis baie moeilik, ook as hulle aansoek doen vir befondsing. Hulle kan byvoorbeeld nie, nou doen ek aansoek by die Lotto vir hulle en namens hulle, maar kan hulle nie ook gaan aansoek doen nie? Want op die ou end van die dag kry nie een van ons nie as gevolg daarvan. So ons het ... baie van ons donateurs en plekke wat ons befonds het vir ons briewe uitgegee en gesê: asseblief, doen een persoon aansoek namens almal, nie ses verskillendes nie. Dis

Crèche provides in educational needs of children

Focus on empowerment

baie moeilik – die vertroue is nog nie daar nie. So dis baie moeilik om daai insig te ontwikkel dat ek niks van hulle wil ontnem nie. Ek gun hulle alles wat hulle toekom. Maar as jy in die verlede kon aansoek doen, nou kan jy nie meer nie. So ons het nou vir die 30ste Junie 'n vergadering met hulle. Om al hierdie befondsings, die voor- en nadele, en hoe alles gedoen moet word, alles fisies met hulle deur te werk in die vorm van 'n *workshop* wat *Mev V* ook gaan doen. Omrede sy langer hier is het ek gevoel laat sy dit behartig, want hulle het meer vertroue in haar as in iemand wat hulle nie ken nie. Laat sy aan hulle verduidelik ons steel fisies nie hulle geld nie. Maar dit is net die prosedure wat gevolg moet word. En dit moet baie goed *gescreen* word en deurgewerk word en reggestel word, so dis 'n lang proses.

Ja, so dis dan deel van hulle behoeftes wat ons aanspreek. Van 'n meer professionele kant probeer ons ook om **voorkomingsprogramme** met hulle doen. Die eerste dag was dit vir my so vreemd, toe ek die crèche gaan besoek, toe begin al die kinders te huil. En ek kan nie verstaan hoekom huil hulle nie. En ek is nie die taal magtig nie – wat dit baie moeilik maak, maar ek verstaan dit al bietjie van dit wat ek opgetel het. En hierdie kinders huil, en as die een begin huil, dan huil die ander een harder. Ek wonder later wat gaan aan, het ek iets verkeerd gedoen? En dan groet ek hulle of ek speel met hulle of wat ook al en toe sê iemand, nee dit is omdat jy wit is, hulle het nog nooit 'n witmens gesien nie. En dit was vir my ongelooflik – dit was die eerste keer wat ek dit ondervind, ek het dit nog nooit in al die skole wat ek besoek het, in al die ander crèches wat ek besoek het en al die ander areas het ek dit nog nooit ondervind nie. Dit was vir my 'n *eye opener* – ek het nie geweet dit is moontlik nie. En dis baie moeilik – ek kan nie die workshop aanbied nie want hulle verstaan nie Engels nie. So hulle moet in hulle moedertaal die opvoeding en die poppespel of wat hulle ookal beplan moet hulle vertaal, en dis hoekom ons hulpwerkers dan verantwoordelik gaan wees daarvoor.

Prevention
programmes

Dan het ons 'n **groentetuin-projek**. Ek dink jy kan dit sien van die uitdraaipad af – hulle het mos daai muur, en reg langs daai muur, 'n hele strook grond so af waar ons groentetuine is. Ons het ses groepe waar daar omtrent 300 mense is altesaam wat verantwoordelik is vir die groentetuine. *J* sal julle ook meer daarvan kan vertel. Die idee was basies oorspronklik om **werkskepping en inkomste te genereer**. Op hierdie stadium word dit nie bereik nie want die stukkie grond wat elkeen het is baie klein. En op hierdie stadium **lyk die tuine chaoties, want die goedjies is droog en dit lyk nie asof die groentetuin bewerk word enigsins nie**. Toe het hulle 'n vergadering gehad so twee weke terug en hier is 'n lysie van aankope wat ek moet doen ten opsigte van alles wat ek moet gaan koop, want hulle het in hierdie tyd soos die inskakeling van al die nuwe personeel en ons hulpwerker is af op kraamverlof, so nou het hulle uit tyd gehardloop en die lysies gegee maar niemand het nog terugvoering gegee nie. **So hierdie groentetuine moet net weer op die been kom. Almal is nog daar, maar hulle wag fisies nog net vir die saad**. So teen die einde van volgende week sal ons die saad hê, dan kan hulle weer aangaan, maar soos ek sê daar's baie min – party kan byvoorbeeld 'n sakkie uie of 'n sakkie wortels verkoop, maar ek meen ons praat hier van twee of drie rand wat nie regtig 'n verskil in hulle lewensomstandighede gaan maak langtermyn nie. **Maar ten minste voorsien hulle vir hulle kinders en hulself**. So dis ons groentetuine – hulle brei nie uit nie. Die mense wat betrokke is – dis 'n groep van 300 wat betrokke is, maar vir die afgelope hoeveel jaar wat hulle betrokke is het ons nog nie uitgebrei nie. Ons beplanning met die nuwe dienssentrum is om dit dalk te verskuif soontoe, omdat ons fisies die grond daar het daarvoor, dan het ons 'n groter mate van beheer – die **hulpbronne gaan beskikbaar wees, die water gaan nader wees**, jy weet al daai tipe van goed. En dis nog een van die redes hoekom die tuin so chaoties lyk, die water moet fisies gaan haal word.

Vegetable garden project

Employment opportunities and income generation

Vegetable garden neglected

Vegetable gardens = potential assets

Provide in basic needs for family

Resources and water available

R: By die skool waar ek werk het die onderwysers ook die behoefte uitgespreek om 'n groentetuin te begin. Sal julle oop wees daarvoor dat hulle julle kontakvir raad, want daar is water en daar is grond en hulle wil

graag die ouers van die gemeenskap betrek om dit te bestuur. Sal dit in orde wees dat hulle jou bel?

P: Definitief. Enige tyd! Want weet jy, **hulle het definitief die vaardighede – hulle weet wat om te doen**. Dis net 'n geval van as die hulpbronne daar is, maak dit dit net soveel makliker. En dis dan maar al van ons groentetuine. Soos ek sê, op hierdie stadium moet ons nou net dringend die saad en die dinge by hulle kry want dan kan dit weer van die grond af kom. Maar op hierdie stadium, ek gaan julle nie eers wys hoe dit nou daar lyk nie.

Educators perceived to be skilled

Dan **doen ons lewensvaardighede by van die skole**. Die twee hulpwerkers gaan nou, hulle het gister begin met hulle nuwe vaardighede met die kinders en dit is 'n langtermynprojek. Hulle het fisiese materiaal wat hulle opgelei is in, dis lewensvaardighede wat die vorige werker met hulle gedoen het. En hulle het fisiese programme wat hulle alles met hierdie kinders doen. En hulle vat nou maar so standerd vir standerd – so dit vat 'n tydjie. Die **behoefte het van die skole af gekom, hulle het ons fisies gekontak** om te hoor waar is ons en wanneer begin ons. So hulle het gister die eerste keer begin met hierdie lewensvaardighede-program, en soos ek sê, dis langtermyn. Ek dink as jy regtig gaan kyk na wat jy alles kan doen, daar is so baie onderwerpe wat jy kan bespreek met die kinders en wat jy voorkomend en opvoedkundig en al hierdie tipe van goed kan doen. Dit kan jou fisies vir 'n jaar en plus besig hou. Wat lekker is, is hulle is twee, wat maak dat hulle in kleiner groepe kan werk, wat die kwaliteit van hierdie tipe van diens wat jy lewer kan verhoog. Want ek voel, al bereik jy 15 kinders per jaar, dit is baie beter as daai 500 wat jy op jou statistiek het en eintlik het jy nie eers een bereik nie. So ek het 'n kleintjie dood as iemand vir my sê hulle gaan 'n praatjie gee, want op die ou end van die dag moet jy evalueer of jy regtig 'n impak gemaak het of nie. Ek meen, vat dit van jouself hoe maklik jou gedagtes dwaal as iemand daar voor staan en praat. So dis waarmee ons besig is by skole.

Life skills programmes at schools: involvement

Networking with schools

Dan het hulle ook 'n karate-klub, maar ons is nie direk meer betrokke nie. Die hulpwerker het dit ook, sy het dit begin en sy het basies die hulpbronne daargestel vir die gemeenskap. Dis nou jammer, ek het eergister of wanneer het ek al hierdie hele tydskrif wat die man vir my gegee het – maar ek het hier iewers 'n prentjie – van hierdie ou, hy's die eerste swart man wat 'n kaptein is van die Springbok karate-klub. Hy't vir my hierdie ding gebring, maar hy rig 'n honderd kinders af, plus minus 'n honderd, dis eintlik al 'n bietjie meer as 'n honderd, gee hy gratis karate-klasse voor, van vyf tot sewe, een keer 'n week in die gemeenskap, by 'n skool. En hy lewer hierdie diens absoluut gratis aan die gemeenskap. Toe het hy ons hulp gevra met die uitrustings spesifiek, maar dit is ongelooflik duur. So wat ek vir hom gesê het is dat ek in my nuwe Lotto-aansoek gaan ek hom inskryf en dan watse befondsing hulle dan ookal toestaan, indien, kan ons net so aan hom gee. Sover is hy gewillig om dit te doen en was bereid om dit van die begin af gratis te doen. Partykeer sal die kinders 'n R5 betaal, maar hulle is so arm wat dit baie moeilik maak want hulle moet byvoorbeeld R10 inskrywingsgeld vir toernooie betaal. En as jy fisies nie daai R10 het nie, dan het jy dit nie. En as jy moet kies tussen 'n karate-klub toernooi en brood en melk op die tafel vir die aand vir die kinders, gaan jy dit definitief nie vir die karate-klub gee nie. So daar is duidelike belangstelling, want daar's oor 'n 100 kinders wat al deelneem, en hy groei per maand hierdie groep. Maar dis hoekom ons gedink het, finansieel kan ons nie op hierdie stadium help nie, maar ons kan dalk van ons vrouegroep vra om later miskien van die uitrustings te maak, maar selfs daai materiaal is baie duur. So dis nie moeilik om daai uitrusting te maak nie want hy vou mos net so oor die broek, maar die materiaal is net so duur en ons het fisies nie die finansies nie, want ons het nie begroot daarvoor nie – om dit te gaan aankoop nie. So die plan met hulle is dan definitief nou om hulle in die nuwe Lotto-begroting in te skryf.

Karate club as asset

Support by women's group

En dan, daar was op 'n stadium 'n netbal groep. Ons het hulle netbalklere alles hier want hulle het 'n netbaldag gehad wat doodgeloop het in die tyd wat ek nou weg was en ons beplan om dit nou weer te

Netball group

begin. Maar ons kry mense uit die gemeenskap – daar's van die skoolkinders wat miskien in die eerste netbalspan speel wat bereid is om die wat nog nooit eers aan 'n netbalbal gevat het nie **byvoorbeeld klasse te gee na skool – na ure – en dan skryf ons hulle ook in die toernooi in. Net vir blootstelling, basiese oefening, want die fisiese en die emosionele en al daai goed werk ook maar saam.** En dieselfde met krieket. Daar is van die kinders wat **graag wil krieket speel en baie van jou gevalle wat uit die gemeenskap kom is kinders wat dalk nie so betrokke is by die skool nie of dalk lankal skool opgegee het, en dan is daar van die jeug wat byvoorbeeld in ons jeuggroep is wat bereid is om van hierdie kinders fisies op te lei.** So dis basies wat ons doen vir sportontwikkeling, maar dis meestal vir die jonger kinders – die jeug.

Classes to children – physical stimulation -emotional well-being

Other children supporting vulnerable children

Dan het ons een keer per jaar 'n **sportdag vir bejaardes** en *gemeenskap X* word ingeskryf, want ons is een tak. Dan, vir die oefeninge wat ons hier doen vat ons fisies van hierdie mense wat meer ondervinding het van die oefeninge wat hulle doen oor 'n baie lang tyd, gaan uit na die gemeenskap toe, hulle gaan leer vir hulle fisies al die verskillende aktiwiteite wat hulle moet doen vir die dag. Hulle elkeen het 'n dans vir die optog – dis eintlik nogal 'n groot ding in hulle lewe. En toe verlede jaar het hulle blykbaar 'n beker gewen, *gemeenskap X* het die beker vir oumense vir die beste sportgees gewen, want daar was een of ander pastoor of predikant wat die musiek moes gebring het, toe daag die ou net nie op nie. Toe het hierdie bejaarde groep, het toe begin sing. Hulle is mos ongelooflik talentvol wat musiek aanbetref. En hulle het sommer, man, blikke gevat en dit gebruik as dromme. En hoe hulle die hele spangees en musiek vir die dag voorsien het en hierdie hele optog toe kon laat voortgaan het met hulle insette wat hulle gelewer het en toe het hulle die beker gewen.

Sports day for the old-aged

So, hulle maak my mal op hierdie stadium, vra aanhoudend wanneer is die volgende datum. So ons weet nie, ons sal eers na die 14de Julie weet wanneer die volgende datum is. Maar dis ook 'n groot dag vir hulle. Daar is al die verskillende mense van Uitenhaag en Jeffreys, en al daai

plekke kom bymekaar en dis die verskillende spanne en takke en wie weet wat, wat alles teen mekaar kompeteer. En in 'n mate is dit meer ontspanning as wat dit regtig bemagtiging is maar hulle word ook blootgestel aan soveel ander goed wat hulle nooit in hulle gemeenskap gehad het nie. En daai goed kan weer vorentoe na hulle gemeenskap uitgedra word en daai diens wat daar gelewer word. En dis ongelooflik hoe baie energie die bejaarde mense het. Dis ongelooflik. Hulle het meer energie as vandag se tieners, dit belowe ek vir jou.

Dan, ons het vier **individuele plasings** – streekshofplasings. Vier lêers, dis die enigste gevalle-lêers wat ons het. Hierdie gevalle kom al jare saam met hierdie tak spesifiek. Dit is almal wat se biologiese ouers fisies oorlede is of net spoorloos verdwyn het. Maar soos ek sê, ons doen nie statutêre werk nie, daardie kinderhof-verrigtinge is al lankal afgehandel. Ons is fisies net verantwoordelik vir die verslae en daai tipe van dinge. Maar dit is my verantwoordelikheid, die hulpwerker doen dit uit die aard van die saak nie. En dan besoek ons hulle nou maar net so een keer in twee weke, een keer 'n maand om te kyk gaan die plasings nog goed. Meeste van hierdie kinders, as daar klein kindertjies is, is hulle by ons crèches ingeskakel, die tieners is by ons jeuggroep ingeskakel en dit gee ons ook 'n beter mate van beheer en kontrole. So daai diens gaan glad nie uitgebrei word nie. Hulle het, op hierdie stadium het hulle gevoel ons moet daai lêers termineer en oorplaas na die Departement, waarmee ek 'n groot probleem het want die ACVV lewer hul diens al vir die afgelope 15 jaar plus. Dit gaan nie tot voordeel van die kind wees om nou ewe skielik by 'n ander persoon te eindig nie. So ek het gesê die meeste is tieners, ons het een kind van 5 jaar oud op hierdie stadium, so die meeste is tieners, jy weet, 15, 16. Agtien jaar is nie so ver weg nie, so as jy 15 jaar teen 3, 4 jaar vat, ons gaan aan met die diens, ons gaan klaarmaak, termineer en dan is dit klaar.

Maar dis sleg, weet jy, **daar is fisies net nie die personeel om daai diens te lewer nie. So ek dink as jy regtig moet gaan kyk – daar is ongelooflik baie gevalle-werk binne die gemeenskap en fisies nie die personeel om**

Social support to individual cases

Limited social services, lack of staff
Great need in community

daai diens te lewer en waar kinders moet verwyder word, om daai diens te lewer nie. Wat baie sleg is want die Departement dink ek nie bereik almal nie. Daar is mense wat 3, 4 jaar al wag net vir 'n grant. Die tendens was op 'n stadium, toe hierdie toelaag net uitgekóm en bekendgestel is, dat nou neem almal almal se kinders aan vir 'n grant, want dis vir my 'n vorm van inkomste. Maar die probleem kom in by die prosessering by die Departement, dis so ongelooflik stadig, julle sal weet wat daar aangaan, maar dit werk nie. En nou moet hierdie kinders versorg word, hierdie 3 of 4 kinders moet versorg word. En intussentyd is daar geen vorm van inkomste nie.

Department cannot meet community's needs
Backlog in grant applications

Grants as income =asset

Dan het ons ook vakansieprogramme vir die jeug, dis maar meestal vir die laerskoolkinders, meer ontspanningsaktiwiteite omdat daar geen fasiliteite is vir ontspanning in die areas nie. So hulle doen opvoedkundige en ontspanningsprogramme gedurende die vakansie. Hulle sal speletjies met hulle speel, kompetisies hou dat die kinders kan pryse wen. Hulle gee byvoorbeeld aan die einde van die vakansieprogram 'n groot partytjie. Net as, dis nie veel bemagtiging nie, maar meer, soos ek sê, as ontspanning net vir die kinders. En ook om hulle besig te hou, want ledigheid is baie sleg. Ons sit hier met 'n situasie waar kinders van 15, 16, besluit het ons is nou klaar, ons gaan nie verder skool nie, hulle kry fisies nie werk met hulle kwalifikasies nie. Hulle is ledig en die volgende stap is dan raak betrokke by al hierdie dinge wat aangaan. Ons het nou kinders wat betrokke is by 'n absolute dwelmnetwerk. En dis al die kinders wat fisies niks het om met hulle tyd te doen nie. So hoe anders moet hulle, hulle word partykeer in geld betaal, ander tye word hulle met dwelms betaal. Hulle word afhanklik gehou, so dis hierdie bose kringloop. So veral vir die kleintjies, elke vakansie, of dit nou 10 dae vakansie is, maar nie oor Desember-tye nie. Meestal vir die veiligheid van die werker word daar nie vreeslik baie met die gemeenskap gelol oor Desembere nie. Spesifiek Kersfees, tussen Kersfees en Nuwejaar, omdat alkoholisbruik hoog is. En dis familie-tyd ook maar meestal, so daar word nie vreeslik aktiwiteite oor daardie tyd aangebied nie. Maar die vakansieprogramme word vir al die ander

Holiday programmes for the youth
Recreational

Children involved in substance abuse

vakansies aangebied en soos ek sê dis maar hoofsaaklik vir die laerskoolkinders. Nou in die April-vakansie was daar oor die 100 kinders elke dag wat gekom het, en ek moes die dag 'n 100 appels gaan koop en 'n 100 eiers gaan koop vir al die aktiwiteite wat hulle aan het. Maar ook, ons het befondsing van die Lotto af gekry vir hierdie vakansieprogramme. So ons kan dit doen.

R: Is hierdie programme oop vir die kinders van *gemeenskap X*?

P: Ja, absoluut vir die hele gemeenskap, wie ook al belangstel. Weet jy, *even* die *life skills* program, die jeuggroep, almal. Dit is absoluut daar vir die gemeenskap. Hoe meer dit bywoon, hoe beter. Want so kan jy uitbrei.

Dan het ons ook nuwe projekte wat beplan word. Die hulpwerkers het gevalle-werk wat hulle doen. Van die gevallewerk wat hulle doen moet hulle uit die aard van die saak soms na my verwys of andersins na die ander maatskaplike werker, afhangend, vanuit die assessering, wat hulle vind die probleem is. As hulle nie in staat is nie of wat ookal, uit die aard van die saak, moet hulle verwys. Hulle is bekend met die gemeenskapshulpbronne, so sou daar 'n aansoek wees – mense wil weet hoe gaan jy te werk om aansoek te doen vir 'n ongeskiktheidstoelaat of die jeug het 'n probleem, verwys hulle basies en stuur die gemeenskap in die regte rigting in. Ek meen *L* werk al vier jaar, so sy het baie inligting rondom die maatskaplike veld en basiese inligting wat hulle kan voorsien aan die kliënte. Hulle sien so gemiddeld, weet jy nie vreeslik baie nie, omdat hulle meestal nie op kantoor is nie – nie vreeslike kantooraafsprake nie maar meer in die gemeenskap – maar hulle sien so gemiddeld tussen 25 en 30 kliënte per maand. En dit gaan meestal oor **grant probleme** wat hulle ondervind. Daar is ook baie **gesinsgeweld, alkoholmisbruik, en dan probleemtienaers**. Dis nou maar wat ek die kort tydjie wat ek hier is uit die bestuursnotas en goed uit kon kry. Dis van die dienste wat hulle lewer, maar die meeste van die dienste moet hulle verwys. En as hulle nie weet nie, kan ek vir hulle die

Community challenges:
-grants
-family violence
-alcohol abuse
-child-related problems

verwysing gee en dan kan ons verder verwys. So daai diens word ook gelewer.

Dan wil ons graag 'n tipe van 'n nuusbrief begin om uit te gee in die gemeenskap, nie soseer as 'n fondsinsameling nie maar ons wil hom graag vir so 50c na R1 toe verkoop net om die uitgawes te dek, want ons het nie befondsing daarvoor gekry nie. Maar basies, wat dit gaan wees, is om vir die gemeenskap in te lig ten opsigte van die dienste wat die ACVV lewer binne die gemeenskap en om dit te bemark in die gemeenskap, maar ook om van ander te hoor en met ander te skakel en daai dienste wat gelewer word vir ander ook daar te wys. En miskien as daar 'n groot gebeurtenis is in die gemeenskap om dit daar in te sit, net as middel van kommunikasie. Wat ek dink op hierdie stadium, ek myself weet nie eers hoeveel hulpbronne daar in *gemeenskap X* is nie, maar ek glo daar's sin in om die kommunikasiekanale tussen almal oop te kry, mekaar bewus te maak van wie doen watse diens, en oorvleueling en duplisering te voorkom op die ou end van die dag. Want weet jy, soos byvoorbeeld, ons wou 'n home-based care projek begin spesifiek vir *HIV* en *AIDS*, toe kom ons op hierdie *support group* af, so jy moet baie mooi koördineer dat jy eerder saamwerk, ook ter wille van die befondsing wat jy het. Stoot dit alles daarin en lewer eerder een goeie diens as wat dié een hier sukkel en dié aan daar.

Planned newsletter to be distributed in the community

Information on available services

Networking ability

Support group in the community

Networks

So die twee projekte is nog in beplanning. Dis wat ons graag wil doen, maar soos ek sê: stop die bus dat ons net eers die mense bymekaar kry en kyk hoe ons die diens kan aanbied en wat ons alles moet doen. Weet jy, en dit is *gemeenskap X*.

R: Het jy dalk enige agtergrond oor *gemeenskap X*, byvoorbeeld die persentasie werkloosheid?

P: Dit sal in ons *service plan* wees, ek kan vir jou 'n afskrif maak as jy wil. Ek dink dis dalk nog 2001 se sensus, maar jy sal alles daarin kan kry, werkloosheid, opvoedingspeil, en so aan.

R: Dankie, dit sal baie gaaf wees as ek so 'n afskrif kan kry.

P: Laat ek net gou kyk of ek vir jou alles kan gee. Ja, "80% of the residents have no income." Ek gaan hierdie stukkie ook vir jou gee, dis maar net die motivering vir wat ons gedoen het – net vir so klein bietjie agtergrond. So dis basies wat ons in *gemeenskap X* doen. Uit die aard van die saak kry ons slegs subsidie van die staat af as ons dienste lewer in die benoemde areas. En absoluut alles wat ons doen se fokus word soontoe geskuif. En ons is baie opgewonde oor hierdie nuwe dienssentrum en alles wat ons gaan bou, want as jy dit kan verander in 'n one-stop service centre – 'n welfare centre – en jy't kantore, dan kan jy al die NGO's betrek wat ook meer gespesialiseerde dienste lewer en byvoorbeeld afsprake maak met mense wat miskien die behoefte het vir berading of *detox* of *whatever*.

80% of the community without income = poverty

Service centre = welfare centre = potential asset
Networking possibilities with NGOs

Die grootste werk gaan wees om die gemeenskap in kennis te stel van die dienste wat jy lewer. Want dit is so baie die geval, jy het die hulpbronne in jou gemeenskap, maar hulle is nie bewus daarvan nie. En weet jy, dit is ongelooflik, hoe bemagtigde mense ander kan uitbuit wat nie bemagtig is nie. Nou die dag sien ek 'n vrou – ek was besig met die groep, deel van die bejaarde groep – hier vertel sy my gou van haar probleem met haar gesinsgeweld. Ek sê vir haar, jy kan óf vir my wag, óf as jy besluit om 'n kriminele saak te open, kan jy solank polisie toe gaan en die kriminele saak open en sodra ek klaar is kan ons gesels. Of andersins, as jy glad nie vervoer of geld het nie, wag vir my dan kan ek jou vat. Maar dan moet sy twee ure wag. Toe sê sy vir my sy gaan eers polisiestrasie toe en dan gaan sy terugkom. En ek wag en ek wag, ek was naderhand so bekommerd ek ry en gaan soek haar en ek kry haar nie. En weet jy, sy kom toe terug en nou het ek vir haar al die inligting so kortweg gegee wat sy benodig. Sy kom toe nou terug en ek sê vir haar ek was so bekommerd oor jou, waar was jy? Intussen sit hierdie kantoor vol, want my mense wag vir my en ek kom nie hier uit nie. Sy sê toe vir my, nee, die polisie het vir haar gesê dis nou maar 'n familie probleem

Resources available but community members unaware (asset-based approach)

en eintlik nou maar 'n huweliksprobleem tussen haar en haar man en sy moet dit nou maar uitsorteer. Hulle weet nie wie het nou vir haar gesê sy moet 'n kriminele saak open teen hierdie fisiese geweld wat plaasgevind het nie. Weet jy, hulle gee vir haar hierdie *soppy* storie, maar ek vererg my. Nou het sy nie die naam van die persoon wat haar gehelp het nie, maar ek is toe polisiestatie toe en ek gaan praat met daai superintendant. Ek sê vir hom, kyk, ek weet nie wie dit was nie maar dit was een van jou mense, en dis net heeltemal onaanvaarbaar. En dis die mense wat die diens moet lewer, en kyk wat sê hulle vir die mense. Dit maak my so kwaad, want op die ou end van die dag is daai ou net so skuldig soos die res. Sulke goed frustreer my so, want dis mense wat opgelei is, wat 'n diens moet lewer, en hulle doen dit nie.

R: Dis waar.

P: En dis basies al inligting wat ek vir jou het van *gemeenskap X*.

R: Baie dankie. Dit help baie.

FIELD VISIT 4 – 4 JUNE 2004
INDIVIDUAL INTERVIEW 10
SOCIAL WORKERS EMPLOYED BY ACVV

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ What are the main challenges faced by the selected community?
- ⌘ Which resources and potential resources can be identified in the community, which might be utilised to address the challenges the community face?
- ⌘ Which services are currently provided by the social workers employed by the ACVV in the selected community?
- ⌘ How is the community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which role is the ACVV currently fulfilling in supporting the community in coping with HIV&AIDS?

KEY OF ABBREVIATIONS	
R:	Researcher
P1:	Participant 1
P2:	Participant 2

R: I am busy with research in *area X*, focusing on the way that the community is coping with HIV and AIDS. For that purpose, I am trying to obtain as much information as possible on existing services and projects in the area, including social services. Could you please tell us about your involvement in the area and about the different services you render? Where is your office situated?

P1: It's at *school G*, in *area X*. When you go into the area you get the first turn, then there's a second turn and if you're at that second turn, then you are very near to the school.

R: Which services do you offer in the community – in general but also relating to the community's way of coping with HIV and AIDS?

P1: We do have a **few gardens** that consist of plus/minus 325 people in different places in this area. There is one that is close to *school Z*, for that people, for that community as a whole, and then there's a second one, that is when you enter *area X*. Before you turn there is a big place there, that has been having ... that has being fenced.

ACVV services
in the
community

R: I've seen it, yes.

P1: Ja, that's one of our food gardens.

R: It does not seem to be operational at present?

P1: No, it's operating, but the thing is there's **no water there**. So the **people have to carry water there and we also don't have seeds**.

Need for water
and seeds

P2: Another organisation promised to give us some seed, to give us free, but they didn't bring it here, so now the people have to buy their own seeds and most of which they **cannot afford to buy the seeds, because most of them they are not working**.

Financial need

Unemployment

P1: So we have food gardens all over, except at *school Z*, but we do have another one near to that school. It's like for each and every area we do have a food garden.

R: If a school wants to start a vegetable garden, will you be able to assist them? For example, if a school's teachers want to start a garden, will you be able to give them advice on what to do?

P1: Yes. And if we've got seeds, then we can give it. **That's what we do, if we've got seeds we give it to people that we know can use it.** And then we've also got a support group, yes, we do have a **support group** but it's a new thing.

Provide advice and seeds if available

Community based support group

R: Tell us about that?

P1: It's a support group that consists of different ages, with the people that are HIV positive.

R: How many people are in the support group, more or less?

P1: Plus/minus 17.

R: And do they meet regularly?

P1: They **meet only on Tuesdays.** There are other people that we know about that's HIV but **they are not ready yet to go to the support group, so we do home visits only to them.**

Weekly group meetings

Denial

Home visits

R: Where does the support group meet?

P1: At the **one church in the community,** the one there at the first ... eh no, at the second turn.

Resource

R: I have seen the church.

P1: Yes, **since we don't have a community hall, we are using that church.**

Mobilising community assets

R: You mentioned that you are aware of community members being infected with HIV. How do you become aware of these community members?

- P1: They do come to us, maybe someone will tell them about us and then they come to us. Disclosure to ACVV
- R: At the school? Resource
- P1: Yes, at the school yes, and, or maybe the family tell us: "I've got someone that is sick at home and they will not come", but we always tell them: "No, first ask this person about me, if I can come and visit. I cannot just come, I must get a permission from him or her." Then that's how we know of other people. } Disclose in order to be visited and supported- told by the family
- R: So you do go out into the community to work there?
- P1: Yes, we do go out and prepare them to also go, to attend the support group.
- R: Who facilitates the support group?
- P1: There are two ladies, they are in the same age group with us. They've been trained by LAMULA, it's another NGO. They help us, these two ladies, because they were trained by LAMULA to do home-based care and also I've been trained for the home-based care. So what I do, I teach people in area X to do a home-based care, so that we can be able to help the people that are sick at home, with different diseases, not just specifically HIV. So these ladies, they are the ones that are more in support groups, since we are doing various things. So there's a lot of things that we are doing, not just concentrating on the HIV and AIDS things. So they are the ones that are doing everything, but we do go there and assist them wherever we can. External resources
Trained people= facilitators
Resource: trained people involved and
Home based care
ACVV assist /facilitates
- R: Were you also trained by LAMULA?
- P1: No, I've been trained Barnabas Trust.

R: Is that also a NGO?

P1: It's another NGO, yes.

Resource

R: How do you think, how do community members who are HIV positive gain from the support groups? For example, do they get emotional support, do they get practical guidelines on what they should eat, or what do they gain from the support group?

P1: We teach them about the healthy food that they're supposed to eat. We give them emotional support. Also, others will find that they thought it's only me that is having this, but then they see other people and they find that they are healthy, they also become like okay, like they are able to accept their situation. And also, sometimes we will find out this person doesn't know nothing about HIV and now the doctors tell him you are HIV positive, you have to accept it *etcetera etcetera*. But they don't know nothing what is HIV, so we're also teaching them about the HIV virus. And also we teach them the life skills so that they can have something to do with their own hands. And then if there's something that we can give them, whatever it is, we also give it out to them for free.

Goal of support groups=
-basic HIV info
-information on diet
-emotional support
-relate to people in similar situation
-accept situation
-life skill training

R: Do you provide them with treatment or medication?

P1: No, there's no medication that they are getting, it's only the supplements or maybe food. And then there are others ... like maybe if someone is having chills or whatever, and they do have some medication that has been homemade medication, they give it to them also.

Medication for specific symptom

R: Could you tell us about your involvement at the schools in the community?

P1: At school Z, from last year we've been approached by the life orientation teacher, Mr N, but last year it was Mrs M, that approached me to come to school Z, to help her with the life orientation. And then last year after the

School visits and provide education at schools eg. Life orientation (per request)

end of the year *Mr N* said: “*May you please carry on again this year, because we’re going to need you?*” So we asked him: “*What do you want us to prepare for the children?*” So he asked us to prepare about the peer pressure, so we were doing peer pressure with the children. And then we found a lot of problems around, because we give the children a chance to share whatever that they want to share. So we find that due to their peer pressure, they are already involved with the criminal things, that’s what I was discussing with the supervisor. And then we decided okay, let’s start first with the principal, let’s speak also with the children so that they know that if they share something to us we cannot just keep it to us, but if it involves the criminal things, they can allow us to share this with the police or with their parents and whatever. So that they can get help, because we cannot just sit and we don’t do nothing, but we want to listen and help them also. So there’s a lot of things that we found out yesterday when we were there at *school Z* from the school children.

Problems

Crime

Resource

R: When we spoke to Deirdré this morning, she told us that the ACCV is widely involved and co-ordinates various programmes in the area. She told us about your youth programmes, the support group you also mentioned, and also the life orientation programmes and food gardens. Which other resources are you aware of that exist in the community, other institutions that might also assist community members in coping with HIV?

P1: I’m not aware of any other people.

R: And services like *Sister E’s* clinic?

P1: No, that clinic is not in the community. They are rather using *clinic Z*, if they need to go to clinic.

Two clinics but very far

R: Where is *clinic Z*?

P1: It's very far away, both of them are, I think the same distance away. They don't have a clinic in *area X*, but fortunately our council is building one for us now – a clinic. It's not in the centre of the whole community but it's there in *area X*, there for the people.

Clinic to be built

R: So from *school Z*, which will be the closest medical clinic to go to?

P1: *Clinic Z*, just across from the National road, close to the university.

R: Yes, I have seen that clinic.

P2: But I'm a hundred percent sure that when they built a clinic in *area X*, *clinic Z* is not going to take anyone from *area X*, they are going to turn them to the new clinic.

R: Yes, because that clinic is quite far from the centre of the community.

P2: Let's get back to our services. We also do *crèche visits*, like talking to the crèche on what they are busy doing and then you see how can you help. Like we found that there was a child that was having a rash to the whole body, and then this child was not healthy, so I asked the clinic to approach them, to hear if they cannot have a *mobile clinic* just to come in that area. But they say since we are in the process already of having ours, they will not be able now to do it.

Crèche visits:
-help where needed
-identify problems and refer to clinic

R: So if I understand you correctly, the members of this community go to *clinic Z* if they need to visit a clinic.

P2: Yes, I also know of some clients of mine that are HIV positive and they are getting to that clinic for their babies.

Clinic

R: I sense that people in this area do not often disclose their HIV positive status. Why not?

- P1: It's because of ... especially to this *area X*, people they still ..., **they are having different beliefs about this**. For instance, if someone is HIV positive and they come and see me, the first thing that they think is they think maybe this person is bewitched, they only talk of the traditional things, they **don't care about medical things, education and whatever**. **They will only think, maybe this child we have to send to a traditional healer**, that is why the child is like this and whatever. And then they **will take the child to a sangoma** then, so that this child can get to the sangoma, they don't think about HIV and they **think someone is bewitching this child and whatever**. So the child decided to keep quiet. And the parents ..., **other parents they don't want to talk about sex yet and if you talk about HIV and AIDS it's sex involved**, and they don't want to listen, they are having ignorance. So the children, sometimes the mothers, they are **not aware that their children they are already sexually active**, so the child who is HIV positive is afraid to tell the mother because the mother thinks the child is still a virgin. **And still they don't believe that you can use the same chair as the infected person and whatever**. So someone does not want to be ignored if he's HIV positive, so they still want to keep it from their families, they are afraid of that. And in *area X*, **most of the parents they are alcoholic**, you know. Then someone will tell you maybe: "*I can tell my mother, but my mother is going to get drunk and tell other people, so I cannot tell her*". Since we are having extended families, very big families, you will find that the families maybe is divided into three, this group is not in good with this one and whatever. So if **I tell my aunt, my aunt is going to tell this aunt and this aunt**, *etcetera*. So there's a lot of things that are involved.
- R: It almost sounds as if they're not aware of the common existence and high levels of HIV and AIDS, together with the fear of rejection, together with the taboo to talk about these things, together with the possibility of gossip by other family members – it's a variety of things.
- P1: And you know, I was speaking with a group of children last year ..., they are **14, 15 and 16 years of age and they are pregnant** and most of them

No disclosure: misinformed/ myths

And ignorance lack of belief in medication and education

Traditional healer=answer

Believed to be bewitched

Stigma- HIV/AIDS is sex related-ignorant (taboo)

HIV disclosure: reveals sexually active

Misinformed Fear of rejection and isolation

Alcoholism

Fear other people knowing

Fear gossip

At risk sexual behaviour

they are friends. I was so worried about the whole process when I saw them, like they were so playful, they thought they are having dolls, whereas they are having babies. So I went to them and I said “*Come on, let’s talk, why are you all pregnant?*” And then I found out that these girls were confused about the AZT thing because they thought if you are pregnant and HIV positive you are going to get a vaccine to prevent your child to have HIV and whatever. So they thought the AZT is going to protect them, now they can sleep with the boys. Because they thought that they won’t get it, if they get pregnant they won’t have HIV because they are going to get a cure. So I had to explain that to them, then they say: “*You don’t know what are you talking about, we hear this from the nurses*” or whatever, then I say: “*No, maybe the nurse didn’t have enough time to explain to you exactly what she’s saying, she thought that you do understand, not knowing that you’ve got your own understanding, so this is not the way, it’s going like this.*”

At risk sexual behaviour due to misinformed

Ignorance

R: What is the role of the church in this community? Does the church support members of the community who are HIV positive? Does it encourage people to disclose? Which roles does the church fulfil?

P2: No, the church don’t do that. My own church is a Christian church and they believe that no sex before marriage. So they see no point to talk about HIV, because as a Christian you are not supposed to have sex before marriage. They don’t care what are you doing after hours, because surely the children will go and do sex, no matter what they are saying. So they will only tell you not to come, not to participate in anything in the church if they find out that you’ve got a boyfriend and whatever. Then you won’t participate in nothing at church. Because if you are HIV positive it’s because of your sin, you’ve sinned in the eyes of the Lord. I always ask my mother: “*Mum, do you understand other people they didn’t know nothing about the Lord, and now they are born again Christians?*” They go to the Christianity with this virus, and they didn’t know maybe, and now in the marriage, they get married with someone and then in their own marriage they find that this person is HIV

Church avoids discussing sex-related topics such as HIV/AIDS

At risk sexual behaviour

Church rejects in care of sexually active (children)

Judgemental

positive. Because even if you want to get married with someone, you must not be involved, but have a courtship, and you must not tell this person. You must go to the reverend and tell that the Lord showed me this person, so I want to get married. And then the reverend is the one that is going to come to me and say: “*So and so wants to get married to you.*” No matter if I also love this guy, I must say: “*Give me a chance, I will go and pray*”, and then maybe for three months I will pray and pray and then I will come back to him and say yes. So the pastor is going to tell this guy that I said yes, then we get married. They don’t check if this guy is HIV positive or where did he come from. All these things I will only see in my marriage. **And if I ask these things they will always ask me: “You don’t trust the Lord? The Lord is there for you, and the Lord is going to guide you.” They will never tell you something that is not right. So it’s like they are having an ignorance with the HIV.**

Ignorance

R: What is the role of traditional leaders? Do they play a role in helping the community cope or not?

P1: I always say to the people, especially to my clients: “*I don’t have a problem with the traditional healers’ medication, but they are very strong.*” I’m telling you they are very strong and secondly, most of them they are not healthy, not healthy because they are not sterilised. **So if you drink a traditional healer’s medication and you are already infected with HIV, it can make you more sick**, because they are very strong. For instance they will cook most of them, most of the medication they cook it. And then when it’s cooked, and then all the ... eh, I don’t know what you call it, but you know the ... eh ... if they are going to cook it, they are not going to mix it with another water when you drink it, you will only drink it as it is. And then you find out it’s very strong and it’s not good, and it go into your own mouth because it’s very strong, even the smell it’s very strong and then you drink something like that. Surely you will become sick more and more. It can be helpful, but also it’s too much maybe for you if you are HIV positive.

Negative effect of traditional healers medication

- R: Does this community still believe that traditional healers can help them? Cure them?
- P1: **Yes** ← For instance, I've got a client of mine that was sick, but fortunately she **usually attend the HIV and AIDS programme** that we do have in the community. So she always say when we talk: "*If I can be HIV positive, I will accept it.*" So then she found out that she's HIV positive, and she **really accepted it**, ← but she became sick maybe after two months, she was really sick. And then she went to the **hospital**, ← ~~to hospital D~~ and then she was very sick. At *hospital D* they didn't say nothing to her, but she knew what was wrong with her, she was HIV positive **so they said it's the flu that made her like this**. So since they didn't come back with a tangible reason, they thought the white people cannot see the cause of her illness. **So she said: "Let me use the black thing – let's take it to the traditional healer."** She knew that she's HIV positive **but she was not ready to tell them**. So they take her to the traditional healer, that traditional healer said: "*The ancestors want you to be a traditional healer*", so it's a long process. Then she had to go to the sea, stay in the bushes, for that whole long process. She had to stay in the bushes, using this medication and whatever, and she was so frustrated, so she kept coming to me, saying: "*I don't know what to tell them because I know what's wrong with me, but I'm not ready to tell them. But look now I have to go to these places and you know that I'm sick, what must I do?*" I said: "*I don't know, it's up to you. If you think you can tell them, just tell them, instead of going, because you are going to be sick in the bush and this wind it will never help, they will just keep quiet. So the best thing is to tell them if you are ready.*" And that was the only solution that helped. She just told the family: "*I'm not sick, this woman is lying.*" So it's only then that they allowed her to go. And now she's fine.
- R: And it sounds like she is now living a healthy lifestyle.
- P1: Yes, she's really fine now.

Traditional healer=regarded as resource by community members

HIV/AIDS programmes in community

Acceptance=important

Resource

Avoid identification

Traditional healer=resource

Avoid disclosure

R: You referred to the HIV and AIDS programme that is running in *area X*. What are you referring to?

P1: I usually ask the **ATICC or NABWA** to come to our area.

NGO's running HIV/AIDS programmes in the community

R: What is NABWA?

P1: It's an **organisation that helps people that are HIV positive**. I think all the people that they employ there are HIV positive, **so they already disclosed**, so they are the ones that are helping people. So I usually ask them maybe to come and do a **workshop for a week**, then I put pamphlets all around the community and invite people to come to the **church**, and then they teach them for a week about HIV and AIDS and STDs. And I do that maybe once or twice a year.

Organisation in wider community

Disclosure

Workshop on HIV and STD'S

Resources= Church ACVV- organising it

R: Who attends these workshops?

P1: **General community leaders**, usually a **lot of people**. Or you know on the first day a lot people, maybe tomorrow we've got new faces, the ones that didn't come yesterday and then some that came yesterday. But if I do it for the whole week then we end up having many people and they really like it. Because NABWA usually bring someone that is HIV positive and then on the last day that person tells them: "*You know what, I'm HIV positive.*" So then **they become very shocked**, that this person who was teaching them about HIV is actually HIV positive. They are then shocked, because they will tell her whatever they think about HIV positive in the week ... They will say: "**I will never stay with someone that is HIV positive**", so they will say all these bad things about what they **think**, and then at the end of the day they are very shocked that they've already done that, staying with someone that is HIV positive. So it's quite challenging.

Workshops for general community leaders

Community members

Disclosure: others are shocked

Stigma= rejection of HIV Positive community member

R: Workshops like these are actually a great resource to the community. To what extent do you cover HIV and STDs in your youth programme that is

offered to high school children? Do you also educate them or is HIV and STD knowledge only included in the life orientation subject at school?

P1: No, we do have a **group of children** that are from the age of 15 years. We meet them every Tuesdays at 14:30 at the church, it's the ones that we are going to the **camp with next week**. We are having a camp and **we invited two ladies that I want to teach them about HIV and AIDS and STDs**.

Weekly group programme

Youth Camp: information session on HIV/AIDS

R: Do you teach them about other topics as well?

P1: **We teach them about various things**, like date rape. And they were very shocked that there's something called date rape. I found out they do **go to the tavern and the guys do buy alcohol for them and they thought it's natural to sleep with these guys if they want to, there's nothing wrong with that**. That they cannot say no if they eat their money, **if they used their money for them, they see nothing wrong to say no. If it's a boyfriend, they are forced to have sex, he has got the right because he is your boyfriend**. So they were asking me that kind of questions – they didn't understand when I said it's a rape. They say: "*Whereas it's your boyfriend, it's a rape?*" I say: "*Yes, whether it's your boyfriend, you don't owe him.*" So they **keep on asking me different questions**, because this date rape thing, they didn't understand it. So there's a lot of things that we teach them, even domestic violence. They thought it's natural if their mother or father is being beaten and whatever, they being chased out and not sleeping at home and whatever. They **didn't know that they have a right to report this**. Because they thought it's a in thing like this, even next door it's happening, it's happening, so there's nothing wrong with that.

ACVV= source of information, teach people not informed

At risk sexual behaviour

Children-sexual favours for money

Form of abuse

Uninformed

R: If I understand you correctly, this community is characterised by high levels of domestic violence and alcoholism, poverty and unemployment. What else? What about prostitution?

- P1: Yes, because most of these children, their parents are **not working**, and they **need lot of money**. I have a client of mine that is HIV positive now, because of the elder boyfriend that usually supports her with everything, and is not a Xhosa person, it's these people that are coming from Africa, North Africa up there, so they come here. **So she was sleeping with this guy because this guy was paying the school fees, buying uniform, doing everything for her.** And she knew that she's not the only woman for **this guy, there are also others**, he also helps the children to pay whatever, and this child is 14 years old. And now this guy was sick, and then when she went there and she told this guy: "**I don't want to be involved with you anymore**", this guy said: "**You can leave, I don't care but you must know that you are HIV positive**". So she was crying and then she came to me.
- P2: Yes, the other day I was near to the church and stopped there. There were two ladies, small children, I know these children. Two children were coming, they went to that car wearing short things and whatever. And then this guy will come after 5 o'clock and stand there and then **these ones would enter the car and go with this white man and then they don't know when they are coming back**, and I was looking for the one. But the following day I found out she's there. I asked her about this, and then she said: "*Where do you think the food comes from? You must not ask me that, because I am getting food and the school fees is being paid, you must not argue where this food comes from.*" And **this child is pregnant, 17 years old**. So they use them. And there are these guys that are called Fishermen that come also to *area X*, it's also their own boyfriends. There's a lady that is my client, she's having eight children from the fishermen. Every time the fishermen is coming, they are leaving this woman with another child, he always leaves this woman pregnant. He **doesn't support the children when he's gone but when he's back, then he gives this woman money**.
- R: I want to ask you something else. If, for example, children are orphaned when their parents die of HIV and AIDS, who takes care of the children – in this community?

Unemployment

Financial need

Sexually active for money

Multiple sexual partners

Purposeful transmission

At risk sexual behaviour

Child sexual abuse and prostitution

Sexual favours for money

Child pregnancy

At risk sexual behaviours for money

P1: It's the relatives, maybe the grandmother or maybe the aunt or whatever, the relatives. As I've explained to you, we have very extended families, so there's always someone from the family that is taking care of the child.

Relatives take care of children

Extended family members will take care

R: And if an adult gets sick, for example when a person discloses and is HIV positive, who will support that person? Like a mother who is HIV positive and becomes sick, who will help her, take care of her and maybe bath her?

P2: That's a major problem when it comes to bathing, because most of the people, they don't want to bath them. Like for instance, I was having a client of mine that was very sick, and every time I visit her she will always say: "If I can only get a bath, there's nothing else that I need", and then if I ask her: "Can I wash you?", then she would say: "No, I'm afraid because if you wash me and then the family will know that I'm talking about them to you." So when it comes to bathing, they are really having a problem here. That is why I think the home-based care is needed to the community, because if we can have this thing, then we can teach them how to bath someone that is bed ridden and then we can provide them with the hand gloves, you know, and teach them everything. So then this person can feel secured, because they are really afraid to wash someone that is bed ridden, there's only a few people that do that.

Basic care-looking after(bathing) Problematic

Fear

Home based care=a need

Fear to touch HIV positive person (myths/misinformation)

R: Who supports the community members who are HIV positive?

P2: There's no one.

R: What about the support group you mentioned?

P1: No, not really. Like there are a few neighbours that can be allowed to come to your house if maybe there's someone that is sick. There are a few people that can be allowed to come in, especially if this person is HIV positive, because they thought he is not so concerned. But it's

Neighbours= supportive

Isolate themselves

because they always close their doors, they are not allowing people to come in.

Avoid disclosure
Due to fear of rejection-due to gossip

R: You mentioned home-based care. Do you provide home-based care services in the community or do you know of possible places or institutions where the members of the community might go to obtain grants?

P1: Yes, like Barnabas Trust. I've done the workshop with them, and then I've asked the kit from them, and then they said they are going to give me a kit. But I don't know whether they are going to give me kit for myself only or a kit for different people. But on that time they told me that the glass are very expensive, when we were busy doing the workshop. Because I've asked the same question – that in these houses you cannot leave the kits, if we know about the people they will want us to leave for them their own kits, whether we do come and deal with them or not, but they will also need a kit definitely. But they say the glass are very expensive and these things are very expensive, so I don't know.

NGO'S
providing
workshops to
community
members

R: Are you aware of any home-based care services that are already provided in the community or is it still a need that should be addressed?

P1: Yes, it's still a need.

Need for home
based care

R: Is there anything else that you can think of, in terms of help that is provided to community members in coping with HIV and AIDS?

P1: No, nothing else.

P2: Maybe just the thing that, uhm ... it's like there's a cry for help in this community. There are children that want to go to school but because of their home situation they cannot, they do not go ... they are forced to not go to school because their parents are alcoholic, they don't wake up the children, they don't buy shoes, they don't do nothing for these children.

Poor home
conditions/paren
ting

Alcoholism

Child neglect

So it's then that the children can say: "Okay let me go to school today, let me not go to school today." So their parents are ... they make no difference. For instance on Wednesday, a child that came to us on Wednesday, this child is 23 years old and she was receiving a foster grant but now the parents stopped having the foster grant and now they don't want to give her money to carry on. And this child doesn't have shoes, and this child doesn't have a uniform and she was doing standard 9, but this time they don't want to carry on anymore. And then another child, she's staying alone now. Her mother is deceased and the father got another wife, but this wife was afraid of this child, the wife didn't like this child, because she was already 19 years old and she was doing standard 10. So they keep on fighting with this child. So this woman decided to move out of the house, so the father moved out with her, with his wife and with the two small children and this child want to go to school but there is no one that is supporting her. So we went to the Department for the support, for the maintenance from the father, but the father stopped working.

Financial need

Material need

Child-headed household

Lack of support (financial)

Unemployed

P1: Yes, so who's going to take care of that child? She was doing standard 10 and then she failed that year. She failed that year and then I begged her to go again the following year, of which I begged her with nothing on my hand, but I keep on saying please don't give up, go back to school again, at least you still have a uniform and the shoes, you still have them. But I don't know in the end what's going to happen and the school fees is very expensive for them. And then that child decided to have a boyfriend that is going to stay with her in the house, and that boyfriend was beating her. And then I had to beg her again to chase out this boyfriend. If she want to go back to this boyfriend she must not stay at her home, he can come and visit and not stay together. So there's a lot of problems here. Even this child that is cleaning our office, we are paying that child the money to clean our office, and it's R100 a month, it's nothing. Well, that child must maintain her own home because her mother is alcoholic, so that to buy paraffin and whatever for her family, she has to go to school with this R100, she has to buy everything for her and she wants to go to

ACVV= motivational support

Domestic violence

Child: responsible for own needs

Alcoholism

school and she's doing standard 8, she was supposed to do standard 9 but she dropped out of school two years ago, because she didn't have money and her mother didn't ask her even one single day why she didn't go to school. It didn't make any difference. And now her mother is contacting her time again saying: "*You thought that you are better than us since you are at school, you are not better than us, you are still the same*", and she's only doing standard 8, for God's sake. But she's treating her as if she's doing medication and now she's very high minded compared to them. But she's trying her best to maintain her home. But she can't do that all alone.

School drop-out

Financial need
Mother's don't care/neglect children

R: I would like to find out more about the role you fulfil in assisting community members obtaining grants. Does that form part of the services you provide?

P1: No, but we only ... we do case work, where people come to us and we listen to their problems. Then, if we find that this one can qualify for a grant then we go, we just tell her: "*You do qualify for a grant, this type of a grant, you can go to hospital D.*" Then we write a letter and ask hospital D to help us with this person. But we don't do it ourselves.

ACVV individual case support

With regard to grants:
-advice
-identify
-referral letter

R: Can you provide me with information about the different grants? How much are the different grants? What are the qualifying criteria for the various grants?

P1: There's the maintenance grant, that is from zero to eleven years this year. It was zero to nine years last year but this year it's to eleven years, and then next year it's going to be thirteen and fourteen years. And this grant is only R170 per month.

R: Who qualifies for this grant?

P1: The people who are getting a salary that is less than R1200 and the unemployed people only. You get it per child, up to six children.

Information on grants=potential financial resource

P2: And then there's a foster grant. I'm not sure, I think it's R560 and this one is for foster. Do you know what is meant by foster?

R: As I understand it, foster care is when a person takes care of a child who is not his own.

P2: Yes, and then there's pension, where a woman must be 60 years old and upwards, and a man must be 65 years old. And its R740. And there's also the disability grant and it's also R740.

R: And within the context of HIV and AIDS, one of the criteria is a low CD-4 count?

P2: Yes, it must be less than 200, the CD-4 count. And the viral load must be 400, or something like that.

R: Which process should be followed to apply for such a grant? Can the people who want to apply go to *hospital D* or do they need to go to the Department of Social Development? Where do they go?

P2: Yes, they need to go to Social Development or to *hospital D*, on the side of the Social Development even at *hospital D* it's there. And then this person must be a South African citizen, and this person if married must bring in the marriage certificate, if divorced that divorce letter also, and a birth certificate or an ID, like anything, something like that. Sometimes they even ask for a title deed, but that's what I don't understand why they need it, but sometimes they do that. And sometimes if you were working and now you want a pension, they usually also want a letter or something, for the month that you stopped working, the salary advice, proof of how much did you get from your work, so that's all those things that they need.

Procedure concerning grant application



R: If you think about this community, community members face various challenges they have to cope with, for example HIV and AIDS, yet they

keep on living and carry on with their lives. What is it that makes this community cope? What do community members have working in their favour?

P1: It's like, okay I think, before I answer you there's something I want to tell you before I forget. Like there's a tendency, we teach them about condoms, that they must use condoms and then they **will tell us that they don't want to use condoms** because they must have it flesh to flesh, and it's not right to have one boyfriend because at the end of the day if you are HIV positive because of that one boyfriend you are going to cry. But if you are HIV positive and then you find that you were also having lots of boyfriends then you will understand that it's also my own fault. And another thing, they say if you come in through sex, when you were born you were born through sex because through sex you get pregnant, it's **good to die through sex again**. And everyone in that matter is going to die, no matter you die of what, but everyone is going to die in that matter.

Unprotected sex-practice sex with multiple partners

At risk sexual behaviour" don't care attitude"

P2: So if you are speaking with this child and then you try to convince the child, and then when the child answer you like this, you just have to know what to say. I wish I can have something else to blow their minds, but I find that I wonder what must I say now. But you **keep on trying, you keep on trying, you cannot just stop**. And I think, the thing is, here in *area X* they see most of the things, that it's natural when some other things happen, because next door it's happening in front of others, so it's a natural thing. That is why they are very shocked when you tell them this is not right, this is not supposed to happen, and then there's only few houses that don't believe you and they start to put that into action.

ACVV workers wanting to make a difference

R: Is there anything else that you think we should know on this community's way of coping? How do you cope with all the challenges you face?

P1: **It's my family**. Because on Monday when I went back home I was crying, crying because in the morning I was having a five year old boy that has been abused, his tongue was cut, the chin was beaten and the child has

Family: way of coping (main reason)

been stabbed by the boyfriend of the mother. And it was difficult for me to take this and then my boyfriend went to work to fetch me and I'm having a four month old baby, so he went to fetch us and then I just broke down. And he was busy talking on the way and then I said: "You know what, I'm not in the mood, but I'm going to tell you why, I will tell you when we are at home." So I said that so that I can tell my family also at the same time, because I won't be able to tell him and then when I'm at home I have to tell again, because if they find me at home that I'm not fine, they were going to ask me what's wrong. So when I was at home, I decided let me say this, they kept on saying: "Are you fine? Are you having a headache?" Then I told them ... It was difficult to finish even one sentence without crying and then I was very angry with this woman, I even wanted to beat her, because I found out she is lying, she doesn't want to tell the truth and she's still willing to go back to this guy, that guy ... and it was not the first time, the child was lost a few days ago, but she didn't do nothing and now Saturday this child get this, so I was very angry with this woman. Then I tried to go out because I couldn't stay with this woman in the same office. I went out with her to ... so that I can also speak to her. I was a little bit fine but every time I speak to her, she lied and then I just changed immediately, but my mother prayed, she's a Christian, and my boyfriend also started crying. I've got a nine year old child, she was also crying now. I felt very hurt, and I wanted to take this child from this woman, but I knew I won't be able to look of this child because I'm afraid of the blood, you have to clean the tongue because the tongue was white and I know that this child only needs that tongue to be cleaned so that the tongue will be a little bit better, but if I take this child from this woman to my home, we have to do it and I won't be able to do it, so I hate to feel unable to do something. That is what really makes me sad, I just left that child like that, I didn't do nothing. I was unable to do something to this child, so that's what really frustrated me, so my mother prayed and asked God to help and whatever, but I was crying.

Physical abuse

Social workers
need for
personal
supportFamily=support
systemFamily=support
Prayer=central

R: It is frustrating to feel that you are not able to make a difference. Thank you for sharing your feelings with us.

P2: Because you know, the children of area X they are very poor, but there's a lot that they can do if given a chance. They have big dreams these children, you know. I was saying to some ladies, if I can only get a sponsor and have a centre in the community, whereby I will take all the children that want to go to school, but because of their situation at home it's hard. But when the schools are closed they must go back to their homes, because I want them also to understand their home situation so that they can know they are having a responsibility to make the difference. Because if I put them in the hostel and then they don't go back to their homes, they won't make a difference to their homes. Something like that, I think that's one of the greatest needs they really need in area X, or maybe even a group of people whereby they can say I can adopt one child at my own home, maybe give R50 per month just for the school things. Then I think they can carry on. I hear that there are people from overseas that are helping children in South Africa and school Z fortunately was one of the schools that have children like that. I went there to ask if it can also be done to another school, to other children that are staying at home, but they said no. Like for instance if you can drive through area X, you will ask yourself: "Who are these children that are not in school?", if there is still a lot of them, and if you can go only to one child and ask: "Why are you not at school?", definitely they will say, it's their own parents. Another child, she was eleven years old, she was not at school, the whole community kept asking about her and buying things this, go and buy this, come again.

Positive future perspective

Bad home conditions

Personal responsibility to cope

Need to take care of children

Financial need

Children are not attending school

R: yes, he was like a runner

P1: Another child that is seven years, the child was nine years old, he has never being to school. He was raped by a woman, this one slept with this child continuously, so he asked the child: "Go and buy this for me", and when the child comes back: "Sleep with this woman, with this child",

School neglect

Sexual abuse

and the husband is at work, but if that child was in school, surely this won't happen and this child didn't know what's wrong or what is it because he's still having a mind of a small child, he is the friend to the nine year old. **So there's a lot of children that are not at school and those** children is the same children that tomorrow that they are going to be **criminal and we cannot do nothing with them.**

School neglect

Loss of hope

R: Thank you, ladies. Good luck with the great work you do.

FIELD VISIT 4 – 7 JUNE 2004
INDIVIDUAL INTERVIEW 11
COMMUNITY MEMBER LIVING WITH HIV&AIDS

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ How are you coping with HIV&AIDS?
- ⌘ Being HIV positive, what are the main challenges you have to cope with?
- ⌘ Which resources in the community assist you in coping with the challenges you face?
- ⌘ Which potential resources might assist you in coping with the challenges you face?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Please tell us about yourself. Where do you work? At the clinic?

P: Yes, I'm a voluntary worker. ← Resource

R: Tell us about the work you do at the clinic.

P: I'm an interpreter sometimes, and a DOT supporter. I'm helping people giving treatment and sometimes the sister in charge asks me to help with the counselling. ← Volunteer worker:
-interprets
-give treatment
-counsels

R: Please explain your role as DOT supporter.

- P: DOT stands for *Directly Observed Treatment*. It's a course you can do, for the voluntary work. Like I was helping the people who take **TB treatment**. Treatment for TB
- R: And you work from the clinic?
- P: **Sometimes at my house**, for some of the patients. Work at:
-clinic
-home
- R: L told me that you also provide support to people who are HIV positive?
- P: Ja, **we do have a support group**. Support group
- R: Please tell us about that support. Hope=central
- P: It's called *Lithemba*, which means **hope**. We **comfort each other, and advise each other on some treatments like herbs**. If I've got a headache, what can I use, if I've got Shingles, what can I use? Things like that. Sometimes we ... eh, at the clinic they told the patients to contact me. Then we gather together every Friday at one to train in the **community hall, that's where we meet**. There we **encourage each other, we comfort each other, all those things, we give each other hope**. Give one another practical advice on how to treat common symptoms
Community hall=physical resource
Regular(weekly) support sessions
Encourage each other-comfort each other
Give hope
- R: You also mentioned that you provide information. Where do you get your knowledge and information from?
- P: I've been **trained for basic HIV education, and for basic counselling**. I did attend a workshop in Bisho for AR, these anti-retrovirals. ~~And I got my training as volunteer from ATICC, when they came to the community hall.~~ Training provided=resource
ATTIC=resource for training
Community based training
- R: How many people form part of your support group?
- P: It's plus/minus 70, but it's not this community's people only, it's from ~~K, KS, G and V~~. **You know, some people don't like to go to support groups in their own areas**, so they prefer coming here at *area X*. Avoid open disclosure in community

R: So it's 70 people coming from all over?

P: Ja.

R: Are most of the people infected with HIV?

P: They are all infected.

R: How did it start and who is part of this support group?

P: There was a lady, *M* from *K* and *T*, she was working at ATICC but now she's working with Dr J, they formed the group in 1999, so I joined them last year in April.

R: Are they still involved at all or are you on your own now?

P: **M has formed another support group** at *K* and *T* is busy, so we only meet sometimes with them.

Community members initiating and running support groups

R: What are the most valuable things you gain from the support group?

P: When I'm with them it's like I'm with my family. **I get lots of love and I become very happy with them.** So when Friday is coming I feel something inside of me, like oh, my "family" is coming, you know and it's **hard when you are going to be parted.**

Support group like family HIV positive supporting one another

Loving positive environment

R: I get the feeling it's about people that truly understand?

P: It is.

R: Are you willing to tell us about your illness.

P: I'm surviving. At first **I was so frustrated, I was on and off in the hospital, but I'm a fighter, so I'm surviving.**

Initial feelings= frustration

R: It's a great challenge to live with HIV and AIDS. How do you cope? I get the idea the support group helps, but what else?

P: I do have my friends. When I was diagnosed, I thought of telling all my friends. I kept it a secret with my family, they only knew that I'm HIV positive late last year, but all my friends knew about it.

Friends=main support (disclosed to them)

Family=support Disclosed later only

R: May I ask you why did you decide to keep it a secret from your family but disclose it to your friends?

P: Because they are so weak you know. I'm the last born at home and they put all their hope in me, you know. And I've got this little child, so I was unable to tell them at the time I was diagnosed because I knew that they were going to feel pity for me and get lots of worries, you know. But at the end I did tell them.

Not disclose: protect family from worrying and sadness and loss of hope

R: So you were actually being strong for them?

P: Yes.

R: And your friends?

P: I got all the support I need from my friends, my family, and my doctor, and he also encouraged me to tell my family.

Support

Doctor: advisor

R: And now you've got the knowledge to live a healthy life?

P: Before I was diagnosed I was just sitting here, doing nothing, you know. But when I was diagnosed that I'm HIV positive, I became to seek knowledge.

HIV positive: need to gather information

R: Where did you get your knowledge from? From the workshop and the doctor?

P: Ja.

R: Where else?

P: And the other people who are HIV positive.

Other HIV positive people

R: You primarily refer to people helping you. Do you have any other assets in the community that really helps you, any resources in the community?

P: No, not really. But I'm also busy doing painting with the church group, with the other members of my support group. We meet every Thursday from nine to four.

Skills development

R: Who leads this group?

P: The name of the lady is P. She's at the church?

R: Does the church support community members who are HIV positive in this area? If it does, what role does the church play?

P: The church does support us. You see, I'm a Methodist, so I did tell my priest and the other church group members, and they give a lot of support. They give advice, emotional support and ... uhm ...

Church= Supportive =Resource

Provide advice/ Knowledge

R: Spiritual support?

P: Ja, spiritual support.

R: Are there any NGOs that you know of that work in this community, helping families or people who are HIV positive or living with AIDS?

P: No, there are NGOs, but they don't get involved.

NGO=potential but not mobilised

R: It's only ATICC that has these training programmes from time to time?

P: Ja, and there's the other group, Ubuntu Education Fund at *street H*, they also give training and support. ←

NGO:
-training and
-support

R: Do they also offer training courses?

P: Ja.

R: So if I hear you correctly, the way that you've been able to cope with this challenge is by means of the helping support of families, friends and the church – people caring for you and giving advice?

Summary:

-support by
family, friends
and church

P: Ja. ←

-people caring
and giving
advice

R: And that's the core, not external people and organisations?

P: No.

R: After you've disclosed and during the time that you went through that difficult stage, what kind of support did your friends offer?

P: There's a friend of mine, she lives now in Uitenhage, she is very supportive. When I was lying in hospital she bought everything for me, pyjamas, food and she also took care of my child.

Family of friends
-provide support
and food
-material needs
-look after
children

R: It seems as if such support helped you carry on with your life.

P: Yes, and I wanted to show people that HIV is alive and that you do not only see the people on TV, that HIV is living inside the people whom you know. It's not only the Nkosi Johnson and other people that are living far. All people must know and realise that HIV is amongst us.

Need for change
in community
belief

R: How did other people react to that? Your friends supported you, but what about other members of the community?

- P: You know, there are stupid people as usual. You know, **I've been called names like**: "*Here she goes, the so-called AIDS*", or they would say: "*Aidsana*", that silly name, but I didn't care about that. I know the virus is in my blood and not in me. I've got that **positive attitude towards** them and I also told them that it's of no use to laugh at me, because you've got kids, you are still having sex, you are working with people, so we won't know when AIDS come to you.
- R: Were these people in your close environment?
- P: Ja, they are people in my area. For instance, **my neighbour is a nurse but she was gossiping**. All the neighbours knew that I'm HIV positive because she told them, but I didn't care. I just confronted her and said: "*You can do whatever you want to do, but I know that one day maybe your child will be HIV positive or you will get another sickness except HIV.*"
- R: It certainly is a challenge to face others. When did you disclose to your friends for the first time?
- P: The very first day I was discharged from hospital, that was in 1999.
- R: Has the community and people changed since 1999? Has it become easier? If people disclose now, will others accept them easier and if so, why do you think it has become better?
- P: Because **if a HIV positive person die, we go to the funeral wearing those t-shirts you know, with that emblem. And we stand and tell all the people who attend the funeral that this person was HIV positive**. It's high time that we have to tell the people that this person was HIV positive, there's no use of saying she's got pneumonia or TB or whatsoever, **we have to tell them that he had it and educate them also**.
- R: It's almost like raising people's awareness?
- Disclosure HIV positive:
-called names
-laughed at
- Positive attitude=asset
- People gossip
- Need to educate community and make aware
↓
Need for community to acknowledge to accept aids
←
Few people propagating this

P: Yes.

R: When you go to funerals, does the whole support group go?

Avoid disclosure

P: No, **there are those who are still living in the shade**, they don't want to be seen, they don't want to be known. **But those of us that don't care, there are still more of them who don't care of what people say.**

Tendency to accept status and not mind others comments

R: Are you aware of another support group in the area, besides the one you belong to?

P: I just heard that they just opened another one, but I don't know where, it's new.

R: And does your support group do home visits?

Support groups

P: **Ja, we do have a committee** for the ones who do **home visits** but only to those who live around here.

R: Tell us about home visits.

P: They can do home visits at any time, because there are **those who are diagnosed but don't accept that they are HIV**, so you have to visit them regularly. Then some **individuals will go to their houses** and help them accept, but it's only some people that can go. Like, for example, if a person discloses to me then I've got a right to go there **but I can't tell the group** that so and so is HIV positive.

HIV positive: difficult to accept status

Individual community members support home visits

Confidentiality

R: I understand. So if I hear you correctly, the role of the members of the support group is to support one another emotionally, spiritually and with advice, and also to support people who have recently been identified or diagnosed, and to help them live positively.

Summary:

- P: Ja, and sometimes we have to share food. Like if someone has nothing to eat, you have to share with them. Provide food if in need
- R: Please tell me about the diet of people living with HIV&AIDS, based on the knowledge that you received at the ATICC workshop. What should you eat and what should you avoid?
- P: I've also got some knowledge from the Skills Factory, when I went to a two day workshop. They are giving information and what they did with us is, they just gave us wellness management. They taught about wellness management, how to live, something like exercises and they gave us some script with herbs and how HIV positive people should eat, so they taught us mostly about nutrition. Skills workshop= information source
Sources of information on:
-wellness
-living positively
-exercises
-food and nutrition
- R: How did you find out about the workshop? HIV positive attend workshop as information source=want to elaborate knowledge
- P: We were organised by G, who's a social worker working in the Department. She took some people from the group, from our group, we were nine and then one from area M and then she organised transport for us and we went there to area S to attend. Social worker initiated and organised and provided for transport
- R: What did you learn there about healthy eating habits?
- P: You know, the diet is difficult, because if you are HIV you have to eat. You can't stay for the whole day hungry, because you will get fits. So with the diet you have to stick with carbohydrates, proteins, calcium and if you don't have those things, you have to get supplements. Like for calcium you can use folic acid tablets, which help when you are feeling dizzy. So with diet it's difficult to follow diet, because some people don't get the disability grant and they don't have any money to buy those things, but you have to stick on fresh fruit and fresh vegetables and then, if you get diarrhoea from something, you have to stop using it. Knowledge on HIV positive persons diet

R: Your support group primarily focuses on infected people. What about the affected people, such as family members and children of people infected with HIV?

P: For children who are infected, there's a group at Ubuntu. I think they start from plus/minus seven years to thirteen if not fifteen years. So Ubuntu is helping them. I think there is also a group, I forgot the name now, for affected mothers, brothers and sisters, but I don't know where, and I'm not sure about that.

Support group for infected children

Also support group for affected family members

R: Is there anything else you think I should know?

Disclosure of HIV positive status can lead to

P: The only thing that I can add is that if you are HIV positive, sometimes your marriage gets broken, relationships, friendship also, but fortunately for me it was only my marriage.

R: What kept you going through that difficult time, because it must have been very disappointing? Who or what helped you to cope?

P: Not so much, because my husband was a play boy. He used to leave me, so I knew that one day there would be a result of this, so I was not that much disappointed. But , they supported me.

At risk behaviour

Support from friends

R: Are you taking any medication?

P: I was last year, but when I got sick I had to stop in December. So in January I was going to take the medication again, but only to find that my husband took me out of his medical aid.

No money for medication

R: Which medication did you take before?

P: I was using tablets, nevaropine, which is viramune, ridex, herbet ds and zaret, but at the moment I'm not using it.

R: Tell me about e-pap and the value of e-pap?

P: It's too bad, I did try it once but I couldn't continue with it, it tastes bad. I just tried it once.

R: And the African potato, what does that help for?

P: It's an anti-biotic, but I've never used it. I just take vegetables supplements, Vitamin B.

R: Thank you for your time and for sharing your story with us. I can see that you are living positively and that you've accepted HIV. Good luck with the challenges you face.

FIELD VISIT 4 – 7 JUNE 2004

INDIVIDUAL INTERVIEW 12

HIV&AIDS CO-ORDINATOR AT THE DEPARTMENT OF SOCIAL DEVELOPMENT

BROAD (FLEXIBLE) INTERVIEW SCHEDULE:

- ⌘ Which challenges are faced by the selected community?
- ⌘ Which resources and potential resources can be identified in the community?
- ⌘ Which services are provided by the Department of Social Development in the selected community?
- ⌘ How is the selected community currently coping with HIV&AIDS and the challenges implied by the pandemic?
- ⌘ Which role is the Department of Social Development currently fulfilling in supporting the community in coping with HIV&AIDS?
- ⌘ Which potential role might the Department of Social Development fulfil in future?

KEY OF ABBREVIATIONS	
R:	Researcher
P:	Participant

R: Please tell us about your position.

P: I'm the HIV AIDS Co-ordinator for the Nelson Mandela metropole, for the Department of Social Development. I'm the District Co-ordinator and then we've got seven service offices. So *area X* falls under *Z*.

HIV/AIDS co-ordinator on sdistrict level for Metropole/Department of Social Development



7 service offices (headed by HIV/AIDS representatives)

R: I see.

P: Then, under Z service office there is J, that is a HIV AIDS rep. So it's myself as the District Co-ordinator, reporting directly to the district managers, then we've got seven service officers and seven reps from all those areas. So that's why they normally say: "*If you want something to HIV and AIDS, go directly to Grace*" (*indicating herself*), although they are there for that area. Our main focus is the focus groups, women, men, people living with AIDS, children, child-headed households and also orphans. What I do, I'm supposed to be a co-ordinator, but I'm playing both roles, the role of facilitation co-ordination, and the role of a hands-on worker because some of the social workers, *in fact most of them they claim that they are overworked.* So which means they are not in a position to handle all the cases. As you all know, that if you talk in terms of funds, you've got most cases that are orphans, there's many emergencies. The children are left alone as child-headed households because the parents die. Then what we do in such cases is we place them in foster care.

Support groups
-women
-men
-people living with Aids
-children
-child headed households
-orphans

Social workers over worked/need for more assistance

Child headed households

Placement in foster care

R: You are a social worker by profession?

P: Yes, I am a social worker by profession, since 1992. So what we do, we place them in foster care, they are the people that are doing the placement. My role is that, because I'm the HIV and AIDS co-ordinator, I'm representing the department in the inter-sectoral forum and in the local AIDS council where there are most of our stakeholders in the metro, so all the cases come directly to me and then I will refer them to the respective offices. So we place them in foster care, some of them we place them in adoption, due to financial problems, but mostly we place them in foster care. The alternative placement like residential case is our last resort because we're preaching home-based care. The Department has made funds available for home-based care, where we're looking at ..., no, in fact as the Department because we are doing that in partnership with Health and the Department of Education. So the Department of Education is focussing on their life skills programme and the Department of Health, although they are focussing on treatment, care and support,

=representation on local/ council level

Refer case

Financial needs

Home based care

Department funding

Partnerships with Departments Services:

we are mainly focusing on care and support, where we visit people that are living with AIDS and encourage that they disclose as early as possible. For instance, if a person is living with AIDS, we support them with food supplements, give them food parcels, and those that qualify for the grants, we give them grants.

Partnerships with Departments Services:

Food supplements and provision

Grant provisions

R: Do they need to apply for the food parcels or how do you get to know about the people who are HIV positive?

NGO's=referral purpose

P: They are referred by NGOs in the communities and by the other home-based care carers in the community, because we're working closely with the Council of Churches, specifically Hope World Wide and others. So what they do, they will identify the people they think are needy. Then I will do the assessments, although the social workers are supposed to do that. Then I will do the assessments and if they are really needy and they meet our criteria, because in terms of our criteria we focus on child-headed households, on orphans, on TB patients and people that are living with AIDS and also the people who have no source of income, let's say the people that have no money for their next meal. So those are the four categories that we do. Then in terms of the food supplements, we focus on infected and affected. Those are the boxes of our food supplements (*indicating boxes in her office*). So we do get so many referrals, but I must say the need is more than what we can offer. There is an element of creating dependency as far as those food parcels are concerned, because we're giving them food parcels for three months and after that we're not there. But there should be continuity because the idea is for us to give them food parcels and they must be involved in programmes or they must be linked to social security to access the grants. If you've got children that are orphans they must be linked to social services in order to access the foster care grant.

Home-based care carers in community

Resources

Social workers do assessment if meet criteria then provide with support

Programmes offered

Grant's available

R: Are grant applications finalised within three months?

P: No, unfortunately not, because as I say there is a backlog and also there's a shortage of staff, most of our people are leaving the country and they are not replaced, unfortunately. So that's why you'll find that I'm playing all these roles. Therefore I start early, I take work home, I'm working Saturday and Sunday, there's no way that you can finish your work.

R: So you provide the food parcels for three months. What happens after the three months have passed?

P: After the three months they are supposed to be already in our system to access the foster care. ~~Then the social workers will do the investigation,~~ so that they can place them in foster care.

Arranges placement in foster care

R: But where do they get food if they don't have an income?

P: Unfortunately the system works according to three months, the food parcels that we have, the two programmes, then after that there's nothing, unless the social worker can mobilise something within the community.

Community= potential resource for survival

R: Tell us about the two programmes you talk about?

P: The food programme is the National Food Emergency Programme, and then there's also the National Integrated Programme, and that one is focussing on home-based care. At the moment we're focussing on *M area*. We've got 45 volunteers that are doing home visits and what do you call it when they go to these houses and do home care, where they wash the patients. So we've got those patients that are caregivers, rendering services to people that are living with AIDS.

Wider area:
Volunteers home based care and home visits

Basic care

R: Do you train them before they go out into the community?

- P: Yes, we train them on basic HIV and AIDS, we train them on home-based care, we train them on trauma, because some of them are exposed in stressful situations, in traumatic situations. Then also we identified that they need to be trained on dealing with loss, because some of them are not used to that.
- R: And there are 45 caregivers?
- P: Yes, for *M area*. The rest of the metro is catered for by the other NGOs, because we've got many NGOs such as Hope World Wide, whose got their home carers, ACVV, they've got their home carers, then there's another organisation that is focussing on home-based care, they call it CHI, that is Community Health Initiative. Then there's also Zwapa, Zwide Women's Association, they've got a poverty programme and they also have home carers. There are many NGOs.
- R: Are you aware of any home carers working in *area X*?
- P: In *area X*? I will have to really find out. I think ... I think the ACVV is working there, but I will have to find out who co-ordinates them.
- R: I have already met with the ACVV co-ordinator of the area, thank you. So you're not aware of any other NGOs working in *area X* at this stage?
- P: What about the CMR?
- R: I met with them too.
- P: Who else? ... You know that area is a little bit neglected, because our social workers are working there but as I say they are not really doing what they are supposed do. They are focussing on foster care and also adoption and also they are focussing on the placement of these children. But you will find that in terms of the resources, linking those people there in that area with other resources that are there in the area they are not
- Training of volunteers
- Home-based care, trauma, and dealing with loss.
- Several NGO's: home based care and carers
- Resource
- Limited services/help-social worker
- Area-under resourced

really doing that. And the area itself is under resourced. Because with our programme, the home-based programme, unfortunately it's focussing on area M.

R: Where's *area M*?

P: *Area M* is the other side of PE on your right, some 19 kilometres from here. It's a little bit further than here, but it's the area that is characterised with a high rate of unemployment, high prevalence of HIV and AIDS, all the social pathologies, as a result it's getting all the attention. That is the problem that we are having, we are focussing that side, maybe now is time for us to move this side.

R: Resources are always limited.

P: Ja, there will never be enough, but whenever we've got a programme that is coming, I mean we've got Urban Renewal there, we've got the NIP, now they've got ... uhm, now we're opening a Social Development complex that's going to have all the people under yard, you see, like a multi-purpose centre. But at the same time we need to focus on this side of the metro. Maybe even with other NGOs as well, I know there's one centre, because it is one of our focus areas, to fund the centres, so I'm providing them with soup. Do you know the centres where you have a couple of activities that are run in the centre, focussing some there, focussing on street children, some are focussing on orphans and neglected children, some focussing on people living with AIDS. So what they do, you provide a meal before the children go to school because they don't have parents and when they come back from school we also provide them with a meal. And from there, the volunteers will maybe be assisting the children with their homework, school work and all that. So they provide lots of services in these centres, like for women they're doing their bead work, poverty alleviation programme, men and women are focussing on gardening projects, and so on. But in PE we are just providing soup, they are just providing meals. I'm trying to maybe guide

Resources else where

Potential resources: NGO's= providing food, assisting with homework

Services

them to see maybe the need to involve more children, to involve women so that they could have something that is measurable, not have a child that is going there just to have food and from there to the streets again.

R: Are you aware of such a centre in or near *area X*?

P: There is a lady that is operating at *area X*, eh ... Sister E. And then there's also another lady but she's doing both areas, *area N* and *area X*, it's S, she's got a soup kitchen, and then there's *J's* soup kitchen, she's right at the back of the university. So she covers some of the people from that area.

Volunteer worker

Soup kitchen

R: And the main goal is combating hunger?

Focus=fighting poverty

P: Ja, it focuses on that, but if maybe they could expand the programme, expand maybe and let the people be involved in other projects, it would be better, But it's not easy, because there are no resources, but they can maybe guide them and let them start at home, so that if you give them these food parcels, give them rice and mealy meal that is there, they can take vegetables from their gardens.

Limited resources

Potential asset: food

R: What does the food parcel normally consists of?

P: It's 10 kilograms of rice, 10 kilograms mealy meal, a package of sugar, 2 litres of fish oil, and there's also a bucket, and inside the bucket there is 2.5 kilograms of samp, and also beans, tea bags, peanut butter, soap, washing and bathing soap. It's a month's supply and the value of that parcel is R200.

R: And it's government funded?

Resource

P: Yes.

R: I've heard a few people mention e-pap. Are you at all involved in providing e-pap to children that are HIV infected?

P: Yes we do. We do, because there is a guy that is providing e-pap, he normally phones me because some of the people will come to me for assistance so they provide me with e-pap, then I provide it to the infected. But as a department we are providing the supplements from Nutrimo, there's porridge there, there's a beverage, there's also a drink. So it's four packs that are there, four 1 kilogram packs as supplement, they are from Nutrimo. This year we provided for 426, because they are divided. We've got 24 districts in the Eastern Cape, each district got 426, that is the number of people that we need to identify, the infected people. And it's a supply of three months. We give them one box per month. Now this is our last supply (*indicating supplies in her office*), it's the remainder of my June supply and from there we will continue doing that, but in three months time.

Food provision/
supplement

R: If I understand you correctly, you had to identify 426 infected people per area. What if there are 500? Will you help the first 426?

P: What I've done is I've provided the 426 that was given by the Department and then from there the others I've given them e-pap.

Food provision/
Supplement for
all in need for 3
months

R: In other words you always try to help, you never show people away?

P: I always try to help. And we are the Department, so they would also expect us to provide. So what I do, I uhm ... you know, it's like a joke when you say it, but I provide the NGOs ~~but sometimes I go to them~~, for instance if I've got a crisis. Like I once had a case of a ten year old, taking care of a four year old. So what I did was, I went to the Salvation Army, because at that stage we didn't have anything. Like now, after these food parcels, this is the last lot that I'm having. And after that we are going to wait for the funding from the provincial office and give them three months. But it's a programme that's going to run for three years.

Seek assistance
from NGO's if
cannot provide=
Networking

So maybe we will be in a position at least to alleviate poverty, even if it's by 20%.

Poverty alleviation attempt

R: Even if it's for one person, it does make a difference.

P: Ja, it makes a difference.

R: Grace, please tell me about the grants. How does it work? For example, what are the criteria to apply for the disability grant, do you know?

P: It's supposed to be a CD count of 200. ~~I think we take the criteria from~~ Department of Health. But last year, I would say 2002/2003, we had an influx of people that were coming to ask for the disability grant. Now, the head of department had to write a letter saying that by virtue of being HIV positive doesn't necessarily mean that you qualify for a grant, because the people were just coming. You go for a test and after you go for the test you come to the department of Social Development for the grant.

Criteria for disability grant

High demand for disability grant

R: It sounds like easy access to money?

P: Exactly, and we could see that in our budget. Then, if the bulk of our budget is going to the grants, we cannot afford it, so then they started to guide the people, so that they know that they won't really qualify. It was such a problem, people were not happy with that, because most of the people, there's an increase in the people that are getting infected. But if you look at that, unfortunately our criteria says you get it when your CD count is 200, which means some of them they only access the grants when they are at the verge of dying. And also, some of them don't even get the grant, because their relatives they would claim the grant and unfortunately some people are deceased without even accessing the grant. But I must say that with the introduction of anti-retroviral we might change our criteria and say there will be more people that will be living, because with the anti-retroviral people will live longer. Then what we need to do as the Department of Social Development is maybe to clean

Department informing people about the grant

Increased infection

Strict criteria for grants access

Relatives accessing grant (people dead)

Hope for future with anti-retroviral provision

our house and be ready for that. When they roll out the anti-retroviral, what are we saying, people will live, there will be more chronic people than people that would be dying. There will be lesser maybe demand on the people that are needing foster care grants because the foster grant people are dying, leaving their children. So more children will stay longer and more parents will live longer, they will be taking care of their children, which means, maybe we need to provide the grant.

Hope for longer life expectancy with anti-retroviral provision

Maybe increase in grant?

R: Yes, only time will tell.

P: Exactly, because the department is not ready yet. We've been asked ... we received a letter from the Metro. So we've been asked what is the plan for the roll out. We need to look at that because Health, they decided on their own without involving us as Social Development. I'm not sure whether we are ready in terms of our budget, because we will be getting more people that will be in need of the disability grant.

Challenge to Department of Social Development

Prepared higher demand for grant

R: Please tell us about the application procedures for governmental grants. Do qualifying people apply here at the Department?

P: They apply here at the department, but because we've got seven service offices, we've got an office in *area M*, we've got an office in *Z*, we've got an office in *N*, we've got another office for in Uitenhage, so they can apply in all those areas.

R: And the closest service point to *area X* would be *Z*? They fall under *Z*?

P: It's not so close, but it's closer than the other offices. ~~And now I'm afraid~~ they are going to travel more than they used to, because those people, I only heard on Friday that they will be coming here, which means they will have to catch a taxi to access that. I don't know whether maybe the people from *Z* will decide to have a satellite office in those areas because that could be an option, to have a satellite office in *area X*. You know, it's so difficult.

Problem= travelling expenses

R: Could we talk some more about the grants?

P: Oh, yes. Then we also, okay, you know the type of grants that we offer as a department?

R: I know about the foster care grant, the disability grant ...

Foster care grant as resource

P: Yes, the foster care grant is for the foster children. It's R500, it went up to R540. Then there's the child support grant that will provide for the children that are under the age of eleven, which is R170 per month and the person's income must be less than R800, less than R800 and they say in urban areas is between R800 and R1000 and for rural as well they've got an amount. So that is child support grant. Then we've got care dependency grant, which is provided to the children that are disabled, physically handicapped, mentally handicapped and also infected children can access that grant. That's now R740. Then we've got granting aid, it's for the people, like we've got the people that are disabled, or that are receiving the disability grant, R740 and the people that are pushed by wheel chairs. The person that is assisting the person that is disabled, or the person that is receiving the disability grant qualifies for that R100, it used to be R100, so that is the granting aid. Then there's the old age pension, for females 60 and for males 65 years, which is R740, and then there's also social relief. Under the programme social security they also provide social relief in cases of disaster, and in cases of people that are waiting for the grant they also get food parcels, for social relief or distress. I think that's all under the grants. The idea when they started with the child support grant was that the people that are receiving child support grant should be involved in programmes, because it started with R150, so they should be involved in programmes, because initially it was for children that are under the age of seven. So there were programmes that are running for people with children under the age of seven, now it's under the age of eleven but people are not motivated when they get money. Although it's not so much, they are not

Child support grant as resource

Dependency grant as resource

Old age pension

Social relief as resources

Provide food parcel

Handling money: not motivated

motivated, some of them are not really motivated, they just want the grant.

R: Could you provide me with some background information on *area X*, as you know the area. What are the greatest social challenges in that area?

P: Poverty, unemployment, rape, domestic violence and mostly drug abuse. And also child neglect, ~~most of the cases there are from that area.~~ I think maybe because of the high rate of alcohol abuse, ~~the children in that area are~~ neglected by the parents.

Social challenges

R: Yes, I have often observed children not attending schools when we go into the area in the mornings.

Abandonment

P: Exactly, and abandonment used to be very high, the abandonment and maybe ... eh ... you know, as I'm talking to you now, I'm just thinking, maybe we need to focus on programmes that are really focussing on substance abuse, ~~because I know when I go to those schools you will get a child with, it's Monday today, but you can't understand why the uniform is dirty and the shirt is not clean. And it's because the~~ parents are not really taking good care of the children, most of them they abuse their children, even if they receive the grant, to an extend that if you do supervision there you must know that you will always end up with something that is wrong. I wouldn't say it's illegal but I don't think we are expected to monitor the foster care grant, but then you will be directly involved, going out into the community, you know.

Potential resource: programmes on substance abuse

Child neglect/alcohol abuse/ substance abuse

You know, I used to have cases where, if a grant is going to be paid on a Wednesday, I would go there as early as half past seven so that when she gets to the pay point, when she gets the money I take her straight to Maka. Then we would go straight to Themba La Bantu, where we then buy school uniform because Mr M complained that some of the children are not paying school fees, they are not paying. Their school needs are not met, they don't have school uniform, no shoes, even an underwear.

Monitor spending of grant to provide in school-related needs

Financial needs School related needs

When I used to go to Themba La Bantu to buy, then I know this month with this grant I will just buy school uniform or shoes, you know the basics, school uniform, shoes, underwear and socks. The next month I'm buying the jersey and the books, and so on.

R: That must have been time-consuming?

P: Exactly, but I used to do that. And imagine, at the stage I was doing that, I was a social worker playing the role of being a social worker and also playing the role of being an HIV co-ordinator at a district level and also an HIV co-ordinator at regional level. And thanks God, the regions were phased out because after they were phased out I had to focus on the metro. And there are so many challenges because of the NGOs in all areas, we've got all the NGOs and now my duty is to facilitate training of the NGOs. The people that are there in those areas, they should empower and capacitate those NGOs, but I'm not playing a role of a co-ordinator, the people are overworked, they can't fulfil that. Then because it's our mandate to identify community initiatives, especially those that are focussing on home-based care and provide funding for those organisations and also if we can capacitate them in forms of any training that we could offer, so that whatever that they are doing is in line with our policy, because most of them are complementing our services. Because I mean, we can't do it alone as a department.

Facilitate training in NGO's- empower and capacitate= mobilise potential resources

Capacitate other organization

R: That's true.

P: Yes, so it's quite a demand on my side, because you're looking at that as well and most of the people, in order for them to render a proper service, I must be there in the community so that I could tell them that the role of the Department of Social Development in HIV and AIDS is focussing on care and support and under care and support they are focussing on placement, alternative placement of children, that is foster care, adoption and institutional placement, which is our last resort. But mainly we focus on home community based care. And home community based care

Care and support

focus on people that are living with AIDS. And you know, I was looking at my operational plan and I was saying: “*You know, there’s so much that I’m doing that is actually not my job*”, because if you could look at my operational plan then you would wonder why I’m like a Jack of all trades.

R: You certainly seem to be involved in various activities.

P: You know, I will provide training on home-based care, focussing on the social aspect, because you know the programme of 59 days, the programme on home-based care that is provided by Health – the training programme, in their curriculum they are not focussing on the social aspect. So I need to now do that training. So they will always ask me: “*Grace we need you for this, Grace we need you for that*”, and okay, that’s part of my job but at the same time I feel that what I need to do is be there in the community, so that I can make a difference. How I wish that social workers can work as a team! As I say that we’ve got seven people, how I wish that those people could really go out into the community and be more visible, because you will find that I’m more visible than them. And they just shift the responsibility to Grace. Because for instance, take an example of the food parcels, my duty to provide the food parcels and then actually they must distribute it. They must identify the families for me and after identifying the families they must assess those families but I do that, even now I’m on my way to do that. I’m going to do the assessment in *area M*, so that I can distribute other food parcels. But there’s no way that I can sit and say this is not my job, because if I’m not doing that, there won’t be a difference in the community. People are waiting there, they don’t know the others, but they know Grace. There are also roles that I’m performing at provincial level, and they asked me to attend a meeting in Pretoria and then when I come back there’s something that they want me to implement, because there’s also a structure, the National Action on Children that are Affected by HIV and AIDS, they call it NACA. They are supposed to have a provisional action which is PACA and we are supposed to have a district action at this level and from there it cascades down to LACA at local

Present training programme on home-based care (collaborate with Department of Health)

Want to make a difference in community

Challenge: social workers not doing their work-shifting responsibilities

Social workers not doing their work

Few people doing much

Variety of action plans to be implemented in the community HIV positive related programmes

level. So we are busy doing that. So you run to the province to make sure that the structure is in place, you come back to the district, you would make sure there's structure and you facilitate the establishment of the structure at grass root level as well, and then there's also so much that needs to be done in terms of guiding even the social workers around the programme, because the programme is demanding.

R: Tell us about that health system programme?

School based programme to be implemented

P: It's a programme that is run by different stakeholders, by Health, Education, Social Development, NGOs and everything. In a certain area you need to have the programme, which means you need to identify the resources in that area so that when there's a problem, you know where to refer exactly. So we have this structure, there must be levels of this structure, but it is run by the school principals as the co-ordinators. The school principals should initiate it as co-ordinators, maybe the first step would be that the principal should call a meeting with the stakeholders, a social worker from that area, HIV AIDS co-ordinator, nutritionists from Health, school nurse, somebody from Education on life skills, you must be in a position to identify the people, looking at the problems that are existing, must have SAPS and Correctional services. So if the programme, if you say substance abuse is a problem in that area, we need to call SANCA, then SANCA must be on board. Then you have the meeting where you are going to introduce us all, like the organisational meeting where all the stakeholders go and from there we elect a steering committee that should run the programme. When there are big events like the Child Protection unit for instance, we have those people. Each and every person will focus on their mandate, I will focus on child protection, looking at the infected or affected orphans and children abandoned and abused and all that. Then you might have a police officer that will be focussing on crime prevention and then youth development as well, you have various stakeholders that will be focussing on that. The principal must be in a position to identify that these are the problems that I see that we encounter in this area, by

Various role players

Principal to initiate

Programme inclusive

Identify resource and get them involved

Potential resources

Programs eg. Child protection

looking at the children. If you say, for instance, that most of the children they come to school with empty stomachs, then I say the high rate of poverty is the focus. Then what do we say, Social Development must be involved and also Department of Health must be involved with their nutritional programme. So it's actually the purpose of that structure, the way I see it is to bring the resources closer, to make the resources accessible. Now this is something that is in the pipeline, it's something that needs to be done. All the schools are supposed to have that.

AB approach-link with: focusing on resources and accessing them

R: Is there a policy document stating this?

P: It's supposed to be, but I don't know what happened. If you can ask maybe the Department of Education, because I'm going to this meeting first. Maybe they will have something, because what I used to have I left it with the social workers from that area. It's just a workshop document from the findings, you know, like a situation analysis of some kind. Then from there we developed an operational plan. If, for instance, you say poverty, how are you going to alleviate poverty, then we talk in terms of income generating projects, such as the gardening projects, whatever and all that. So there is this professor from Rhodes University, I can't remember her name, but she initiated it and she was leading it.

Proposed plan to address problems – not yet on the ground (in pipeline)

R: Grace, will it be in order for the teachers at the school where I work to contact you if they need advice, as they should be starting an initiative like this within the near future. Will it be okay for them to contact you for guidance?

P: It's okay.

R: But I don't want to add to your work load.

P: No, it's okay. I know they probably won't be impressed with me because *Mr M* referred 3 cases to me. Then, even though I'm not supposed to go out, in this particular case, I took the car and ran to that family but when I

got there, the child is ... she was at that stage full-blown. I left the e-pap.
I left the food parcel. Then my duty was to refer that case to the social worker. And you know, to be honest, I was so disappointed to hear that there's been a social worker that has been working on that case, and yet there was no improvement. And it was the social worker from our Department that is operating from hospital D.

HIV positive child- provide food supplements refer to Social worker
 Social worker not doing their work in the area = problem

Hospital based Social worker from Department

R: If I listen to you and from everything that I've gathered during our conversation, it seems like *area X* is kind of a neglected area at this stage. However, the people still seem to cope. What do you think, why or how does the community manage to cope?

P: I would say maybe it's because of the community involvement. The community members they help each other, but I would say some credit must also go to the NGOs, like Siphuthando and the CMR. I know the CMR is working there, there's a social worker B, and also child and family welfare. And I would say maybe the two schools, the teachers play a role, because some of the resources, they access them through the schools. Mr M has been doing quite a wonderful job and also the teachers from school G. So for example, the children, the parents would be called by the teachers at school so that they could see a social worker. And you know with the social workers, if there is a teacher involved, it's better. Because the people are not really educated about their rights, so they sometimes would sit at home not knowing what's going on, then the school teacher would phone and ask: "How far are you with that case?" You see, that's terrible, but it's the truth. I hope I won't lose my job by saying that (*laughing*).

Community involved with each other

NGO's
 Social workers
 Schools
 Educators
 Principal in school

Schools and teachers refer to social worker and advise to go for follow up

Community members ill informed

R: Could you please tell us about this hospital across the street?

P: *Hospital E?* It's a TB hospital, but I suppose a lot of HIV cases.

P: Do you know what the capacity of the hospital is?

- P: No, I don't know the capacity, but what I know is that they are ... uhm, they are dying like flies. Unfortunately when you go there, you go in and park your car on the other side. When you go in, you will see a person that has just died covered with a white sheet, when you get out you see another one and I'm so scared to go there. I don't know how the social workers is coping there. The social worker from *hospital E* has been sick, I don't know, maybe it's due to the work. I don't know whether it's work related stress, but she's been sick almost the whole year. She works there and arranges the grants for the people there and also maybe arranges home visits.
- R: Is she from the Department?
- P: Department of Health.
- R: As I understand it, the social workers that work in this area are either employed by the Department of Health or by your Department or by the ACVV or CMR?
- P: Those that are in hospitals are employed by Health, then you've got seven social workers in those seven service office areas that I mentioned, they are appointed by the Department, then you've got those that are appointed by child and family welfare, CMR and ACVV. And then there's also FAMSA.
- R: Grace, thank you for all the information. Is there anything else that you would like to add that might help me to understand how the community in *area X* is coping with HIV&AIDS?
- P: Nothing that I can add. But what I can do, let me see if I do have it ... (*searching for documentation*), this is the national guideline for services to children infected and affected (*handing over a document*). There's a lot of information in there that might help you, there's information on the

High TB related deaths

Difficult to cope with

Social worker arranges grants and home visits

Department of Health – hospital based

Department of Social Development: 7 social workers in 7 service offices
Appointed by Child and Family welfare-CMR ACVV

FAMSA= Another organisation

options for child care, types of financial assistance, the statutory business plan, home community based care, you might find it helpful.

R: Thank you so much. This is a great resource, thank you.

P: It's a pleasure, and it can maybe guide you, because it has everything about Social Development in there.

R: Thank you! Is there anybody that you would suggest I talk to, that could provide me with information? I have already spoken with the teachers, with people of the churches, to you now, to Department of Health at the hospital.

P: What about ATICC?

R: Yes, I've been to ATIC, and I've also met with *Sister E*.

P: I can't think of somebody else now. But you know what I forgot to tell you about us in the Department is that we've got programmes that are running, like HIV and AIDS programmes, with the co-ordinator – myself, and then we've got a co-ordinator for victim empowering, that is a programme that is focussing on domestic violence, abuse and all that and then we've also got a programme on care for the elderly. Then there's a programme on substance abuse and also a programme on child protection services. So those are the programmes that are running. They are led by social workers within the Department, so that you could really focus.

8 programmes led by Social workers – by Department of Social Development

R: And to summarise your task, and I'm sure I'm going to leave out something, your task is to co-ordinate the food parcels and the applications for the grants and to assist all the people that is infected and affected, as well as do assessments, which is actually not part of your job yet you do that, as well as organise the home-based care programmes. And then you also organise the volunteers and train them, and attend all those many meetings. You are involved with the Department of Health,

you also work with Education, other stakeholders and NGOs. Is that correct?

P: Yes, but mainly it should be the home-based care programmes. And I have to attend that inter-sectoral forum in the local AIDS forum, because you know, it's like, uhm, this thing is like a guide. What you need to do is to focus on the implementation and preventative programmes, co-ordinate the programme, implementation of educational programmes on HIV and AIDS, targeting all vulnerable groups. Those are the children, infected and affected, the women and their children, then you develop an implementation plan to integrate HIV and AIDS issues into all the departmental programmes. So the programmes that I mentioned to you, like social security that is dealing with grants and poverty alleviation where it's my duty to link the people, for this programme I must monitor and evaluate the implementation plan, alleviate levels of poverty through food security and income generating programmes, that is in line with the community development principles and practices. Then we've got the co-ordination of identification and assessment of TB patients and HIV infected and affected people. And I also co-ordinate the distribution of nutritional programmes and dropping centres and soup kitchens, like the one that I mentioned, like the food supplements and also the soup kitchen. And this involves distribution, co-ordination of the distribution of food supplements to HIV and AIDS and TB patients.

Networking role

Alleviate poverty by:
Community Development

Identify and assess TB and HIV/AIDS

Distribute nutrition and programmes

Organise and run soup kitchens-provide food supplements to HIV positive individuals

R: That surely keeps you busy! Grace, thank you once again. Is there anything you would like to add?

P: Just that if you need any support or more information I will make a plan. Or maybe if you are coming again and would like to have a meeting, I will meet with you. Otherwise, I would like to know about your projects, because it looks like you are bringing the resources to the people.

R: It's about making the community aware of resources that are already there.

P: But at the end of the day, make sure that these resources are acceptable to people and that they are accessed, you know, when you talk in terms of accessibility and acceptable by them. So what we need to do is to look at the community involvement first, ~~maybe we can assist you with~~ regard to that. We can look at that, mobilise the community with the teachers, maybe have a steering committee because what they want, what they are going to do now, if I heard you correctly, is to have a team leader in that school, and then that team leader will make sure that the programme works. Then maybe our role there will be to support that person and guide that person. Then what I need to do is ~~maybe on our~~ side as the social workers, maybe guide them and say this is what we need to do because that could really help us, even if ~~they would say as a school we are dealing with this office~~, if you want to come as social workers you can come on Wednesday. Because as we don't have resources, we don't have an office in that area. But maybe if the community could have access to just have one social worker it will make a difference. So we would really love to help.

Link with AB approach: resources should be acceptable and accessible

Community involvement

Mobilise assets

Support and guide community members

School= community asset

R: Thank you, Grace. I will keep you informed and also tell the teachers to contact you.

14 November 2003

On our way to the community I experienced feelings of excitement but also uncertainty. Although I had planned the session and felt that I was ready to enter the field, I speculated as to whether or not my ideas would work out, to what extent we would be accepted by the participants, whether or not they would all turn up and be willing to participate, whether or not I would succeed as facilitator within a group of people who in so many ways differ from us ...

These feelings of uncertainty and hesitance were soon replaced by excitement and amazement, with me feeling overwhelmed. All participants turned up (in fact, one more joined), they participated in all activities (yet initially with suspicion) and shared their amazing stories. Yet on the down side, many (but not all) of the participants appeared to be there primarily due to the fact that they are going to be reimbursed for their time.

The lengthy lunch and socialising component was successful in establishing rapport and paved the way for a rich discussion on HIV&AIDS. However, it emphasised the fact that I will have to be flexible and be guided by the pace of the participants – which seems to be much slower than the one I had planned.

After today, I am left speechless by my experience. In the heart of this poverty-stricken community with seemingly limited external help and resources lies a school with amazing educators and so much potential – indeed a huge asset to the community! Yet they don't seem to believe in themselves and the role that they are already playing ... I feel humble.

I am happy that my selected methods worked well today. I believe that the focus group discussion allowed all participants to make contributions, within the safe environment of a group. Participants could also support one another and elaborate where they wanted to add information or differ from someone else.

Although it is still early days (literally), I get the idea that this community (more specifically the participants) might (from a PRA perspective) benefit from the research. They have so much to offer and possess such a wealth of skills and compassion – yet they seemingly do not believe in their own abilities. This could be mobilised! The participants seem to be convinced that outside resources can assist the community in facing the challenge of HIV&AIDS and that we might be of valuable assistance to them. However, and in this regard, a distinct need to be informed on HIV&AIDS related issues seems to exist.

17 November 2003

This weekend I could see how PRA can be put into practice. Wow, it works great! Involving the educator-participants in visual concrete activities worked so well! Not only did it result in the planned outcomes for the visit, it also led to lively discussions, energy and excitement amongst all present. I am convinced that a mere discussion on the lay-out of the community would not have resulted in the rich information co-generated by using mapping activities, as proposed by PRA. I am therefore satisfied that I employed a suitable approach and methods.

However, I did not only experience the positive outcomes of employing PRA principles in practice. The potential hurdles of PRA that I read about also became a reality. I had to constantly remind myself that the participants were to determine the process, agenda and the pace of activities. Although a flexible approach during sessions came easily, it took me a while to accept the idea that we were not going to be able to finish all the activities planned for the first visit. We in fact only managed to address half of my ideas ... thus reflecting the golden rule of "*The participants determining the process...*"

At the end of our first visit to the community, after four days of hard work, I am exhausted, yet overwhelmed by the great response I received. I am excited about my study and happy about the way that I facilitated activities over the past few days. I am already looking forward to the next visit. Although the participants still seem to be cautious when discussing HIV&AIDS related issues, they are progressively becoming more open and appear willing to share their perceptions with us. Some of them, however, indicated the stigma attached to the pandemic within the community, constantly refraining from using the term HIV&AIDS.

Based on the participants' contributions and my own observations of the community, I want to predict that the asset-based approach may be suitable as theoretical framework in analysing this community's way of coping with HIV&AIDS. The school, principal and participants themselves are great assets to the community, although they do not seem to be aware of the fact yet. In addition, we identified various resources and potential resources in the community, some of which were also mapped by the participants as part of the mapping activity.

23 January 2004

On our way to the school today, I wondered whether or not all of the educator-participants would turn up, as two months had passed since our first visit. As with our first visit, I was a bit anxious and uncertain about the activities I had planned, and whether or not they would be appropriate and suitable to generate the raw data I aimed to obtain.

Once again, I was astonished at how well the activities worked out. Participants easily identified with the symbols I selected, enjoyed the session, participated with enthusiasm and created rich and extensive raw data. Nine of the eleven educators that participated during our first visit turned up, with one withdrawing from the study and one becoming involved in extra-mural activities, sending a replacement. In addition, a new participant joined us, once again resulting in eleven participants. All of the educators were glad to see us and visibly more relaxed with us being there than during our first visit.

The willingness of the participants to be part of the study and – even more important – make a difference in the community is truly remarkable. However, in spite of their enthusiasm and motivation to make a difference, they initially still tended to focus on the problems of the community and external support addressing them. During our facilitation we had to constantly redirect participants to the resources and potential resources as ways for the community to solve problems and face challenges. In response to our attempts (towards the end of the visit), participants demonstrated insight into the basic principles of the asset-based approach. Based on the assets and available, but not yet utilised, resources that the participants identified, I can reach the preliminary conclusion that the community is indeed relying on some assets available to them in order to cope with the challenges they face, including HIV&AIDS. However, several assets do not seem to be utilised – maybe necessitating the process of asset mobilisation?

10 June 2004

Viona accompanied me during the third and fourth field visits. I wondered how her presence might impact on the educator-participants and the dynamics of the group – she being a new face and yet another outsider entering a semi-closed circle ... I was happy when the educator-participants accepted her in the same manner which they accepted Liesel and me up until now. I do, however, partially ascribe the ease with which Viona established rapport with the participants to the firm relationships of trust that had been established already. During last week's visit, I faced the challenge of telling the educator-participants that they would not be receiving reimbursements from visit five onwards, as the funds were exhausted. Despite my anticipation that they would show resistance, the participants accepted this fact fairly easily, indicating that they were there to make a difference in the community, and that it was no longer about the money.

I experienced Viona's intervention as beneficial part of the participatory intervention initiated by my study. Viona's intervention afforded me the opportunity of spending more time in the field and in the presence of the educator-participants, strengthening relationships and constantly learning more while in the field. I could sense that the participants appreciated the fact that I kept on returning – honouring my commitment of being involved in the community for a lengthy period of time and adhering to the basic principles of PRA. As such, I got the idea that I lived up to their expectations and that they in turn respected my commitment, once again strengthening our relationships of trust even further. During the individual interviews that I conducted, I appreciated Viona's support as field worker. In the same manner, I benefited from fulfilling the role of field worker whilst she conducted her individual interviews – elaborating on my existing base of raw data.

On the other hand, I did initially experience concern with regard to the potential (negative) impact that Viona's intervention might have on the future progress of my study. I could not be sure whether her intervention would support or compromise my project, as her intervention aimed at raising an awareness of coping within the educator-participants. I speculated about the possible impact that such an awareness might have on future coping strategies, as employed by the participants... Upon reflecting on my concerns I, however, soon realised that Viona's intervention is a piece in the participation and intervention puzzle that will contribute to the final end-product, as she focused on addressing a need identified by the participants during the first phases of my study. As such, Viona's intervention supplemented mine, thereby adding to the bigger participatory picture.

15 June 2004

I gathered extensive information from the individual interviews I conducted over the past few months. Despite my initial concerns pertaining to whom to involve and how to gain access to them, I was able to schedule and conduct numerous interviews without too much difficulty. One interview led to another and towards the end of my field work I had to force myself from making more and more appointments, meeting more and more people. To be quite frank, I even believe that the last few interviews were probably not necessary at all, as data saturation had probably been reached by the end of the fifth field visit. However, I was already so involved in the community and my process of investigating various possible resources at that stage, that I simply continued exploring. I relate this to the fact that I experienced some difficulty to negotiate my roles as researcher and interventionist, constantly having to remind myself that I entered the community as researcher and therefore had to remain focused on fulfilling that role.

I found it easy to conduct the individual interviews. I relied on the interviewing skills that I possess and established sound rapport without difficulty during all the interviews. With the exception of one, all interviewees were willing to contribute after I had explained the purpose of my study and the principles of confidentiality and anonymity to them. Based on my experience in the field and the rich data that I obtained, I regard my choice of informal conversational interactive interviews as appropriate for exploring ways of coping with HIV&AIDS, as employed by the community. I am already able to identify asset-based trends (such as community members' reliance on aspects like faith, inner strength, family and friends when faced with challenges) in the data I had obtained on the community's way of coping with HIV&AIDS – thereby suggesting that they may be relying on the asset-based approach in coping with the pandemic.

The interviews with the caregivers of the orphaned children (HIV infected), as well as those conducted with participants who were infected with HIV and the family members of infected individuals, were difficult. Visiting the homes of infected community members and their families and seeing the children living with AIDS was emotionally laden and painful. One of the lowest lows of my field work was most definitely the death of *L* a month ago, whom I met in February when conducting an interview with her aunt, who was taking care of her at that stage. Also, observing the fear, bewilderment and confusion in the eyes of the persons living with AIDS, as well as in the eyes of their loved ones, brought a lump to my throat. I am so grateful that I always had a co-researcher by my side, to debrief with after an emotionally difficult interview!

29 October 2004

Tilda's part of the intervention formed part of the broader participatory work that I had been doing over the past few months. I was excited to see whether or not the educator-participants would be able to apply the knowledge that they had obtained on asset-based principles. Up till now, they displayed potential skills as well as the motivation to utilise their skills in making a difference in the community, yet they seemed to lack the confidence to take action.

The outcome of Tilda's section of the interventionist research study was truly amazing. Although participants displayed motivation and energy to put their plans into action after her first intervention session, I pondered on how much would have been accomplished, when we were on our way to the school today. Standing next to a large vegetable garden (on the school premises) upon our return, left me feeling humble and ashamed. How could I ever have doubted the participants' motivation to make a difference and set the wheels rolling? – in fact doubting my own theoretical assumptions regarding coping, agency and the asset-based approach! Their feelings of joy, pride and accomplishment cannot be expressed in words! The three identified projects in an attempt to mobilise potential, but not yet utilised, resources demonstrated a success in terms of participatory research!

Tilda's intervention enables me to distinctly link the theory of the asset-based approach to the community's coping with HIV&AIDS. After identifying assets and potential assets in the previous phases of the study, the educator-participants were facilitated into action. They applied their knowledge of potential resources, as well as the knowledge obtained on asset-based principles, in putting their plans into action. By doing this, they were not only empowered themselves – they also seemed to have empowered other community members in coping with HIV&AIDS and its related challenges.

In addition to the work prior to her intervention, I relate the research outcomes of Tilda's intervention to the methodology she employed. Building on my previous field visits and relying on symbols and methods which the participants were familiar with, proved to be successful. Relying on group activities where participants were not provided with the answers but facilitated to come up with solutions themselves, further contributed to the research outcomes.

18 October 2005

Maria and Malize's interventions maybe constitute some of the last pieces of my puzzle. It aimed to address the needs of the participants, paying honour to them determining the process and agenda. This is PRA in action! As always, the educator-participants contributed and shared their experiences openly during the sessions over the past few days. By now, they are acquainted with the basic principles applied by PRA and the methods we rely on. The already present assets of the educator-participants could be expanded on further. Based on their willingness to make a difference and their motivation to help people in need of support, their skills were built on. In empowering them, the underlying principles of both PRA and the asset-based approach were adhered to – all adding to the community's way of coping with HIV&AIDS.

We are on our way to the community – possibly for the last time during this study. I am quiet ... reflective. The past two years have been enriching and fulfilling in many ways – both professionally and on a personal level. Conducting research in the field with people who experience the challenge of HIV&AIDS on a daily basis, whilst employing PRA principles, broadened my skills as a researcher.

Despite the challenges I faced, I had the opportunity to learn and in the process gain invaluable experience, insight into my area of interest and confidence as a researcher. As I strongly believe that I still have much to learn from this community, I am already contemplating the feasibility of a follow-up study in the near future