

BAMBISANANI

Community orientation to HIV/AIDS prevention, care and support



Bambisanani
of Respect



BAMBISANANI

COMMUNITY ORIENTATION TO HIV/AIDS PREVENTION, CARE AND SUPPORT

A COLLABORATION BETWEEN CADRE AND PPASA, EASTERN CAPE

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EXECUTIVE SUMMARY

The following represents a summary of key findings of research conducted by CADRE, in collaboration with PPASA staff based in Mt Ayliff, the Regional Education Office in Kokstad and the Bambisanani Co-ordinator. Each of the following points, plus a large range of additional data, is elaborated more fully in the body of the report.

1. Objectives

- To develop research procedures and instruments for understanding community responses in the fields of HIV/AIDS prevention, support and care within Bambisanani target communities.
- To conduct research using these tools in order to describe community responses to HIV/AIDS in Bambisanani target communities.
- To interpret findings so as to gain an understanding of intervention needs and possibilities, in the areas of prevention, support and care.
- To report on key issues which will: orient Project implementers to the realities, needs and capacities of beneficiaries and targeted communities; describe key problem areas likely to have an influence on Project development; and describe factors likely to optimise community reception and participation.
- To draw out implications for Bambisanani Project development and strategy.

2. Research process

The research process followed the following steps:

- Field visit to rural area and hospital followed by focus group with PPASA health promoters and Bambisanani co-ordinator.
- Focus groups in nine sites, with a total of 90 respondents in the following categories: adult community members in deep rural areas and upper deep (deep rural but close to transport routes) rural areas; out of school youth; school going youth; traditional healers; church members involved in home visiting; PWAs; health workers in a rural outpatient clinic; and healthworkers in a rural inpatient facility.
- Analysis of focus group data and construction of three questionnaires.
- Administration of questionnaires to grade 6 students (ave. age 12.5 years), grade 11 students (ave. age 18 years) and community members (ave. age 41 years) in defined communities located near Bizana, Lusikisiki and Umzimkulu. A total of 355 respondents were surveyed.
- Interviews with teachers and students in above sites.

3. Social context and availability of services

- Media/communications access in the home as measured amongst adult respondents: 85% radio; 42% television; 9% newspaper; 11% magazine; 17% telephone.
- A self-report measure of socio-economic status reveals: 37% of adults report 'Not even enough money for basic things like food and clothes' and 58% report 'Money for food and clothes, but short on many other things'.
- Of the six schools visited all are poorly equipped with no electrical equipment, there is gross over-crowding with as many as 90 in one classroom, all are without lights in classrooms and most are without running water.

- Services in community for persons with HIV/AIDS are either non-existent, rudimentary, or of poor quality.
- No evidence of systematic life-skills training in any of the six schools visited. Some have not been visited by health educators for more than two years and there are clearly no programmes of health education in place in the schools.

4. Risk and prevention

Direct exposure to HIV/AIDS

- Reporting someone in the household who is said to have died of AIDS: children 7%; youth 16%; adult 14%.
- Reporting relative sick with AIDS: children 10%; youth 9%; adults 10%.
- Reporting relative who 'may have' died of AIDS: children 22%; youth 29%; 21%.
- Reporting a friend who is HIV+, sick or dead from AIDS: children 12%; youth 12%; adults 13%.
- Reporting someone chronically sick in the household over the last year: 30%. Of these sick people 43% are 30 years old or younger.
- These figures suggest that the reality of the impact of AIDS at a personal level is relatively high. Furthermore, all communities reported families where both parents have died, and where grandmothers are looking after children.

Knowledge of HIV/AIDS

- Knowledge of AIDS amongst youth and adults is generally good, but poor amongst children (average age 12.5). For example, 57% of 12.5 year olds believe that one can get the HIV virus from using the same cup, but only 16% of youth believe this and 27 % adults.
- Only 9% of youth and 13% of adults believe that AIDS can be caused by witchcraft, suggesting that although this explanation is sometimes used, particularly by deep rural people, a bio-medical explanatory model prevails.
- The top information source for HIV/AIDS amongst all three age groups is radio.
- Eighty three percent of children (average age 12.5 years) report that AIDS has been discussed in class either not at all or only a little. This is part of a body of evidence which suggests that children have been least exposed to AIDS education messages of all three groups.
- Eighty nine percent of youth have discussed AIDS with friends 'at least a little' and 53% of youth 'quite a lot' or 'very much'. Seventy percent of adults have discussed AIDS with friends 'at least a little' and 40% have done so 'quite a lot' or 'very much'. However, interpersonal communication about AIDS does not necessarily serve prevention directly, and the levels of having discussed AIDS with boyfriends, girlfriends and partners is much lower. There is need to promote communication specifically in the context of such relationships.
- Seventy percent of children and 82 % of youth have been 'warned' by their parents about AIDS, although it seems that there is little communication between parents and children about sex.
- Only 41% of children say that AIDS can be prevented, supporting other evidence presented, that there has been little exposure of this group to HIV/AIDS education.

Perception of and response to risk

- There is much evidence that adults and youth are concerned about the risk of HIV infection. Fifty seven percent of adults and 77% of youth report that they have changed aspects of their behaviour to prevent the risk of HIV infection. However, response is by no means uniform, and irregular use of condoms

suggests that although there is a perception of vulnerability, personal vulnerability may be underestimated.

- Condom use has been the most widely promoted prevention measure, but secondary abstinence (becoming abstinent after having had previous sexual experience) is proving to be a prevention method of choice for many youth.

Sexual activity

- Ninety eight percent of male youth surveyed (Grade 11) report having had sex before, whilst only 66% of females report this. However, sexual activity is irregular and younger people who have had sexual experiences before are not necessarily currently sexually active.

STD

- Fifteen percent of youth report having had a sexually transmitted disease.

Number of partners

- Forty percent of youth report having more than one partner over the past six months and 21 % of adults report more than one concurrent partner.

Age and first sexual intercourse experiences

- Median age at first sexual intercourse for youth amongst males is 13 years and females is 16 years. Median ages for first sexual intercourse amongst adults is 17.5 years (m) and 17.8 years (f) suggesting that the age of sexual debut has reduced considerably for males. However, early sexual experimentation amongst young adolescent males does not imply ongoing sexual activity. It does imply a need to intervene early and to examine factors leading to early sexual experimentation.

Age differentials between sexual partners

- Seventy two percent of female youths (compare 22% of males) had a first sexual partner who was two or more years older than themselves. Twenty two percent of females had a first sexual partner who was five or more years older (compare 2% of males). Twenty five percent of female youths had 'last sexual partners' five or more years older (2% of males). These and other data show that female, school going youth in grade 11 are often in sexual relationships with much older men. Technically an age differential of two years or more for under sixteen year olds is classed as child molestation, which was the case for 27% of female youths in this sample, at age of sexual debut. Such relationships are likely to involve significant power differentials which impact on young women's ability to make sexual choices and to negotiate risk prevention.

Factors affecting sexual decision making

- Eighteen percent of youth report having been 'forced' to engage in sex before and 19% feel that they are not able to say 'no' to sex, even if they do not want it. The data presented suggests the need to promote self-assertion in the sexual domain as a campaign objective. There is considerable pressure on young women to have sex and there are gender differences around the interpretation of the needs of women in sexual relationships.

Condom acquisition and use

- Adults are more inclined than youth to believe that condoms are a safe method for preventing HIV infection. However, there is a considerable degree of uncertainty about this from both. It also seems that people from rural areas are generally less likely to rate condoms as a safe means of protection, and are less inclined to use them than other groups.

- About one third of adult and youth participants in the study used a condom in the last sexual act.
- There is a widespread familiarity with condoms as an effective HIV prevention measure.
- Twenty seven percent of youth who have had sex in the last 6 months have had sex with someone who refuses to use a condom, suggesting that it is necessary to address the communication contexts in which condom use is negotiated. There is a strong gender dynamic here with males tending to be more resistant to condom use.
- Confidential condom access is poor in all communities. Only twenty six percent of youth and 21% of adults report that there is a place where they can obtain condoms confidentially.
- Condoms are not easily obtainable in deeper rural areas. In one of the three communities where the survey was conducted, the only permanent clinic is more than 15 Km away and the mobile clinic requires at least a 3 Km walk for many members of the village, and then it visits only twice a week. One of these times is during school hours.
- Twenty seven percent of youth who have had sex in the last 6 months have had sex with someone who refuses to use a condom, suggesting that it is necessary to address the communication contexts in which condom use is negotiated. There is a strong gender dynamic here with males tending to be more resistant to condom use.

Condom acquisition

- Confidential condom access is poor in all communities and condoms are not easily obtainable in deeper rural areas. Only twenty six percent of youth and 21% of adults report that there is a place where they can obtain condoms confidentially.

Abstinence

- An encouraging 24% of youth, having had sex before, have not had sex in the past year, suggesting that abstinence is a strategy being employed, especially by young women. This is an indicator worth tracking and although abstinence has not been widely promoted as a prevention measure it may enjoy wider support than is currently believed.

5. Care and support

Response to people with HIV/AIDS

- The response to people with HIV/AIDS is characterised by fear, but is not expressly negative. However, 28% of adults report that there are people in their community who are unkind to people with AIDS. Although negative attitudes are not normative, there is a negative and unempathic response on the part of enough members of communities to make disclosure problematic. Further, perception of HIV as a death sentence creates a sympathetic context for response to people with HIV/AIDS, but a poor context for responding to them in an affirming way. There are clear indications that attitudes to people with AIDS are changing and 55% of adults report that attitudes to PWAs have changed positively over time. On most indicators of attitudinal response children proved to have significantly more negative attitudes to people with AIDS, corresponding to their much poorer understanding of HIV/AIDS and less exposure to AIDS education or messaging than adults or youth.

HIV testing and disclosure

- In general it appears that the quality of counselling services is poor, and very poor in some instances, and there is very little follow-up counselling.
- Negative diagnoses are often not followed up and reporting back of results is a problem area for health workers because people often do not return for results.
- There is a poor context for disclosure of HIV positive status given little support available for PWAs, and poor understanding amongst community members of the possibilities of positive living.

Care of the ill

- There is a generally negative attitude on the part of the public to the health services. Youth and elderly people are particularly negative about what the health services have to offer them.
- There is a low orientation of the health services to the ongoing needs of PWAs, which means that such services are often not turned to for assistance.
- A positive context exists for home care, partly because of the prevailing negative view of what the health services have to offer, and given that 80% of adults report that they would be willing to care for someone with AIDS in the household.

Mobilisation of resources

- The presence of AIDS in communities has not, in general, led to community mobilisation or activism with only 27% of adults reporting that they have attended a meeting in their community where HIV/AIDS is discussed.
- Although 24% of adults have thought that they should become involved in 'helping with the HIV/AIDS problem' most of these do not know ways in which they might meaningfully become involved (84%).
- PWAs, church home visiting groups and traditional healers offer opportunities for co-operation in the field of care, and specific opportunities and development needs are pointed out in the case of each of these groups.

6. Summary of implications for intervention

The report outlines: needs for much higher levels of functional integration of services in prevention and care; the need to develop models for community mobilisation which are decentralised and local; and possibilities for harnessing existing care and support resources to better effect. A number of recommended key interventions in the areas of prevention, care, support and services delivery are described.

7. Pointers for monitoring and evaluation

The report draws attention to the need to track programme implementation using a range of suggested indicators for monitoring developments in the areas of prevention, care and services delivery.

1. INTRODUCTION

This report represents the key findings of research conducted by Centre for AIDS Development, Research and Evaluation (CADRE), in collaboration with Planned Parenthood Association of South Africa (PPASA) staff based in Mount Ayliff, the Regional Education Office in Kokstad and the Bambisanani Project Co-ordinator.

The Bambisanani Project is a comprehensive HIV/AIDS care and support programme which aims to serve the needs of communities surrounding Bizana, Lusikisiki and Umzimkulu in Region E of the Eastern Cape Province. The Project consists of five main components: advocacy, marketing and partner mobilisation; community capacity building; support groups and income generating activities; home based care; and care and support for children in distress. Key partners in the Bambisanani Project are the EQUITY Project (ECDOH and MSH); The Employment Bureau of Africa (TEBA); Goldfields Ltd; Bristol-Myers Squibb (B-MS) Secure the Future; Planned Parenthood Association of South Africa – Eastern Cape (PPA, EC); Hospice (Transkei and South Coast); and National Education Health and Allied Workers Union (NEHAWU).

Much attention has been drawn to the need to ground programme development in contextual research which identifies key issues relating to how development programmes are likely to be received in target communities. Community responses to HIV/AIDS intervention programmes can be influenced by a great many factors including: cultural issues; previous programmes and development initiatives; the impact of the HIV/AIDS epidemic on communities; the infrastructure, resources and services available to communities; the alliances between organisations working in the area; the communication dynamics within communities; socio-demographic factors such as access to media and transport; and many other factors. It is important, firstly, to describe community responses and their variations, and then to understand what critical factors drive these responses. This lays a foundation for developing intervention programmes which are likely to target the key problem areas and to harness existing strengths. Based on this understanding, the purpose of this assignment was to undertake a baseline study to ensure that as the Bambisanani Project starts, the Project is informed about the realities, needs and capacities of the beneficiaries. Towards this end the objectives of this research were formulated as follows.

2. OBJECTIVES OF RESEARCH

- To develop research procedures and instruments for understanding community responses in the fields of HIV/AIDS prevention, support and care within Bambisanani target communities.
- To conduct research using these tools in order to describe community responses to HIV/AIDS in Bambisanani target communities.
- To interpret findings so as to gain an understanding of intervention needs and possibilities, in the areas of prevention, support and care.
- To report on key issues which will: orient Project implementers to the realities, needs and capacities of beneficiaries and targeted communities; describe key problem areas likely to have an influence on Project development; and describe factors likely to optimise community reception and participation.
- To draw out implications for Bambisanani Project development and strategy.

3. RESEARCH PROCESS

A schematic depiction of the research process is provided in Appendix 1.

1. Scoping and planning of focus group study

The research process was initiated by a field visit to Greenville Hospital which was followed by a focus group with three PPASA health promoters based in Mt. Ayliff, and the Bambisanani Co-ordinator. Key issues relating to community response to HIV/AIDS were explored with a view to identifying focal issues for the study.

Together with this group, nine areas were identified where focus groups would be conducted. It was deemed important to target deep rural areas, 'upper deep' rural areas (i.e. 'deep' but closer to transport routes), as well as urban areas. The spread of groups and locations was done so as to include Bizana, Lusikisiki and Umzimkulu areas. It was also decided, arising from the focus group, that health workers in an inpatient medical facility and a day clinic, PWAs, traditional healers, church home visitors, out of school youth, school going youth, and community members at home during the day should be targeted. The methodology for the focus groups was discussed and a basic training in the conduct of focus groups was conducted with the PPASA field workers.

Following this, a focus group protocol was constructed to address particular questions of relevance to each group (see Appendix 2).

2. Focus groups

Nine focus groups were conducted, with a total of 90 respondents in the following categories: adult community members in deep rural areas and upper deep rural areas; out of school youth; school going youth; traditional healers; church members involved in home visiting; PWAs; health workers in a rural outpatient clinic and a rural inpatient facility. See Appendix 2 for details of areas covered and Appendix 3 for a map of the areas covered.

Focus groups were conducted by PPASA staff, working in pairs. These were tape-recorded, translated and transcribed. A thematic analysis was conducted, to identify key issues of relevance to the Bambisanani Project. These were, in the first instance, analysed to inform the development of questionnaires. After the questionnaire stage of the research, the focus group transcripts were more closely analysed, for purposes of constructing this report.

3. Construction of three questionnaires

The questionnaires were constructed with a view to quantifying issues which emerged as important in the focus group analysis. The development of questionnaires was also led by previous experience in conducting behavioural surveillance studies and other research in the area, including standard protocols for behavioural surveillance. The questionnaires were phrased in Xhosa.

During this process the researchers again met with the Bambisanani Co-ordinator, PPASA staff based in Mt Ayliff and a representative of the Regional Education Office based in Kokstad. A sampling methodology was jointly worked out, based on sampling three age groups from three different communities and related primary and high schools.

Different questionnaires had to be constructed for each group with due caution paid to ethical issues. Children's questionnaire formats focussed largely on their orientation to, and understanding of, HIV/AIDS and people with HIV/AIDS (PWAs). Youth questionnaires included many of the same questions but were longer and included questions on sexual behaviour and HIV prevention practices. Adult questionnaires were less probing on sexuality and more probing on care and support issues. It was planned that administration should take 30-45 minutes.

4. Administration of questionnaires

See Appendix 3 for map of areas covered in survey.

Prior to the survey, the researchers went through all the questionnaires and were trained in sampling and questionnaire administration procedures. In communities, a random sample method was used with each of the 7 researchers walking down a section of road and selecting every second house. The sections of road were selected to obtain a geographic spread across the particular township area from which the two schools draw students. The housing types were fairly consistent in each community and there was no need to quota sample for housing type. Each researcher was instructed to approach the household looking for one of the following: male 25-45 years; female 25-45 years; male 45 + years; female 45 + years. The first person available who fitted the sought after category was selected for the study. If no one was available in that category someone from the next category was selected. In the next household a person from the following category was selected and so on until the required 40 respondents had been obtained. When the full quota in a particular category was not obtained using this method (for instance younger men tended to be out of the home) the category was 'topped up' through locating a person from this category away from the household (for instance on the roadside or in the fields) ensuring that they did not represent one of the already sampled households. In each instance, respondents were read a letter requesting participation, explaining the purpose of the survey and describing conditions of anonymity and confidentiality. On completion of the interview they were thanked and given a red ribbon badge.

Attempts had been made to contact each of the schools district and sub-district offices, but in three of the six cases, messages had not been received. However, principals and teachers were willing to accommodate the researchers at short notice and this was greatly assisted by the presence of a representative of the Regional Education Office. The school-based questionnaires were completed in a group setting and were self-completed. In each of the three primary schools a random sample of 40 students in grade 6 was sought. The researchers explained the purpose of the questionnaire and provided the students with pens. Students were carefully shown how to fill in the questionnaire. They were led through the questionnaire on a question-by-question basis, and students were encouraged to ask questions should they be unclear about a particular question. At the end of the procedure, respondents and teachers were thanked and provided with red ribbon badges. A similar procedure was followed in the three high schools.

The following table shows the numbers and ages of respondents in each category.

AGE OF SURVEY RESPONDENTS												
	Children				Youth				Adult			
	Male		Female		Male		Female		Male		Female	
	Ave.	Inter-quartile range	Ave.	Inter-quartile range	Ave.	Inter-quartile range	Ave.	Inter-quartile range	Ave.	Inter-quartile range	Ave.	Inter-quartile range
Bizana	13.6	13-15	12.9	11-14	19.3	18-20	18.3	18-19	35.4	25-43	45.2	32-53
Lusikisiki	13.0	13-15	12.0	11-13	17.4	17-18	16.9	16-18	37.3	25-39	40.3	32-45
Umzimkulu	13.2	13-14	11.7	11-13	19.3	18-20	18.9	17-20	44.6	34-51	46.0	32-59
All	13.3	12-14	12.2	11-13	18.7	17-20	18.0	17-19	39.2	26-45	44.3	32-58
N = 345	n=55		n=59		n=59		n=62		n=55		n=55	
	n=114				n=121				n=110			

5. Contextual data gathering

On-the-spot interviews were conducted with teachers, students and health workers during the scoping and survey phases of the research. The purpose of this was to deepen understanding of the contextual features of the different communities and schools, which assisted in interpreting data. For instance, it was important to understand some of the issues around life-skills education in schools, and the infrastructural features of these environments.

6. Analysis of data

Questionnaire data was captured on Statistica software and analysed using basic descriptive statistics.

7. Limitations of the study

Much has been said about the reliability of self-report questionnaires, and the balance in recent literature tends towards the conclusion that self-reporting is an acceptable means of access to people's experience. There are possible problem areas and in such research one needs to be very careful that people do not respond according to what they anticipate desirable responses to be. Also, given the private and confidential nature of this research and the fact that it concerns the weighty issue of HIV/AIDS, we can expect that people might tend to answer in ways designed to avoid anxiety or embarrassment. However, by obtaining different types of data one is able to corroborate or reformulate emerging findings by checking different sources against each other. In compiling this research a composite picture has been developed by looking for contradictions between data sources, and by focusing on the more strongly supported trends.

Although the study fulfils its primary objectives, there is another level of understanding which is important – that of looking more closely at the context of community response to HIV/AIDS from the perspective of community and infra-structural level indicators. For instance, whilst this study looks at condom availability and HIV counselling and testing services from the perspective of the experiences of members of these communities, it would have enhanced the study to have conducted

an audit of testing and counselling services available, availability of support and care services, lines of communication and patterns of referral, prevention programmes, organisations working in the area, community programmes, and so on. As will be seen in this report, community response is significantly determined by aspects of the surrounding context, for instance, the health service delivery and infrastructural contexts. Whilst individual responses in the areas of prevention, care and support such as are measured in this study are important, development programmes also need to monitor and evaluate aspects of the surrounding context, which is where the determinants of public response are laid down.

4. SOCIO-DEMOGRAPHIC CONTEXT

The three communities researched fall within Region E of the Eastern Cape which is the northern part of the former Transkei area. This is one of the poorest areas of South Africa and is predominantly rural with only 2% of the population living in urban settings.

The largest town in the area of the project are Umzimkulu, Lusikisiki and Bizana. However, the larger part of the area consists of a network of many small villages connected by a few arterial routes and a maze of gravel roads and dirt tracks. There is a strong trend towards villagisation with most of the population clustered in constellations of households, usually with some form of locally owned retail outlet. In more densely populated areas fixed clinics and schools are found. There are generally no village halls or 'centres' and the layout of the villages, except in the three commercial centres, is not organised around a central hub of activity. There are also numerous outlying areas where there has been little villagisation, with households, usually consisting of a cluster of small one or two roomed dwellings, scattered through the countryside and often without road access.

Although some households have food gardens, there is very little crop agriculture in evidence as one travels through the area. There was a net population loss of 206 000 in the Eastern Cape between 1992 and 1996, which is partly a consequence of depopulation of rural areas and migrancy to cities for the purpose of work seeking (NPU, 2000). This trend is evident in much arable and terraced land lying fallow, reflecting a process of de-agrarianisation (move away from farming-based livelihood). In more remote areas there are also abandoned homesteads, possibly reflecting the same trend. There is also little evidence of livestock farming on a commercial scale, although small scale herding is evident in some areas.

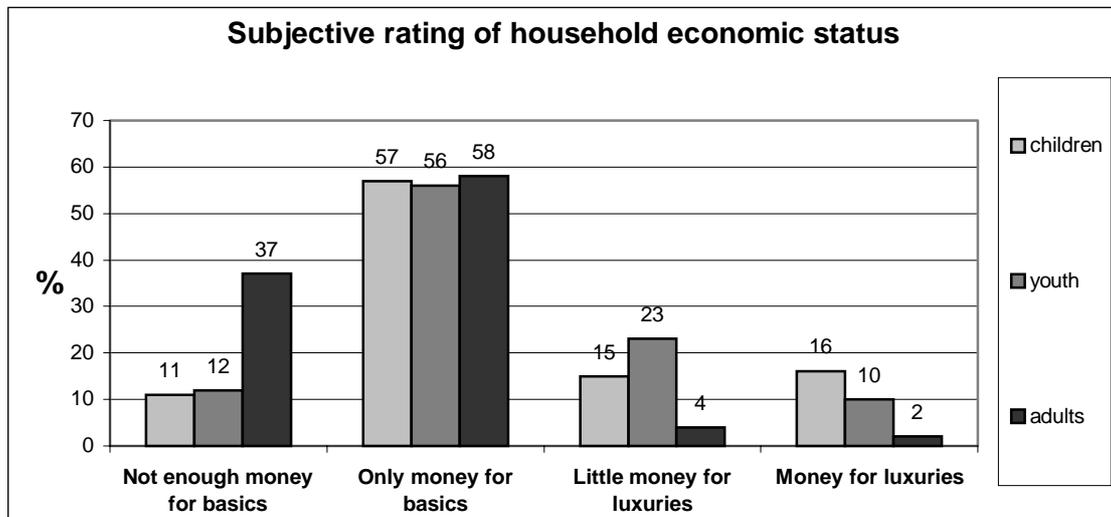
There are few opportunities for employment in the rural areas or the former Transkei area, although there are some timber and sugar plantations in the vicinity and commercial activities in the towns. The predominant trend is for people to seek work elsewhere and this means high levels of migrancy. The area has been one of the main recruitment areas for the mines and for seasonal sugar plantation labour. The area borders on KwaZulu-Natal which, together with Gauteng, is seen as a potential place of employment.

Piped water and electricity are rare in the more remote areas, as are telephones (see below). Community members were generally of the view that not much is changing in their material circumstances, and if things are changing, they are perceived as changing very slowly. However, in the sites visited, there were a number of signs of development evident even in some of the more remote areas, including the provision of electricity, building of classrooms and the upgrading of rural roads.

The research was conducted in a total of thirteen different localities (see map Appendix 3). As can be seen some of these areas are deep rural areas and some are located closer to towns. Proximity to a town is generally an important socio-economic mediator. The further from a main centre the less likely people are to have electricity and water and the more likely they are to have poor access to health and education facilities.

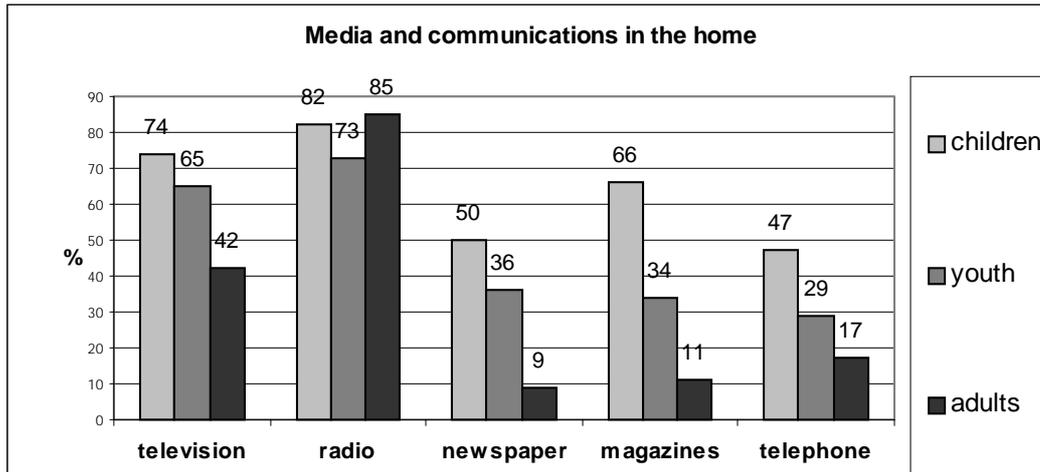
There is an extensive system of mobile clinics in more remote areas, and fixed clinics in larger communities, and the routes to hospitals appear to be quite well serviced by taxi operators.

The following graphs provide a further understanding of the socio-demographic context.



The full descriptions of the above categories are: 'Not even enough money for basic things like food and clothes'; 'Money for food and clothes, but short on many other things'; 'Most of the important things, but few luxury goods'; 'Some money for extra things such as going away for holidays and luxury goods'. The majority of respondents rate their household circumstances as falling within the second category. Interestingly there is a divergence between the ratings of children, youth and adults in the first category (poorest category) with significantly more adults rating their circumstances as falling within this category as compared to children and youth. This may reflect that children and youth are less aware than older people of the household economic realities, but it could also reflect different households. The adults polled in the community survey were adults at home on a week-day, and thus are mostly unemployed (only 19% of the respondents are working for a salary (full-time or part time)). Thirty seven percent reported 'not even enough money for basic things like food and clothes' as compared to 11% of children and 12% of youth. , Another explanation for the different ratings of adults, youth and children is that primary and high school children may represent households with working parents which would not have been picked up in the household survey as there was no-one at home during the day. These salaried households would not be represented in the adult survey, suggesting that the 37% in the 'not enough money for basics' represents an over-sampling of the poorest households.

The general picture of the communities surveyed is one of very poor but not destitute communities. Houses are of mixed construction, but mostly permanent small one or two roomed structures clustered together in groups of 2 or more, usually housing an extended family.



The above graph provides further evidence that the samples of children, youth and adults may refer to different sub-populations. However, there are other possible confounders and children, youth and adults may interpret presence of a media form differently; for example, children may say that there is a newspaper presence at home, because of an occasional newspaper, but adults in the same home might not regard this occasional newspaper as significant. In all media categories, except radio, the children sample is highest, followed by youths, then adults. It can safely be said that most households have access to mass media of some sort with radio being the most prevalent media/communication form in all groups, followed by television, then magazine, newspapers and telephones.

Of the six schools visited all are poorly equipped with no electrical equipment. There is gross over-crowding with as many as 90 students in one classroom. All are without lights in classrooms and most are without running water.

5. Risk and prevention

5.1 Understanding of HIV/AIDS

5.1.1 Direct exposure to HIV/AIDS

The following tables provide an indication of the extent to which community members have been directly exposed to HIV/AIDS.

Perceived prevalence of HIV/AIDS in the community %									
	Children			Youth			Adults		
	Yes	No	Not Sure	Yes	No	Not Sure	Yes	No	Not Sure
Do you have a relative who you think is sick with AIDS?	10	45	45	9	43	48	10	61	29
Do you have a relative who you think may have died of AIDS?	22	54	24	29	56	16	21	63	16
Do you have a friend who is HIV+, sick or dead from AIDS?	12	60	28	12	62	26	13	65	23
Is there anyone in your household who is said to have died of AIDS?	7	93	X	16	84	X	14	86	X
Are there any children in your community who have lost both parents because of long unexplained illnesses or AIDS?							42	32	25

Prevalence of chronic illness		
	Adult %	
	Yes	No
Is there anyone in your household who has been too sick to work or perform their normal duties for at least three months over the last year?	30	70

Ages of sick people (35 cases reported)
4; 18; 19; 20; 20; 24; 24; 26; 28; 28; 29; 30; 30; 30; 30; 31; 31; 31; 32; 38; 39; 44; 45; 46; 48; 50; 50; 55; 63; 65; 67; 75; 80; 86; 92
<ul style="list-style-type: none"> • 30% of households with chronic illness in last year • 86 % of sick 65 years or younger • 77% of sick 50 years or younger • 43% of sick 30 years or younger • 14% of sick 20 years or younger • 34% of sick fall within the 20-30 year age range

The following are some of the key points from the above:

- Reporting someone in the **household** who is said to have died of AIDS: children 7%; youth 16%; adult 14%.
- Reporting a **relative** who is **sick** with AIDS: children 10%; youth 9%; adults 10%.
- Reporting a **relative** who they think may have died of AIDS: children 22%; youth 29%; adults 21%.
- Reporting a **friend** who is HIV+, sick or dead from AIDS: children 12%; youth 12%; adults 13%.
- Reporting children in their community who have **lost both parents** through a long unexplained illness of AIDS: 42% of adults.
- Adults reporting someone in the **household** who has been too **sick** to work or perform their normal duties for at least three months over the last year: 30 %, with 43% of these being 30 years old or younger.

The above provides evidence that AIDS illness and death are a concrete reality in these communities. These figures suggest that the impact of AIDS at a personal and familial level is high. Furthermore, in all three communities there were reports of families where both parents have died, and where grandmothers are looking after children.

The levels of respondents answering 'not sure' in the first table above is consistent with high levels of uncertainty about the causes of chronic illness and unexplained death. AIDS is sometimes referred to as "the disease with no name". The following excerpt from a focus group illustrates:

Interviewer: *What is the community's reaction to those people who had disclosed their HIV status? What is your reaction as a community here?*

Response: *Well let me talk about myself. For example if they have AIDS then nobody will come out and say that they have AIDS, myself included. Its only after I have died that people will say things like we knew that they had AIDS because he had the same symptoms that so and so had. So ...it's families that are the problem because they do not disclose the illness. And therefore it's difficult for us to do anything about it.*

Even at funerals where the community may strongly suspect that a person has died of AIDS, it is usually not acknowledged as the cause of death. Oddly, when there has been open disclosure of HIV/AIDS (see box below) it has been met with sympathy and support by the community rather than derision. There is an expectation of shame, and this is all the more powerful for older people who feel embarrassed to have been affected by a sexually transmitted illness.

Interviewer: *Can we now look at AIDS specifically? You know in your community here, have there been people who have been identified as having HIV/AIDS? Perhaps at a funeral or just generally?*

Response: *No, no they've never said this. Not directly. We always have to assume that this is the case.*

Response: *Well there has been one case. You know a person who was diagnosed with AIDS and when they came home they told the family directly that they have AIDS. And at the funeral you know it was said that this is a first. We've never actually heard of someone admitting, or the family admitting, that someone has AIDS. You know people were very impressed with, you know, the honesty, the patient's honesty and the honesty of the family instead of the lies that are usually told by families about Idliso and other such things.*

(Adult community members rural area near Bizana)

The problem of not acknowledging AIDS for what it is, begins with diagnosis, and it is not a surprising phenomenon, given the lack of a supporting context around diagnosis. More is said of this in the section on testing, counselling and disclosure. The disease has been shrouded by secrecy and to the extent that a youth from a deep rural area near Lusikisiki can say: "We often hear of people having died of AIDS but we don't actually see them." AIDS is strongly present in these communities but its reality is hidden in corners 'under blankets', behind the walls of houses. Any attempts at mobilising support and care in this context need to begin by "calling it by its name". This is not a matter of simple agreement within communities to do this, as there are many reasons, ranging from the mass media to the availability of services and treatment, that militate against calling it by its name. Clearly HIV/AIDS is a disease process that carries meanings far beyond its physical effects on people and those around them, and this meaning negatively impacts on the tendency to disclosure and hence to be aware of its presence.

5.1.2 Exposure to HIV/AIDS information

Where have heard or seen information about AIDS in the last month?						
() = rank of prominence all media above 50%						
	Children		Youth		Adults	
Television	(2)	73	(5)	64		44
Radio	(1)	82	(1)	78	(1)	82
Newspapers		48	(6)	61		17
Magazines	(5)	55	(7)	57		12
Road signs		11	(8)	53		20
Posters		47	(9)	50		18
Leaflets	(4)	57	(7)	57		8
Painted walls		49		41		7
Meetings		43		26		16
Plays		31		42		0
Parent		49	(2)	72		5
Doctor		7		25		13
Teacher		24	(4)	65		10
Health educator		43		37		28
Nurse		36	(3)	68		43
Priest/minister		23	(6)	63		18
Relative		19		25		18
Friend	(3)	61	(3)	68		39
Work		28		0		3
Peer educator		35		43		4
Other		32		4		3

HIV/AIDS information has been disseminated to Bambisanani communities through a wide range of media and communication forms. Note that youth are exposed and attentive to, the widest range of communication forms, and adults the least.

Radio, across all three categories of respondents, is the medium which seems to have most successfully delivered HIV/AIDS information to these communities. Amongst adults, radio has been a particularly important medium of information dissemination.

Television has played the second biggest role in disseminating HIV/AIDS information for children, and it is amongst a range of different communication channels falling

within the 60-70% band, although ranking only fifth. Although television ranks second for adults, it was seen as a source of HIV/AIDS information in the past month by only 44% of adult respondents.

It is also notable that parents are ranked the second highest source of information amongst youth. In the tables below it can be seen that 70 % of children and 82 % of youth have been 'warned' by their parents about AIDS, although discussion about the sexual context of AIDS is limited. We might conclude that parents need to be thought of as being concerned about the risks of HIV/AIDS to their children and not simply negligent in this respect, as is often assumed. This concern of parents needs to be harnessed, especially since it appears that it does not translate into community level mobilisation around HIV/AIDS education, or cultural level response to the problem. The following tables illustrate.

	Children %		Youth %	
	Yes	No	Yes	No
Have your parents warned you about AIDS?	70	30	82	18

	Children %		Youth %	
	True/ Mostly true	Mostly not true/ Not true	True/ Mostly true	Mostly not true/ Not true
Sex was not discussed with my parents.	42	57	63	38

	Youth %			Adults %		
	Not at all	A little	Quite a lot/ Very much	Not at all	A little	Quite a lot/ Very much
I can discuss AIDS with at least one member of my family.	43	35	23	30	22	48

It can be seen in the last table above that most youth and adult respondents are able to discuss AIDS with at least one member of their family. Thus, AIDS is not, as is often assumed, a completely taboo subject in most families, at least to the extent that there is at least one person with whom the topic can be discussed. This is especially true for adults.

	Children %			Youth %			Adults %		
	Not at all	A little	Quite a lot/ Very much	Not at all	A little	Quite a lot/ Very much	Not at all	A little	Quite a lot/ Very much
Have you discussed AIDS with your friends?	52	31	17	11	36	53	31	30	40

	Youth %			Adults %		
	Yes	No	Not applicable	Yes	No	Not applicable
Have you discussed the risk of AIDS with your boyfriend, girlfriend or partner?	56	33	12	53	40	7

Fifty three percent of youth, 40% of adults and 17% of children have discussed AIDS with friends 'quite a lot' or 'very much'. Eleven percent of youth, 31% of adults and 52% of children have not discussed AIDS with friends at all. Eighty nine percent of youth, 70% of adults and 48% of children have discussed AIDS with friends at least 'a little'. Clearly children are notably less likely to have discussed AIDS with friends, with the majority of children not having discussed AIDS with friends at all. This is relevant as many of these children (female ave. age is 12.2 years and male ave. age is 13.3 years) will have experimented with sexual activities already, and certainly many will be sexually active within two years. There is clearly a need to promote concern about AIDS within the domain of peer communication, where risk reduction practices will ultimately have to be negotiated.

Compared to the levels of discussion of AIDS with friends, it is notable that for both youth and adults, there are lower levels of having discussed the risk of AIDS with boyfriends, girlfriends or partners. More is said about this in relation to condom use, but it suggests that general discussion has not necessarily translated into discussion of personal susceptibility and consequence in the context of relationships. This is consistent with a number of other findings of the report which suggest that the presence of AIDS does not always translate into a matter of personal and interpersonal significance. However, we should not underplay the fact that the majority of youth and adults have discussed AIDS with partners. The way that this question was asked does not control for the nature and content of the discussion, and we don't know that such discussions have been about the significance of AIDS in the context of the relationship. But it can safely be assumed that the subject is not taboo and this provides opening for development of more personally significant discussion, and especially discussion which leads to action. (As an aside, it is often assumed that rural people are reluctant to discuss issues relating to sex, but in focus groups we had very open and explicit discussion around sexual topics, even in mixed gender groups. Far from being a taboo subject, sex was discussed with little anxiety or shyness.)

Returning to the first table in this section it can be seen that teachers, priests and health workers have disseminated information, but there is little contextual evidence that this occurs in anything other than an erratic fashion, and there is certainly a lack of strategic planning and programmes at this level. The following box summarises.

Interviewer: *I am wondering what kind of information you've heard about regarding AIDS.*

Respondent: *I suppose we often do hear snippets of information here and there regarding AIDS but I think what we need is something consolidated, something that we can hold onto and something that will give us proper knowledge about the disease.*

It is particularly troubling that in schools, where it is arguably easiest to address AIDS, at least from the perspective of having a captive audience, there is little indication of systematic education. Given the practical difficulties involved in gathering people together in these largely remote areas, schools would seem to be the obvious place to locate sexual health education efforts. It is thus of concern, considering the tables below, that 83% of children (average age 12.5 years) report that AIDS has been discussed in class either 'not at all' or only 'a little'. This is consistent with much evidence to suggest that children have been least exposed to AIDS education messages of all three groups. Amongst youth only 71% report that a health educator or nurse has ever visited the school to talk about AIDS. This varies across sites with Bizana showing a much lower positive response to this question. Even in Lusikisiki, where there was highest response to this question, there has not been a visit by health educators for more than two years. In primary schools there was no evidence of such visits having occurred. In high schools visited, these visits

are not programmed into any of the school years and occur erratically. Furthermore, it appears that these programmes are largely based on the initiative of the NGOs or health services which offer this kind of education. There appears to be little system in place anywhere, which even aims to cover all learners in all schools. It should be noted that there are educators in these schools which take it upon themselves to talk about AIDS and who are even sometimes quite committed to dealing with HIV/AIDS in the classroom. But their efforts are individual ones, rather than part of a systemic response and they are limited to the learners in their classes.

Children %			
	Not at all	A little	Quite a lot/ Very much
If you are at school has AIDS been discussed in class or lectures	56	27	18

Youth %		
Has a health educator or nurse ever visited your school to talk about AIDS?		
	Yes	No
Bizana	55	45
Lusikisiki	81	19
Umzimkulu	78	22
Total	71	29

However, even if there were to be regular visits by health educators to the schools, this does not constitute the type of school based interventions that are generally considered to be adequate practice in the field. There was no evidence of systematic life-skills training in any of the six schools visited, although, again, there are some high school teachers who are strongly interested in this aspect of education. According to one principal, life-skills education is not given priority given the challenges of trying to deliver satisfactory standards in teaching the 18 subjects that are taught at the school. Teachers interviewed showed that there are obstacles to life-skills education within the school setting. Many of these are of a relatively local nature including tensions between staff members, arising from perceptions that life-skills training involves less of a burden in terms of teaching-load. It is also a consequence of educators seeing life-skills education as an 'add-on' rather than an intrinsic feature of education.

It is notable that in the Eastern Cape 4 800 teachers were trained in life-skills education two years ago, and there has to date been no follow-up in terms of developing training, monitoring activity, or promoting the activities in which they have been trained. It would seem that there is a strong need to interact with health and education systems towards building accountability of the education system to delivering on the mandate to provide HIV/AIDS education and the related life-skills training within the context of school education systems.

With adults there is the problem of AIDS information dissemination which is made difficult by the problem of gathering people together. There are often not venues in rural areas for people to meet. Discussion of this issue in one focus group went as follows:

Respondent: *I think what would work out best would be if there could be a certain hour, say during the lunch hour when the nurses are away for lunch, then you could come with your AIDS.*

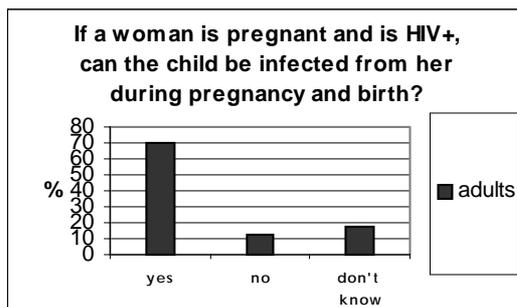
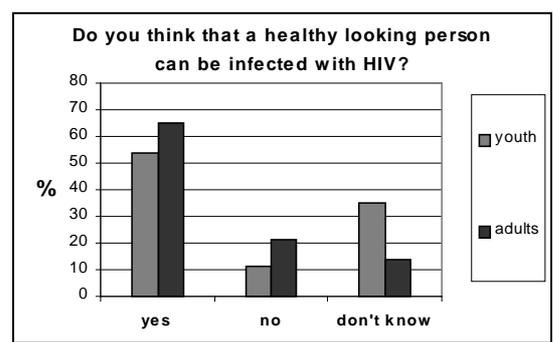
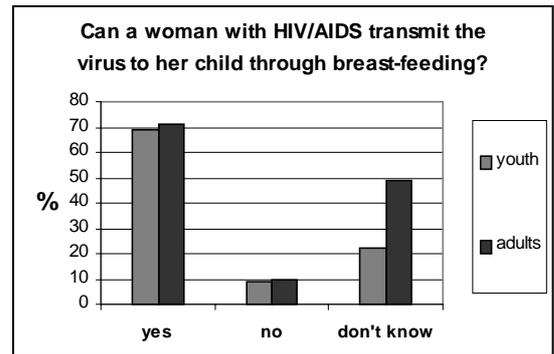
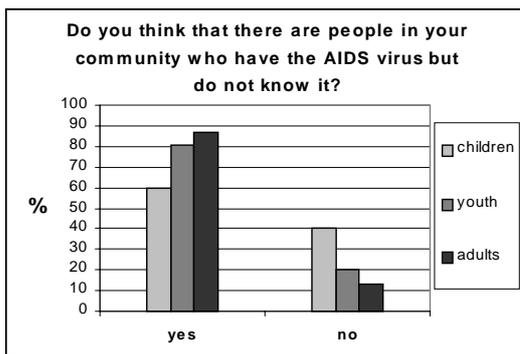
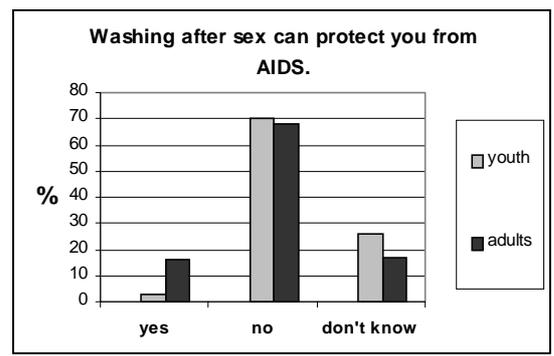
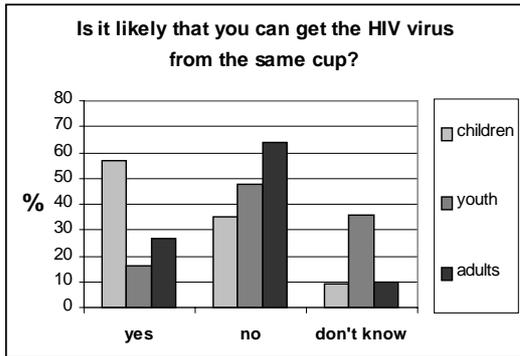
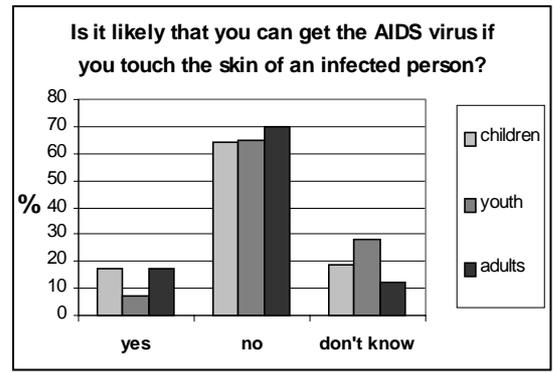
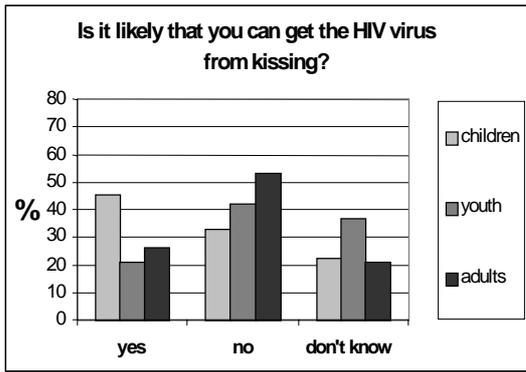
Interviewer: *It's your AIDS too!*

Respondent: *No, no, no I was saying that because you are educated and have all the knowledge about AIDS and things like that, you could then come and ask the people not to leave so that you could address them.*

In rural areas especially, this raises the critical issue of how to mobilise communities where there are difficulties associated with physically bringing people together. Only 27% of adults reported that they have attended a meeting in their community where HIV/AIDS was discussed. To this point in time it has largely been mass media that has shaped community responses, together with a public service environment which has had a negative impact on community response (this issue is discussed more fully later). The sum total of influences has not led to anything near adequate community mobilisation around HIV/AIDS issues, and later in this report some avenues for more effective community mobilisation and organisation around prevention, support and care are discussed.

We now turn to examine the net effects of information dissemination in the form of what people know or don't know about HIV/AIDS.

5.1.3 Knowledge about HIV/AIDS



It is often said that general knowledge about methods of transmission of HIV are satisfactory in South Africa, but there are definite areas of knowledge inadequacy in these communities. Areas where there are elevated levels of 'don't know' responses and incorrect responses need to be focussed on.

Whereas knowledge that HIV is mainly sexually transmitted is pervasive, the need for knowledge does not only relate to prevention issues, but is part of the context for creating a caring environment. Some of the areas of knowledge inadequacy are likely to impact on the experience of those living with HIV/AIDS, given, for example, that upwards of 30% of the public are uncertain as to whether the virus can be transmitted through touch, and around 50% are uncertain about whether it can be transmitted by sharing a cup. The consequence is evident in the experiences of some PWAs, who reported that their families are sometimes hesitant to eat food prepared by them, and who also say that they take offence to being handled by health workers with surgical gloves in cases where this is not necessary.

Knowledge of children (average age 12.5 years) is notably poorer than that of youth and adults. For example, 57% of children believe that one can get the HIV virus from using the same cup, but only 16% of youth believe this and 27 % of adults. Children's knowledge is also weak on the risk of sharing the same cup with a person who is HIV infected, and on the possibility of people being HIV infected without knowing it. Below it can be seen that most children have heard of HIV and AIDS, but only 41% know that it can be prevented.

Children %		
	Yes	No
Have you ever heard of HIV or the disease called AIDS?	93	7
Can HIV/AIDS be prevented?	41	59

In focus groups it emerged that witchcraft is often used to explain invisible causes of illness, so where there is no obvious cause, witchcraft is sometimes used as an explanation. However, this should not be overstated since only 13 % of surveyed adults thought that AIDS could be caused by witchcraft and only 9% of youth thought the same. Thus, although this explanation is often mentioned, particularly by deep rural people, a bio-medical explanatory model tends to prevail.

Amongst older members of communities, as was seen in the Mhlanga-Taweni focus group (deep rural area near Lusikisiki), understanding of causative factors leading to illness shows a strongly environmental model of explanation. For instance poor drinking water and chemical pollutants in factories are seen as leading to TB. The concept of an invisible or imperceptible germ is apparently not easily accepted. It follows that explanation of the causes of AIDS need to be brought across in a way that first establishes the existence of germs.

There is a strong perception of an association between 'place' and HIV/AIDS, with a prevalent assumption that AIDS comes from cities, as does TB. Whilst epidemiologically this might not be altogether incorrect, the belief poses risks as it seems to be associated with a belief that HIV transmission tends not to occur when there is no migrancy, and this leads to a reduced estimate of risk and consequently of prevention behaviour between rural partners. It is relevant to mention Lurie's (2000) research in a rural area of KZN, which showed a significantly higher prevalence of HIV seropositivity amongst rural women than amongst their migrant partners.

There is a tendency to believe, particularly in rural areas, that it is mainly young girls who are affected by HIV/AIDS. Evidence for the truth of this belief was provided during a visit to Greenville hospital where there were more than four times more women than men 'AIDS patients' hospitalised at the time.

There seems to be quite good recognition of the symptoms of AIDS, with diarrhoea, incontinence, stomach ache, fever blisters, swollen glands, persistent headaches, loss of weight, weakness, coughing, TB like symptoms, shortness of breath, poor quality hair, gaunt faces, sweating, hot flushes and confusion being listed by members of lay focus groups, as symptoms associated with AIDS. AIDS is well known by adults as a disease syndrome, even in deep rural areas. But it is also referred to as "The disease which we don't call by its name".

The following extract is from a discussion about common illnesses, amongst adults from an 'upper deep' rural area near Bizana:

"There is something else I want to go back to. We (the group) mentioned, you know, the illness I was referring to in fact, where one will have diarrhoea and ultimately his mind will be affected. And then again the person will develop sores and then when you take them to the doctor and perhaps to the hospital they will only spend two or three days there and then they will be discharged. You may take them to another different hospital now and the same thing will happen. I have seen a lot of cases like this and I must tell you that they have all died. And sometimes it affects small children, babies in fact, right after they've been born. What happens is the baby gets sick and dies, and very soon after, the mother also gets sick and dies."

Interestingly, the speaker is referring back to an earlier part of the conversation where she had discussed what she understood to be AIDS, but hadn't at the time called it this. This is commonplace, that AIDS can be spoken about, or people as individual's might understand that AIDS is being referred to, but it is not named as such. This refusal to socially recognise what is already recognised at the individual level appears to be an important social mechanism for holding at bay social phenomena which communities are unable to deal with. Later it is suggested that a prime cause of this dynamic is the apparent lack of capacity to treat or assist in dealing with AIDS.

One of the ways of achieving this denial is through attributing AIDS to *Idliso* (and *Impundulu*), which means a form of harm inflicted externally by ill-wishers and/or witchcraft. It is not uncommon for people to say that their symptoms are a result of bewitchment, throughout AIDS illness until death. This appears to be used as a way of avoiding recognition of being affected by HIV/AIDS; that is, it is a way of accounting for otherwise inexplicable symptoms. This is discussed elsewhere in the report and it should be pointed out that *Idliso* is recognised in South Africa as a widely used way of skirting acknowledgement of HIV/AIDS, sometimes even after an HIV positive diagnosis (cf. Ashworth, 2001). But if data presented above is to be believed, that AIDS is perceived as caused by witchcraft by very few only, this explanation cannot be based on 'knowledge'. Rather, it is a consequence of the difficulties which people have in admitting to a condition which has been constructed in an extremely negative light, with little hope for the possibility of treatment or support.

Another finding worth noting is that adults have a much better appreciation of the symptoms of AIDS than youth do, and are much more aware of how AIDS manifests as an illness. Youth were not as able to describe the symptoms of AIDS, although they were well versed in prevention aspects of HIV/AIDS. Prominent amongst their

answered questions that youth listed, were questions about how AIDS manifests itself, “what it looks like” and “how you recognise it”. Youth speak of wanting to “see AIDS”, but there is very little media which has addressed aspects of AIDS illness and care. This is illustrated by the following:

Interviewer: *Would you say AIDS is a disease that really kills and is a dangerous disease or is it just something that you hear of and you don't believe that it is dangerous?*

Respondent: *No I do believe that it is a dangerous disease and that it really kills people, but what I do not know is how it manifests itself.*

(youth respondent)

HIV/AIDS communication in general has been overwhelmingly about prevention and especially about condom use. This is true for all three age categories in this study, although adults show a much better understanding of symptomatology due to greater direct exposure to illness. The impact of this is that the illness aspects of AIDS have not been sufficiently stressed leading to a sense of distance from the realities of illness and suffering that AIDS involves.

There seems to be little media delivered in Xhosa, and there is a need for this, as many members of these communities have only a poor capacity to read English. This was also an explicitly stated need in focus groups. Most of the AIDS posters and billboards displayed in the area and which are designed to alert people to HIV/AIDS are in English, and given that English is a seldom spoken language for the majority of the population, this is quite inappropriate. Furthermore, some of the most prominent signage in the form of ‘Love Life’ billboards proved to be quite incomprehensible to the youth spoken to. But it is rural adults in particular who feel that there is a dearth of information available for them, and particularly information about aspects of care.

Myths

Interviewer: *Are there instances where people are said to get AIDS through perhaps witchcraft?*

Response: *Ja, I once heard over the radio that there is, you know, a tablet that people are given, that causes AIDS. I've also heard that doctors and even Mister Stofile, they do cause AIDS. So you never know who to trust because you can turn to a doctor for a headache and then he will infect you with AIDS.*

Response: *Then I heard that some people infect others with HIV through oranges. We don't know how true that is. You know I once bought a pocket of oranges in Durban and they were very cheap. I got the pocket for R1 but when we got home you know and peeled the oranges we found that there were sort of red specks inside the oranges. We weren't sure what the dots were but they were blood-like in colour and we ended up throwing the oranges away. We were very worried because we had eaten some of the oranges before we had noticed the red specks. I had heard about this practice, but I don't think I really believed it until I saw the oranges for myself.*

At this point there was a chorus of “*You were infected!*”. But it was said with good-natured laughter, much as a joke would be shared.

(Focus group with adult community members near Bizana)

Such stories abound, but it is seldom clear whether or not people actually believe them. There are beliefs that the lubricant on condoms are what cause AIDS, or that health workers are secretly injecting people with AIDS and that government ministers are involved in this, and a range of other such stories which were encountered in the course of the research. Belief in such stories is fuelled by uncertainty and inadequate knowledge. These myths can be understood as attempts, using existing conceptual tools and frameworks, to make sense of an illness which, in many respects, has been difficult to understand and respond to constructively.

5.2 Perception of and response to risk

Worry about HIV infection									
	Children %			Youth %			Adults %		
	Not at all	A little	Quite a lot/ Very much	Not at all	A little	Quite a lot/ Very much	Not at all	A little	Quite a lot/ Very much
Have you worried before that you might have the HIV germ?	54	28	18	52	34	15	45	18	37

There is a surprisingly high percentage of children who have worried before that they might be infected by HIV. It should be remembered that many of these 'children' would already have had sexual experiences (see section 5.5) and their anxieties would be based on this, and probably on misperceptions about non-sexual means of transmission, which have already been discussed.

Also notable in the above table is that 49% of youth and 55% of adults report having worried about being HIV infected, at least 'a little', and 52% of youth and 45% of adults report not having worried at all about being infected. These figures might be interpreted as encouraging as it should not be expected that all people are exposed to risk, because, as is shown elsewhere there are those who are not sexually active, those that consistently use condoms and those that are in mutually faithful relationships. We can safely conclude that the majority of sexually active people have had at least some worry about being HIV infected. Thus, in terms of the health belief model, they have considered themselves at some point as vulnerable and susceptible, which may be thought of as a step towards prevention. However, whilst there is a general perception of vulnerability, personal vulnerability is often underestimated. In particular the belief that HIV comes from 'elsewhere' means an underestimation of risk of 'local' infection. In the words of a youth from a deep rural site in the Lusikisiki area: "If you come from somewhere around the Eastern Cape then I don't think that there is a problem because we don't have a lot of AIDS in this area, but once you go beyond this province to other places that is when the problems starts. That is how we from this area view the whole situation."

We now turn to consider the extent to which perceived levels of vulnerability have translated into behaviour change.

Self-reported behaviour change (unspecified)						
	Youth %			Adults %		
	Yes	No	Not applicable	Yes	No	Not applicable
Have you changed your sexual behaviour because of AIDS, even a little?	77	7	17	57	19	23

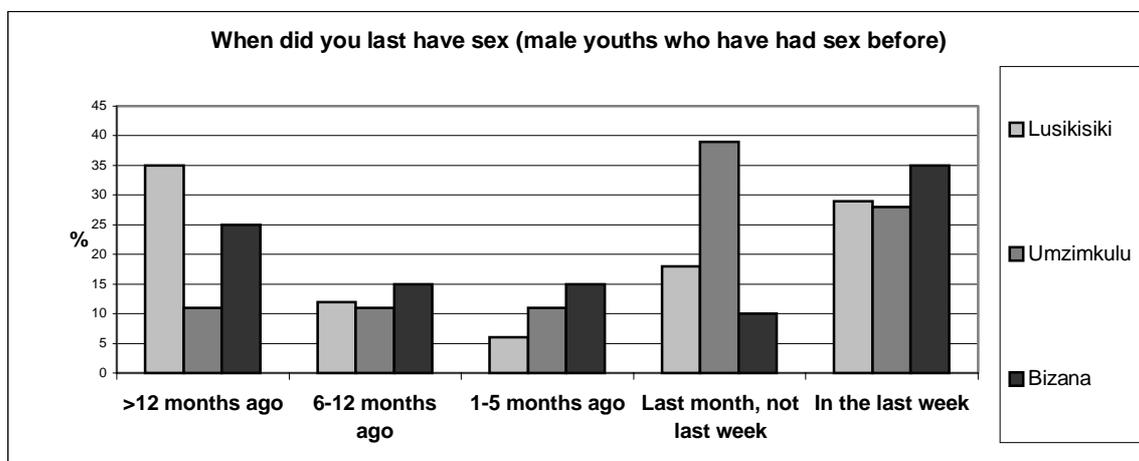
Fifty seven percent of adults and 77% of youth report that they have changed aspects of their behaviour to prevent the risk of HIV infection. Elsewhere in the report, specific responses in a number of areas of risk are explored, ranging from condom use to abstinence. Responses vary and assessment of levels of prevention behaviour is made complex by the range of prevention responses that are employed,

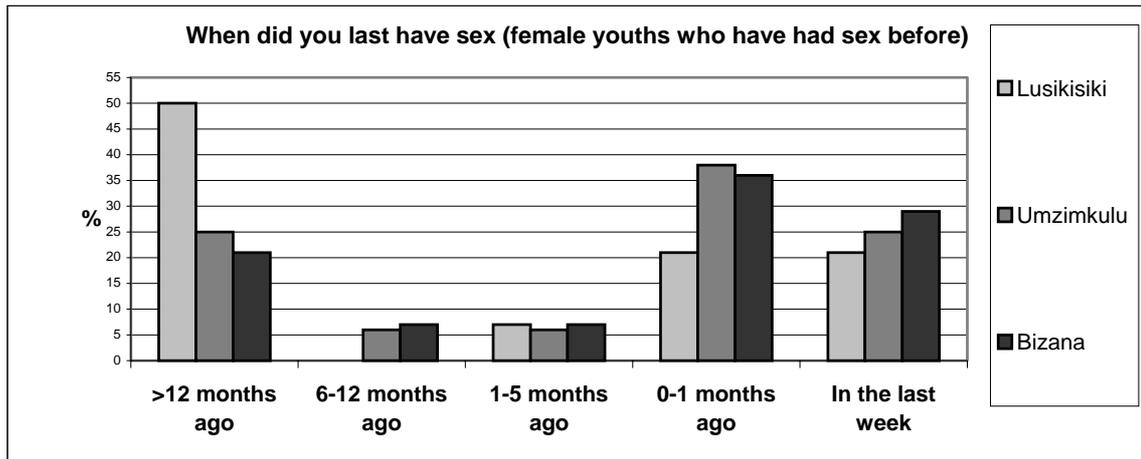
most of which are problematic to measure especially given that they are often not employed consistently. In the following sections, risk and prevention behaviours are described in depth and some of the factors associated with specific behavioural outcomes are described.

It should be said that vulnerability also needs to be looked at on a community level, and there is a corresponding need to understand how communities, as entities, are supporting change. At the level of the community, there appears to be little evidence that community structures are seriously concerned about the vulnerability of community members. There has been remarkably little community level discussion and only 27% of adults surveyed say that they have attended a meeting where HIV/AIDS has been discussed. At a cultural level, there also appears to have been little organised response and there seems to be little discussion of the cultural dimensions of HIV/AIDS risk. In the Umzimkulu area there was talk of virginity testing as a possible cultural response, but more as a response that is being tried elsewhere in the area than as a local response. This appears to be a cultural trend more closely associated with Zulu than Xhosa culture.

5.3 Sexual activity

Youth sexual experience												
	Not had sex before % N = all		When did you last have sex? (youth) % N = those who have had sex before									
			More than one year ago		In the last 6-12 months		In the last 1-5 months		In the last month		In the last week	
			m	f	m	f	M	f	m	f	m	f
Bizana	0	30	25	21	15	7	15	7	10	36	35	29
Lusikisiki	5	26	35	50	12	0	6	7	18	21	29	21
Umzimkulu	0	24	11	25	11	6	11	6	39	38	28	25
All sites	2	26	24	33	13	4	11	7	22	31	31	24
	<u>m and f</u> 14											





It can be seen from the above that young women in grade 11 are less likely than their male counterparts to have had sexual intercourse before. Young men have almost all had sexual intercourse before (98%) whilst only 74% of Grade 11 females have. One of the factors that needs to be taken into account is the lower average age range for women in grade 11, which is found in all sites. In Bizana females are as much as one year younger than males. The following table provides ages for youth respondents.

	Youth age	
	Male	Female
	Ave.	Ave.
Bizana	19.3	18.3
Lusikisiki	17.4	16.9
Umzimkulu	19.3	18.9
All	18.7	18.0

In the literature on self-reported sexual behaviour it is often claimed that young men tend to over-report their sexual experience, whilst young women under-report their sexual experience. We do not have evidence from this study to know whether this is the case or not, but we can safely assume that more females than men are virgins, and the qualitative data on questionnaires tends to corroborate this. However, it is not all that meaningful in understanding youth risk behaviour only to ask if respondents have had sexual intercourse before. Previous sexual experience does not imply current sexual behaviour. The crude indicator of having had sex before provides little understanding of the patterns and especially changes that might be occurring in sexual behaviour. The two graphs above are more informative.

The graphs refer only to the 86% of those who have had sex before (98% male and 74% female). Perhaps the most important feature of these graphs is the high level of respondents who have not had sex in the last year, but only 'more than one year ago' (33% of females and 24% of males who reported having had sex before). Only 53% of males and 55% of females who have had sex before have had sex in the past month. Thus it must not be assumed that because youth have had sex before that they are all regularly sexually active. The following table provides further insight.

How many days did you have sex in the last four weeks? (n = those who have had sex in the last four weeks)		
	Average	
	m	f
Bizana	7.6	8
Lusikisiki	1.8	2.8
Umzimkulu	2.4	2.3
All	4	4

Interestingly, in the group of youth who have had sex in the last four weeks (which represents 46% of all youth surveyed: 41% of females and 50% of males), males and females appear to be equally sexually active, measured in terms of number of times they have had sex over the last week. (This is not inevitably the case, as the male and female cohorts are mostly not having sex with each other, with the females having sex mostly with out of school men, and the males with school-going girls). Those who have had sex in the last month in the Bizana site tend to have more frequent sex (i.e. sex more times).

The value of knowing these trends is that they tell us about the possible behavioural trends which drive the spread of the HIV/AIDS epidemic. We know from this data that across sites about half of this grade 11 sample are regularly sexually active. If we are only to consider whether or not a person has had sexual intercourse before, we could easily assume very high levels of HIV infection risk as it would seem that youth are highly sexually active. In fact, by no means all of these youth are having regular sexual intercourse. Also, because of this, programmes aimed at endorsing abstinence, and not simply the more widely emphasised messages about condom use, are indicated. Secondary abstinence is a distinct choice to youth who are not necessarily stuck in patterns of regular sexual activity. Further strength is added to this position in the section of this report on abstinence.

5.4 Number of partners

“Sometimes even old men will have other partners you know. There are even songs about such infidelities in this area.” (older male, Bizana area)

Interviewer: *I want to hear from you now your personal experiences. Am I correct in assuming that you no longer have other partners, that you only sleep with your spouses?*

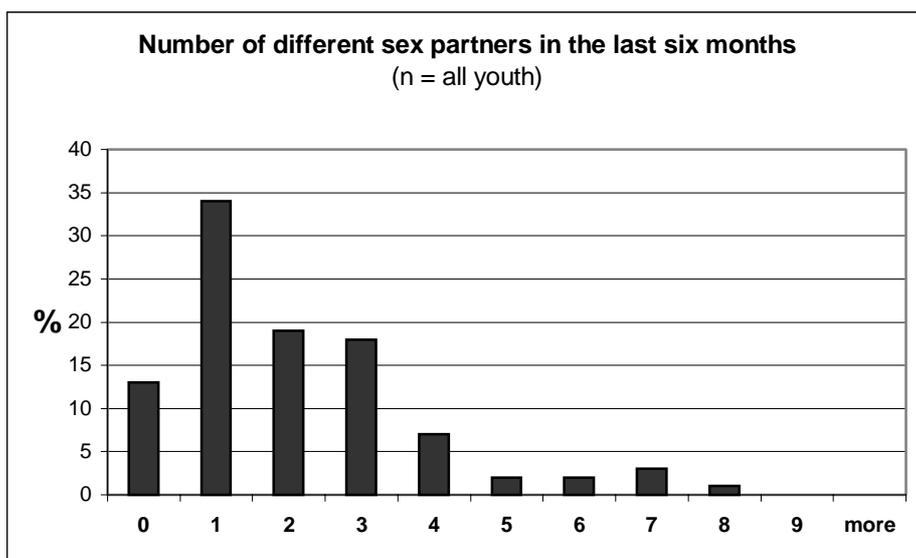
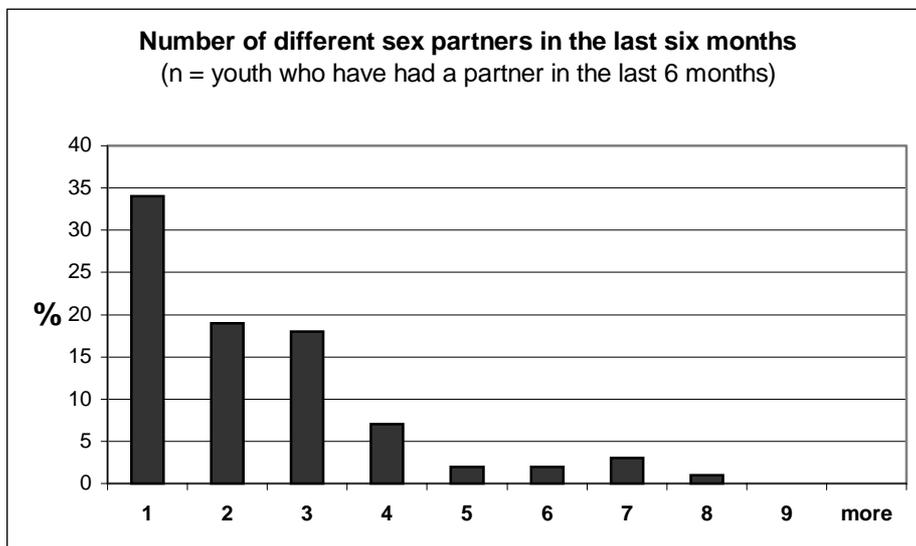
Respondent 1: (female) *There are no sugar daddies here.*

Respondent 2: (male) *No, no, no, no, we need to be honest. Here we Pondos have other women. No one has changed here. I would say that one who doesn't have other partners is someone who wants to save themselves. I wouldn't say that people do this but it's really up to the individual. Sometimes even old men will have other partners you know. Ther are even songs about such infidelities in this area.*

(Adult community members Bizana area)

Forty percent of youth and 21% of adults report having more than one sex partner 'at the moment' (concurrent sex partner). If we consider the youth percentage against the following graph (which reflects numbers of partners) we can infer that there is not a very high changeover of partners, although there is a fairly high level of concurrent sexual partners. Fifty two percent of youth have had more than one partner over the past 6 months, and if 40% of these have concurrent partner relationships, it follows

that the predominant pattern of multiple partnering is concurrent partners, as opposed to a strong serial monogamy pattern (i.e. rapid changing of partners) with rapid turnover in one partner relationships. Interestingly, this pattern is more consistent with the profile found in a deep rural area in KZN than the pattern found in a deep rural area near Fort Beaufort in the Eastern Cape, where serial monogamy was a more predominant mode of multiple partnering (Kelly, 2000).



One implication of the above is that prevention efforts need to focus on the tricky area of multiple concurrent sexual partners. The HIV prevention message of being faithful to one partner seems to run contrary to an entrenched social pattern. Any change in this pattern would thus require a focussed and intensive campaign. Fortunately, with low partner turnover (more than 3 partners in six months is rare), the risk of rapid spread of infection is less than it would be in a high-turnover serial monogamy situation. Additionally, it is arguable that it is easier, as a prevention strategy, to encourage people to 'stick to one partner' than it is to encourage people not to change partners. The latter would be the necessary intervention in situations where the prevailing pattern is short-term relationships, and a higher number of different partners for the same number of sexual acts.

5.5 Age and first sexual intercourse experiences (sexual debut)

Median age of first sexual intercourse is the age at which half the sample had had sexual intercourse. Median age at first sexual intercourse for youth, amongst males is 13 years, and females is 16 years. Median ages for first sexual intercourse amongst adults males is 17.5 years and amongst females is 17.8 years. This suggests that between the time that the adult sample were having their sexual debut and the time when the youth sample had their debut, the age of sexual debut has reduced considerably for males (median 4.5 years less) and females (median 1.8 years less). However, as has been pointed out already, early sexual experimentation amongst young adolescent males does not imply ongoing sexual activity. It does imply a need to intervene in developing lifeskills relating to sexuality early.

Age at first sexual intercourse: youth who have had sexual intercourse %						
	Have had sex before		Average age of first intercourse		Median	
	m	f	m	f	m	f
Bizana	100	70	14.2	15.6	15	16
Lusikisiki	95	74	11.8	15.6	12	16
Umzimkulu	100	76	11.4	16.3	13	16
All	98	74	12	16	13	16

Age at first sexual intercourse: adults %				
	Average age of first intercourse		Median	
	m	f	m	f
Bizana	17.2	17.5	16	17.5
Lusikisiki	17.5	18.3	18	18
Umzimkulu	17.9	17.6	18	17
All	17.5	17.8	17	18

There has been very little attention paid to understanding what lies behind the age of first sexual intercourse becoming progressively younger. Explanations of this phenomenon range from the impact of increasingly sexualised television and music, to the introduction of injectable contraception, to experimentation initiated by the widespread availability of condoms which allow young teens to avoid pregnancy risk without having to adopt other measures, to lower ages of biological maturity. Whatever the causes, it needs to be studied, and sexuality education efforts depend on a proper understanding of the nature of early sexuality. The next table throws further light on trends of early sexuality.

		Age at first sexual intercourse: Adult N = those who have had sexual intercourse before										Age at first sexual intercourse: Youth N = those who have had sexual intercourse before														
		Cumulative % *										Cumulative % *														
Age	Bizana		Lusikisiki		Umzimkulu		Total		Bizana		Lusikisiki		Umzimkulu		Total											
	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m	f	m&f							
≤9																										
≤10																										
≤11																										
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≤27																										
≤28																										
≤29																										
	n=19	n=15	n=15	n=15	n=21	n=22	n=55	n=52	n=107	n=19	n=14	n=19	n=17	n=20	n=16	n=58	n=47	n=105								
		0-20%					20-40%					40-60%					60-80%					80-100%				

* Cumulative % means that the % at each age is the % for that age and younger; e.g. the % at 16 is the % who have had sex by age 16.

The table on the previous page provides a picture of how the age of sexual debut has decreased in time (compare adult and youth sides). It is important to note that the table refers only to those who have had sex before and the percentages should not be taken as referring to all youth and adults. So the table should, for example, be read: Of the youth who have had sex before, 64% had sex at or below the age of 16.

Note that the average age of adults is 41 years and the average age of youth is 18 years. On average, the adults were 14 years old, 27 years ago (1974), and the youth sample were 14 years old, 4 years ago (1997). So, for example, we might say that the table provides a comparison of youth sexual experience in 1974 and 1997. We can say from this table that in 1994 when our adult respondents were 14 years old, only 6% had had sex before. We can say that in 1997 when our youth respondents were an average age of 14, 30% had had sex before.

The following features are particularly noteworthy:

- Male ages of sexual debut have dropped dramatically over time, but this effect, although evident in females, is not nearly as pronounced.
- For sexually experienced youth, 84% of males and 38% of females had had their sexual debut by the age of 16, as compared to 29% of males and 25% of females in the adult sample.
- Lusikisiki and Umzimkulu sites show this effect more dramatically and it is noticeably less evident in Bizana.
- Amongst male youth the age where there is the largest percentage increase in sexual experience is 15-16 years (18% rise). Amongst female youth there is a 23% rise at 15-16 years and a 39% rise at 16-17 years. For males and females combined the percentage rise at 14-15 years is 13 %, at 15-16 years it is 21% and at 16-17 years it is 20%. This means that 54 % of those youth who have had sex before had their first sexual experience in the 14-17 year age period.
- Young men start to have sexual debut experiences very early.

It begs to be understood how it can be that young men report being sexually active so early and yet young women do not. An in-depth exploration of this phenomenon by Kelly and Parker (2000) and Ntlabati and Kelly (2001), in another rural area of the Eastern Cape Province, shows that childhood games like *Undize* are often the context where children have first sexual intercourse experiences. These experiences often happen between older girls and younger boys, but we believe that the marked differences between boys and girls at very early ages are, to a large extent, a product of what they interpret as sexual experience. For girls, the sexual penetration that occurs in such contexts does not count as “real sex”, at least from the perspective of looking back after more mature sexual experiences, which are more about desire than play. So we would tend not to call this type of experience “real sex”, at least until the age of puberty at about 12 years. But the effect of this early experimentation which increasingly involves penetration and not only “playing on the outside”, is that the concept of virginity has tended to have less cultural significance. This means that the transition to “proper sex” is often not based on decision or forethought, in which case a psychological hurdle does not need to be crossed. Interestingly, in some contexts there has been reinstatement of the significance of virginity through the practice of virginity testing (Scorgie, 2001), which might be understood as an attempt to reinstitute a concept of virginity, and to make the transition to being sexually active a more deliberate step. This is a specific type of response to the HIV/AIDS crisis, which reflects the need to address the phenomenon of increasingly early sexual experience in the HIV context.

Both boys and girls are experimenting with sex very young and the foundations for later sexual experience are being laid down at least by the age of 11-12 years (grade

5-6). There is thus a need to lay foundations for sexual and reproductive health at this stage, but more along the lines of basic HIV education, affirming sexual rights and helping children to understand their maturing bodies and sexual feelings. Given the data presented above, it seems appropriate to suggest that reproductive health education and HIV prevention would need to be implemented at around the age of 14 years or grade 8, which is also the first year of high school. In the high schools visited in this study, there seems to be little understanding of what forms of education are appropriate at what age, and where there had been HIV/AIDS education efforts these had been targeted at the older students, usually grades 11 and 12. Clearly, more attention needs to be given to the stages of sexual socialisation, which are shown above to differ quite markedly in different areas.

5.6 Age differences between partners at sexual debut

Youth respondents: Partner age differences at sexual debut (*difference between respondent's age at first intercourse and age of first sex partner) n = those who have had sexual intercourse before										
	Partner age difference*	Cumulative %								
		Bizana		Lusikisiki		Umzimkulu		Total		
		Male	female	male	female	male	female	males	female	males and female
partner older	≥10 years		13						4	2
	≥5 years		33		6	5	29	2	22	12
	≥4 years		33		17	5	47	2	30	17
	≥3 years	11	39	5	23	15	59	11	40	25
	≥2 years	22	72	10	51	30	94	22	72	46
	≥1 year *	28	93	26	67	60	94	39	84	60
	Same age	17	0	11	33	5	6	10	14	12
partner younger	≤1 year **	56	7	63		35		51	2	28
	≤2 years	34		47		35		30		16
	≤3 years	17				25		11		6
	≤4 years									
	≤5 years									
	≤10 years									
		n=19	n=14	n=19	n=17	n=20	n=16	n=58	n=47	N=105

* ≥ means greater than or equal to ...
** ≤ means less than or equal to ...

Age at first sexual intercourse: youth						
	Average age at first intercourse		Average age of 1 st partner		Age differential	
	m	f	m	f	m	f
Bizana	14.2	15.6	13.6	18.9	0.6	-3.3
Lusikisiki	11.8	15.6	11.4	17.4	0.4	-1.8
Umzimkulu	11.4	16.3	12.0	20.1	- 0.6	-3.8
All	12	16	12.3	18.8	- 0.3	-2.8

Adult respondents: Partner age differences at sexual debut (*difference between respondent's age at first intercourse and age of first sex partner) n = those who have had sexual intercourse before										
	Partner age difference *	Cumulative %								
		Bizana		Lusikisiki		Umzimkulu		Total		
		Male	female	male	female	male	female	males	female	males and female
partner older	≥10 years				7		32		15	8
	≥5 years		31		28	5	41	2	35	18
	≥4 years		37		50	5	46	2	44	23
	≥3 years		56		64	5	50	2	56	28
	≥2 years		75	13	86	5	68	6	75	40
	≥1 year *	5	88	13	100	10	82	9	88	48
	Same age	0	0	13		10	5	7	2	5
partner younger	≤1 year **	95	12	74		82	15	84	10	47
	≤2 years	63	6	60		63	15	64	8	36
	≤3 years	37		27		44	15	38	6	22
	≤4 years	26		7		24	5	21	2	12
	≤5 years	15		7		15		14		7
	≤10 years									
		n=19	n=15	n=15	n=15	n=21	n=22	n=55	n=52	N=107

* ≥ means greater than or equal to ...
** ≤ means less than or equal to ...

Age at first sexual intercourse: adults						
	Average age at first intercourse		Average age of 1 st time partner		Age differential	
	M	f	m	f	m	f
Bizana	17.2	17.5	14.4	20.8	2.8	-3.3
Lusikisiki	17.5	18.3	15.8	22.2	1.7	-3.9
Umzimkulu	17.9	17.6	16.0	22.6	1.9	-5.0
All	17.5	17.8	15.4	21.9	2.1	-4.1

Key points from the above four tables:

- Twenty two percent of young women had their first sexual experience with someone 5 or more years older than themselves. Whereas a five year age difference between partners may not seem so significant at the age of say 25 years, at the age of 16 years at which stage 38% of sexually experienced female youth have had intercourse, this is a significant age difference. The psychological gap between a 16 and a 21 year old is much greater than that between a 25 year old and a 30 year old, and this gap provides a context for manipulation.
- The maximum age gap between between male youth and their first sexual partners is 3 years. Interestingly, 22% of sexually experienced male youth had a first sexual experience with someone 2 or more years older than themselves.
- There are significant differences between sites in relation to these patterns, with Lusikisiki females, in particular, much more likely than females in other sites to have partners their own age. Again, this points to the need to understand local contexts

and the very varying patterns of sexual socialisation which need to be addressed in HIV prevention work. We cannot assume a norm across the region and education efforts and methodologies for the same, need to begin with an exploration of the nature of sexual socialisation in each area.

- Very interestingly, the adult cohort show that the age differentials between sexual partners were even greater in the past. Thirty five percent of adult women had a first sexual partner who was five or more years older compared to 22% of youth. It strongly shows that age differentials are not a new phenomenon, unlike the declining age of debut. The trend also holds for men, with 21% having an age gap between themselves and their partners of 4 or 5 years younger. This compares to 11% of male youths who had partners 3 years younger at sexual debut.
- Because this trend is a long-standing one, it is likely to be more culturally entrenched than is the more recently declining age of debut. For this reason the latter may be a more important primary campaign message, and a more fundamental campaign focus. However, age differentials need also to be addressed as high age differences provide a context for manipulating younger people into sex (although historically this has not led to the early age of debut which we find now).

5.7 Age differences between youth sex partners

Youth: Age differences between recent sexual partners (* difference between respondent's age and age of most recent sex partner) n = those who have had sexual intercourse before										
	Partner age difference *	Cumulative %								
		Bizana		Lusikisiki		Umzimkulu		Total		
		Male	female	male	female	male	female	males	female	males and female
partner older	≥10 years		9		6				5	2
	≥5 years		27		12	8	35	2	25	10
	≥4 years	8	36		24	8	59	4	39	13
	≥3 years	8	36		35	8	71	4	48	21
	≥2 years	8	63	11	53	15	94	11	70	26
	≥1 year *	8	72	11	70	15	94	11	80	45
	Same age	23	9	16	30	23	0	20	14	17
partner younger	≤1 year **	68	18	73		62	6	69	6	38
	≤2 years	53	9	47		23	6	53	4	29
	≤3 years	38	9	16		39	6	28	4	16
	≤4 years	15				18	6	10	2	6
	≤5 years					18	6	6	2	4
	≤10 years									
		n=13	n=11	n=19	n=17	n=13	n=17	n=45	n=45	N=90

* ≥ means greater than or equal to ...
** ≤ means less than or equal to ...

Last time had sex: Youth (average age differences between partners)						
	Average age		Average age of partner		Age differentials between partners	
	m	f	m	f	Male age minus female age	Female age minus male age
Bizana	19.3	18.3	18.1	22.6	1.2	-4.3
Lusikisiki	17.4	16.9	16.2	19.4	1.2	-2.5
Umzimkulu	19.3	18.9	16.2	22.7	3.1	-3.8
All	18.7	18.0	16.8	21.4	1.9	-3.4

Key points from the above two tables:

- Across all sites males have younger current partners, with an average of males being close to two years older than their partners. On average boys who are 18.7 years old, have partners who are 16.5 years old, and girls who are 18 have partners who are 21.4 years old.
- In the Umzimkulu site there is a much higher age differential between males and their girlfriends, with an average age differential of just over three years compared to a little over one year for the other sites.
- In the Bizana site females tend to have older boyfriends (average of 4.3 years older) than they do in the other sites, especially compared to Lusikisiki (2.5 years older). It should be noted in interpreting this that in the Lusikisiki (urban) site grade 11 males are nearly two years younger than their rural grade 11 counterparts in Bizana and Umzimkulu. A similar trend exists for females, although less pronounced, in Bizana. The two rural sites (Bizana and Umkimkulu) seem to have similar patterns, especially with a tendency towards greater age differentials both at debut and with the most recent partner. The urban site (Lusikisiki) also shows higher levels of same age partners than the other sites. This feature of rural areas is consistent with patterns found in a study by Kelly (2000) in six sentinel sites across the country. It might be concluded that high age differentials are an issue particularly worth addressing in rural areas.
- Female youth in grade 11 (presumably also in grade 12 and possibly in grade 10) are having sex, for the most part, with out of school counterparts. HIV prevention education targeted at girls in schools is not going to reach their partners. This is particularly relevant with respect to partner compliance in using HIV prevention measures. Education needs to address not only what needs to be done, but importantly, how to gain co-operation of older, out of school partners.
- Both grade 11 males and their partners are likely to be reached in school based education programmes.
- Age based sexuality education is not easily done on a grade basis because of the large age ranges per grade.

5.8 Factors affecting sexual decision making

Seventeen percent of youth report having been forced to engage in sex before and 18% feel that they are not able to say 'no' to sex, even if they do not want it. This points to the need to promote self-assertion in the sexual domain as an education campaign objective.

Young females are much more likely than young males to be able to have relationships without sex, and in focus groups they were quite unambiguous in saying that whilst sex may be pleasant it is as often as not engaged in to “please” the man, rather than because of their own need. The following table provides evidence of this gender difference.

Could you stay in a relationship without sex? %		
N = all youth		
	Yes	No
Male	42	58
Female	84	16
Total	64	36

On the other hand men tend to have an image of their own sexuality as being irrepressible once it has been discovered. In the words of one young man: “Perhaps if you are born again or saved, then you would be able to go without sex, but otherwise not.”. Another male youth commented: “It’s fun and then after that you all want to go on having fun and then it’s difficult to think of having fun without sex”. But there is also interpersonal pressure for young men to be sexually active. They tend to tease each other if they do not have a girlfriend, and if a young man is no longer “visiting” (implying a sexual relationship) his girlfriend, he will feel that he should get another girlfriend to “visit”, or risk being teased by friends.

Young men expressed what appears to be quite a widely held belief on the part of male youth culture in the region, that women pretend that men are pressurising them for sex, but that women simply like to be pressured. This opens up a potentially complex gender debate, and it is certainly an issue which fired emotions in focus groups. This is potentially a powerful generative issue to use in understanding gender dynamics and discussion of which quickly cuts to the core of miscommunication between the sexes.

There are peer pressures on both males and females to have boyfriends or girlfriends and there is social status associated in being partnered with someone, quite apart from having sex.

A common explanation offered for the higher prevalence of HIV amongst young women is that they become involved with ‘moneyed’ older men who work in cities. The existence of “sugar daddies” who entice young women into sexual liaisons through gifts and money is a phenomenon well known within these communities. Girls sometimes “earn” money from boyfriends and it is said that parents sometimes choose to ignore this as they too are enticed by what is brought home. Another form of HIV risk exposure brought about through material relations takes place when young women go to cities to find work and are taken in and “looked after” by men who expect sexual favours in return. Because young women have to move from place to place to find work they may be exposed to many men in this way and thus become vulnerable to infection. These are largely forms of sexual relatedness and risk exposure in which young women have little negotiating power, and to which they are drawn to alleviate material hardship.

It is difficult to quantify levels of sexual coercion, because coercion can take many forms which can be defined in different ways and can happen to different degrees. The following two tables give some indication of differences between sexes in terms of the experience of being pressured or coerced into sexual relations. The way that these questions are asked, one relating to the past year and the other relating to ‘ever’, should not be seen as anything more than a measure of whether people see

their sexual relations as forced or pressured. Fifteen percent of women feel that they have been forced to have sex in the past year when they didn't want it, and 31 % have had this experience in the past. We shouldn't imagine that these women have been raped, only that sex is remembered as having had a coercive element. Interestingly, there are also some men who have experienced this.

Youth: During the past 12 months did a sexual partner force you to have sex with them even though you didn't want to have sex? %		
N= those who have had sex before		
	Yes	No
Male	7	93
Female	15	86
Total	11	89

Youth: Have you ever in the past been forced to have sex by a sex partner? %		
N = those who have had sex before		
	Yes	No
Male	7	93
Female	31	69
Total	18	82

Sexual needs

Respondent 1: (female) *I think the problem is with the men, because they always want us there at night and in the morning, I mean they are always the ones who want to have sex.*

Respondent 2: (female) *What I am objecting to is that fact that they say that we call them, that we are the ones who want to have sex, they shouldn't say that.*

Respondent 3: (female) *But if they didn't want to they wouldn't come even if we were the ones who call them or initiate things.*

Respondent 4: (female) *No that is not true because if I refuse to come when he wants me to go over then he starts thinking that I am up to no good, that there is something that I am doing on the side. He might even beat you.*

(out of school youth)

5.9 Condom use

Condom as a means of HIV prevention						
	Youth %			Adults %		
	Yes	no	don't know	yes	no	don't know
Condoms are usually safe as HIV protection	52	8	40	62	13	25

Adults are more inclined than youth to believe that condoms are a safe method for preventing HIV infection. However, there is a considerable degree of uncertainty about this for both adults and youth, but more especially for youth. Compared to six other sites across the country (Kelly, 2000), where this same question was asked, the youth response in this site rates as low as the lowest of the six sites, which was in rural KZN. Condom use in the last sex act, as shown below is not quite as low as in the KZN site (33% as compared to 22%), but is significantly lower than the average of the six sites. It seems that people from rural areas are generally less likely to rate condoms as a safe means of protection, and are less inclined to use them.

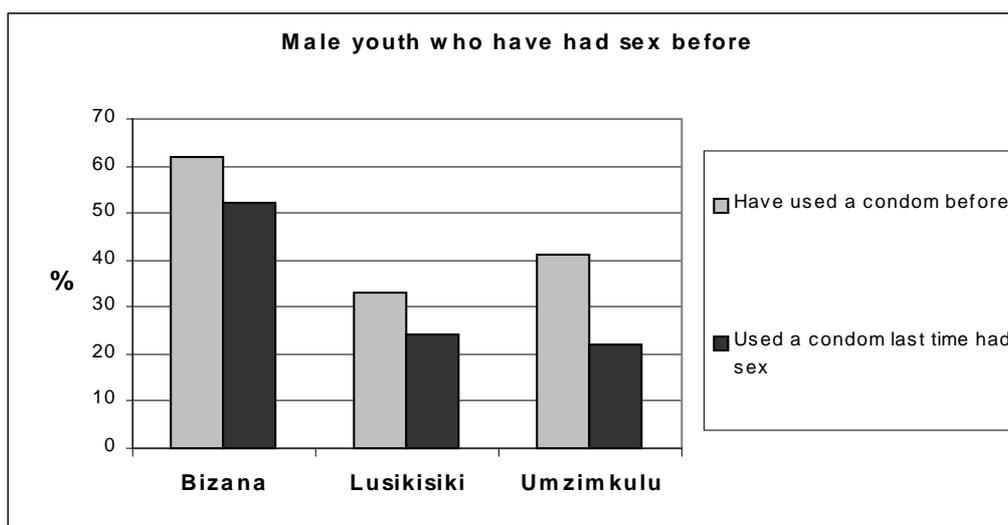
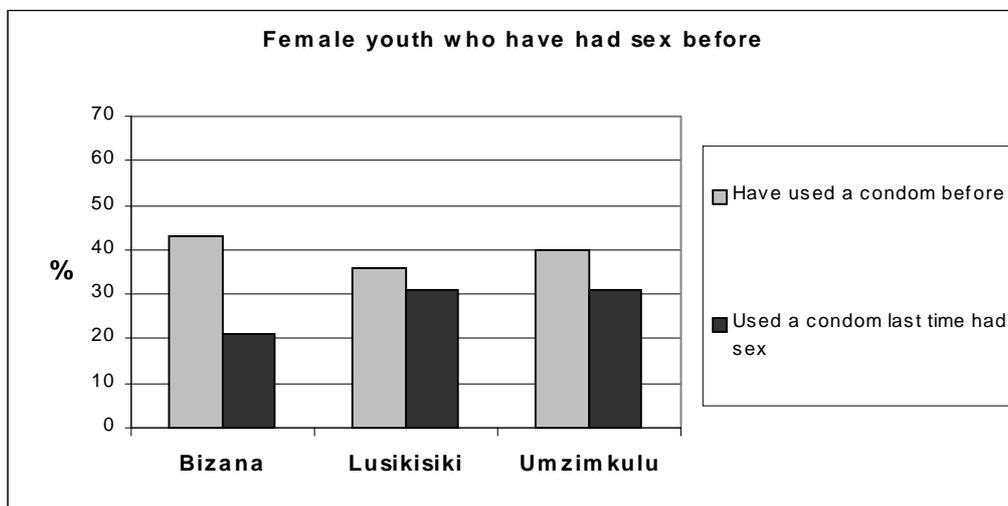
Condom use						
N= those who have had sex before						
	Youth %			Adults %		
	Used a condom before	Used a condom in last sex act	Difference	Used a condom before	Used a condom in last sex act	Difference
Bizana	56	39	17	28	27	1
Lusikisiki	34	27	7	52	50	2
Umzimkulu	41	26	15	38	29	9
All	44	31	13	38	34	4

Key points:

- Levels of current condom use (last act) amongst adults and youth are more or less equivalent.
- Compared to youth there is greater consistency in condom use for adults, evident in a smaller difference between 'used a condom before' and 'used a condom last time'. However, the elevation of the 'ever' percentage for youth may indicate experimentation with condoms following condom distribution at particular events; for example, when there is HIV education (albeit irregular) at schools, condoms are often freely distributed. A pattern of regular use does not necessarily follow.
- The rates of 'last time' condom use compare favourably with two rural sites researched in 1999 (22% in KZN and 27% in E Cape) (Kelly, 2000), but are well below urban rates found in the same six sentinel site (42% in a W Cape coloured suburb of Cape Town to 79% in a private school in Gauteng).
- It should be noted that the above data applies to those who have had sex before. This data includes youth who have not had sex in the past year (see 5.11 *Secondary abstinence*), and youth who have reduced risk in other ways

such as reducing numbers of partners. Thus, it should not be assumed that the 56% of youth who have had sex but have never used a condom before are at high risk of HIV infection, or have not done anything to lower their risk of exposure to HIV. The same could be said of adults, although we don't have as much data on sexual and prevention practices for adults. Five percent of adults said that they are not sexually active, and a proportion of the remaining 57% of adults who are sexually active and have never used a condom before, would be in low risk marriage relationships. One shouldn't expect the entire population of adults to use condoms, and the data obtained suggests that those who have used condoms before mostly used condoms in the last sex act. We can infer that about one third of adult participants in the study are regular condom users. This compares favourably, for example, with 14.3% for 'ever used a condom' and 6.1% for 'used a condom in the last sexual act', which was reported for the Eastern Cape, in the 1998 South Africa Demographic and Health Survey.

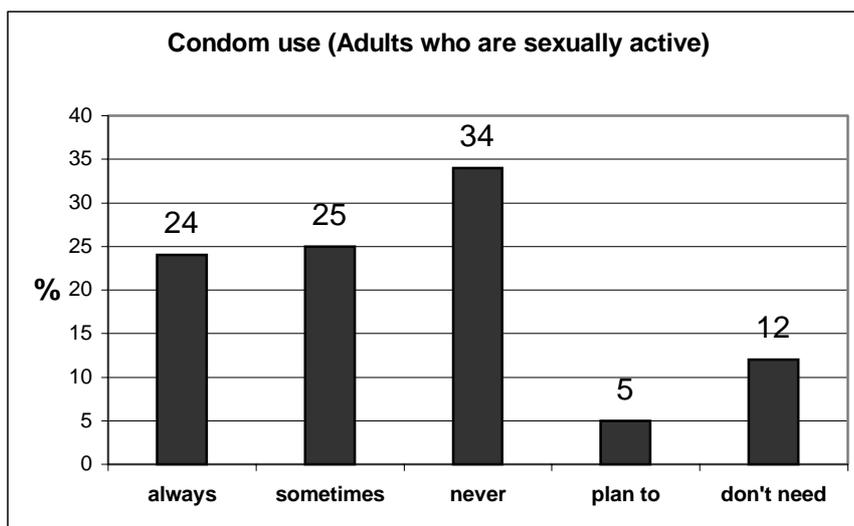
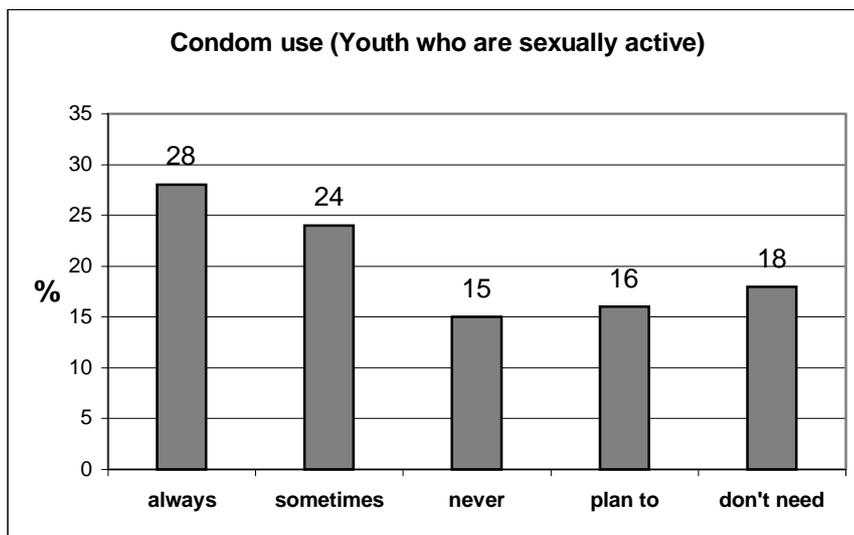
The following two graphs split the youth group by gender.



The above graphs show that there are marked inter-site differences, and also differences between males and females, with respect to 'ever' and 'last time' use of condoms. Particularly notable is the high level of condom use amongst male youth in Bizana, possibly a consequence of the proximity of a hospital (Greenville) to the community. Interestingly this higher level of use is not reflected

in female youth. This may relate to the fact that grade 11 girls have sex with partners who are a few years older, and who may spend much of their time out of the area, as opposed to males who have sex largely with younger females, who reside in their home communities. And so we might speculate about reasons for inter-site and inter-gender differences, but all that can really be concluded from the data available, is that contextual differences need to be taken into account in thinking about prevention and education. Communities differ markedly according to a host of factors ranging from confidential access to condoms, to specific patterns of sexual activity.

The following two graphs provide a more refined insight into the patterns of condom use. Note that in these graphs, those who say they are not sexually active have been excluded.



The 'plan to' and 'sometimes use' columns can be assumed to be people who need to be targeted by condom promotion efforts. However, we must not assume that 'sometimes' users all need to change their behaviour, as a 'sometimes' response may reflect use of condoms with non-regular partners only, with there being no need to use condoms with the regular partner. The 'don't need' column reflects the statement 'I am sexually active and do not use condoms because me and my partner are not HIV infected'.

As with the above data, the overall picture is encouraging and condom use promotion has clearly begun to have an impact. Asked to list the things which they had done to protect themselves from AIDS, the method that was by far the most commonly cited was condom use.

Condom negotiation				
	Youth %		Adult %	
	Yes	No	Yes	No
Have you discussed using a condom with your boyfriend, girlfriend or partner? (n = those who have had sex before)	70	30	46	54
In the last six months have you had sex with someone who refuses to use a condom? (n = those who have had sex in last 6 months)	27	73	X	

Twenty seven percent of youth report having had sex with someone who refuses to use a condom, suggesting that it is necessary to address the communication contexts in which condom use is negotiated. Interestingly, in this instance there was not a significant difference between male and female youth. Male and female youth are as likely to refuse to use a condom, when the partner wants to use a condom. The issues at stake in negotiating condom use concern trust and faithfulness.

Interviewer: *Are you saying that you don't see the need for these condoms?*

Respondent: *Ja, we do see the need but you feel that you can't use it because there is the question of trust in the relationship so you end up feeling for the sake of trust and good relations you end up doing away with the condom.*

Of those who have had sex before 75% of youth and 46% of adults report having discussed using a condom with a boyfriend, girlfriend or partner. The difference between youth and adults is not surprising as cohabiting partners are less likely to consider the need to use condoms, and adults are much more likely to be cohabiting (although we do not have quantitative data on this).

Concerning reasons given for not using condoms, it is important to distinguish between justifications for actions, and causes of actions. In other words, the explanations respondents give for not using condoms are not necessarily the whole story, or the best explanation for their actions. Given this reservation about taking reasons at face value, there are numerous reasons given for non-use of condoms including 'the condom coming off and remaining in the vagina' and the diminished pleasure of having sex with a condom. The latter seems to be of more concern to men. Other reasons given for not using condoms include: male fear that a woman will leave them for others if they insist on using condom; females not having the power in relationships to force men to wear a condom if they do not want to; and the assumption that if one insists on using condoms one has been unfaithful, or one suspects that one's partner has been unfaithful.

It is believed that bought condoms are superior: "People often say that those you get from the clinic are not right, the ones that you buy are far more reliable, but we just don't know whether this is true or not." (school going youth, deep rural area, Lusikisiki). Youth are definitely developing a familiarity with condoms and condoms have become normalised to an extent. The above quote reflects a youth culture where condoms are a part of the world of youth, rather than a foreign or extraordinary phenomenon. This is encouraging, and there is a strong need to 'normalise' the culture of condom use amongst youth, so that it becomes something to be expected, rather than something which has to be negotiated on a case by case basis.

5.10 Condom acquisition

Condom acquisition						
	Youth %			Adults %		
	yes	no	don't know	yes	no	don't know
Condoms are easy to get hold of	68	14	18	72	14	14
There is a place where I can get condoms privately (without others knowing)	26	45	29	21	54	25

Whilst condoms are mostly 'easy to get hold of', only 26% of youth who have had sex before, and 21% of adults, report that there is a place where they can obtain condoms confidentially. This is very low, and is contrary to a generally held belief that condoms are 'easily' accessible. Access means more than having a distribution point available. It requires provision of a context which is relatively free of possible embarrassment and anxiety. Reflected above is a distinct difference between 'physical access' and 'confidential access', which holds for both adults and youth. In some health facilities condoms are available outside and these can be picked up without queueing or being asked any questions. Yet, in some facilities it is thought that condoms are picked up by children who play with them, and this is considered wasteful. For this reason the condom distribution box has been moved back inside, and one has to enter the health facility to collect condoms. Condoms are often not available in ways which accommodate the concerns and anxieties of those who would access them. In most contexts youth report negative attitudes expressed when they request condoms and being questioned and admonished makes condom acquisition an uneasy experience. Further, in rural communities community members tend to know each other, and in some contexts a visit to the clinic cannot be made without drawing community attention to oneself.

The South African Health Review 2000, reports high levels of availability of condoms in all provinces in 2000 (fixed clinic waiting rooms - 87%; rural clinics - 85%). However clinics are not always easily accessible. In one of the three communities where the survey was conducted, the only permanent clinic is more than 15 km away and the mobile clinic requires at least a three kilometre walk for many members of the village; and then it visits only twice a week, and once of these times during school hours.

There are significant distribution gaps in rural areas, which mean that condoms are often not locally available. In a context without cheap public transport and very low levels of vehicle availability, this is significant. There is a clear need for alternative forms of condom distribution in rural communities. A number of possibilities exist including marketing and distribution of condoms through spaza shops and perhaps through individuals. This issue links to the need for local level action around HIV/AIDS and the formation of community response groups.

5.11 Abstinence

Youth sexual experience												
	Not had sex before % N = all		When did you last have sex? (youth) % N = those who have had sex before									
			More than one year ago		In the last 6-12 months		In the last 1-5 months		Last month, not last week		In the last week	
			m	f	m	f	m	f	m	f	m	f
Bizana	0	30	25	21	15	7	15	7	10	36	35	29
Lusikisiki	5	26	35	50	12	0	6	7	18	21	29	21
Umzimkulu	0	24	11	25	11	6	11	6	39	38	28	25
All sites	2	26	24	33	13	4	11	7	22	31	31	24
	<u>m and f</u> 14											

Perhaps most important in the above is the percentages in the columns 'More than one year ago' and 'In the last 6-12 months'. In the bottom row we see that (33% + 4%) 37% of female youths have either not had sex before or have not had sex in the past year. The male figure is also 37%. Also, if one adds up the 'last week' column and the 'last month, but not the last week' column, one sees that only about half of these grade 11 respondents who have had sex before are regularly sexually active (53% of males and 55% of females).

In effect the above means that there is a large group of youth who are practically sexually abstinent, although they have had sex before. We know from qualitative data that some of these are sexually abstinent as a result of a decision to be so, to avoid the risk of HIV infection. One in five youth said in response to a question about what, if anything, they had done to reduce their risk of HIV infection, that they had abstained from sex. But, it is probably not realistic to isolate HIV risk prevention as a sole reason for abstinence, at least not in all cases. There are other reasons cited for abstinence such as religious conversion and not being in a relationship. But, the data at least tells us that abstinence from sex is by no means unusual and this suggests that abstinence is a prevention possibility well worth endorsing. However, as has been said above there are gender dynamics involved here and taking into account data presented in the section on sexual decision making (5.1), abstinence messages are much more likely to be supported by females than males.

The prevailing belief, judging from the emphasis of most national HIV prevention campaigns, is that youth are an homogenous lot who are unavoidably sexually active, and therefore can only reduce their risk of HIV infection by condom use. However, the general conclusion from the above data is that although abstinence has not been widely promoted as a prevention measure, it may win wider following as a prevention practice than is often thought, especially amongst younger women.

6. CARE AND SUPPORT

6.1 Responses to people with HIV/AIDS

ATTITUDES TO PEOPLE AFFECTED BY HIV/AIDS						
	Children %		Youth %		Adult %	
	Yes	No	Yes	No	Yes	No
If someone in your family had AIDS, would you be happy for them to eat with your eating utensils?	12	88	38	62	51	49
Would you buy food from someone who has AIDS?	8	92	29	71	47	53
If a teacher in a school has HIV, should they be allowed to continue working as a teacher?	25	75	59	41	64	36
People with AIDS deserve it as they are to blame.	49	51	47	53	23	77
Are there people in your community who talk openly about having the AIDS germ?	21	79	18	82	16	84
Are people in your community unkind to people with AIDS?	18	82	26	74	28	72
If a student is HIV+, but is not sick, should he/she be allowed to continue attending school?	21	79	73	27	75	25
If a member of your family became infected with HIV, would you want it to remain a secret?	31	69	21	79	29	71
Has your attitude to people with AIDS changed positively over time?			24	76	55	45

On most indicators of attitudinal response, children proved to have significantly more negative attitudes to people with AIDS, corresponding to their much poorer understanding of AIDS and exposure to AIDS education, compared to adults or youth. In general, adults seem to have a better attitude to people with HIV/AIDS than do youth.

In the last row of the above table, we see that attitudes to people with AIDS are reported as changing and 24% of youth and 55% of adults report that their attitudes to PWAs have changed positively over time.

The response to people with HIV/AIDS is characterised by uncertainty, but the norm is not expressly negative. However, it takes only a few people with prejudices, given the insecurity about acceptance on the part of people who have HIV/AIDS, to affect their quality of life. Twenty eight percent of adults report that there are people in their community who are unkind to people with AIDS.

The focus group with PWAs showed that community prejudice needs to be addressed both to improve their quality of life and to promote a context for greater openness and disclosure. PWAs report that the negative orientation to people with HIV/AIDS (albeit on the part of a minority of community members) is sufficiently strong to provide reason for PWAs not to be open about their status in their own communities. PWAs described how they had found it much easier to talk about their HIV positive status in other communities and only later within their own community. There was at least one member of the focus group who was immediately able to freely disclose her status, but this was noted as unusual.

PWAs seem to be highly sensitive to peoples' reactions to them. They are sometimes publically humiliated by cruel comments, but more commonly, they suffer many small indignities such as people being reluctant to eat food that they have prepared. The

above data indicates that there are uncertainties about HIV infection through eating and food, which need to be dispelled. PWAs spontaneously spoke about this, and reported feeling hurt when people refuse to eat food that they have prepared. They are also sensitive about being handled with gloves when this is not necessary, and they are sensitive about being a source of conversation for others.

It only takes one or two such incidents to create stress for them, and even if the community as a whole is not strongly prejudicial, a feeling of being regarded with suspicion may prevail. PWAs need psychological support and guidance to know how to deal with these issues. They find themselves having “to be nice to everyone”, to gain acceptance.

Although extreme prejudice is not commonplace, the ongoing struggle to normalise their lives is stressful for PWAs. They lack any sort of significant institutional support and for the most part feel quite alone in their struggle to lead positive lives. It would seem to be vital to build a strong support base for PWAs and to promote social norms around support, so that they are supported without being singled out for special care. It needs to be promoted that in respect of almost all areas of community life, PWAs need to be treated as essentially no different from those not affected by HIV/AIDS.

Perception that HIV is a death sentence has created a poor context for affirming people with HIV/AIDS, and responding to them in an normal way. PWAs report that others believe that “we have only 10 years to live” and this is disheartening and annoying, and “breaks our spirit”. It is important to bring across the perception that HIV can be well managed and it is vital to create a climate of hope, but as will be pointed out below, this is no easy challenge given the poor infrastructural support that exists for PWAs.

6.2 Counselling, HIV testing and disclosure

In the previous section, it was shown that there are very low levels of people talking openly about their HIV status. Around 80% of all three categories of respondents reported that there are no people in their community who talk openly about having the HIV virus. We need to understand the process of disclosure, which begins with counselling and testing.

PWAs report having been subject to what amounts to very poor standards of counselling practice. Instances mentioned are a counsellor conducting the counselling session by reading off a pamphlet, and talking on the telephone during the session. PWAs feel that counsellors are not really sensitive to the experience of newly diagnosed HIV positive patients. Nurses often do not know what doctors have told patients about their HIV status and sometimes enter counselling sessions not knowing whether patients have been informed of their status. Often there will not be pre-test counselling and the nurses frequently do not know what kind of preparation the patient has had for the possibility of a positive result. The overall picture is that whilst counselling is accepted as necessary and important, and whilst there are personnel in place to do this, the surrounding communication systems are not adequate. Also, with health personnel by now having had some experience of such counselling, it seems important that skills be developed so that the first experience of counselling is a positive and supportive human experience for those receiving it. Accounts of the events around discovery of HIV positive status suggest that these experiences may set the context for how people approach their status, in the early phase at least.

The way that the initial diagnosis is handled makes a significant difference to how the person adapts to HIV positive living, and to whether or not the person is likely to use the health services for support. As it happens, according to the accounts of PWAs, there is little to no follow-up and many HIV positive people are lost to the health system. When results are sent away (results may take a week or more to return), patients who are not confined to hospital, have to return to the hospital to obtain their results. It often happens that patients do not return. In the case of an HIV positive result, there is usually some attempt to trace the patient, but negative diagnoses are often not followed up and they never receive their results. Transport is a key issue here. Patients are often not inclined to initiate follow-up themselves. A visit to a clinic often takes an entire day in rural areas and, together with the anxiety patients have around possible sero-positivity, this leads them often not to return for their results. They tend to avoid the health system until they are very sick and “often only return to the hospital to die”.

Follow-up support is important, amongst other reasons, for the purpose of assisting the person to inform his/her partner and family. Without this there is a greater chance of them being exposed to risk, quite apart from family not being drawn on as a support resource. People are alone when they hear of their HIV status and all indications are that many of them never get to sharing their status with anyone else. It would be important to introduce pro-active approaches which aim at encouraging HIV positive people to reveal their status in steps. A gradual approach to disclosure seems to have worked best amongst PWAs, but they have had to discover this themselves, rather than having been guided to it by health workers.

There is uncertainty amongst hospital staff about how to deal with confidentiality within families. Often patients are tested in hospital and a relative may return for the result. It is said that the relative may tell one or two people about the person's sero-status when still in a state of shock, and this leads to dissemination of the information, leading to community-wide knowledge of someone's HIV status. In general hospital staff are unsure about how to deal with issues of disclosure with regard to family. It seems that the attempts to safeguard the rights of patients have led to an overemphasis on confidentiality in the case of HIV/AIDS, and it might even be speculated that this has been a contributory factor to the general levels of secrecy that surround HIV/AIDS. Certainly, the issue of confidentiality needs to be discussed amongst health workers and standards of practice need to be promoted, as opposed to the high levels of uncertainty that currently prevail.

In one of the hospitals, a register of HIV positive patients is kept, but there are few attempts to trace or follow-up on discharged patients because of a lack of capacity to do so. Health workers say that the lack of physical addresses makes direct follow-up difficult. In other hospitals there is no register of people needing follow-up, and once patients are off the wards there is no system for keeping track of them.

From the hospital staff perspective, counselling is regarded as a once-off event rather than the beginning of an ongoing supportive process. Patients are usually given a form which acts as a referral note to a social worker, but there is usually no specific appointment made and it seems that there is only seldom follow-up counselling support. It would be important to know what percentage of patients referred on to social workers and community clinics, are ever seen for follow-up counselling support. According to PWAs very few of them are.

At only one of the three hospitals where this research was conducted were there rapid testing facilities. At another facility all testing has been discontinued because the hospital where the samples are analysed has sent through a directive that because of lack of funds no more tests will be conducted until further.

There seems to be a poor understanding of how the referral systems work. Part of the problem, which urgently needs to be addressed, arises from confusion about confidentiality expectations. Patients are usually referred to clinics for follow-up treatment, but the HIV positive diagnosis is not recorded on the referral note. As a consequence, the clinic is often not aware that a case is an HIV positive case. HIV positive status is only recorded in the hospital file, on a TB register, or on an HIV positive patient register, which never get to the clinics.

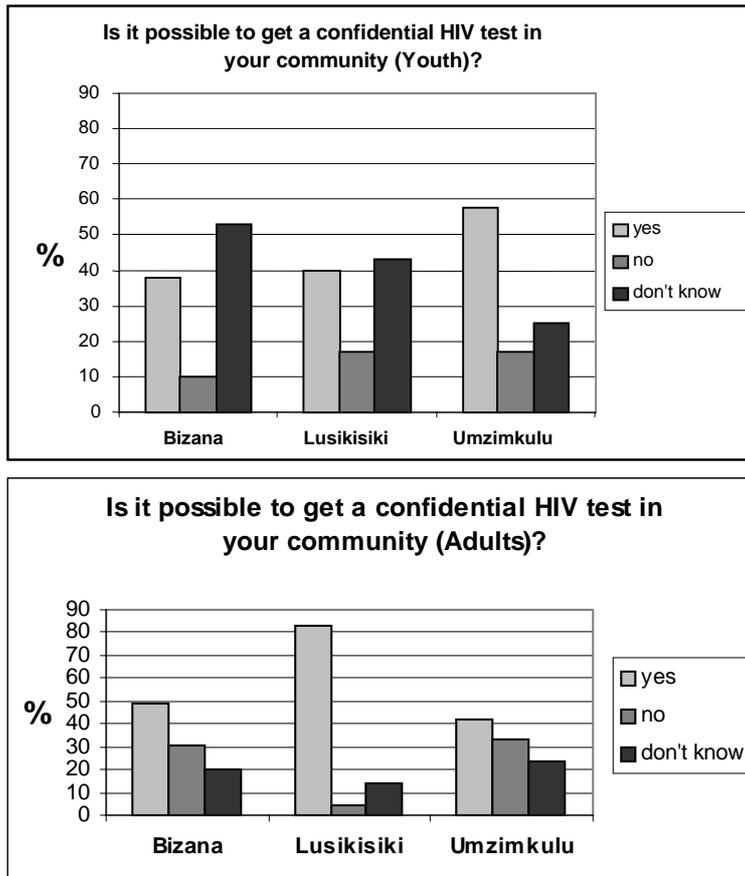
Within hospitals various systems have been used for recording HIV positive diagnoses ('TB plus', 'retro', 'immuno-suppression') so that staff will know the diagnosis, but no-one else will be able to recognise this. Whilst there appear to have been attempts to establish standards of practice in this area, hospital staff themselves seem to be unclear about expected procedures.

There is a perception that people who are diagnosed HIV positive "take it badly" and this was given as a reason for people not looking after themselves after a positive diagnosis. However, there is good evidence that there is very little support for HIV positive people, very little social work or health follow-up. It is not surprising that there is a reported high tendency to deny that "it is AIDS, even when they all know". It seems that the lack of availability of treatment, and the perception that AIDS is a terminal illness, leads to people wanting to avoid recognising and naming it as a condition. Also, when people do not disclose their status, they do not get help.

A recent survey of PHC services across South Africa (van Rensburg et al, 2000) shows that HIV testing is available at only six out of every ten fixed clinics. But this does not mean that voluntary counselling and testing (VCT) services are available. In the area of study, although blood samples may be taken at clinics for HIV testing, the testing services in the sites where research is conducted seem to be used mainly or exclusively at the request of medical personnel. It is important to distinguish between medically referred counselling and testing, and voluntary counselling and testing. It seems that facilities in the region are oriented towards the former purpose. There appears to be little awareness that VCT and medically referred testing are, psychologically speaking, very different kinds of contexts requiring different emphases. For the most part health resources are for the sick, rather than oriented around prevention. The VCT approach to prevention will require reorientation of the health services and would probably need to be conducted in special facilities and using protocols which have not been locally implemented as yet, although national Department of Health protocols do exist.

The following table and graphs depict respondents' beliefs about whether one can obtain a test for HIV in their community.

	Youth %			Adult %		
	Yes	No	Don't know	Yes	No	Don't know
Is it possible in your community to get a confidential test to find out if you are infected with HIV?	45	15	40	55	25	20



From the very mixed response depicted above, it is evident that there is little uniformity between adults and youth, and across communities, about whether it is possible to obtain a confidential HIV test. The phrasing of the question is possibly responsible for this. Two separate questions should have been asked: about the possibility of obtaining a test; and about whether this would be confidential.

As it happens, only in Lusikisiki, amongst adults, was there a clear direction to the response, reflecting the belief that it is possible to be confidentially tested. This research has not included an evaluation of whether HIV testing services *are* available on request, but for the most part, if they are available their use has not been promoted. It was pointed out above that in one site (Umzimkulu) these services are definitely not currently available (all testing has been put on hold because of financial restraints), and anecdotal evidence from the three hospitals included in the study shows that counselling and testing services are oriented around medically referred testing, as opposed to voluntary counselling and testing. It remains to be investigated where and how in the area it is possible to obtain an HIV test on request, and what the procedures are for this. We know from this research, only that there is uncertainty about the availability of such services.

The process of becoming open about HIV positive status is a slow and halting one, which usually starts with one or two family members or close friends, and does not necessarily end in full public disclosure. Full disclosure is rare and only 21 % of children, 18 % of youth and 16% of adults report that there are people in their community who talk openly about being HIV infected. Some PWAs who have for years been talking about their HIV status in other communities, are still unable to do so in their home communities.

The disclosure process proceeds at a different speed and in different ways, and there are some who are able to fully disclose their status almost immediately. Others never

disclose their status and refuse to acknowledge it to themselves, until death. The manner and extent of disclosure probably depends on psychological characteristics, as well as the immediate social context, including family relations and social support networks.

Denial is supported by the perception that there is little that can be done for HIV positive people, and there is little practical or health value in disclosing their status. The result is that they often do not reach out for support until they are seriously sick, in which case it is often too late. If it were known that support services were available it would enhance the possibility of people admitting their illness. Further, PWAs report that it is vital to their well being that they do not collapse into despair or fatalism, and having a positive and active stance in relation to their illness, greatly assists them to remain healthy . Their lived experience is that psychological well-being strongly correlates with physical health and they were in agreement that PWAs rapidly deteriorate under adverse psychological conditions. The process of developing a sense of well-being begins with the end of denial and the gradual process of public disclosure. This process is brought about, amongst other things, through knowledge of the availability of support. So it is very important for people to hear of their status in a properly supportive context which fully informs them of what resources and assistance they are likely to be able to access. By most reports this process of disclosure is cut short right at its inception, by less than satisfactory standards of initial counselling and orientation.

According to the accounts of PWAs, they derive much strength and confidence from being open about their condition. Whilst there are many challenges along the path to full disclosure of their status, the process leads ultimately to feelings of strength and resilience, which are experienced as health enhancing. But promotion of disclosure requires creation of a supportive environment, including forums for PWAs to meet and discuss the challenges facing them.

In summary, in the area of counselling, testing and disclosure, there are some fundamental problems that need to be addressed. Systems for managing the early stages of HIV diagnosis are essential for the development of a positive framework of response on the part of people with HIV/AIDS. Active advocacy for improving these systems would need to be part of the early activities of the Bambisanani Project, and as the success of a system of care requires a continuum of care, this has to be followed through from initial testing to community support structures (Grimwood, Crewe & Betteridge, 2001). It would seem to be especially important to look to the development of better standards of functional integration of the different providers and facilities within the system, which appear to lack adequate or clear protocols for practice.

6.3 Care of the sick

6.3.1 Perception of health services

“What I mean is that you do not get medication in that hospital. It’s just nothing there. If I get to hospital at around seven in the afternoon on Friday you will be told that there are no doctors and you will just be given painkillers. Then you will have to wait until Monday. The doctor will get there on Monday and he will ask from you what is wrong, if you can still talk, and if you can’t he will call in a relative to give a history. The relative will also be asked to bring blankets and sheets, you know, for me to use in hospital, because they don’t have those in the hospital. Education is not dispensed, you know, and if I get two tablets I will thank the Lord and count myself very lucky. And what patients do is to ask relatives or friends to bring them Dispirin, for example, because it is not available in the hospital. That is why they prefer being at home to being in hospital you know. And sometimes if someone has been incontinent, you know, and has made a mess, then it is

us as the person's relatives who have to clean him up when we go and visit."
(Adult community member from an area close to a hospital)

Concerning the attitude of community members to the health services, there is clearly a great deal of frustration, but also resignation about the levels of care available in rural clinics and health facilities. Community members describe health services in a poor light and the following are the most prominent complaints: lack of availability of 'correct' medicines; long waits (e.g. waiting for assistance until 5 p.m. and then being told that they can't be seen by the doctor who is too busy); impatient and unfriendly attitudes of some nursing staff, especially to youth; lack of understanding by health services of the medical conditions of the elderly (e.g. the perception that if one is elderly one's illness is a result of one's age, and therefore nothing can be done); waiting rooms being over-crowded; and poor quality of food in hospitals.

People are often reluctant to go to hospital because of what they perceive as ill treatment from nurses, especially when they have previously defaulted treatment. People who have previously been diagnosed as HIV positive and who have not followed up on referral to social workers or a clinic are reluctant to go back to the hospital, anticipating that they will be harshly treated for not having sought help earlier.

The above factors lead to a situation where people frequently obtain "leftover" medicines from neighbours when they have diagnosed themselves as having a particular illness, or they will consult a traditional healer. Going to hospital is seen as a last resort, and often decisions are taken to go to hospital after the illness has progressed too far for anything to be done.

Poor perceptions of the health system might or might not reflect the prevailing situation in the health services, but they certainly reflect a widely felt negative evaluation of the health services and the type of treatment which can be expected. It should also be said that these statements might not reflect more recent development and improvement in the health services, as community perceptions can lag behind development.

Perceived poor orientation of the health services to the needs of PWAs means that such services are often not turned to for assistance. Youth and elderly people are particularly negative about using the health services.

Quite apart from perceptions of health system users, in the eyes of health care providers, the system is perceived as often not adequately equipped to meet basic needs of patients and providers. Health providers speak of occasional 'stock-outs' of basic equipment such as linen savers and surgical gloves; and nurses are anxious about what treatment they might expect in the context of needle-stick injuries. It has also already been mentioned that testing has been stopped in one facility because of a lack of funding. These are systemic factors that cannot be remedied at the community level.

It seems that the health services are not yet adequately geared for dealing with HIV/AIDS and much development work is necessary towards this end. Whatever development work takes place, it is necessary to promote these services in communities and to orient the health services towards a more user friendly approach which, for example, actively aims to apply Batho Pele (the people first) public service principles. Advocacy aimed at mobilising the district health system towards addressing these needs would seem to be a priority.

6.3.2 Home care in context

Interviewer: *Have there been cases of say for example a woman who asked to be taken to hospital so that they can be looked after there, until perhaps they die? Or conversely where people in hospital have asked to be brought back home to be taken care of by the family?*

Respondent: *They will come back from hospital and they will tell you that it's better to come home to die in the hands of loved ones. They complain of ill treatment at the hospitals and they feel that it's better to come home, to come and die in fact at home.*

(Adult female from near Bizana)

It was noted earlier that 30% of adult respondents reported that someone in their household had been too sick to work or perform their normal duties for at least 3 months during the course of the past year. Of this 30%, 59% report having received help from outside the household in caring for these sick people. Forty one percent received no outside help. This amounts to a significant burden of caring for chronically ill people on 12 % of the 117 households represented by the adults surveyed.

It is important in understanding the burden of illness to appreciate two main factors which exacerbate the situation; namely, the relationship to the health services and the added burden of caring for a taboo or secret illness.

A positive context exists for home care given the poor evaluation of what the health services have to offer. In rural areas, there is little support for PWAs by the health services or any other agencies, and there are few services available for them. There is little access or offer of access to palliative drugs or care of any sort, and for this reason there is little incentive to disclose status and seek treatment. Psychological counselling and support services are rudimentary.

Secrecy around AIDS is also a reason for wanting to care for people at home. Some people who already know their HIV positive status do not want to go to hospital because they will be classified according to their illness. Part of the mechanism of denial of HIV/AIDS, as previously discussed, is avoidance of contact with the health services.

Focus group respondents were almost unanimous, that it is better to be cared for at home. The one aspect of hospital care for the chronically ill that was seen as effective and not possible within a home care framework was the use of a drip. But after stabilisation of the very ill, the home context was seen as being considerably more conducive to getting better. In deep rural areas especially, being in hospital is perceived as being cut off from one's life and concerns. The need to care for children and livestock is seen as an important reason to remain at home if possible.

ORIENTATION TO HOME CARE						
	Female %		Male %		All %	
	Yes	No	Yes	No	Yes	No
If a female relative of yours became ill with AIDS would you be willing to care for her in your household?	84	15	71	29	78	22
If a male relative of yours became ill with AIDS would you be willing to care for him in your household?	82	18	79	21	81	20

The above table represents the orientation of adult respondents to home care. Consistent with material gathered in focus groups it shows a largely positive orientation towards home care. It also reflects a strong tradition of people being

cared for at home in these areas and it is regarded as preferable to be sick at home, as opposed to hospital.

There is a tendency for males to be less willing to care for female relatives than they are to care for male relatives (71% as opposed to 79%), and for males to be less willing than females in general to care for sick relatives in the household. Females seem to be as willing to care for male and female relatives. These figures under-state the following, which emerged in a focus group:

As we were saying it's true that women will look after their own, and men will take care of other men who are sick. Um, we are not saying that women do not look after men at all but we're talking about handling the patient now. Washing them you know helping them put on their clothes, things like that. If it's a man it will be done by a man. But the women do help in looking after these male patients.

(Adult community members from near Bizana)

Similar sentiments were expressed in other focus groups, and there needs to be a recognition of sensitivities around cross-gender care, especially with regard to washing and directly handling a person's body. Direct physical care is usually provided by older members of families, but youth sometimes assist in the direct care of both siblings and friends.

There are well established traditions of home visiting by church groups. The responsibilities of such groups include praying for the ill, making arrangements for transport to hospital, and persuading people to have themselves admitted to hospital. They may also have a role to play in identifying people in need of care. More is spoken about the possible role of such groups in the following section.

PWAs who have disclosed their HIV status and are taking active steps to care for themselves, report that others come to them to ask how they manage to stay well. They say that often they suspect that these people are themselves HIV positive and are looking for guidance about managing their condition, without admitting their status. Those who know of their HIV status but have not admitted it to others (by the accounts of PWAs and health workers this may be the majority of HIV positive people), cut themselves off from direct ways of obtaining help. There seems to be a need to make information about care more widely available so that it does not have to be sought out. There has been little media dissemination around care issues, and most of communications campaigns seem to have been about prevention. There seems to be a strong need for information dissemination around care issues, for instance around dietary requirements of people sick with AIDS. Focus group respondents involved with care feel that such information is needed and not easy to access.

Finally, traditional healers are often turned to for support by those being cared for at home. The dynamics of interaction with this group of healers are explored in the following section.

6.4 Mobilisation of community resources

Only 27% of adults report ever having been to a meeting of people where AIDS has been discussed. This supports the impression that there is very little community level mobilisation around HIV/AIDS issues. Additionally there is little evidence that structures for prevention, care or support are emerging. There is a need for access to advice, information and support at village level. The unit of organisation needs to be at village level because of the remoteness of some areas, with some clinics being fifteen or more kilometres away from villages, in areas where there is poor communication capacity and transport systems.

It would seem important to explore different options for community mobilisation, recognising that community contexts differ. In some communities schools provide adequate space for community level meetings, whilst in other communities there are no schools and halls available. Some communities have well functioning civic structures, whilst others scarcely have any local level community organisation. It needs to be asked: What forms of local level organisation for mobilisation of HIV/AIDS response are appropriate for what kinds of localities? The need to mobilise around prevention and care is amply evident, but models for the same are not clear. It has been pointed out that there is a need to mobilise around prevention and care in communities; but models for how to do this need to be developed.

	Children %		Youth %		Adults %	
	Yes	No	Yes	No	Yes	No
Have you ever thought you should become involved in helping somehow with the HIV/AIDS problem?	18	82	44	56	24	76
Do you know of ways in which you could become involved in helping with HIV/AIDS?	17	83	40	60	16	84

Although 24% of adults and 44% of youth have thought that they should become involved in 'helping with the HIV/AIDS problem' most of these do not know ways in which they might meaningfully become involved (84% and 60%). Children, by comparison, are less likely to have thought of becoming involved or of knowing how they might become involved.

It is important to develop understanding of how these three different categories of people, each with their different needs and orientations, could become meaningfully involved. At the moment, only a small minority know how to be of help. It is important to develop pathways for action, and to disseminate ideas about small ways in which people might be of help in dealing with the AIDS crisis. It is also important to assist groupings with specific roles within their communities (e.g. parents, grand-parents, partners) to explore ways of developing responses to HIV/AIDS, and models for initiating such processes of mobilisation would seem to be important.

There is little evidence of any form of traditional cultural response to the AIDS epidemic. Virgin testing was spoken about in one of the Umzimkulu discussion groups and also emerged as a possible cultural intervention in discussion groups, but it is not practiced in the area. This practice seems to be associated with Zulu culture more than Xhosa culture, and it did not emerge in sites outside of the Umzimkulu district.

In summary, there is little to no evidence of sustained community mobilisation, although there is ample evidence of once-off, and often event-oriented awareness campaigns. Even in the area of care, it is not communities that are involved in carrying the burden, but families. Furthermore, often it is individuals within these families who carry the burden. The only groupings that are already part of the broad care framework are PWAs, church home visiting groups and traditional healers. These will now be discussed briefly in turn, with a view to understanding their potential role.

6.4.1 Role of PWAs

There has been little done to use PWAs as educators in rural areas. Those PWAs who have become involved in NAPWA activities (which, however, do not have a

widespread presence as an organisation in the area) often have to use their own resources to get to training meetings and support groups, and there appears to be little ongoing support for them to access, or organisational structures for them to fit into.

PWAs frequently report being approached about HIV/AIDS symptoms and management and in their individual capacities those that have disclosed their status appear to be a well used resource within their communities. However, they feel that there is much more that they could, and would, like to do, but there are limits to their capacities and skills. PWAs report that they are often asked questions that they do not know the answers to, and they need “proper training”. They also need to have access to information and advice on how to deal with problems they encounter.

It appears that people only look for support once they have begun to admit their status to themselves or others. The process of disclosure is sometimes motivated by the hope of gaining access to support and care resources, although it has been pointed out that these often prove to be unavailable. Disclosure is positively influenced by optimistic perceptions of the prospects for living positively, which are created by being exposed to PWAs who live constructive and active lives.

PWAs suggest, based on their own experience, that they could usefully contribute by being properly trained as counsellors who could then work in health facilities doing pre- and post- test counselling and follow-up support. They report that there is a lack of understanding on the part of nurses and social workers of the experience of being diagnosed HIV positive and little appreciation of the kinds of support needed by a person who has received an HIV positive diagnosis. They feel that it would be encouraging for someone to be counselled by someone who has faced the same challenges and with whom they might share experiences.

The problem of transport for conducting education work was raised, as were feelings that more extensive involvement would require some reimbursement for costs incurred. However, the PWAs asserted that they did not necessarily expect to be paid for their work, so much as supported in doing it, pointing out that their efforts are often conducted at their own expense. The issue of pay for such work was discussed and it was felt that if they were properly trained and provided an official service, for example at hospitals, they would expect some payment for this.

Discussions with PWAs did not reach any finality about how they could meaningfully participate in the Bambisanani Project. However, there are a number of specific advantages to their active involvement including: optimising their access to a support network; creation of a climate for disclosure by the active involvement in public life of disclosed HIV positive people; harnessing a willing group of motivated contributors with personal experience in the field; promotion of a positive image around living with HIV/AIDS; use of PWA experience in counselling; facilitation of support groups; and development of PWAs as sources for dissemination of information about prevention and care.

6.4.2 Churches

Church visiting groups see themselves as a kind of last resort. Church groups usually visit the very ill and serve as an emotional and spiritual support, sometimes breaking the isolation of families who are suffering. These are not groups specifically for people with AIDS. Rather they are a kind of community support for families in distress. Their expertise does not extend into direct care, generally speaking, although they do sometimes become involved in physical care. In such cases, they say that they lack equipment, for instance gloves. Focus group respondents were of

the view that church health visitors would readily become involved in the Bambisanani Project if provided with appropriate training and equipment.

There is some perception that churches only care for their own, but church home visitors say that this is not always the case and sometimes they will visit someone in need even if the family does not go to church.

There is little evidence of sustained efforts to mobilise churches around AIDS care, although in many rural areas there exist well established church-based health visitor groups. It would seem that this is a well established and coherent community-based care and support resource, that has hitherto not been involved in caring for the AIDS sick specifically, and which lends itself to involvement in the Bambisanani Project.

6.4.3 Traditional healers

Traditional healers are often used as a first port of call in seeking help for chronic health problems. They are also resorted to as a last resort, when nothing else seems to help. They could play an important role in community health education, in identifying HIV/AIDS cases, and assisting with palliative care.

However, there is much division within the ranks of traditional healers (“There is no unity between us as traditional healers... What I am saying is that it is not easy to bring these people together and I don’t think that they will want to be brought together and receive this training and they are quite resistant to these efforts”). Also, it seems that traditional healers represent a vast range of different skills and standards of practice, and there has been little regulation of training. For these reasons it would seem to be an especially difficult group with whom to develop associations at a formal level. Nonetheless, there is a strong sense amongst traditional healers that they have an important role to play in dealing with HIV/AIDS, and since they offer well used health services, often to people with AIDS, attempts should be made to explore their possible contribution to dealing with education and care needs.

The use of the concepts of *Idliso* and *Impundulu* (processes involving the impact of externally inflicted harm and possession) to understand the causes of AIDS are strongly endorsed by traditional healers. These concepts are also much tied to the denial of AIDS, and people may die of AIDS still believing that they have been bewitched. This could lead to the conclusion that it is better not to work with traditional healers who endorse such explanatory models. Yet it appears that such explanatory models can exist in parallel with bio-medical models, and although conceptually they are at odds, they may coexist. Whilst *Idliso* is used to justify denial, it is not the cause of denial, which has more complex roots (Ashworth, 2001; Joffe, 1999). It seems that traditional healers for the most part do acknowledge the existence of HIV/AIDS and its transmission, but without, for example, using the concept of a ‘germ’. The different explanatory concept is exemplified in the following statement: “What I am trying to tell you is that I don’t believe that there is anything like this whole system of germs and viruses.” Yet this same traditional healer has been on an HIV/AIDS training course, is able to recognise the symptoms of AIDS, and is aware that HIV is transmitted through body fluids, primarily through unprotected sex.

It would seem preferable to create passages between these two worlds, than to ignore the traditional healing world, which in any case thrives, and is widely used as a resource, without official recognition. However, there are some areas of concern. Claims to cure AIDS seem to be commonplace, as are claims to cure other serious illnesses. In the words of one healer “Yes, cancer is a sore that is on the inside and

(refers to himself by his surname) can heal cancer, that is why he wants to work hand in hand with doctors, so that where doctors fail he can take over.” However, traditional healers do generally recognise that they cannot cure all diseases, and a distinction is made between healing and the handling of diseases. In the case of the former the traditional healers tools are useful, in the case of the latter they often accept that their tools are limited. If AIDS were to be recognised as a disease, in these terms, it would seem that an avenue to co-operation would have been opened, for traditional healers to play a complementary and supportive role.

Traditional healing practitioners need to be considered as an ‘at risk’ group as well, especially because of their frequent contact with sick people, many of these cases never get to the health services until they are critically ill. A context of safe practice needs to be created. For instance, traditional healers need surgical gloves and there do not appear to be clear lines of supply for the same. Some traditional healers are involved in the process of *Intlanga* (incision) and it would be necessary to endorse standards of practice around this. It would also be of value to promote dispensing of condoms by traditional healers, especially in suspected HIV/AIDS cases, and it seems that some of them may be willing to do this.

Although only a total of three traditional healers were interviewed for this study, they have provided insight into the different perspectives within their tradition, and it seems that involvement in HIV/AIDS prevention and care is for the most part welcomed by them. However, the nature of their involvement is an issue around which much energy could be expended, without coming to consensus. It would thus seem indicated that an ‘in-reach’ rather than an ‘out-reach’ model should be adopted. If resources and training were to be made available to traditional healers, and avenues of communication were opened through provision of models, and standards of best practice were made available, there would be those who would see this as an opportunity to better their training and to draw closer to the health services. This is desired only by a segment of the traditional healing community, and it would seem that energy would best be expended at this level, rather than by attempting to reach out to the traditional healing community as a whole.

7. SUMMARY OF IMPLICATIONS FOR INTERVENTION

The following represents a summary of the many recommendations that have been made in the body of the report, flowing out of the findings. The report shows that there has been very little development of local programmes in the area of prevention, support and care. There is a strong need to advocate for programmes to be developed in the public services sectors of health, education and welfare, parallel with the development of Bambisanani Project interventions. Without a better service infrastructure and much better functional integration of services in the Public Sector, the success of the Bambisanani Project will be severely limited.

Key intervention areas

Reducing risk and promoting prevention

- **Condom distribution:** There is a need to increase access by development of local distribution points preferably within the parameters of weekly mobility of community members. It is vital for prevention that arrangements be made for distribution of government issue condoms in community locations other than health facilities, to overcome problems of condom access, which are more severe in some areas than others. It is especially important that condoms should be made available in locations where they can be accessed without consultation, and with sensitivity to the need for privacy. In addition co-operation of condom social marketing agencies should be sought for establishment of supply lines of ‘for sale’ condoms to local spaza shops,

noting the preference for bought condoms amongst some members of the community. It is also suggested that traditional healers be provided with information about how to access condoms for distribution.

- Condoms should be promoted as a triple prevention strategy which prevents pregnancy, STDs and HIV infection. There should also be promotion of the need to continue using condoms, even in a long-term relationship, until both partners are committed to monogamy and have been tested HIV negative.
- There is a need not only to promote condom use but also to endorse the full range of responses which people are spontaneously adopting in response to the risk of HIV infection. Notably, support should be given to the trend towards secondary abstinence, but there should also be support for other options including limiting numbers of partners, more judicious partner selection and delaying sexual onset in relationships.
- Community discussion needs to be promoted around HIV prevention and in particular around the problem of early sexual experimentation, culturally appropriate ways of promoting delay of sexual debut, and establishing new expectations and norms around the risks involved in having multiple concurrent partners.
- It is important to promote preventive behaviour as a positive response rather than as a prohibition, and endorsing spontaneous changes (for instance the trend to secondary abstinence which has been largely unsupported by mass media), rather than only promoting adoption of behaviour change. It is important that prevention messages, having established the need to change, now aim to create norms and expectations around sexual risk behaviour. Prevention behaviour should move towards establishing and supporting prevention behaviours, recognising that there has already been considerable uptake of prevention behaviour which now needs to be consolidated and entrenched at the level of social practice. For example, norms around condom use need to be created through endorsement of condom use as socially expected, and through negative branding of the refusal to use condoms.
- There is a need for a communication campaign informing people that the risk of infection is in fact higher in the Bambisanani Project area than it is in many other areas in the country, to counteract the tendency to believe that HIV prevalence in the area is low compared to other areas.
- There is an urgent need for development and promotion of HIV counselling and testing services. Appropriate resources for voluntary counselling and testing (VCT) are not available. A long term strategy for development of the capacity for VCT needs to begin with the upgrading of counselling services and ensuring that testing services are made more widely available. This is an important prevention measure especially for couples and partners embarking on sexual relationships.
- Feeding back HIV negative results needs to be promoted as an important prevention measure, and counselling procedures for negative tests need to be developed and promoted.
- There is a need to situate concern about HIV/AIDS in schools, given the alarming lack of evidence of anything more than erratic provision of HIV/AIDS education in schools, where there is good opportunity to work with captive learners and to harness the interest of parents. To enable fast-tracking, emphasis should initially be placed on short-term development and delivery of programmes specifically aimed at HIV/AIDS, recognising the urgency of the need to provide minimum education services in the area. It is necessary to ensure commitment to seeing HIV/AIDS as an issue of utmost importance in schools. Advocacy for fast-tracking school level activity would primarily need to target district health, education and welfare offices, which jointly should be pressurised to produce a plan for implementation of basic programmes in

schools. There is a need to decide whose responsibility it should be to deliver such programmes, as no agency appears to have taken responsibility for the same, with health and education departments, school authorities, motivated individual teachers and non-governmental agencies having provided piecemeal inputs to date. A further way of developing response on the part of these departments would be to directly advocate for formation of AIDS Crisis Committees in schools, involving parents, students and teachers. An expectation of a satisfactory response might be annual presentation of schedules for HIV/AIDS education within schools.

- It is suggested that 'bare minimum' HIV/AIDS education programme packages be prepared, involving no more than three focussed lessons in Grades 6, 8 and 11, which would need to be delivered in every school, every year at each of these levels. A fuller life-skills and reproductive health education approach is obviously desirable in the longer term, but this would be over-ambitious given the current state of unpreparedness and low capacity within schools.
- It is especially important to begin HIV/AIDS education with pubescent children who were shown in the survey to have received little input on HIV/AIDS. At the Grade 6 level, learners (12 to 13 years) would need to cover: basic understanding of HIV/AIDS infection and illness; awareness of personal risk of HIV/AIDS and means of avoiding infection; need to support people with HIV/AIDS; understanding of the need to make choices about getting involved in sex; motivation to consider abstinence as a preferred method; and instruction about the legal framework whereby it is considered to be a punishable offence when there is a two or more year age difference between partners when the youngest partner is under the age of 16. Further instruction in Grade 8 (14-15 years) is necessary at point of entry into high school, re-emphasising the above issues, and in addition: incorporating use of specific role play methods to rehearse sexual self-assertiveness; understanding of gender issues around sexual coercion; and discussion of gender differences in the area of 'sexual interest and emotional needs'. Grade 11 (17-18 years) pupils should also be targeted with particular focus on: treatment of STDs; sexual rights and gender issues; negotiation of prevention practices in relationship contexts; and for girls in particular, negotiation of sexual relationships with out of school partners. Promotion of testing as a prevention measure amongst this age group should be actively encouraged, once these services are adequately developed.
- It would be important to challenge parents to respond to the fact that their children receive little to no formal education on matters relating to relationship values and sexuality. Noting the fairly high levels of parental concern, evidenced by the pervasiveness of parents warning their children about HIV/AIDS, there needs to be information provided to parents about what children need to know about HIV, at what age.
- Following the findings of this research, there needs to be distribution of educational messages to the effect that HIV/AIDS cannot be spread by touch, by using the same eating and drinking utensils, or through preparation of food. These issues have a direct bearing on the way community members relate to people with HIV/AIDS and have been shown above to be areas where knowledge of HIV/AIDS is least satisfactory.

Care and support:

- There is a need to promote a positive context for living with AIDS, and especially to promote the idea that HIV/AIDS is not a death sentence, but can be approached constructively, and actively managed.
- There is a need to promote acceptance of HIV positive people, as essentially no different from other members of the community.

- In strategic planning, it is important to develop an understanding of the need for a continuum of care, from counselling and testing to development of community support structures and care of the sick. This begins with provision of good quality supportive counselling. There needs to be further training in counselling to develop understanding amongst health workers of the need for counselling, as well as the need for ongoing counselling support. This training needs to incorporate an understanding of the emotional needs of HIV positive people and an understanding of the process of disclosure and how the process of disclosure may be promoted and assisted. It also needs to include an understanding of the need for counselling with people who test negative, and promotion of counselling skills development, possibly through occasional supervision, such as is standard in development of counselling skills.
- Health workers need to be informed about the psychological aspects of HIV diagnosis, and need to be more aware of the feelings and concerns which typically arise around first receiving a diagnosis, and how these might be addressed.
- Health workers need to be encouraged to be supportive of people who have absconded from the health care system, and to promote re-entry into the system by welcoming people back.
- There needs to be a communication campaign around "Calling it what it is: HIV/AIDS". This needs to be accompanied by dissemination of an understanding of how AIDS manifests in symptoms, with youth, in particular, needing to know more about AIDS as a disease condition. The concept of a virus needs to be emphasised in order for there to be a higher level of appreciation of how HIV can be in the body without being noticed, and to develop understanding that HIV transmission does not require specific environmental conditions, such as is discussed in the report.
- Encouragement of disclosure of HIV status needs to be preceded by development of support services, without which there is not likely to be much reason for people who are HIV positive to acknowledge their status. Also disclosure requires development of a more accepting community environment and whilst disclosure seems to lead to acceptance (people become accepting through contact with those who are HIV positive), there needs to be sensitivity on the part of counsellors and health workers to the problems of disclosure. Disclosure should be understood and promoted as a gradual process which does not necessarily have to end in full public disclosure, and which must reduce rather than create stress, and take into account the real social difficulties involved in disclosure.
- There needs to be dissemination of information about care issues, especially basic information about: diet and healthy living for people with HIV/AIDS; treatment of opportunistic infections; palliative care; and the rights of people with HIV/AIDS. This information needs to be made accessible at a local level through distribution of appropriate media (e.g. pamphlets and posters) and obviously through Bambisanani community care supporters.
- Direct support for PWAs needs to involve NAPWA as an organisation. It is vital that people with AIDS have a local, organised presence and participate in Bambisanani activities, both for reasons of their own well-being and to create a positive perception of what it means to live with HIV/AIDS.
- The human resources of willing church groups, the personal understanding of HIV/AIDS which PWAs have (and their willingness to contribute), and the potential contribution of traditional healers in areas of prevention, support and care, require a process of development, before these potential resources can yield what they have to offer.
- There should be encouragement of the formation of inter-church forums around creating a climate for acceptance of people living with HIV/AIDS, and

around strategising ways of becoming involved in care activities with the help of the Bambisanani Project. Church group involvement in home visiting needs to be harnessed. This is a natural extension of services already provided by churches and there appears to be a willingness to help more directly with home care amongst some church groups at least. Basic training in home care would be required as well as provision of basic equipment, which they already express a need for. Training needs to be provided to PWAs who could potentially offer a valuable and remunerable education service in communities and schools. It would also be important to develop the skills of PWAs in community-based counselling and support work.

- There is need for offering continuing education for those traditional healers who have an interest in understanding the disease processes of AIDS. It is suggested that this be done using an 'in-reach' model involving offering opportunities for skills development, but without necessarily developing formal associations with the Bambisanani Project, which for reasons outlined in the report, may prove to be problematic. Supply lines for basic care supplies should be established, including surgical gloves, and disinfecting materials.

Services development

- There is a need for development and promotion of key practice protocols and minimum acceptable standards in a number of core areas of health service delivery including: communication between health workers in hospitals about HIV positive status; referral to clinics and social workers; closer follow-up of people in distress; and provision of a continuum of care.
- There is a need to develop commitment to Batho Pele (people first) principles in health, welfare and education. This would need to be advocated for through health, welfare and education department district offices. Promotion of development of clinic committees to establish positive relationships between health services and clinic committees would also help to develop the image of the health services and would improve relationships with communities. It would also help to develop more accommodating health services, especially for youth and the elderly, who feel particularly misunderstood by the health services.
- There is clearly little integration of health, education and welfare services in areas of prevention, support and care. The new district-based local governance framework provides an easily 'targetable' context for advocacy, and for mobilising personnel, resources and activities aimed at functional integration of services both within, and between, government departments.
- The HAST (HIV/AIDS, STDs, TB) committees of the two DOH district health offices in the area of the Bambisanani Project, provide a platform for advocating for integration of services. Participation of the Bambisanani Project would strengthen existing attempts to bring about integration, and participation would also be useful for co-ordinating Bambisanani projects with public service department programmes. HAST committees also provide a context for mobilisation of task groups for bringing about the necessary recommendations as suggested above.
- There needs to be advocacy for development of a strategic plan between health and education departments for systematic provision of HIV/AIDS education programmes.
- Clearer and more reliable systems of referral between health and welfare agencies need to be developed.

Communications framework

- There is a need to develop Xhosa media items for distribution in the area in relation to the above suggestions for communications projects.

- Radio is the single medium most likely to reach the full range of the population from children to adults.
- HIV/AIDS prevention should be presented as a manageable societal problem, rather than an overwhelming and complicated task.
- Given problems of access to remote communities there appears to be a need to develop local rather than centralised frameworks for mobilisation and response such as community HIV/AIDS forums or crisis committees, recognising that there has been negligible community level mobilisation to date.
- There is a need to mobilise existing (and willing) human resources, notably church groups, PWAs, and traditional healers, although each of these groups require specific input as suggested above, to optimise their potential contribution.

8. POINTERS FOR MONITORING AND EVALUATION

Based on an understanding of key issues which have emerged in this study, concerning community orientation to HIV/AIDS prevention, care and support, the following issues are identified as important to monitor in tracking and evaluating the progress of the Bambisanani Project. Not all of these areas relate directly to Bambisanani Project activities, but all have a bearing on development of a comprehensive community-based response to HIV/AIDS. Also, this list is not exhaustive and there are some areas which are central to the Bambisanani Project which are not covered here. For example, there is a need for development of indicators relating to income generating activities and access to welfare grants, areas which have not been looked at in this study, as they are covered by parallel research projects.

Prevention

Presence of media promoting changes relating to shifting norms around age of sexual debut; measurable change in normative thinking about age differentials when one of the partners is under the age of 16 years; confidential condom access within the parameter of weekly activities; regularity of condom use amongst sexually active youth; number of concurrent sex partners for youth and adults; evidence of secondary abstinence (percentage of youth who have had sex before, but not in the last 6 months); presence of a schedule in schools for HIV/AIDS and lifeskills education; access to sources of further information; funerals where cause of death is acknowledged as AIDS.

Care

Existence and membership of active community care and support groups; existence of local level community HIV/AIDS action forums; local availability of basic materials for caring for PWAs; involvement of PWAs in support and education services; training of PWAs in counselling and support activities; registry of families and children in distress and families providing home care to members; local availability of information about care; percentage of hospital cases referred to home care; existence of a practicable system of referral from hospital to home care; success of requests for personal care met within a specific period of time; knowledge of availability and means of access to home based care; actual home-care visits; assessment of transfers between hospital and home which show family and client satisfaction; HIV cases in hospital that should have been discharged to home care.

Service delivery

Availability of key services including voluntary counselling and testing; social worker access and follow-up on positive diagnoses; registry of people needing home care support; percentage of cases tested in a health facility where there is pre- and post- test counselling; percentage of HIV negative cases where there is feedback of the results to the client; evidence of promotion of use of key services; clinics with availability of essential medicines for, and approach to STD treatment; successful referral of HIV positive patients to clinic; follow-up contact after HIV positive diagnoses; evidence of functional integration of services for people with HIV/AIDS; evidence of inter-departmental (welfare, health, education) meetings and projects.

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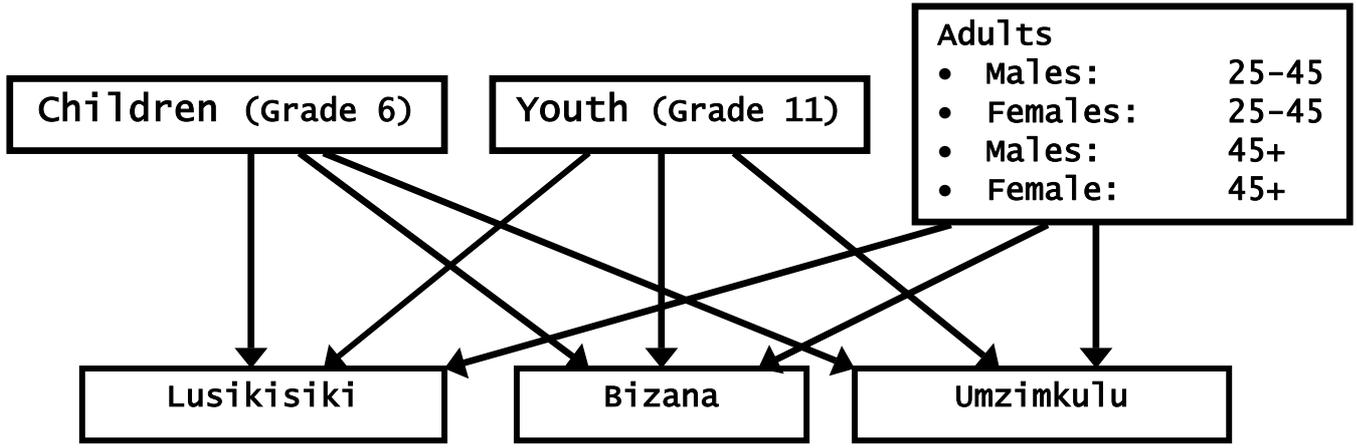
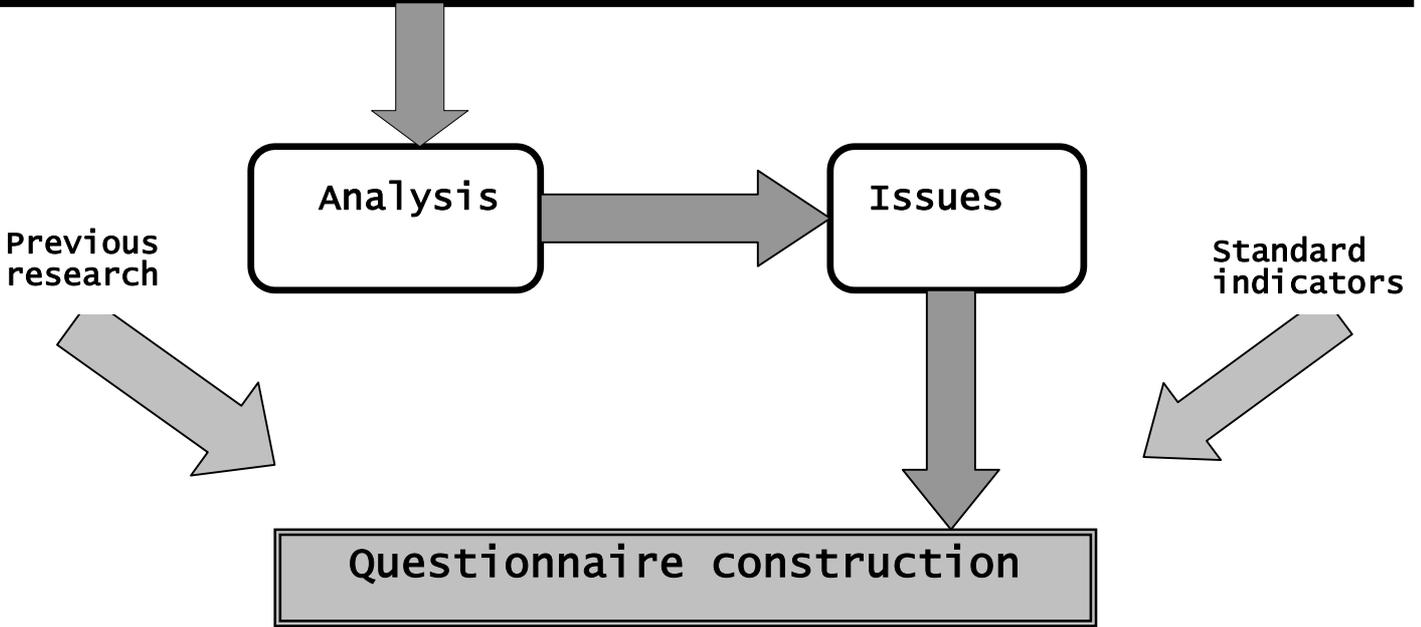
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APPENDIX 1: FOCUS GROUP RESEARCH PROTOCOLS

RESEARCH PROCESS

FIELD VISIT AND FOCUS GROUPS

- FOCUS GROUPS**
1. Deep rural area, adult community members at home during week-day
 2. Upper deep rural area, adult community members at home during week-day
 3. Out of school youth/young adults
 4. School going youth
 5. Traditional healers
 6. Church members involved in home visiting
 7. PWAs
 8. Health workers in a rural outpatient clinic
 9. Health workers in a rural hospital with inpatient care



APPENDIX 2: FOCUS GROUP RESEARCH PROTOCOLS

1. SAMPLING FRAMEWORK

Sampling principles

For all focus groups apply the following principles:

- Maximum variation within framework of selection criteria. Maximum variation means an attempt to gather together the widest range of perspectives.
- Important to ensure that participants are not from the same social circle, or do not represent a particular kind of person (e.g. all volunteers or all immediate contacts of tribal authority).

Specific sampling criteria for nine focus groups

<p>1. Deep rural area, adult community members (30yrs+) at home during week-day, two older men (50+), two older women (50+), two younger men (30-45), two younger women (30-45).</p> <p>Site: Lusikisiki, Mhlanga Administrative Area, Taweni Tribal Authority.</p>
<p>2. Upper deep rural area (closer to road, households closer together), adult community members (30yrs+) at home during week-day, two older men (50+), two older women (50+), two younger men (30-45), two younger women (30-45).</p> <p>Site: Bizana, Ndlovu Location, Sikelweni Tribal Authority</p>
<p>3. Out of school youth/young adults (22-30), including two men (22-26), two women (22-26), two men (26-30), two women (26-30)</p> <p>Site: Bizana district, Mangutyana Tribal Authority</p>
<p>4. School going youth (14-18) including two boys (14-16), two girls (14-16), two boys (16-18), two girls (16-18).</p> <p>Site: Lusikisiki district, Mantlani tribal authority</p>
<p>5. Traditional healers, access through organisation for traditional healers, range of healers if possible including amagqira and herbalists (ixhwele)</p> <p>Site: Umzimkulu, access through traditional healers organisation</p>
<p>6. Church members involved in home visiting and care of sick people. From a range of churches involved in care and support work for the sick.</p> <p>Site: Umzimkulu, Rietvlei, Sandile Tribal Authority</p>
<p>7. PWAs, 8 participants possibly split into two groups for transport reasons, including 4 women and 4 men, spread of ages, variation in terms of extent of disclosure and recency of disclosure.</p> <p>Site: Lusikisiki and to make up numbers possibly Bizana. If both sites then run two focus groups.</p>
<p>8. Health workers in rural outpatient clinic situated close to community,</p> <p>Site: Umzimkulu District, St Margaret's Hospital (Health Centre)</p>
<p>9. Health workers in rural hospital with inpatient care, involved in medical or TB wards, including staff involved in HIV testing and counselling, and including staff involved in contact with patients' families.</p> <p>Site: Lusikisiki, Bambisana Hospital</p>

2. FACILITATION GUIDELINES

- a. Try to get participants to talk about **their own stories and experiences** rather than to talk only generally about what others think or what they think should happen. One way of doing this is to often ask: "Can you give me an example of a time when that happened?".
- b. However, use the focus group to **look through the eyes** of the participants to describe not only **their own** experiences, but also stories of **other** people in their community who they have access to and which are relevant. If you are not sure how widespread a perspective is, ask: "I wonder if there are people in your community who would feel differently about this?".
- c. Be aware of the tendency in focus groups to focus on extreme or unusual stories and **try to get a sense of the normal, everyday experiences of participants, as well as the more dramatic experiences.**
- d. Ensure that you access the **range of perspectives and experiences** within the group.
- e. **Reflect back** to the group every now and again to see if you are getting them right, and also to stimulate further discussion.
- f. Maintain the **energy level** of the group, but rather aim at a thoughtful and serious mood, as opposed to a light, joking mood.
- g. **Draw in** those who are **shy** or who only speak a little. Watch the group dynamics and ensure that the discussion is not dominated by one or two outspoken people, and that everyone gets a chance to share their story.
- h. **Manage the time** well, so that you get through the questions in the agreed upon time (about 1 ½ hrs).
- i. **Role of assistant is primarily to record; i.e. audio-tape and take notes.** Assistant to record as much as possible in writing, but also to ensure that audio recording is effective. Assistant also to ensure that facilitator is covering the range of issues and make suggestions to facilitator should this be necessary.

3. FOCUS GROUP PROTOCOL FOR GROUPS 1, 2, 3 AND 4

The following protocol is divided into five parts, covering: 1) introduction; 2) response to illness; 3) response to HIV/AIDS; 4) suggestions about appropriate response; 5) fuller introduction to Bambisanani.

1) Introduction (max 10 minutes)

- Brief introductions and explanation of purpose. Explain that the results will help in planning of Bambisanani Project which will be explained more fully at end of focus group.
- Explain the procedure: Questions and discussion.
- Explain tape recorder and confidentiality, and reassure that names will not be written into any reports.
- Explain that the Bambisanani Project is concerned about helping communities to cope better with serious illness. Don't talk about Bambisanani and specific connection to HIV/AIDS in beginning, as will be opportunity at end to talk about it.

2) Response to illness (20-30 minutes)

- ***What are the major illnesses in your community?***

Don't introduce HIV/AIDS at this stage, although allow it to be discussed if it comes up. Find out what type of illnesses they perceive as being especially prevalent and whether they have any sense of illness profile changing.

- ***What are the causes of illness?***

Explore understanding of causes of the most prevalent illnesses. Explore views on the treatment of different illnesses, to get a sense of explanatory models of illness. Ask for specific examples.

- ***Who cares for people in the community when they are sick for a long time?***

Gain an understanding of *who* (types of individuals or groups) cares for sick people and understand whether it differs according to the type of illness (for example, men tend to care for men with certain types of illness). Explore **what kinds of care are offered?** Explore attitudes to caring at home vs. hospital care, and understand perceptions of how decisions are made about when hospital care is necessary (e.g. when a person is too weak to walk).

- ***What do people need when they are sick at home***

Gain an understanding of the difficulties of caring for people at home, the attitudes and responses of communities to the sick, the nature of support offered, and the difference of attitude towards different types of illness and different ages and gender of sick people.

3) Response to HIV/AIDS (20-30 minutes)

- ***Are there members of your community who are sick with AIDS, or who have died from AIDS?***

Explore in particular the extent of recognition of the problem of HIV/AIDS within their community.

- ***How do you know when a person has AIDS?***

1. Explore how they recognise AIDS and their understanding of the symptoms of AIDS.
2. Explore their understanding of the concept of HIV.
3. Explore whether they know about HIV testing and what this means.

- ***How does your community respond to people who are sick with AIDS?***

Elicit stories about response and **attitudes** towards people who have been suspected or known to be sick with AIDS. Explore **stigmatisation** and stories about how communities have responded to care needs of PWAs. Ask for stories about **funerals** to get a sense of how communities are acknowledging and dealing with AIDS deaths and bereavement. Look for positive and negative stories.

- ***Who is at risk of contracting AIDS?***

Explore beliefs about **vulnerability to AIDS** and understanding of how exposed to risk they experience themselves and different groups in their community to be. Who is at risk and who is not at risk, from their perspective?

- ***What does your community think is the cause of AIDS?***

Explore beliefs around the origins and cause of AIDS. Try to get stories to illustrate. Is there a difference between what people say to each other about what causes AIDS and what they know to be the case?

- ***What is being done in your community to prevent the spread of HIV/AIDS?***

Explore community responses. Explore existence of **community networks** and any **mobilisation** around HIV/AIDS that exists in their community. Ask about youth groups, health forums, or any other organisations which have tried to address the problem of HIV/AIDS.

2) Willingness and capacity for mobilisation and involvement (10 minutes)

- ***What kind of role, if any, do you think you could play in addressing the HIV/AIDS problem in your community?***

They may come up with nothing, in which case explore whose responsibility they think it is. Look at both **care of the sick** and **prevention**.

- 3) **Introduce the vision of the Bambisanani Project and say that everyone can play a part in making it successful. Allow for questions and discussion. (10 minutes). Thank them for participating and offer refreshments.**

4. FOCUS GROUP PROTOCOL FOR GROUP 5: TRADITIONAL HEALERS

Use the same protocol as for groups 1-4, but ensure that you get an understanding not only of how their perceptions of how the community responds, but also how they as a community of traditional healers respond. As with other groups try to get them to give examples as much as possible.

4) Willingness and capacity for mobilisation and involvement (10 minutes)

- ***What kind of role do you think that traditional healers could play in addressing the HIV/AIDS problem in their communities?***

Explore whose responsibility they think it is, and what specific role they think they as traditional healers could play. Look at what they are already doing and what they could do, in relation to care/support and **prevention** (e.g. condom distribution, education).

- ***What problems do you think would be encountered in fulfilling these roles?***

Explore both **prevention** and **care** issues. Explore issues concerning their interaction with the health system and their experiences of interaction with members of the health professions.

- ***Is there anything that you need to assist your clients to better address the problem of HIV/AIDS?***

Explore possibilities of training, and need for particular resources.

5. FOCUS GROUP PROTOCOL FOR GROUP 6: CHURCH MEMBERS / HOME VISITORS

For the first part use the same protocol as for groups 1-4, but the last part differs where there is more of a focus on understanding their contribution and possible contribution, and the challenges facing them as a community of church based home visitors. As with other groups try to get them to give examples as much as possible.

4) Willingness and capacity for mobilisation and involvement (10 minutes)

- ***What kind of role do you think your churches could play in addressing the HIV/AIDS problem in your communities?***

Explore whose responsibility they think it is, and what specific role they think their churches could play. Look at both **care of the sick** and **prevention**.

- **What problems do you think would be encountered in fulfilling these roles?**

Again, explore both **prevention** and **care** issues. Explore issues concerning their interaction with the health system and possible problems associated with their being involved in visiting hospitals.

- **What role do you think there is for people living with AIDS in your work as a church?**

Explore both **prevention** and **care** issues.

6. FOCUS GROUP PROTOCOL FOR GROUP 7: PWAs

This focus group is maybe going to take longer than the others because each member will have stories to tell.

4) Introduction (max 10 minutes)

- Brief introductions and explanation of purpose. Explain that the results will help in planning of Bambisanani Project which will be explained more fully at end of focus group.
- Explain the procedure: Questions and discussion.
- Explain tape recorder and confidentiality, and reassure that names will not be written into any reports.
- Explain that the Bambisanani Project is concerned about helping communities to cope better with HIV/AIDS. Say that their participation is very much appreciated and that it is very important to understand their experience as people who personally experience HIV/AIDS, and their possible role in the fight against this disease.

5) Experience of being HIV positive (20-30 minutes)

- ***We know that it is a bold thing to be open about one's HIV status. What has been your experience of disclosing your status?***

We can assume that they are more open to some people than to others. Try to get a sense of what point they are at in being open about their HIV status and the struggles they have about this. Try to get them to talk about their personal experiences and the responses of others focusing on the following:

- 1) Partners
- 2) Families
- 3) Communities
- 4) Has it been easier with some sectors of the community than others?

- ***How did you first learn about your status and what was this experience like?***

Explore whether there was any counselling involved, and the private experiences, struggles and victories they went through from then until now.

- ***What are the needs of people who know their status?***

Explore the needs for information and support.

- ***What is needed to assist people to be open about their status?***

6) Response to AIDS (20-30 minutes)

- ***How do you know when a person has AIDS?***

Explore their understanding of difference between HIV and AIDS and their understanding of the symptoms of AIDS.

Explore their understanding of the concept of HIV.

Explore whether they know about HIV testing and what this means.

- ***How does your community respond to people who are sick with AIDS?***

Elicit stories about their own experiences. Explore the forms of **stigmatisation** and stories about how communities have responded to care needs of PWAs.

- ***Who cares for people in the community when they are sick for a long time?***

Gain an understanding of *who* (types of individuals or groups) cares for people who are sick with AIDS-related illnesses. Explore **what kinds of care are offered**. Explore attitudes to caring at home vs. hospital care, and understand perceptions of how decisions are made about when hospital care is necessary (e.g. when a person is too weak to walk).

- ***What do people need when they are sick at home***

Gain an understanding of being sick at home, although it may happen that none of them have ever been sick with AIDS related illnesses. Be especially sensitive about not suggesting the inevitability of chronic illness and death.

- ***What do people need when they are sick in hospital***

Gain an understanding of their personal experiences of being in hospital and the needs they experienced in that situation. Especially look at experience of the support and understanding or the lack of this.

- ***Have you received any counselling before?***

Explore their experiences of counselling support. Include informal counselling like support of members of churches or support from health workers. Try to get stories about these experiences and the effect on them.

7) Mobilisation and involvement (20-30 minutes)

- ***Have you become involved in any way in addressing the HIV/AIDS problem in your community?***

Ask them to talk about their own experiences of communicating with other people about HIV/AIDS, even on a one-to-one level.

- ***What kind of role, if any, could you as people who are HIV positive play in addressing the HIV/AIDS problem in your community?***

Look at both **care of the sick** and **prevention**.

- ***What challenges or difficulties would you, or do you face in getting involved in addressing the HIV/AIDS problem?***

Try to get a sense of their material and support needs.

8) Unanswered questions (10minutes)

- ***Where can your go to find out what you need to know about HIV/AIDS?***

Try to get a sense of what resources exist and their access to resources.

- ***What do you need to know about HIV/AIDS that you don't know?***

Try to answer their questions.

9) Introduce the vision of the Bambisanani Project and say that everyone can play a part in making it successful. Allow for questions and discussion. (10 minutes). Thank them for participating and offer refreshments.

7. FOCUS GROUP PROTOCOL FOR GROUPS 8 AND 9: HEALTH WORKERS

In this focus group be aware of the need to describe the way things actually happen, as health workers may tend to describe how it should happen rather than how it does happen.

1) Introduction (max 10 minutes)

- Brief introductions and explanation of purpose. Explain that the results will help in planning of Bambisanani Project which will be explained more fully at end of focus group.
- Explain the procedure: Questions and discussion.
- Explain tape recorder and confidentiality, and reassure that names will not be written into any reports.
- Explain that the Bambisanani Project is concerned about helping communities to cope better with serious illness. Don't talk about Bambisanani and specific connection to HIV/AIDS in beginning, as will be opportunity at end to talk about it.

2) Response to HIV/AIDS (1 hour)

- ***What are the major illnesses that are dealt with in your health facility?***

Get a sense of the most prevalent illnesses dealt with in their facility and an idea of who is most affected by HIV/AIDS?

- ***How do you know when a person has AIDS?***

Explore how they recognise AIDS and their understanding of the symptoms of AIDS. Work with *examples of particular patients*.

- ***Describe how a decision is made for a patient to have an HIV test in your health facility?***

Ask for specific examples.

- ***Describe the procedure for testing?***

How does it happen? Who does it? Where does it happen? What is explained to the patient? Get a sense of how it actually happens rather than how they think it should happen.

- ***Describe the procedure for giving the result back?***

Where does it happen? How long does it take in minutes? What about negative results? Do these get fed back?

- ***Is there any communication with families about results?***

Get a sense of what happens in communication between patients and families and between health workers and families.

- ***What is the response of patients to positive results?***

Get an idea of the range of responses that they have experienced as well as typical responses.

- ***Is there any follow-up counselling for those who are diagnosed positive?***

Explore whether the counselling is limited only to the time when the patient is given the result.

- ***How is the diagnosis documented in files and is there any communication with other health workers at a primary level to mobilise possibilities of care and support?***
- ***How does the community respond to people who are sick with AIDS?***

Elicit stories about response and **attitudes** towards people who have been suspected or known to be sick with AIDS. Look at both families and the general community.

- ***What does the community think is the cause of AIDS?***

Explore their experiences of communicating with people about HIV/AIDS.

- ***Are you ever concerned that as a health worker you are more at risk of contracting HIV?***

Explore their personal experiences and what is done to reduce their HIV infection risk.

- ***What do you think would be the problems associated with caring for those who are sick with AIDS at home?***

3) Their needs as health workers and need for changes in the health system (10 minutes)

- ***What do you think should happen in your health facility to improve the care of people with HIV/AIDS?***
- ***As a health worker what needs do you have for further information and support in the face of HIV/AIDS?***
- ***What changes need to happen in the health system as a whole and what extra resources are needed to improve the situation with respect to HIV/AIDS care and support.***

4) Introduce the vision of the Bambisanani Project and say that everyone can play a part in making it successful. Allow for questions and discussion. (10 minutes). Thank them for participating and offer refreshments.

Appendix 3: Focus group research protocol

