Booklet 2

Community orientation to HIV/AIDS prevention, care and support

BAMBISANANI

The disease which we don't call by its name

2001

BAMBISANANI

Community orientation to HIV/AIDS prevention, care and support

A collaboration between
CADRE and PPASA, Eastern Cape

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For the
Bambisanani Project

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Foreword

The HIV/AIDS epidemic is progressively decimating community resources and support structures in the former Transkei. The Bambisanani Project was initiated in 2000 as an integrated community-based response to assist three communities (Umzimkulu, Bizana and Lusikisiki) to respond to the emerging HIV/AIDS related needs for care and support.

In order to inform the elements of the Project, three studies were commissioned:

- An assessment of mechanisms for identifying children in distress (or CINDI)
- An assessment of community orientations to HIV/AIDS prevention, care and support
- An assessment of income generating activities

This booklet summarises the report of a study into **community orientations to HIV/AIDS prevention, care and support** conducted by CADRE in collaboration with PPASA (Eastern Cape). The study was conducted from December 2000 to March 2001, and funded by the EQUITY Project.

Abbreviations

CADRE	Centre for AIDS Development, Research and Evaluation
PLWHA	People living with HIV and AIDS
PPASA	Planned Parenthood Association of South Africa

Background

Region E, in the north-eastern part of the Eastern Cape Province, is severely under-resourced whilst facing significant transformation challenges. Despite some recent improvements, the health and social services are poorly developed and over-burdened.

TB and HIV have reached serious proportions and the burden of care can no longer be carried by the public health sector. In addition, every week mine workers, cane cutters and other migrant workers who are disabled as a result of HIV/AIDS (with or without associated TB) are repatriated to Region E. Their care becomes the responsibility of women (often old women) and children who frequently have little or no access to appropriate resources or support.

Whilst the establishment of home-based care has been identified as a Provincial priority, this care can be synonymous with home neglect if appropriate planning, capacity building, community participation and support are not in place.

In order to meet the emerging needs for HIV-related care and support, innovative, integrated, community-based approaches are required focusing on women and children and involving public-private-NGO partnerships, with the partners taking on non-traditional roles.

However, it is first necessary to understand community perceptions to HIV/AIDS and to home-based care. Only then can effective and appropriate responses be developed.

CADRE was commissioned by the EQUITY Project to conduct a study into community orientations to HIV/AIDS prevention, care and support in the three communities served by the Bambisanani Project. They were assisted throughout by PPASA (E. Cape), who are one of the Project partners.

Terms of Reference

The terms of reference for the study were:

- To develop research procedures and instruments for understanding community responses in the fields of HIV/AIDS prevention, support and care within Bambisanani target communities.

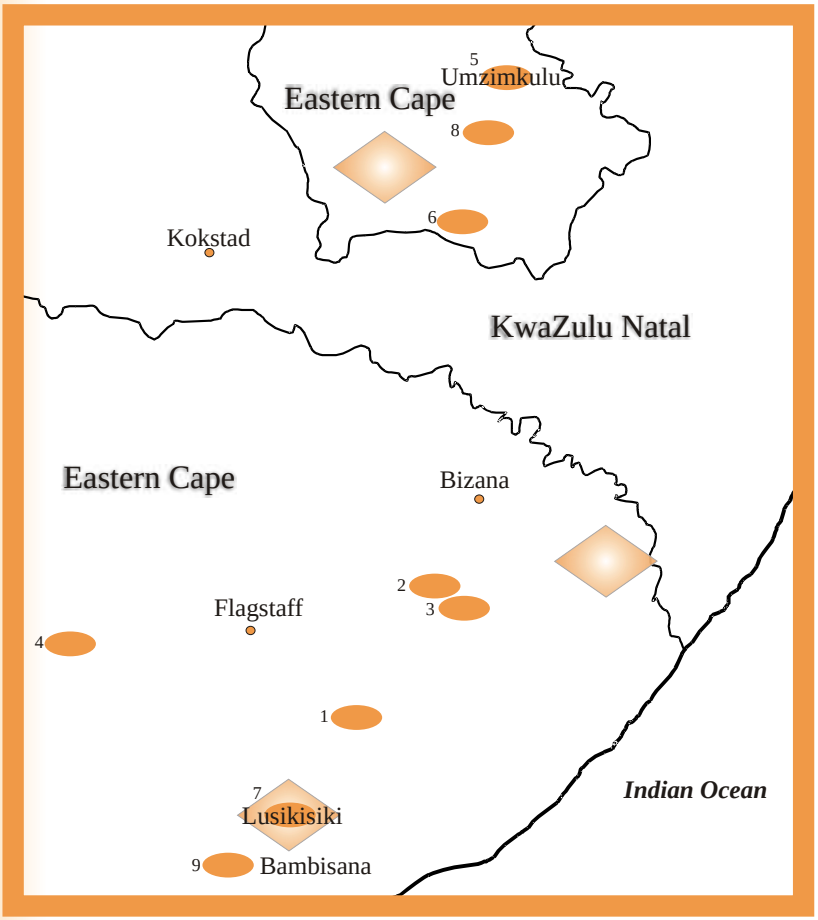
- To conduct research using these tools in order to describe community responses to HIV/AIDS in Bambisanani target communities.

- 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.

Map indicating Project Areas and Research Sites



Methodologies

The research process followed the following steps:

- Field visits to rural areas and hospitals followed by focus groups with PPASA health promoters and the Bambisanani Project 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 rural areas; out of school youth; school going youth; traditional healers; church members involved in home visiting; PLWHAs; health workers in a rural outpatient clinic; and health workers in a rural inpatient facility.

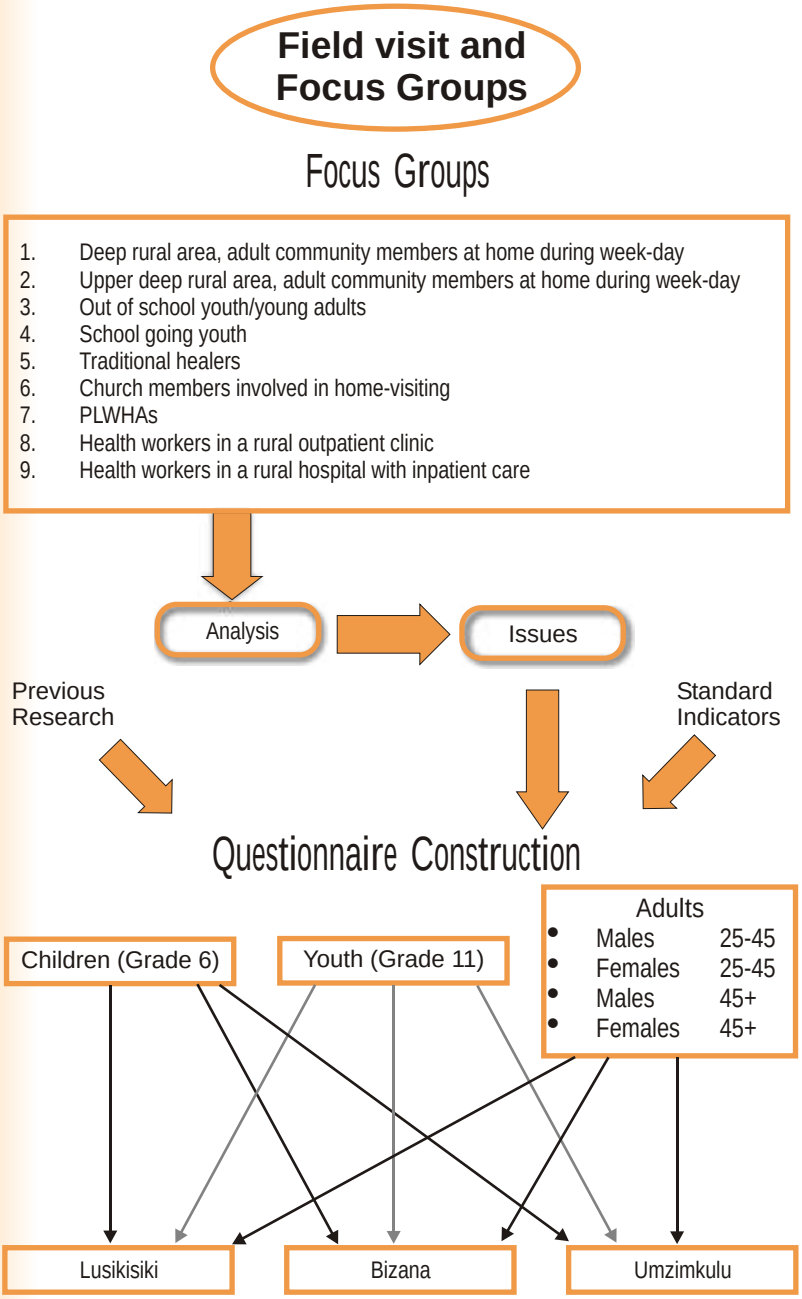
- Analysis of focus group data and construction of three questionnaires.

- Administration of questionnaires to grade 6 students (average age 12.5 years), grade 11 students (average age 18 years) and community members (average 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 the above sites.

The research process is depicted diagrammatically on the next page.

Research Process



Findings

The following represent the key findings of the study.

1. Demographic context

The largest towns 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 though the countryside, and often without road access.

There is very little crop agriculture in evidence as one travels through the area, and there are very few opportunities for employment in the rural areas, 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.

2. Socio-economic context and availability of services

Community members are 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, even in some of the more remote areas, including the provision of electricity, building of classrooms and the upgrading of rural roads.

- Media access in the home as measured amongst adult respondents was:
  85% radio; 42% television; 9% newspaper; 11% magazine; 17% telephone.
- A self-reported measure of socio-economic status revealed as follows:
  37% of adults reported 'Not even enough money for basic things like food and clothes'; and 58% reported '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 learners in one classroom, all are without lights in the classrooms and most are without running water.
- Some of the schools 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.
- Services in community for persons with HIV/AIDS are either non-existent, rudimentary, or of poor quality.

3. 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%; adults 14%. [1]

1 *Children are defined as being between 11 and 15 years*
Youth are defined as being between 16 and 20 years
Adults ranged between 25 and 59 years

- 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+, or 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, 43% are 30 years old or younger.

- Reporting children in their community who have lost both parents:
  adults 42%.

These figures suggest that the reality of the impact of HIV/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 HIV/AIDS amongst youth and adults is generally good, though there are definite areas of knowledge inadequacy. Knowledge of HIV/AIDS is poor amongst children. For example, 57% of children believe that one can get HIV from using the same cup, but only 16% of youth believe this and 27% of adults.

- Only 9% of youth and 13% of adults believe that HIV/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 report that HIV/AIDS has been discussed in class either not at all or only a little and there was no evidence of systematic life-skills training in any of the schools visited. Efforts that have been made are individual ones rather than part of a systemic response.

- Fifty three percent of youth have discussed HIV/AIDS with friends and 45% of adults have done so, suggesting that there is need to promote greater communication around HIV/AIDS.

- Seventy percent of children and 82% of youth have been 'warned' by their parents about HIV/AIDS, although it seems that there is little communication between parents and children about sex.

- Only 27% of adults reported that they had attended a meeting in their community where HIV/AIDS was discussed.

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. In particular the belief that HIV/AIDS comes from 'elsewhere' means an underestimation of risk of 'local' infection.

- 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.

- The predominant pattern of multiple partnering is concurrent partners, as opposed to a strong serial monogamy pattern (i.e. rapid changing of partners). One implication of this is that prevention efforts need to focus on the tricky area of multiple concurrent sexual partners.

- The age of first sexual intercourse is becoming progressively younger. Explanations of this phenomenon range from the impact of increasingly sexualised television and popular culture, to experimentation initiated by the widespread availability of condoms to lower ages of biological maturity. Whatever the causes, it needs to be studied, and sexuality education efforts must understand the nature of early sexuality.

Age at first sexual intercourse: youth %						
	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: adult %				
	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

The two tables provide a comparison of the situation in 1974 to the situation in 1997, demonstrating the differences in sexual experiences between girls and boys and the lower age of sexual debut amongst youth today.

Other features that are noteworthy are that:

- 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.

- Twenty two percent of young women had their first sexual experience with someone five 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, 5 years is psychologically speaking a significant difference.

- The adult cohort shows that the age differentials at sexual debut between young girls and their first sexual partners were even greater in the past. For the adult female group the age difference was 4.1 years as opposed to 3.2 years

- for the youth group. This suggests that age differentials are not a new phenomenon, although as pointed out above, the psychological significance of age differentials has increased with the declining age of sexual debut.

- Twenty four percent of youth, having had sex before, have not had sex in the past year. There is qualitative evidence that the motivation of HIV risk reduction may account for this trend which is especially evident amongst young women. This suggests that 'secondary' abstinence is an HIV prevention strategy worth promoting. 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.

- 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.

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

> ***"I think that 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 (female)*

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

- 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.

Condom use and acquisition

- 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 method.

- 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 26% 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 15km away and the mobile clinic requires at least a 3km walk for many members of the village, and then it visits only twice a week. One of these times is during school hours.

4. Care and support

Response to people with HIV/AIDS

- The response to people with HIV/AIDS is characterised by uncertainty, but is not expressly negative. However, 28% of adults report that there are people in their community who are unkind to people with HIV/AIDS. Although negative attitudes aren't normative, there is a negative and unempathetic response on the part of enough members of communities to make disclosure problematic. Further, perception of HIV/AIDS as a death sentence creates a sympathetic context for response to people living with HIV/AIDS (PLWHAs), but a poor context for responding to them in an affirming way. Fifty five percent of adults report that attitudes to PLWHAs have changed positively over time. On most indicators of attitudinal response children proved to

Attitudes to people affected by HIV/AIDS

	Children %		Youth %		Adults %	
	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

- have significantly more negative attitudes to PLWHAs, corresponding to their much poorer understanding of HIV/AIDS and less exposure to HIV/AIDS education or messaging than adults or youth.

- The focus group with PLWHAs 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. They are sometimes publicly humiliated by cruel comments, but more commonly, they suffer many small indignities, such as people being reluctant to eat food that they have prepared.

HIV testing and disclosure

- The overall picture is that whilst counselling is accepted as necessary and important, and whilst there are personnel in place to do this, in general 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. Transport is a key factor, as a visit to a clinic often takes up an entire day.

- There is a poor context for disclosure of HIV positive status given that there is little support available for PLWHAs, and poor understanding amongst community members of the possibilities of positive living.

Care of the ill

- Concerning the attitudes 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.

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

- A positive context exists for home care given the poor evaluation 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 HIV/AIDS in the household.

- Secrecy around HIV/AIDS is also a reason for wanting to care for people at home.

- 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. Therefore, there needs to be recognition of sensitivities around cross gender care, especially with regard to washing and directly handling a person's body.

- 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.

> ***"They will come back from the hospital and they will tell you that its better to come home to die in the hands of loved ones. They complain of ill treatment at the hospitals."***
>
> *Respondent (female)*

Recommendations

The recommendations include the need 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.

1. It would have enhanced the study to have conducted an audit of testing and counselling services, the 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.

   Community responses are significantly determined by aspects of the surrounding context including the services provision context.

2. 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 HIV/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. 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.

3. 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 PLWHAs.

   Active advocacy for improving these systems should 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.

4. There is little or 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, it is often individuals within these families who carry the burden. The only groupings that are already part of the broad care framework are PLWHAs, church home visiting groups and traditional healers.

5. PLWHAs 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 capabilities and skills. They say that they need 'proper training'. They also need to have access to information and advice on how to deal with problems they encounter.

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

6. Traditional healers are often used as a first port of call in seeking help for chronic health problems. They could play an important role in community health education, in identifying HIV/AIDS cases, and assisting with palliative care. 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.

   In addition, because of divisions in the ranks of traditional healers, they seem to be an especially difficult group to develop associations with at a formal level.

Pointers for monitoring and evaluation

Based on an understanding of key issues which has 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 the 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 the 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 were covered by parallel research projects.

Prevention

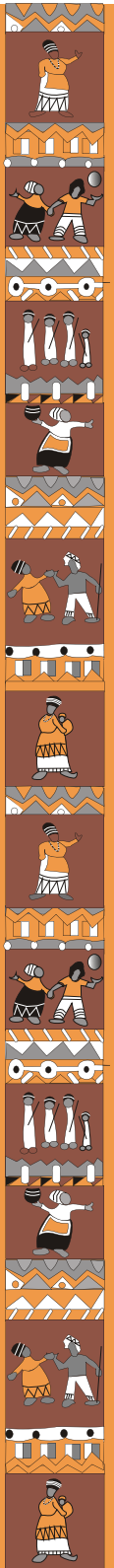
- Presence of media promoting changes relating to shifting norms around age of sexual debut
- Measurable change in normative thinking about age differentials when one of the partners is under the age of 16 years
- Confidential condom access within the parameter of weekly activities
- Regularity of condom 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 life-skills education
- Access to sources of further information
- Funerals where the cause of death is acknowledged as HIV/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 PLWHAs
- Involvement of PLWHAs in support and education services
- Training of PLWHAs 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/AIDS 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
- 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 PLWHAs
- Evidence of inter-departmental (welfare, health, education) meetings and projects



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