MAKING HIV/AIDS OUR PROBLEM

YOUNG PEOPLE AND THE DEVELOPMENT CHALLENGE IN SOUTH AFRICA

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Save the Children

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Note

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CHAPTER 1

AIDS DEVELOPMENT AND YOUNG PEOPLE – THE CHALLENGES

During 2001, Save the Children commissioned a number of studies related to HIV/AIDS, children and young people in South Africa. This included the development of a literature review of young people's responses to HIV/AIDS in South Africa entitled: *Pathways to action: HIV/AIDS prevention, children and young people in South Africa.*[1] Running parallel to this study was the exploration, through formative field research, of approaches to engaging youth response to HIV/AIDS. This involved the development of two action research interventions – one in Amatole Basin, a rural community in the Eastern Cape, and the other at Sibonile School for the Blind, located at Klipriver in Gauteng. The overall aim was to examine in detail, through two case studies, the challenges facing the community and young people in particular, in developing a sustained and effective response to HIV prevention. Objectives included:

- Exploration of the challenges of HIV prevention in two different communities, based on the findings of *Pathways to action*.
- Exploration of the mediators of HIV/AIDS response in each of these communities.
- Engaging young people in the challenges of reorienting their personal, interpersonal, communal and social lives in a way that is conducive to HIV prevention.
- Engaging the community context through exploring and addressing the community and social[2] dynamics (including service delivery) that impact on young people's responses to HIV/AIDS.

…it is important to recognise the heterogeneity of young people in South Africa when developing HIV/AIDS responses.

In *Pathways to action* it is suggested that it is important to recognise the heterogeneity of young people in South Africa when developing HIV/AIDS responses. Bearing this in mind, the case studies reported on here were deliberately conducted in two very different contexts. There is clearly a need to explore many other contexts of young South Africans in order to know the challenges facing young people. But the two contexts described in this report provide much to reflect on. This is of relevance beyond the boundaries of these communities, and many of the emerging issues and practices have application in other communities and contexts.

Work with the group of young people from a poor and under-developed rural environment in the Eastern Cape allowed for reflection on the challenges of responding to HIV/AIDS in a community where the general social environment offers few resources and little support for young people trying to take hold of their lives. In many respects, the predicament of these young people exemplifies, in stark relief, the context of many young South Africans who encounter the

1 Kelly, Parker & Oyosi, 2002

2 We use the term community to refer to the context of relationships between people and groups of people who have shared concerns and aspirations, including structures and practices that determine these. The term 'social' refers to the broader context of the society as a whole and the structures and operations of this society that have an influence on the opportunities and aspirations of individuals and communities.

challenge of responding to HIV/AIDS in environments that afford little support for their efforts.

Working with visually impaired young people allowed for reflection upon what it means to develop a response to HIV/AIDS in a context where access to information, social integration and independence are compromised, and where there are higher levels of custodial care than is the case for able-bodied young people. In this context the challenges of independence which exposes young people to risks as they venture beyond that which is familiar and well known, were examined.

From crisis to development

The concept of 'crisis to development'[3] conveys a critical tension between social development and the exigencies of responding urgently to what is in many respects a crisis. Analyses of the context which has contributed to the severity of HIV/AIDS in South Africa have often pointed to problems of poverty, lack of access to resources, poor service delivery and so on – all of which are typically slow to ameliorate, and require a developmental approach. Appeals to 'declare a national emergency', 'to declare a war against AIDS' and 'to unite together against a common enemy', are well and good, but they represent a particular kind of discourse that over-simplifies the steps necessary to address social and community development, poverty alleviation and access to opportunities.

There can be little doubt that behaviour change approaches underpinning many communication campaigns in South Africa have a fundamental limitation in not addressing the complex contextual factors that mediate behaviour. As is described in *Pathways to action*, behaviours and practices in relation to HIV/AIDS are not framed by simple individual choices, but rather, are shaped and framed by access to resources and services, social justice systems, economic factors, gendered aspects of sexual negotiation, and the prevalence of sexual violence, amongst other factors. In contexts where individual choice is diminished it is clear that a focus on the individual is insufficient and inappropriate.

3 This title is borrowed from a publication by the Transitional National Development Trust: Meer & Rodwell, 2000.

The two projects reported on here set out to explore the capacity of young people to respond to AIDS, and specifically involved exploration of how contextual factors mediate response at individual and community level.

The two projects reported on here set out to explore the capacity of young people to respond to AIDS, and specifically involved exploration of how contextual factors mediate response at individual and community level. In each context many obstacles to the ideals of appropriate preventive behaviours and practices were found. In each context the challenge was then to look at what needed to be done to address these obstacles.

Response needs range from simple development of the intention to address prevention at the level of the individual, to the need to address allocation of resources in community administration. In some instances opportunities for change were already available and easily mobilised. In other cases longer term development initiatives are necessary.

It has been said that 'Not only will it [HIV/AIDS] mean development goals are unattainable, but in fact that there may be a real reversal in the development status of many nations, and "development" can not be business as usual'.[4] HIV/AIDS is sometimes spoken about in this way, and with good cause. The numbers of people infected and the social impacts predicted have far-reaching impacts that need to be reflected in all areas of social planning. But it is also true to say that HIV/AIDS brings attention to the need for development including the need to address socioeconomic issues, public service delivery problems, and social inequalities including gender issues. In some respects, the need to address HIV/AIDS has mobilised a focus on issues that may otherwise not have received the attention they have. For instance, gender issues were identified early on in AIDS campaigns as a critical factor needing to be addressed and many AIDS programmes[5] have included this as a focus. Similarly, rural health service development promises to draw attention to long-standing problems associated with health delivery. The point is that what needs to happen to manage AIDS makes good sense from a social development perspective, AIDS aside.

In *Pathways to Action* one conclusion was that there is a pressing need to endorse and focus on social mobilisation at all levels. It was stated in this report that there is a need to move beyond the over-emphasis on mass media campaigns, and to develop a second wave of response, which is development of local and district-level initiatives.

It was suggested in the review that there is a growing wave of attempts at local level to find ways of responding to the threat of HIV/AIDS. Even in some of the remotest areas of the country one can find community leaders, cultural groups, or service clubs that have tried in different ways to do something about HIV/AIDS. But these nascent attempts are mostly unsupported, are seldom directly funded, are often not strategically developed or sustained, and are sometimes even at odds with the needs of the broader society. It is important therefore, for campaigns at this level to take into account the development of the society's capacities to respond to the epidemic. It is important not to offer solutions without simultaneously advocating for and creating a context for such delivery. Further, communication activities do not go very far in addressing the many underlying structural, organisational, capacity and developmental problems that need to be addressed in creating effective local level responses to the epidemic. In fact, in general, it appears that there has been an over-reliance on high budget HIV/AIDS communication activities at the expense of

4 Badcock-Walters & Whiteside, 2000, p 1

5 Kelly et al, 2000

systematically developing and supporting a primary, community-based response.

Young South Africans responding to HIV/AIDS

In *Pathways to action*, a number of observations were made in relation to the development of young people within an HIV/AIDS context. These included:

- The need to take stock of programmes for young people, and even though there are a wide range of programmes, there is little coordination of efforts.
- The need to take stock of what has already been achieved through prevention interventions, and to consider what types of efforts have been more and/or less successful.
- The need to understand that certain appropriate attitudinal and preventive responses have taken place, and to endorse and promote these – for example, high levels of condom use and secondary abstinence.
- The need to understand areas that have been overlooked, for example: delaying sexual debut, addressing age differentials between partners in early sexual experiences, treatment of sexually transmitted infections, protection of children from sexual abuse, and reduction of sexual partners.
- The need for awareness programmes to place a greater focus on children, and for a developmentally sensitive approach to sexual education.
- The need to target the contexts where prevention behaviours are exercised – within interpersonal relationships, family relationships and at community level. This requires a social mobilisation and community development emphasis.
- The need to move away from once-off event-based approaches towards more integrated and sustained activities.
- The need to target interpersonal, community and environmental supports necessary for enabling and supporting appropriate behaviours and practices. These include the development of lifeskills; development of youth norms around HIV prevention; enrichment of young people's recreational and cultural environments; development of services appropriate to adolescents; and development of the regulatory environments that endorse social commitment to the needs and rights of young people.
- The need to recognise and address the gender disparities in sexual activities, especially the gendered and cultural aspects of sexual negotiation. These need to be targeted at a social as well as an individual level, and should be couched in the broader framework of legal and human rights.
- The need to adopt models of intervention which emphasise maintenance of specific behavioural decisions and which focus on individual, cultural

and social elements which support decisions to avoid risk, including value systems, rights and legal frameworks.

- The need for response to be consolidated at local level and district level, through the development of practical models for social mobilisation in different areas of prevention, care and support that can easily be applied by organisations working within communities.
- The need for programmes and interventions to be developed to a much greater extent on the basis of sound research and evaluation. There is a need to understand the relative costs of different kinds of interventions, measured against the types of achievements that they might be expected to deliver.

Young people are often grouped together under the category of youth, and it is all too easy to assume that they aspire to the same things, deal with problems in the same ways and face the same difficulties. But whilst young South Africans may share many challenges, there is also much heterogeneity.

A good deal of HIV/AIDS activism has followed an ad hoc approach, often based around common sense thinking about what needs to be done, how it should be done and in what order. To a large extent a 'one size fits all' approach has been followed and there has been much too little appreciation of the unique challenges facing distinctive populations of young people. Young people are often grouped together under the category of youth, and it is all too easy to assume that they aspire to the same things, deal with problems in the same ways and face the same difficulties. However, whilst young South Africans may share many similar challenges, there is also much heterogeneity.

Whilst globalisation is undoubtedly becoming a major influence on the aspirations and lifestyles of young people and whilst the advent of a more open and racially desegregated society is breaking down some of the historical legacy which created divisions, distinctive communities of young people remain in place. Exposure to risks of HIV infection and opportunities for responding effectively to HIV/AIDS have been shown to differ by: locality (rural/urban, urban/peri-urban); socioeconomic status; educational level; age; gender; and physical capacities (able-bodied/disabled) amongst other characteristics. In spite of whatever homogenising forces may impact on young people, the mediators which underlie these differences continue to impact in a major way on HIV vulnerability and response.

With this in mind the action research projects reported on here were conceived of as contributing to understanding, developing and implementing strategies for addressing some of the seemingly more intractable problems facing specific communities of young people in responding to HIV/AIDS.

The parameters of the project

The two action research case studies focus on challenges facing the society, and young people in particular, and the development of a sustained and effective response to HIV prevention. Objectives include:

- Exploration of the challenges of HIV prevention in two different communities, based on the findings of *Pathways to action*.
- Exploration of the mediators of HIV/AIDS response in each of the communities of young people.
- Engaging young people in the challenges of reorienting their personal, interpersonal, communal and social lives in a way that is conducive to HIV prevention.
- Engaging the community context as a whole through exploring and addressing the community and social dynamics (including service delivery) which impact on young people's responses to HIV/AIDS.

Sites

The sites used in this study were chosen because they involved young people who have been particularly overlooked in developing HIV prevention responses in South Africa, namely, disabled young people and young people living in rural areas. It was felt that the lessons learned in these two kinds of environments would be of a more general value, as they represent extremes of the predicaments that are common to young people more generally. These issues are: the relation between care/protection/sheltering and independence/risk; and the challenge of taking hold of one's life and developing a sense of the future and self-protection in an environment that is less than accommodating and which offers little support.

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The rural site was one which the project team had had previous contact with as a research site and also through previous development projects, notably around pre-school development. This allowed relatively easy access – certainly making the task of gaining access and winning support for the project much easier.

The disabled children's site was approached without any previous contact and this was a valuable experience through which much was learned about being visually impaired. The involvement of custodians in the life of the visually impaired works both for and against the independence of young people and this issue proved to be an important one in understanding the challenges of HIV prevention in this context.

Research and development approach

The approach was an attempt to understand the challenges of implementing contextual and developmentally oriented HIV/AIDS responses building on the foundation of what has already been achieved through the collective impact of various multifaceted interventions.

The approach was 'action research' oriented which meant implementation of ideas included participation and social action as ways of testing and extending their viability and practicability. It also meant that the ideas were never seen as fixed or static, but rather in a state of development through implementation.

The project sequence in each instance was led by the need to identify and address the contextual mediators of response to HIV, which meant that the focus was inevitably not only on the immediate life-worlds of young people, but also about the environmental mediators of experience. The interventions were conducted with a view to developing potentially sustainable localised responses. The approach in each site was resource limited and each project was approached with a view to achieving success within these limits.

It was intended that the achievements of each project would be 'institutionalised' in some way, so that maintenance of achievements and momentum for further development would be built into the system. The entire approach was also useful towards understanding what tools and models are appropriate and useful for different types of interventions and at what stages.

CHAPTER 2

RURAL YOUNG PEOPLE AND AIDS DEVELOPMENT

The site: Amatole Basin

Amatole Basin is a deep rural area, consisting of 13 villages situated between Alice, Hogsback and Middledrif in the former Ciskei area of the Eastern Cape. The villages are organised into three clusters and there is a central village – Komkhulu: Great Place – where the tribal authority, high school and clinic are located.

Access is on a dirt road that winds 20 kilometres along the course of the Amatole River. The villages lie scattered on the sides of a valley between two ranges of hills. Each village consists of 40 to100 homesteads made up of a collection of permanent wattle and daub (and sometimes brick) structures. The number of people living in each homestead varies from one to ten. Many of the multi-generational households are female-headed and in the course of this project we also came across a few households with children living on their own under the supervision of older siblings, due to parents being away for work reasons.

The socioeconomic profile of Amatole Basin is typical of what can be found in many areas of the Eastern Cape. In a questionnaire-based survey conducted in 1999,[6] 25% of respondents indicated that they had not enough money for basic things like food and clothes, whilst a further 62% indicated that they had money for food and clothes, but were short on many other things.

There is very little employment within Amatole Basin. Adults residing here are mostly unemployed, receive pension money, or survive off earnings of family members living and working in towns and cities. The population has unusually high proportions of people of pensionable age and school children, although some out of work young people stay in the village before they move to cities to

6 Kelly, 2000

find work. Many of the elderly adult population are former migrant workers who previously worked as domestic workers, or at mines, factories and farms. Some villagers work at a nearby agricultural college and the nearby commercial forestry station, but there are no other major employers in the area and there is little growth other than government-initiated infrastructural development. The local economy is largely dependent on state grants to pensioners. There are a few small shops and liquor stores as well as some *spaza* shops (at least one per village), and a number of drinking taverns in the area. Villagers mostly purchase goods on account which are paid when pensions are received or money is sent from towns.

The Amatole Basin has one secondary school (320 pupils) and eight primary schools. There were no matric passes in the high school over the 1997 to 1999 period, in 2000 there was an 11% pass rate and in 2001 there was an 8% pass rate.

The Amatole Basin has one secondary school (320 pupils) and eight primary schools. There were no matric passes in the high school over the 1997 to 1999 period, in 2000 there was an 11% pass rate and in 2001 there was an 8% pass rate. Many of the teachers commute to the Amatole Basin on a daily basis.

Gravel roads and flooding rivers contribute to isolation of the community, and some villages may be cut off for days at a time during the rainy season. The villages are serviced by a once daily government bus service and private taxis are also used.

Very few villagers till more than a small vegetable patch and even this is not common. Agricultural activity is mainly restricted to the keeping of livestock. A few households have horses which are used for transport. There appears to be a declining knowledge of farming practices and decreasing agricultural outputs.

The Amatole Basin has one health clinic located in the central village, which is as much as 14 kilometres away for some residents. The nearest hospital is in Alice, which is about 30 kilometres away and the area is not serviced by ambulances. There is a family planning service at the clinic and a medical doctor visits on a monthly basis. There are no dental services. A village health worker in each of the villages is mainly involved with health education work and health visiting. People also draw on traditional healers for common illnesses and knowledge of plant-based remedies is good.

Most of the villages have acquired a water system of communal taps, which distribute water pumped from local streams, but many people still collect and carry water to their homes from some distance away. No households have running water and there is no waterborne sewage. Electrification of the area is underway and in the course of this project many households obtained electricity, managed by a system of pre-payment. Only a very few households have generators, and batteries have usually been used to power televisions and radios. Some of the villages have public telephones and there are very few private telephones. There is poor cellular telephone reception in the area.

The governance processes in this area are complicated due to overlapping of Traditional Authority and democratic systems. The Amatole Basin is under the control of a traditional leader (widely referred to as the chief) in his 20s, who replaced his deceased grandfather in 1999. He acknowledges that the community is mixed in their allegiance to his authority and in many respects his mother is the de facto traditional leader of the area, as he spends relatively little time there. Traditional Authority jurisdiction relates mainly to agricultural matters such as management of grazing land and dipping of cattle. The traditional leader presides over the Traditional Authority which consists of one representative and one residents' association chairperson from each village. The responsibility

for enacting the decisions of the Traditional Authority rests with the chairperson of the residents' association (who is elected annually). After the 1994 elections the villages were represented in the Eastern Cape parliament through a councillor elected to the Transitional Rural Council. However, it seems that villagers have very little real contact with government and the relationship between the elected councillor and the tribal authority appears to be uneasy.

There are a number of Christian churches in the area with varying levels of membership. Churches are an important part of community life and church halls are the only spaces available for community meetings. The area like most rural areas has a strong traditional culture. Further, because young people tend to leave the area and there are few newcomers, there is relatively little generation of new forms of cultural expression.

Project objectives

Within the scope of the action research programme set out in Chapter 1, the following were adopted as specific objectives of the project.

- Create a context for addressing sexual health issues with special reference to HIV/AIDS, which takes into account the particular needs and challenges facing young people in a remote rural environment.
- Engage young people in a programme of action aimed at developing the foundations of a lasting HIV/AIDS prevention initiative.
- Assist the community in mobilising a framework of support for them in this endeavour.
- Evolve a more supportive environment for disclosure of HIV status and assisting people living with HIV/AIDS.

Engaging the community and establishing a support framework

Although we had previous contact with Amatole Basin communities through involvement in sentinel site evaluation of young people's responses to HIV/AIDS and pre-school development projects in the area, in many respects initiation of the action research process required fresh foundations to be laid.

As might be expected of a relatively isolated and under-developed rural community, when something new happens, people quickly know about it and it is important not to establish allegiances with particular sectors of the community as there is the risk that the project is identified with particular interests and this may preclude the involvement of others. Engagement thus involved a strategic approach.

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The process of engaging with the community involved various parallel activities.

- *Meetings with district health, education and welfare managers:* It was anticipated that the project would need ongoing support, and district offices of these government departments were already involved in these communities in various ways. Enthusiastic support was expressed, and offers of assistance were made. This support provided a sense of legitimacy in approaching schools, the clinic and the Traditional Authority. This became more important as the programme developed and active involvement of educators and health workers in particular was sought.

- *Meetings with the Traditional Authority:* The Traditional Authority endorsed the project and offered support. Leadership support was essential for gaining cooperation of various groups throughout the project. In the meeting with the Traditional Authority a number of sectors of the community were identified as needing to be specifically engaged with including: schools; traditional educators; young people in and out of school and youth groups (especially soccer clubs and gospel groups); male and female parents and guardians; churches; traditional healers and educators; and the local health clinic.

- *Engaging the community:* The initial plan devised with the Traditional Authority had been to divide the community according to the above groupings and to meet each group in a central venue. It was then realised that this would be practically impossible considering the distances that had to be covered between the 13 villages. The team therefore grouped the villages according to proximity and a set of questions was prepared for discussion by each of the groups involved.

- *Engaging young people to coordinate the project:* Whilst there was interest on the part of the Traditional Authority in coordinating the project, this institution lacks youth representation. It was also evident that the coordination of early development activities would proceed very slowly in the periods when the research team was not present. Two willing young organisers, a male and a female in their mid 20s, with previous involvement in development work expressed willingness to assist with the task of sustaining the impetus between visits of the research team. The organisers were offered small monetary incentives to cover costs involved in travelling and communicating with stakeholders. Selection of local organisers was potentially problematic as there was no democratic process involved. However, because they were coopted early on, it meant they were associated with the project from the start and their role in the project was never questioned. It seems important in such circumstances to balance expediency with sensitivity to community needs. Had volunteers been called for, much time would have been expended in selecting people and the outcome may have created division. As it happened, the two coordinators formed a planning committee and there was ample opportunity for enthusiastic people to become involved.

Having established a relationship with the community, a process of enquiry began as a precursor to development of an action plan. At this point, it was not clear what direction the project would take. *Pathways to action* suggested that it would be important to explore the challenge of establishing a sustained HIV/AIDS response framework, and that it would be necessary to consider and address the mediators of community response to HIV/AIDS. Further details of this process of enquiry are provided below.

The context of young people in Amatole Basin in relation to HIV/AIDS

It was the subjective impression of the Cadre project team that there are many depressed young people in the area. It is notable in this regard that there have been at least six suicides in the area over the past year, although only some of these have been young people. This is perhaps indicative of a socioeconomic environment that offers little promise and a social fabric which in many respects

has worn thin. There is little social support for young people. Their poverty, isolation and lack of any evidence that their situation is changing provide little real reason for hope.

There is little social support for young people. Their poverty, isolation and lack of any evidence that their situation is changing provide little real reason for hope.

Young people in Amatole Basin are all too aware of the lack of post-school opportunities. It is only the exceptionally talented and fortunate ones that can realistically imagine their way out of this situation. Even those who might go on to receive further training are constrained by the lack of finances available to support them. For the rest, young people rely on soccer clubs and singing groups to pass their time, and even then they are constrained as these activities require them to travel if they are to be successful and show the world what they have to offer.

Growing up in Amatole Basin

Young boys, without exception, undergo a process of initiation involving circumcision to mark the transition from boyhood to manhood. This usually occurs at around the age of 18. Traditional educators oversee this process. However, there is actually very little lifeskills education involved, although warnings about the risk of HIV/AIDS are given during the process.

After initiation the status of young men changes dramatically. They are afforded more respect by older members of the community and are freer to express their opinions and to participate in community affairs. Young men typically build their own outside rooms after initiation and become more sexually active. Unfortunately, whereas initiation prepares young people for culturally sanctioned adulthood, it does little to provide them with the opportunities that they need to escape dependence on the pensions of their grandparents, or to become mature people able to stand their ground in the wider community. Most of these young people are destined to go to cities to seek work, and if they are lucky they are able to find and remain in menial and poorly paid jobs in order to survive.

There is no equivalent initiation process for young girls, although it is reported that there used to be a female equivalent. The economic situation of young girls is possibly more dire than it is for young men, as there are generally fewer

employment opportunities for young women. Their plight, and the inevitable journeys to the city to find work make them vulnerable to men with some resources.

Sexual experience

In the 1999 survey, it was found that 92% of youth had previously had sex. 22% of this group had had sexual intercourse at or below the age of 11 years and 62% had had sexual intercourse at or below the age of 15 years. The average age of first intercourse was 14.8 for males and 15.9 for females. In respect of age of sexual debut, this site stood out from five other sites across the country, as having a significantly lower age of sexual experimentation and intercourse debut. There are various factors which underlie this phenomenon[7] including:

- the breakdown of family culture over a period of many years, which is associated with high levels of migrancy and high levels of father absenteeism;
- lack of stimulation and activities for young people and poor career or future-orientation;
- breakdown of a previously widely practiced culture of non-penetrative sexual practices, such as thigh sex;
- breakdown of a culture of monitoring and regulating early sexual activity;
- changing practices and expectations in relationships; and
- liberal administration of injectable contraception for young girls at the first signs of having sexual interests.

The predominant pattern of sexual partnering is serial monogamy. Being a tight knit rural community people tend to know who is associating with whom, and HIV risk is probably associated more with high turnover of monogamous partners than multiple concurrent partners.

Sexual education and communication

The expectations of parents and community are unclear and contradictory and there is a sense of resignation about the inevitability of young people being sexually active.

In the survey mentioned above, Amatole Basin stood out as the site with the highest 'yes' response to 'Sex was not discussed with my parents'. It seems that whereas parents and the community previously had clear expectations supporting culturally sanctioned ways of delaying sexual activity, these have largely fallen away. The expectations of parents and community are unclear and contradictory and there is a sense of resignation about the inevitability of young people being sexually active. Young people learn about sex largely through observing the behaviour of others and from older siblings and friends. There is little formal sex education beyond an occasional visit of health educators to schools, and there is very little interactive health education. Some teachers and community members have attended HIV/AIDS educator courses, but there is no plan within schools to accommodate what they are able to offer in a systematic way.

The only formal programmes on HIV/AIDS education are talks given by clinic sisters and an itinerant health educator at the local high school. The clinic sisters say they lack resources such as charts of the reproductive system, which

7 Kelly & Ntlabati, 2001

have to be brought in from the district office when they are needed. The clinic has HIV/AIDS educational posters on the inside walls and condoms are reportedly distributed to anyone over the age of 13 who requests them.

Sexual activity begins with sexual experimentation in the context of childhood games like *Undize*, which is a form of hide and seek which has progressively become sexualised over the years. The changing nature of this game reflects the general change in sexual culture in this community. Young people learn about sex from each other in such games and there is very little by way of inter-generational input on matters of sexual and reproductive health.

Knowledge of HIV/AIDS

Knowledge of HIV/AIDS was lower in this site than in six sites studied across the country. This is not surprising given the relative low exposure to mass media by these young people and few other opportunities to learn about HIV/AIDS. A study of media[8] sources in the home shows that these young people have had significantly lower exposure to television than their urban counterparts. However, this is changing rapidly as electrification comes to the area, and it is expected that this will provide opportunity for exposure to a wider world of ideas.

Media sources in the home by percentage include: television (45%), radio (86%), daily newspaper (10%), weekend newspaper (2%), magazines (11%) and telephone in home (2%).

It was surprising that few people in this community seem to know someone who is HIV infected. The village health worker reports that people have become more secretive about tuberculosis because of its association with HIV/AIDS and there is a general veil of secrecy around AIDS. Clinic sisters and village health workers are aware of only a few cases of HIV/AIDS, and primary school teachers reported knowing of only three people who have died of AIDS. The high school

8 Kelly, 2000

principal was not aware of there having been any HIV/AIDS cases in his school. Thus there is not widespread evidence of the presence of HIV/AIDS in the area, and it seems that this community is still in the earlier stages of the epidemic.

Reproductive health

There are strong cultural disincentives around teenage pregnancy and it is common for young women to attend the clinic for 'injection'.

Recent records of sexually transmitted diseases at the clinic were not available. Concerns about the consequences of unprotected sex in the community tend to focus on pregnancy rather than sexually transmitted infections or HIV/AIDS. There are strong cultural disincentives around teenage pregnancy and it is common for young women to attend the clinic for 'injection'. The nurses report that girls come to the clinic for contraceptive injections as a matter of course after the age of 16. Mothers also bring their daughters to the clinic at the first signs of sexual activity.

Condom acquisition and use

Given that use of the contraceptive injection is common, young men have not had to be concerned about contraceptive measures and this has created a poor context for adoption of male condoms for HIV prevention. Condoms are available at the clinic and are occasionally distributed through local health education campaigns, but not generally throughout the villages. In 1999, 27% of young people reported condom use at last sexual intercourse, which was lower than in other research sites and this can partly be attributed to lack of confidential access at the clinic. As a result some young people stock up on condoms when they visit larger centres and supply these to their peers.

Implementing the action research project

Development and implementation of the project followed a number of interconnected stages:

- gaining access, and developing a programme support framework;
- initiating a process of enquiry leading to the formulation of an action plan;
- developing community mobilisation and support for the plan;
- adoption and implementation of the plan;
- development of parallel support initiatives.

Enquiry leading to an action plan

In exploring the possibilities for intervention, there was a need to take stock of existing responses to HIV/AIDS. Questions included:

- How is the community organised in terms of AIDS?
- What mediates responses to HIV/AIDS?
- What structures/processes are involved?
- What opportunities are there for development and who might be key stakeholders and initiators?
- What should the next steps be?

This process involved a four-day, live-in visit of the project team in the community to assist in the complex task of gathering information in multiple sites, which had been organised by the two coordinators.

The main activity was meetings with sectors of the community organised in clusters of villages (for example, parents from three villages). These were held in each of the 13 villages to discuss the response of the village to HIV/AIDS. There were also meetings at the clinic about the possibilities of developing youth-friendly services and meetings with schoolteachers about the possibilities of school-based initiatives.

Attendance at meetings varied across villages and were related to levels of organisation and cohesiveness within a particular village. Target groups within each sector (for example, church members, female youth out of school) were provided with questions that were used to facilitate discussion around HIV/AIDS issues. These questions clarified their values and perspectives on HIV/AIDS and assisted in orienting them to how they might respond more constructively as a social group.

The task was explained as providing a platform for developing realistic commitment to tackling AIDS at a level where each group might make a small but appreciable difference.

Questions considered by groups included:

- What is the prevalence of HIV/AIDS in the community? Is HIV/AIDS a problem?
- How is HIV/AIDS being dealt with in the community?
- How do you feel it should be dealt with?
- In what ways can you as a group help with HIV/AIDS issues?
- What would you like to see happening in your community regarding HIV/AIDS issues?
- What specific role do you think you could play in this area?

Following a sequence of two meetings within each village, responses to these questions were translated into ideas about actions to be taken. These were then transformed into a mission statement for each sector. There were many gaps due to certain groups not participating as actively for various reasons and this required further enquiry and inclusion of opinions not previously voiced.

After this process, the various groups, coordinated by a planning committee, fed back the results of their discussions to a large community meeting which the project team attended. This formed the basis for the Amatole Declaration,[9] a single declaration of commitment to addressing HIV/AIDS as an issue of concern for the whole community.

As part of the process of facilitating planning and adding momentum to the initiative the Cadre project team provided HIV/AIDS pamphlets and posters, and red ribbon badges were given to those who participated actively in planning. As the ideas were disseminated throughout the various communities, the notion of an inauguration day emerged. Youth cultural groups became involved, and the concept of 'the launch' was born.

Further community mobilisation and support for the plan

A committee of young people was set in place specifically to plan the day. There was much to be organised, from the cooking of food for a few hundred people, to payment for electricity to power the sound system. Attempts to elicit letters of support from government ministries were unsuccessful, and the event remained largely unpublicised and unrecognised outside of Amatole Basin.

The event was largely planned by the community, with the Cadre project team providing advice and assistance via telephone and occasional site visits. Some materials were supplied for making a sign to mark the day, and a modest amount of money was supplied to assist with catering and planning. The planning committee, comprised mainly of young people, took responsibility for inviting

9 See Appendix 1

guests, publicising the day, and arranging a programme. A locally developed billboard to announce 'the launch' was constructed by members of the planning committee, and was intended to be a symbolic, visual and permanent representation of the initiative as a whole. It was set conspicuously at a crossroad in the main village.

The Launch Day

The purpose of the day was to celebrate what the community had achieved, to formally adopt Amatole Declaration and its associated commitments and to acknowledge this was a community process that was everyone's to share.

Many women and girls dressed in traditional dress for the day, which lent the occasion a sense of cultural importance. Many young girls dressed like older women to further emphasise the significance of the event. Food was prepared by a catering committee on fires outside the venue. Attendees included approximately 300 people of all ages and included local dignitaries and welfare, education and health workers and officials.

A key address was made by a representative of the Department of Health district office who highlighted abstinence as a primary prevention measure for young people and stressed the importance of valuing oneself and looking after one's health. An address by the young person heading the planning committee reiterated the significance of the event in the life of the community. Older women took the opportunity of this event to present their views on HIV/AIDS through prayers, praise poetry, songs, questions and comments. Their contributions, like those of younger people, were enthusiastically received by participants through ululation, singing and dancing.

More than 20 community and cultural presentations were made. Many of these were presented by gospel groups, and also by *isichatimiya*[10] groups. There was enthusiastic crowd participation and a festive atmosphere. The presentations

10 Groups of young males who sing in a traditional fashion.

showed signs of much preparation and most of the content of the songs and dances, which had been created especially for the day, related directly to HIV/AIDS issues. For example, one of the chorus lines translated into: 'No cure, no vaccinations, protect yourself, wear a condom'. Many of the songs presented condom use messages, the importance of not 'sleeping around' and sticking to one partner. One song by a group of women went: 'The black nation is in peril. What should be done? The answer lies in the condom.' Another song, on a more mournful note, challenged different sectors of the community to respond to the crisis: 'We're still young – but we're dying of this AIDS. Young men are dying, young women are dying of this AIDS. Where are our mothers, where are the preachers? Where are the women of the mother's union? Where are the ministers?' At this stage the entire audience stood up and joined in singing the song. Other songs appealed to young people to go back to their 'customs'.

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The Cadre project team and some of the young coordinators of the project, presented a mini AIDS drama piece dealing with disclosure and the need for care and support. This raised key issues around social response to someone else's disclosure. The audience was invited to suggest solutions to the predicament presented and this raised a number of issues and differences amongst members of the community. This was helpful in that it made constructive debate about AIDS issues part of social exchange, and in a sense modelled what the Amatole Declaration was essentially about, namely the community making AIDS a problem which they needed jointly to discuss and address.

Other features of the day included the distribution of condoms, and the distribution of Xhosa language AIDS education materials. The red ribbon, which had been promoted throughout the campaign, was extensively used in developing media for the day. Young people had painted ribbons on their cheeks and young bare breasted girls had painted it on their chests (although white paint was used for this). A large wire mesh ribbon was created and displayed. Much significance seems to rest in wearing AIDS badges across the different sectors of the community. There was great demand for badges, not only by those who attended meetings but also for friends and family. This seems a reflection of a positive attitude both towards the issue of AIDS and the project itself.

Acceptance and support for people with HIV/AIDS was a key theme of the day and it was supported by a talk and first public disclosure by a young HIV positive woman from Grahamstown. Community members were unusually silent and attentive during the young woman's discussion and disclosure, and this was followed by numerous questions. Discussion prompted a touching story of the young woman's loss of her child and own subsequent struggle with AIDS. She emphasised how disclosure can be seen as a release from the stress of keeping a secret. She also stressed that AIDS is not a death sentence, and that people with HIV/AIDS should strive to lead a full life. Towards the end of the day, the Amatole Declaration (the Xhosa terms used to refer to the declaration are *isimis*, *umnqophiso*, *izibambathiso*) was read out to the community by the chairman of the residents' association. The Declaration was symbolically accepted by community members standing and raising their hands. They then spontaneously sang an uplifting song about raising the dead.

After the Launch Day

The following comments were gathered in a visit to the community about one month after the inauguration day. They show that the day had meant different things to different people, and that it has undoubtedly led to a wide range of positive responses, some of which are seemingly enduring.

> *It was a great day, young and old there together all hearing about AIDS. Since then have tried to change everything I've been doing, to a new style of living.*
>
> *If people become bored, they leave. This time people enjoyed it and it went deeper. Usually there are only a few people at health events.*
>
> *Even though some people are not interested in the AIDS problem, they (mostly male youth) now come to me and ask about the AIDS project.*
>
> *I was at the pension office, and then went to the ANC office in Xesi. They want to be part of the AIDS activities. They wanted to be part of the launch. I wish we had invited them!*

In response to a question about whether AIDS had continued to be discussed after the meeting we received the following responses:

Yes, in our mother's meeting, and men's meetings. And also we have had prayers about AIDS. It has given us more responsibility.

It is different. Nurses have been talking about AIDS. Before we have had a series of workshops where we talked about AIDS, but people did not talk about AIDS after that. I've just come now from a residents' meeting and they did mention a lot about AIDS there.

At the school there was a report back to Std 9 and 10. The English teacher said that we must write a whole page on the event. Then we debated it, told what happened.

We discussed the person who disclosed and how she handled herself; we discussed the sketch about discrimination and how we didn't like it (discrimination).

The HIV disclosure also had important impacts:

Seeing and hearing someone who is positive was very good. I was impressed with that lady's speech and her courage to say 'I am able to sit around people just as I am'. This speech has given them (people) another picture of it (AIDS).

A lot changed in me. It gave hope to me that even if I had AIDS I would live my life and be strong. I may have AIDS. I now have a will to go and be tested, it's easier now.

She said that when we have the virus of AIDS, what will torture us most is not telling people, but keeping it inside. She said that when you tell about it, you are free.

The most important thing was that it was great to know that a person with AIDS can live in the community and be accepted, and not be rejected.

There were also concerns expressed that it is not possible to obtain an HIV test in Amatole Basin. The presentation created interest in HIV testing, and in the wake of this the need to have testing facilities available has been added to the agenda of what the newly appointed working committee is endeavouring to address.

Since then not a single one has disclosed. We need to work on the blood-testing thing, because people don't know whether they have it or not.

One girl who is pregnant at school, because she learnt that a child could be affected through the mother, became concerned and wanted to know her status.

This now needs to be followed up with practical work to ensure that those who want or need to know their status have the opportunity to do so.

Development of parallel support initiatives

Parallel to the community process described above, a programme for involving health and education sectors in the initiative was pursued. This initiative was premised on the idea established in *Pathways to action* that it is important to mobilise and adapt existing resources for being effective in HIV/AIDS prevention efforts. This involved three specific activities:

- Formation of a health promoting schools initiative in the high school and four primary schools.

- Attempts to develop a greater degree of adolescent friendliness in the local clinic and health services.
- Training of 30 young people through a three-day HIV/AIDS peer education and support course.

Health promoting schools (HPS)

The concept of HPS and its application was discussed at length in *Pathways to action*. It was suggested that this is an ideal vehicle for developing an integrated plan of action based in schools, which mobilises not only departments of health, social development and education, but also learners, educators and parents. In essence, the model involves a stage-wise analysis of health indicators, and this then leads to developing a framework for action.

The departments of health, social development and education endorsed the value of the concept of HPS in Amatole Basin and agreed that members from each department would be incorporated into the process. An initial workshop was arranged to introduce teachers in a few schools to the concept. The idea was supported and a committee including government department representatives was elected to oversee this development. It was agreed that committees would also be formed within schools and this would include school governing bodies, learners, educators and parents.

There is evidence of some progress in some of the schools with regard to the HPS initiative. However, it is necessary to provide a more comprehensive introduction to the concept within schools and there is also the need for some material support. For instance, the provincial government department of agriculture was approached and asked if they could supply gardening implements to assist in developing school gardens as part of the HPS initiative. They responded that they would be willing to do this but requested a needs assessment and more detailed proposal. The problem is that there is no experience amongst the individuals involved and there is no support network for these schools. Support and training by those more experienced in this area is necessary, but there is no national structure for developing HPS projects. Until there is a readily accessible resource base for health promoting schools, and an initiative set in

place to actively promote the concept, poorly resourced and communicatively isolated schools are not likely to develop much momentum in this area. As it is, the model needs to be re-developed for rural schools and until this is done the prospects do not look promising. However, the community has the concept embedded in its HIV/AIDS response plan, committees are in place, and a number of government departments have expressed support. It now needs support in the form of expertise and modest funding.

Youth/adolescent-friendly health services

The aim of orienting existing services to the specific needs of young people proved to be one of the more daunting tasks attempted, and this was achieved with limited success only.

The community, with the assistance of the Cadre project team, was able to gain endorsement for the principle of adolescent-friendly health services by the Department of Health at district level. The following step was to introduce the concept of adolescent-friendly clinics to the clinic staff by an appropriately skilled person. However, intended training in the youth-friendly clinic concept has still not taken place. The district team has been put in touch with trainers in this area and further developments are awaited.

It should be noted that whilst interest in the project was expressed at the district health management level, the culture of the local clinic and its relationship to the community are sticking points in the reorientation of the health services. The clinic staff did not attend many of the meetings and seemed less than enthusiastic about commitment to the initiative. They do not live in the area and leave for home at 3pm every day.

Development of a youth-friendly service will ultimately mean needing to change these and other arrangements and there appeared to be some reluctance around such possibilities. This is clearly a process that will need to be motivated from both district management level and community level. This critical element of the response cannot be put aside without leaving a significant weakness in the response framework. The adequacy of the response framework that has been established for tackling these difficult issues is discussed below.

Training

After the launch event the launch committee identified the need for follow-up activities and in particular the need to become more expert in understanding HIV/AIDS issues.

> *We need some kind of training so that we are more informed and more knowledgeable.*

> *We must not leave anyone behind, youth are more there now. I think that there should be people around the Amatole Basin, so that they can look after the progress (of the initiative). Training of some kind is needed.*

A clearly identified need that emerged during the course of the project was for basic HIV/AIDS education and training. It was necessary to develop the stock of knowledge in the community with sound educational input and the Cadre project team felt it would be important to provide training to support the development of an AIDS response plan.

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Training involved each sector and village sending a representative to a three-day workshop in peer education and community counselling organised by members of the AIDS Training, Information and Counselling Centre (ATICC) in East London. Thirty-eight people attended this from the community, including two traditional healers, one traditional educator, 28 young people (14 males and 14 females) and eight adults (three males and five females).

Training took place after the inauguration day and it was intended that this would constitute the start of an ongoing initiative in keeping with the intention of the Declaration. The content of the training included basic counselling on HIV/AIDS issues, education around modes of transmission of the virus, the symptoms of AIDS, care and support for people infected and affected by HIV/AIDS and presentation skills. The workshop also dealt briefly with a number of other topics including the appropriate use of traditional remedies and ways of taking care of the immune system through diet.

Following the workshop a group of people from the workshop agreed to meet and discuss how they could implement this training in the area.

Further development activities

> *People showed big interest, and were very excited. On the way home they were asking if this was the end of this?*

> *There could be sponsors to get funding to associate it (the initiative) with sport, then it will continue.*

As was pointed out in *Pathways to action* there is a danger in locating AIDS response in single events, and what is needed is programmes of action that are sustained and supported over long periods of time. Event-based campaigns may do little to address development and behaviour maintenance needs, and may serve to lull communities into a sense that something is being done, or that something is changing. At the launch of the Amatole Declaration, the Cadre project team felt uncertain about whether the process would move forward beyond the day of the launch. The community had focused their efforts on the launch and the demands of organising the event. The sense of purpose this gave overshadowed questions about the next steps. At the launch there had been numerous calls to keep the initiative going and encouragement of the

At the inauguration day there had been no clear response to questions about what would 'happen next' and it emerged afterwards that people did not want to be pushed into responding. However, after the inauguration day the Cadre project team returned to the community and discovered a process of deliberation about future activities already in progress.

community by various speakers to support the initiative. However, the Cadre project team were concerned that this would be another instance of an event-driven campaign. At the inauguration day there had been no clear response to questions about what would 'happen next' and it emerged afterwards that people did not want to be pushed into responding. However, after the inauguration day the Cadre project team returned to the community and discovered a process of deliberation about future activities already in progress.

At the launch, a key member of the tribal authority had suggested that the need for an ongoing AIDS response initiative should be taken up by the Development Forum (part of the Traditional Authority structure). Three weeks after the launch nothing had come of this suggestion and the launch planning committee decided to meet of their own accord. At their meeting they acknowledged that they were an interim structure established for the launch only and that it was necessary for a formal HIV/AIDS committee to be elected.

Follow-up meetings were held through which a steering committee was elected for the purpose of taking the process forward. Some of the activities already identified by this committee include calling other stakeholders (for example, HPS and clinic committees) to a meeting to ensure they are integrated into the community process. The committee members have also undertaken to ensure that other structures like the tribal authority, the development forum and village chairpersons are informed of developments. The committee has called itself 'Siyazama (we are trying) working group against HIV/AIDS', and though mostly made up of youth, adults and different sectors of the community are well represented.

Rather than focusing on education per se, this project has focused on establishing mechanisms and processes that would bring about community mobilisation and participation. The project created a desire for community organisation and training, and has set in motion community processes oriented around responding to HIV/AIDS where before there were none.

Because the community as a whole has been fully involved in this process there has been recognition that a 'one size fits all' intervention is neither desirable or possible. Different sectors of the community have formulated responses that represent their own socio-cultural beliefs and practices.

The intervention has contributed towards shifting notions of the AIDS epidemic as a 'catastrophe', towards the concept that united action is possible and desirable. The community has a sense of how HIV/AIDS prevention could realistically be addressed. However, there are limits to understanding the broader challenges that are to be faced – for example, there is little understanding of the challenges of caring for people sick with AIDS. The existence of a community organisation dedicated to AIDS response will be of great value when this community is faced with care and support challenges. The community has made a crucial first step in '*calling AIDS by its name*' and recognising the need to respond.

The ultimate goal was seen to be the community's adoption of a concept of themselves as an AIDS responsive community. They have consciously connected the need to respond to AIDS with the need for community development in a more general sense. There can be no doubt that the issue of AIDS has united this community through this effort in an unprecedented way. Further, the needs of young people have been recognised and young people have had a say in

community affairs, and continue to do so in a way that is also new to this community. They still have not been fully integrated into school, clinic and church committees but there are discussions and developments in these areas.

There are weaknesses in the response structure at a number of levels. The sectors, for example churches, could have emphasised issues that are known to be areas of strength in developing responses to HIV/AIDS. Churches have been shown to be a useful resource in developing care, support and solidarity with people living with HIV/AIDS. This was not a notable feature of church responses to the project. However, as the initiative continues these churches will be more receptive to the activities of their mother bodies in responding to AIDS. Being involved in the community initiative means that the these community bodies are receptive to future learning and development in this field. A vital first step has been taken.

There are many structural issues to be resolved and discussed and most of these involve developing greater degrees of cooperation between the community needs and health services. For instance, in developing the project, condoms were distributed to all villages, as it was clear that condoms are difficult to access. Distribution was done through the management of male youth who were central to the project. This was also done to assess the levels of demand. It seems that condoms definitely do need to be distributed in villages, but questions remain about how the condoms are accessed from the clinic, who takes responsibility for distributing them, how they are stored and a host of other practical matters. This requires the involvement of the health services in a way that goes beyond their current duties and responsibilities. The community is all too used to poor services and there is definitely a need for advocacy based on the rights of young people to appropriate health service delivery and health education. Without a community representative structure little could have been achieved. It is hoped that the new structure, will be able to gather sufficient momentum to tackle head on this and other problems that have been identified.

There are many structural issues to be resolved and discussed and most of these involve developing greater degrees of cooperation between the community needs and health services.

It should be said that the initiative has captured the attention of relevant government departments. Their attention to such community-led initiatives is consistent with the national Department of Health's white paper for the

transformation of the health system which lists as one of the functions of a health district 'the provision for community participation in health promotion and health service provision'. The project has captured local government attention in the areas of health, education, agriculture and welfare and they are beginning to regard it as a site where they can put policies and practices into place, which have hitherto been only 'on paper'. Further, the level of community interest has drawn the attention of surrounding communities and the possibility that this neglected and impoverished community can become a showpiece has added energy to the project. But to get there it needs further support and ultimately funding. There also seems to be a need for an advocacy type agency that can assist initiatives such as this one to garner further support and to develop.

Since the launch the Cadre research team has played a peripheral role in facilitating processes within the community. Cadre has helped in some direct ways, for instance through locating a trainer from ATICC for peer education training. It seems inevitable that assistance will continue to be requested. Given the significant communication challenges and difficulties in accessing information and discovering opportunities, rural communities do require the support and assistance of outside agencies.

The research team could be of valuable assistance to the Siyazama committee in drafting funding proposals and in advocacy, for instance in taking the HPS and adolescent-friendly clinic initiative forward, in the face of slow government uptake. However, whereas in this instance the Cadre project team may be willing to do this because they have formed a relationship with this community, the same might not be true of other communities which have not developed a relationship with outside agencies. Whereas this project has fairly successfully connected the idea of AIDS response and community development, it needs to be acknowledged that this could not be expected to happen without a catalyst. Thus there is a need to explore ways of supporting development initiatives.

CHAPTER 3

IMPACTING VULNERABLE POPULATIONS: CHILDREN WITH DISABILITY

According to the *White Paper on Integrated National Disability Strategy*, between 5% and 12% of the South African population are moderately or severely disabled. The national baseline survey, reports that 6% of the total population in South Africa (approximately 2.5 million people) have a moderate or severe disability. Disability in this context is defined as a limitation in one or more of a number of day-to-day activities, including seeing, hearing, communicating, moving, getting around, intellectual learning and emotional activities.[11]

In discussing disability it is important to acknowledge the heterogeneity of disabled people, as it is all too easy to categorise disabled people together, as if their disability creates a social identity that transcends all other identities they have. The term 'disability' cuts across a number of categories that define the specific incapacity, including vision, hearing, intellect, physical abilities, amongst other abilities. Further, within each of these categories people experience varying degrees of impairments. Differences amongst disabled persons in the country, both generally and amongst specific age groups, may be further defined in terms of: their experience of disability; age of onset of disability; cause of disability; the type and number of disabilities; gender; race; contextual factors including rural-urban domicile and access to resources.

In discussing disability it is important to acknowledge the heterogeneity of disabled people, as it is all too easy to categorise disabled people together, as if their disability creates a social identity that transcends all other identities they have.

Despite forming a significant part of the population, the disabled are often excluded from mainstream policy-making and implementation. The South African Federal Council on Disability's submission in the development of the HIV/AIDS/STD strategic plan for South Africa, for example, underlined '… the lack of vision of inclusion, of disabled persons'.[12] The need for inclusion of the disability sector and people with disability in prevention programmes remains largely unaddressed. Programmes dealing with education and awareness, home-based care, and voluntary counselling and testing have done little to address the education and service needs of people with various disabilities.[13] Development of strategies and programmes for both the infected and affected who are disabled are notably lacking. Materials developed for educational and lifeskills programmes appear to have overlooked the needs of people with perceptual disabilities. Little effort has been made to reach blind or partially sighted people with messages of HIV/AIDS prevention in Braille, for example. How well young people with specific disabilities and combinations of disability are able to receive and engage in the communication campaigns directed to the broader society is a question that has as yet not been given proper attention. This oversight is prominent in relation to policy and research on information need,[14] ie, the lack of appropriate information on which to base choices that could lead to benefits or services that may improve well-being.

Amidst the environment of a high prevalence of HIV/AIDS in the country and

11 Schneider, 2000

12 Sait, 2000 p 3

13 Schneider, 2000; White Paper on an Integrated Disability Strategy, 1997

14 Tester, 1992

in sub-Saharan Africa in general, it is especially important to examine and understand information needs of adolescents with specific disabilities in relation to their disability. Whilst the importance of appreciating the disabled and protecting their rights has been highlighted in various campaigns, notably by *Soul City*, the need to further examine and develop the perception of rights, and development of relevant programmes related to sexual abuse remain unattended.

Disabled young people have to cope with problems in relation to job access general health problems, problems of inclusion in normal social activities, and problems of social integration, amongst others. HIV/AIDS exacerbates all of these.

No figures as yet exist as to how many of the disabled in the country are infected or affected by HIV/AIDS. It can be assumed, however, that the impacts of HIV/AIDS on individual health, psychosocial well-being, and livelihoods, are exacerbated in the case of disabled people. Disabled young people, for example, have to cope with problems in relation to job access general health problems, problems of inclusion in normal social activities, and problems of social integration, amongst others. HIV/AIDS exacerbates all of these. Furthermore, although little hard data is available, disabled people are in various ways vulnerable to infection because of poorer access to information, being subject to relationships of dependence on others and being subject to poverty, which provides an environment conducive to HIV infection.[15, 16]

In discussing the inclusion of the disabled in HIV/AIDS strategic development, it is important to consider that disability cuts across society. Although in one sense disability unites young people from a wide range of social backgrounds through a common predicament, inequities at the level of the broader society are also represented in the lives of young disabled people. Access to opportunities, and capacity to participate and be included in social processes are variable in much the same way as they are for able-bodied young people of different social classes and backgrounds. Thus, whatever negatively impacts on the South African society, also impacts on the lives of the disabled persons.[17]

Vulnerability amongst disabled persons in the face of HIV/AIDS is especially severe amongst the disabled poor. Impoverishment means lack of access to appropriate medical care and healthy diet, and harsh and often unsupportive environments are bound to significantly impact, not only on the health of the persons, but also the lifespan of disabled PWAs.

In relation to information needs, two aspects are important to consider:

- the need to access information considered important for the general population to have in combating the HIV/AIDS epidemic;
- the need to receive information related to the specific risk and exposure of people with various disabilities to HIV/AIDS.

The significant role of education in the life of the disabled has often been underlined. Education has been described as the means of enhancing the integration of the disabled into mainstream society, equipping disabled persons with the necessary skills to address the exclusion and seclusion that often prevails amongst the disabled in the various sectors of society.

With regard to schools, there has been criticism of the value of education in schools, especially schools for the disabled, with calls for an inclusive education prevailing in the recent past.[18] It has been pointed out, however, that 'Neither

15 These and other factors are explored later in this study.

16 The problem of poverty amongst disabled people is exacerbated by a general inaccessibility to socioeconomic opportunities and a general discrimination from workplaces and society.

17 As noted by Sait, 2000

18 SAFCD, 1995

special nor mainstream schools are currently providing the quality of education disabled children need to develop their potential'.[19] It was also suggested that isolation and attitudinal problems are important factors negatively impacting on the education experiences for disabled children. In the context of disabled young people, families tend to view disability as a socially sensitive issue and many children with disabilities are hidden from the public. According to the national baseline survey,[20] the level of education amongst disabled persons is related to the age of onset of disability, and those either born with disabilities or who acquire disabilities early in life, are especially at risk of being educationally compromised. Disabled young people are inevitably channelled into institutional settings that offer specialised services for disability, with schools being the primary institution.

…the level of education amongst disabled persons is related to the age of onset of disability, and those either born with disabilities or who acquire disabilities early in life, are especially at risk of being educationally compromised.

The project site: A school for blind and partially sighted young people

There are 390 special schools across the country specialising in providing education to children with various disabilities including hearing, physical, and visual disabilities.[21] Following a review of schools for the disabled, two schools in the Gauteng Province were selected for follow up. Following this process, the Sibonile School in Klipriver was identified as suitable for case study.

Sibonile School for the Blind is a mixed gender boarding school providing for children ranging in age from 6 to 19 years, and offering grade R (reception) to grade 8. Age ranges vary quite considerably in each class. One class, for example, had both a 19 and a 12 year old. As noted by the reception teacher class:

> *You know some parents only bring their children to a school like this when it is very late. Some children come when they are very big. As a parent you may have a disabled child, but you are in complete denial, and may not want to face the fact. You see when you bring your child here you are actually accepting that she or he has a problem and you realise that she may even lose her sight completely. Many parents cannot bear to think like that! Even when the child is diagnosed early, it is sometimes only when he or she has lost their sight or can hardly see at all, that is when they end up here.*

19 Schneider, 2000 p 3

20 Schneider et al, 1999

21 Department of Education, 2000

There are 14 salaried educators at the school with an additional temporary educator and one volunteer. The school has 124 learners with an average of eleven per class. The disabilities of the children include partially sighted, blind and deaf-blind. Some learners have conditions that are stable, whilst others have progressive incapacity, which requires ongoing adaptation, both in terms of skills and psychosocially.

On entering the school learners are placed in a reception class, where they learn appropriate skills for coping with their disability. In the words of a teacher:

> *Especially for a child who had some sight, the reception class is very important. That is where we teach them the basic skills of operating even without one's sight. They would not cope in the upper class if they do not pass through the reception class first.*

The learners are academically assessed before being placed in suitable grades. The eight deaf-blind children are in a class of their own, while the vocational class consists of 16 children with more severe visual incapacities, including learners who are totally blind.

While the partially sighted learners can read large type and others can write, all the learners are trained to cope with blindness. They are trained to read Braille and each learner in the upper class has their own Braille machine. The school is geared to educating learners with the physical coping skills including, for example, using a guide stick, or crossing the road. There is, however, less emphasis on learning psychological coping skills – for example dealing with stigma and socialising in the outside world.

Objectives of the action research project

The following were specific objectives of the project:

- To create a context for addressing sexual health issues with special reference to HIV/AIDS taking into account the particular needs and challenges facing young people who are vision impaired.
- Assisting young people in the school to make personal choices and commitments around their sexuality and sexual health based on an understanding of their specific needs and personal choice.
- Mobilising stakeholders to address the issue of vulnerability to sexual manipulation, abuse and violence in relation to the needs of visually impaired young people.
- Creating a supportive environment for healthy sexual behaviour

Gaining access and understanding the challenge

Most institutions have gate-keeping systems to mediate access, and this extends to research activities. At Sibonile, initial access to the school was through the principal. Researchers were then referred to a staff member who became the primary contact point, and co-facilitator in various activities. Other staff members were also involved. As part of action research, the initial and continued contacts with the school staff allowed for continuous access to information and reflection regarding the school structure, various programmes at the school, experiences in HIV/AIDS awareness, amongst others.

The initial interaction with the school administration and extended interaction with staff ensured efficient processes, and also contributed to the development of various activities. The primary contact staff member had a personal interest in HIV/AIDS work, and this allowed for perpetuation of activities beyond the direct action research process.

Whilst school staff assisted in access to learners by organising workshops and interactions, and assisted in initial processes of dialogue, they were also prepared to withdraw from the interactive sessions. This allowed for the development of an alternative space for dialogue that was not mediated by the presence of institutional authority figures. Various techniques were also used to allow for the development of a relaxed atmosphere that encouraged openness.

HIV/AIDS interventions at the school, both past and present, were the subject of interviews with the principal, educators, administrators and learners. The needs and challenges in relation to HIV/AIDS were explored with a view to assessing potentials for sustained activity in this area. Provincial-level education authorities were also interviewed, as were two parent representatives of the primary organisation for disabled young people (DICAG). This framed a series of interactions with learners.

The context of visually disabled young peoples lives

A number of initial discussion sessions and interviews were conducted in June and July 2001 to explore the world of young people, both in the context of the school, and also in relation to HIV/AIDS. The project facilitator, on the basis of a list of the student body, randomly selected young people. Initially 22 were selected in the 12-17 age range. Sessions took place in the time allotted to sports activities. The structure of these sessions varied, but generally took the form of three-hour workshops which incorporated general discussion, participant-led focus groups, writing activities and interviews. At various points discussion was tape recorded, and in smaller focus groups, learners took additional notes usually in Braille.

In relation to community and social context, the following points emerged:

There are many obvious benefits to institutionalised support for young disabled people, but there are consequences of long periods of separation from family – specifically in creating bonds with parents and other family members, but also in relation to community-level social networking.

- *Primary community context:* All children spend at least nine months of the year at the school and it is thus the primary context for socialisation. There are many obvious benefits to institutionalised support for young disabled people, but there are consequences of long periods of separation from family – specifically in creating bonds with parents and other family members, but also in relation to community-level social networking. Reflecting on the school environment, one female learner said: 'It is good here. At home my mother says I must not go out of the house, I get very lonely, and I miss my friends. I miss school. Similarly, at home I do not have permission to go out and play. My mother says I must stay at home, that they will hurt me outside. Sometimes I am alone, because my brothers and sisters, they are allowed to go and play.' (female learner)
- *Stigma:* The learners talked much about stigma which they face at home, including from parents, neighbours and other members of the community. A teacher-parent told of how some of the parents in the neighbourhood try to restrict their children from playing with her child who is disabled: 'You know the problem lies with us parents, the whole community. People have not come to accept disability. For the disabled children the situation is worse. You can imagine how a child feels when they know that the neighbours have instructed their children not to mix with him or her because he or she is disabled. It is a pity that parents perpetrate the stigma on disability even amongst their children. So the whole society discriminates against these children.'
- *Shared predicament:* Being together as part of a community which shares the predicament of visual impairment creates a social bond rather than a sense of social difference. Young people alluded to the important relationships and strong bonds developed with their peers in the institutional environment.
- *Physical environment:* As the children grow older at the school they master their physical environment, and are thus comfortable in the physical space of the school environs.
- *Peer support:* The partially sighted, especially amongst the very young children, can be seen taking the lead in physical mobility around the school. They provide assistance to the blind in a natural and unquestioning way, characterised by care and closeness.

In relation to sexuality (and vulnerability) there were a number of important trends:

- *Confinement in the home environment:* Disabled children are often confined at home, not given a chance to play with other children, and generally isolated from the rest of the community by their parents. The children express negative sentiments regarding such confinement, whilst parents see this as the only means to keep the children away from perpetrators of sexual abuse.
- *Sexual abuse:* Visually disabled children are particularly vulnerable to sexual abuse, and confinement in the family home does not necessarily remove risk. Some young people indicated that neighbours and relatives were perpetrators of sexual abuse.
- *Peer sexuality education:* Schoolmates provide an opportunity for the children to ask questions and seek answers from each other. Said one female learner, about menstruation: 'When it started, I asked G. I was very afraid, but then

she told me what it was, and what I must do. Many of us learnt about it from the older girls.' Educators consciously encourage a culture of older learners caring for younger ones. Said one teacher: '…this process of learning from each other is very important, because when a blind boy gets a wet dream, or a blind girl starts menstruating, they may have heard about these things, but they cannot see. You can imagine, because these experiences are confusing and alarming even for the sighted children!'

In relation to HIV/AIDS information, the following points emerged:

- Radio was mentioned as the primary source for HIV/AIDS information.
- Older schoolmates were an important source of information and dialogue on sexuality generally.
- Sporadic efforts to engage the children in direct sexual education were made at the school. This was mainly done informally by a teacher and was mainly directed at male learners who 'showed signs of being sexually active'.
- Learners are unanimously aware that HIV/AIDS is an incurable disease mainly transmitted sexually. However, there was also the belief that a person with HIV/AIDS would be visibly thin and that blood donation posed a risk for HIV infection.
- Methods of transmission were correctly identified, but there was some lack of knowledge about casual transmission.
- Abstinence was prominent amongst perceived methods of prevention, followed by condom use.

Sexual behaviour and experience

The following points emerged:

- *Sexual debut:* In discussions on sexual behaviour, it appeared that sexual activity was initiated at an early age amongst some learners. It was suggested that sexual involvement is expected after someone reached a certain age – although the suggested age range was from 10 to 18.

- *Abstinence:* Younger girls alluded to the importance of abstaining from sex until after marriage. Whilst this was regarded favourably by the group as a whole, some pointed out the difficulties of abstaining until marriage. Factors affecting this included peer pressure, partner pressure (mainly from boyfriends), and difficulty in holding back when kissing.
- *Sexual activity:* Sexual activity was more common during the school holidays and outside the school environment for both girls and boys. Multiple partners were explained to exist due to lack of trust between partners and time spent away from each other while at school.
- *Older partners:* Both boys and girls reported sexual relations with older partners.
- *Consequences of sexual activity:* Problems associated with sexual behaviour include unwanted pregnancy, HIV/AIDS and sexually transmitted diseases. Unwanted pregnancy was clearly the most prominent concern, and condoms were seen as the most accessible method for prevention.
- *Sources of condoms:* Shops and clinics were reported as the places for obtaining condoms. Older brothers and friends were also common sources for obtaining condoms.

Implementing the action research project

Following two initial discussion sessions with learners, the methodology of interaction was extended to six further specifically focused workshop sessions oriented around particular lifeskills themes. Methods included participant-led focus groups, role-plays, storytelling and letter writing.

Topics covered included:

- understanding puberty and sexual development;
- sexual activity and consequences of sex;
- HIV/AIDS/STDs and pregnancy;
- sexual violence, vulnerability and risk.

Shared learning

The workshops encouraged the concept of shared learning amongst the participants. One means of enhancing shared learning was the use of a story told by the discussion group's moderator. The story entitled, *Lebohang and Lerato* was basically a story about a young girl aged 13 and her boyfriend aged 15. The two went to school together, did their homework together, and had fun together, going to various places. After their friendship had gone on for a period of time, the boy started pressurising the girl to have sex with him. One day, the boy asks the girl to go with him further into the bush, where there was no one else. Here his pressures for sex increase, and the girl gives in. After the encounter the girl panics.

Points of discussion in story included:

- sexual abstinence;
- condom use;
- sexual coercion and vulnerability.

Within the workshop process, points of discussion were addressed using various techniques including role-plays. Role-plays served to articulate problems and conflicts, and through group discussion were used to explore solutions. The experience of role-plays led to the formation of a drama presentation later on in the project.

Abstinence

Strategies for abstinence were identified as:

- knowing whether one wants to abstain from sex as an individual;
- making a promise to oneself to remain abstinent;
- raising the issue early on in a relationship and being ready for any eventualities including losing a 'stubborn' partner;
- reaching agreement between partners about abstinence;
- consciously avoiding situations that would make abstinence difficult.

In talking about the story of *Lebohang and Lerato*, the following points were made:

> *Lerato and Lebohang could have avoided going into the bush alone. You know when you are spending time alone with your girlfriend, away from others then you will start touching and one thing will lead to another.*
>
> *They could have promised to each other not to have sex. When you make a promise (pledge) to yourself, then you know you do not want to have sex, so you will also tell your girlfriend.*
>
> *When I propose to girl, I will tell her that I am not a person who does sex, so she will be knowing from the beginning.*
>
> *Feelings can get in when you brush a boy so you must be careful.*
>
> *Lerato and Lebohang should not have gone to the bush alone. Because you know when you are all alone, where no one can see you, then you will start*

touching, and all that and before you know it you are having sex

I think Lerato could have said, 'I know you are my boyfriend, but we must wait first before doing sex, we must finish school first, start working, get married, then after marriage we can start having sex.'

Condom use

The following emerged as practical actions in relation to condom use:

- Make a decision about whether one wants to have sex with their boyfriend or girlfriend.
- Review possibilities for condom access, and physically access condoms.
- Make a decision to use condoms consistently.
- Discuss sex and safer sex with partner.
- Make a pledge to only have sex if it is safer sex, and if it is considered appropriate to have sex.

Participants saw these steps as very important because they enabled partners to reach consensus on the issue of condom use, to know each others expectations and develop respect for each others opinions regarding safer sex.

In talking about the story of *Lebohang and Lerato*, the following points were made:

The mistake Lebohang made was to go to the forest with Lerato alone without carrying condoms. You know when you are going to be alone with your girlfriend, you will start kissing, and then you will want to have sex. So it is better if you carry the condoms. You see there were no condoms in the forest, so even if he wanted, he could not use one!

It is because they had not agreed to have sex. Your girlfriend has not agreed, you may not carry condoms, they can put you in trouble with her!

Put the condoms in the pocket! He needed to have carried the condoms in his pocket!

I think condomising is better because, they say sex is healthy, they say it is cool.

Sexual violence, vulnerability and risk

A number of participants indicated concerns and experiences with sexual violence, and there is clearly a greater vulnerability in the case of visually disabled children and young people.

A number of participants indicated concerns and experiences with sexual violence, and there is clearly a greater vulnerability in the case of visually disabled children and young people. Sexual violence affects both boys and girls. Discussions centered around: the meaning of sexual abuse, occurrence of sexual abuse, environments/factors promoting sexual abuse, addressing sexual abuse at individual, familial, community levels.

It was not easy to examine issues of sexual abuse within a mixed gender setting and a few of the more vocal boys often aired gender insensitive understanding. While most of the children and specifically girls did not share similar sentiments, it became clear they were hesitant to air them and even when a few did. Discussion groups were thus split on a gender basis. Story and letter writing activities formed the core of group activities.

Emerging issues included:

- Children with disability are more vulnerable than other children.
- Children in homes where parents are violent with each other are more likely to be sexually abused.
- Sexual abuse is most perpetrated by people known to the children – for example, relatives including uncles, stepfathers, neighbours, friends of siblings.
- Families that are facing abject poverty are more likely to have their children abused by outsiders who offer to 'help'.
- Homes where alcohol consumption is high, (selling, drinking of alcohol) foster an environment for sexual abuse amongst the children.
- Children in single parent families, (as a result of death, or divorce) are more prone to sexual abuse.
- Sexual abuse is also common between adolescents especially when the boy is older.

Quotes from letters and stories included:

Others do it because they think that a blind child will not know or see them.

They think being disabled means that you are not able to speak for yourself in court and that they can win the case easily.

This is my opinion, someone who doesn't see anything can be raped, the one who is sighted can take them to a dark area where they can be attacked.

Someone who is blind is vulnerable and can be attacked anytime.

…if you stay at home, people will know that you are staying alone. The gangsters will come and attack you.

…believe that if you are HIV positive, in order to get cured you must sleep with a blind or disabled person.

There was a girl who was raped by her uncle, but he promised to kill her if she told someone. He started touching her and after that he raped her. After years she told her best friend and her best friend told her she must tell her mother. But her mother didn't want to hear anything from the child and said 'How could you speak like that about your uncle?'. She told her best friend that her mother did not want to hear her story, and her friend told her she must go to the clinic and talk to a nurse about this abuse. It was difficult to talk about it but she phoned child line. They told her she must keep on telling someone until someone listened to her. She told the nurse and this nurse went with this girl's home. They found her mother and her father who were angry, but because the nurse was there they believed her. They phoned her uncle and told him to come. Then they phoned the police and the police took him to jail and she was so happy and said thanks to her friend and the nurse. (Letter written to an imaginary friend.)

Sexual abuse is difficult to identify and address because: parents or older relatives tend not to listen to, or take seriously a child seeking to disclose sexual abuse; perceived inadequacies of the criminal justice system in dealing with cases of sexual abuse lead young people to believe that there will be no value in disclosing sexual abuse.

Sexual abuse is difficult to identify and address because: parents or older relatives tend not to listen to, or take seriously a child seeking to disclose sexual abuse; perceived inadequacies of the criminal justice system in dealing with cases of sexual abuse lead young people to believe that there will be no value in disclosing sexual abuse.

The participants continually relayed either in their letters, stories and through discussion, how 'a child continued to experience sexual abuse because of a parent who didn't listen', 'police who did not catch the rapist', or 'allowed the rapist to escape'. These young people are sensitive to the need for justice part and parcel of the healing process. Thus acts of 'hiding' perpetrators of sexual abuse especially when they are family members and accepting out of court settlements are significantly problematised.

There is clearly a need for parents and other stakeholders to be receptive, sensitive and well resourced in dealing with sexual violence affecting children. Programmes like children's help lines are perceived to be important for addressing sexual abuse. Personnel in clinics, hospitals and the police departments, while traditionally dealing with parents, may also need to be flexible and proactive enough to provide assistance to children who may not have parental backing.

Activities and processes

The workshop sessions provided important insights into general problems related to HIV/AIDS, but also pointed to areas of specific concern. In exploring problems and solutions, role-plays were used extensively. This experience of dramatising problems had the potential to form the foundation of a drama presentation. This idea was introduced by the research facilitator, and accepted by both the school-based teacher/facilitator and group participants. The teacher fostered independent exploration of themes for the play through setting aside time for the participants to do this. He then assisted in consolidating ideas and formalising the content of the drama.

In parallel to the exploration of the play, the idea emerged for holding an Open Day at the school focusing on issues of sexuality and HIV/AIDS. This idea was readily accepted by the school administration and a specific day was identified.

The research facilitator and teacher facilitator shared ideas on the format of the Open day and a loose programme was developed which allowed for addresses

by key stakeholders, interaction with a person living with HIV/AIDS, dancing and presentation of the drama.

The play

The play was developed over a period of three weeks and incorporated songs, slogans, a gumboot dance, other dances, and pledging. The story line was as follows:

- *First scene:* This depicted a dance hall where various HIV risk activities were portrayed.
- *Second scene:* A young girl does her make-up in front of a mirror in preparation for a date.
- *Third scene:* Her date arrives, and they begin talking. It is learned that they had previously discussed having sex, and it is clear that the girl remains hesitant. She outlines the importance of dealing with HIV/AIDS and having an HIV test.
- *Fourth scene:* The surrounds of the community are shown including street children, two gay boys, and children playing soccer.
- *Fifth scene:* The boy appears alone and reflects on his dialogue with his girlfriend. He decides to follow her suggestion of having an HIV test.
- *Sixth scene:* The partners decide to have and HIV test.
- *Seventh scene:* The partners are shown going through an HIV testing process, but their HIV results are not revealed.
- *Eighth scene:* Gumboot dance.
- *Ninth scene:* The actors form a semi-circle and read out pledges related to sexuality and HIV/AIDS.

The Open Day

The Open Day was held in October 2001 in the school hall. Invitations had been made to various officials, parent representatives and also to neighbouring schools. HIV/AIDS materials including leaflets, stickers, posters, red ribbon pins and educational booklets were made available. The programme ran from 10 am to 2 pm including lunch and included addresses by the school principal as well as a representative of the Department of Education. This was followed by an address by a member of National Association of People Living with HIV/AIDS, and children were able to ask questions in this session. The play was then presented.

An important aspect of the play was the pledging process. Each participant stepped forward, said their name, age and class, and then made a pledge in relation to abstinence or condom use. Following these pledges various participants made short presentations related to key points about sexual abuse, HIV/AIDS as well as HIV/AIDS and related resources and services.

Following the play, a social worker, the teacher/facilitator and the research facilitator made brief presentations. Perceived benefits of the the Open Day included:

- 'normalising' of visually impaired learners through allowing interaction with non-disabled learners;
- leadership by the Sibonile school with regard HIV/AIDS and related issues;
- advocacy of healthy sexual behaviour by learners in the presence of children from Sibonile and other schools;
- promotion of awareness of issues of sexual health;
- promotion of respect and non-stigmatisation of PWAs;
- public pledging of preventive practices by learners;
- involvement of the school body as a whole.

The Open Day was generally a day of advocacy, seeking to involve children, educators, and the school administration into taking further steps in the development of sustained programmes on sexual health amongst the children.

The Open Day was generally a day of advocacy, seeking to involve children, educators, and the school administration into taking further steps in the development of sustained programmes on sexual health amongst the children. The day also served for advocacy and enhancement of networking amongst other stakeholders surrounding the school including, social workers from the Department of Social Development and officials from the Department of Education.

Using slogans in a youth campaign

Slogans help to create a rallying point around an issue which is otherwise not identified as needing attention.

Slogans help to create a language for referring to an issue.

Slogans must be brief, memorable, catchy, and easily recalled.

Slogans can be a substitute for deeper understanding and should not be used in place of this. They can easily become devoid of meaning if not backed up by ideas around how to implement ideas.

Further developing and sustaining activities

The intervention worked at four different levels: individual, interpersonal, community and institutional. It was certainly not equally successful in each of these areas, and we now look at potentials for building on the foundation of the research activity.

It was not intended that the research activity be formally evaluated, nor was there specific evaluation of follow-on activities. However, it is possible to assess broad outcomes, and developmental issues.

It was envisaged that the process amongst the learners would continue even after the Open Day with arrangements to engage more learners in the school in sex education.

The three educators involved in the process were seen as the core custodians of the project. On one level it is appropriate and practical that educators would be custodians of the project, especially given that learners come and go. However, the initiative ultimately needs to be embedded at the level of school policy, although policy provides no guarantee of transformed practice.

Beyond this, continuation needs to be entrenched at the level of expectation and monitored by higher education authorities. In *Pathways for action* the rights of learners were discussed and at the level of over-arching education policy and even at a consitutional level, ongoing initiatives are required for including interventions of this sort into the school curriculum. But such macro factors need to be brought to bear on the realities of the school day, and the question is how this can be brought about. Clearly it must operate at different levels and custodians of such initiatives need to be based in institutions. We feel however that the initiative rests on weak foundations without being embedded at other levels, including school authorities, organisations advocating for the needs and rights of disabled people, school governing bodies, parents and learners themselves.

To date, the three custodians of the project have:

- Taken responsibility for facilitating a referral and follow-up process. Resources include parents, the local clinic, local social workers, the AIDS Helpline, the police and other structures involved in support of young people.

- Committed themselves as a group to being available on a continuous basis and to be recognised as being open to answer further questions from learners regarding sexual and reproductive health.
- Undertaken to maintain HIV/AIDS and related information resources in the school.
- Undertaken to organise similar workshops at Sibonile and in other schools. The initial play and dance presentation was intended to be used as a vehicle in interacting with other schools.
- The workshops helped to develop and improve the pool of knowledge on which learners at the school could draw. Development of this resource even amongst a few learners is much more likely to yield fruit in a community such as this, where there are relatively cohesive internal social networks.
- The overall project was strongly endorsed by the school principal and head teacher and this has contributed to institutionalising further initiatives.
- It is known that at least one student reported sexual abuse to the teacher/facilitator, and it was possible to take the necessary action.

Amongst recommendations made by the research facilitator to the school were:

- The school administration should provide a 'space' dedicated as a reference point for the mission of 'healthy adolescence'. Information and reference materials should be made available to the learners. There are practical possibilities of using a section in one of the recreation rooms.
- An outdoor garden facility could be developed and maintained by the learners themselves and this could incorporate a mural to symbolically sustain commitment.
- Involvement of learners in HIV/AIDS programme development should be encouraged.
- Involvement of other schools should be maintained.

Given the positive orientation towards HIV/AIDS and related activities, the opportunity for engaging in a more elaborate and sustained HIV/AIDS programme involving majority of the children within the school is clear. This however, immediately raises the need for appropriate teacher training and support in issues related to family life and sexual education covering broad areas including sexual abuse, sexual behaviour and HIV/AIDS.

Another further aspect of a sustained project includes teacher-parent interaction, education and general involvement of parents, and other stakeholders including parental organisation of children with disabilities, and other umbrella bodies of people with disabilities.

CHAPTER 4

CONCLUSIONS AND DISCUSSION

The Cadre project teams set out to explore ways of developing responses of young people to HIV/AIDS in two distinct communities. The action research methodology involved individuals and community members taking stock of their own responses to HIV/AIDS and engaging in interventions which were appropriate given the contextual mediators of HIV/AIDS response in each case. Each of the projects involved a series of activities culminating in public events – an HIV/AIDS response plan: the Launch in Amatole Basin, and an Open Day at Sibonile School.

In *Pathways to action* it was pointed out that event-based activities should be approached with caution, for they are often costly and do not necessarily contribute to sustained action. However, it is important to differentiate between the two events that are described in this report, and the types of events that are not grounded in a developmental process at community level. In these case studies, the events were a focal point in consolidating a series of steps involving research, reflection and action. Importantly, the events were specifically positioned within a continuum of activity that is forward looking, and involved pledges and plans for future action.

In these case studies, the events were a focal point in consolidating a series of steps involving research, reflection and action.

So what can be learned from the two projects? Are there general learnings or is each project so distinctive that it would best be discussed as a unique process? In one respect they are very distinctive. The communities in question were chosen for their distinctiveness and to this extent the challenges faced were and are particular to the contexts in question. However, the operational principles used in developing the projects do share some foundations and young people in South Africa do share some common challenges, even when the manifestations of these and the ways of overcoming them take different forms.

In discussing the project, the distinctive aspects of each environment were examined. The challenge now is to set out some of what has been learnt in a way that might be useful to anyone involved in the establishment of HIV/AIDS mobilisation activities. Some of these foundations were established at the outset of the project and in *Pathways to action*. Others have been refined and identified en route, including during the process of writing this report. Further case studies would no doubt lead to further clarification, refinement and development.

Elements of a programme development model for promoting and sustaining HIV/AIDS response amongst young people

Three project development processes were distilled from the research, each of which needs to be pursued at individual, community and societal levels. The three phases are:

- taking stock of contextual mediators of response to HIV/AIDS;
- mobilising participation in AIDS action; and
- sustaining response.

Taking stock of contextual mediators of response to HIV/AIDS

Young people are not homogeneous and the particularities of their individual lives, their community contexts and broader social parameters need to be taken into account in understanding how they are impacted upon by the vagaries of the HIV/AIDS epidemic, and how they engage with the disease.

It is necessary therefore, to employ a wider lens to examine not only the individual, but also to consciously and specifically examine community and social contexts that surround the individual.

It is important to address aspects of impact and response at the levels of individual, community and society. Predominant theories of behaviour change tend to look primarily at the individual as the unit of analysis, and extrapolate response within a conceptual framework of the individual as the primary actor for change. It is easy to understand that in well resourced environments, where services and support mechanisms are established, individuals may be sufficiently empowered to make conscious shifts in their behaviours and practices. But in under-resourced contexts, and in societies underpinned by complex socio-cultural and economic constraints, individuals can be understood to be distinctly disempowered in relation to choices about their present and future. It is necessary therefore, to employ a wider lens to examine not only the individual, but also to consciously and specifically examine community and social contexts that surround the individual.

At each of these levels it is important to assess the factors that determine existing impacts and responses, as well as to explore how impediments to addressing HIV/AIDS might be rapidly and sustainably addressed. A particularly useful method called Dynamic Contextual Analysis[22] has been developed for taking stock of the mediators of responses to HIV/AIDS which details the issues one would need to include in a comprehensive analysis. Whilst this approach was not specifically used in the two action research projects described here, it echoes the approach taken, and offers a suitable methodological framework for engaging communities.

With reference to individual level experiences, the motivations and personal characteristics of each person – their personality and psychological make-up has much to do with determining how they might respond to HIV/AIDS. Within a particular community one often finds large variations between individuals in respect of their responses to HIV/AIDS. Taking stock of this involves engaging young people to reflect on their knowledge, attitudes and practices in relation to HIV/AIDS prevention, care and support. This can be assessed through behavioural surveillance surveys, focus group discussions or interviews. Processes of reflection on such issues may also be explored through a range of more creative methods. In these studies, group discussions, story writing, interpretation of stories and playlets and role-plays were used, as ways of eliciting spontaneous responses and orientations. This is useful as a way of averting the tendency to say 'the right thing'.

The notion of empowerment or individual self efficacy is clearly also an important element to address, as it informs an understanding of the capacity and resources people might have to tackle problems they face. This is important as it defines the creativity and energy which they are likely to bring to a development project.

At the community level perhaps the most useful concept for describing how responses to HIV/AIDS are mediated is 'social capital'.[23] Social capital refers to

22 Campbell 1999

23 Hawe & Shiell, 2000

those characteristics of a community that promote cohesion and a sense of belonging and that enable its members to participate in civic affairs and to cooperate in endeavours that are of benefit to the community. 'Simply put, social capital can therefore be described as a process embracing clear but culturally nuanced mechanisms for enabling people and organizations to work together in trust for mutual social benefit.'

High levels of social capital augur well for information exchange and enhancing the level of support amongst groups participating in development projects. Where civic engagement and the structures for this are lacking, social problems will not be satisfactorily understood or analysed as the key interests of some groups will not be understood or taken into account.

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In Amatole Basin it was found that the levels of social capital were low, particularly with respect to young people having a role in civic affairs. It was necessary to engage in building a communication framework and ultimately a community organisation, to enable community networking and action and the involvement of young people. In the case of Sibonile, within the school community, levels of social capital are high, but the relationship of the young people in the school to the broader community proved to be problematic. Analysis of this – that is, the analysis of the relationship of these young people to the broader community and their integration into it – proved to be critical to understanding where they are most at risk and proved to be an important area of focus in developing the intervention. Ultimately the project, albeit in small ways, attempted to address this, with the result that young people were able to reach out to the broader community through their open day, and the project team developed a mission which involved outreach from the school-base. This goes some way to addressing the relationship of visually impaired young people to the world. Other aspects of community functioning which are important to understand are:

- patterns of communication (within and between groupings defined by: gender, family ties, generations, sub-cultural identifications);
- social networks;

- social hierarchies;
- relationship to service providers;
- relationships to person's affected by HIV/AIDS;
- beliefs held by communities about HIV/AIDS; and
- other discernible trends which are defined and held in place at community level and which impact on response to HIV/AIDS.

The way in which the two communities functioned in terms of social capital indicators was not easy to assess at the outset. However, during the action research process, the structure of the community, the rules of communication and the relative power of different groups, gradually became evident. Sometimes this understanding was quite contrary to what was expected. For instance, in Amatole Basin it was assumed that young women would participate more actively and that young men would be difficult to coopt to the project, because young women seemed more concerned about HIV/AIDS and more personally motivated to do something about it. However, young women were difficult to engage with as a group and tended to hold back from becoming involved at the outset. This illustrated to the Cadre project team the importance of learning from how the community functions (social capital) in response to the project. In this instance the way that the community responded was part of the problem itself, and drew our attention to the need to develop the involvement of women and especially to take a more active interest in supporting the involvement of young womens' groups.

At the societal level it is important to assess the relationship of a community of young people to the world beyond their community, and to understand the levels of support that are available.

At the societal level it is important to assess the relationship of a community of young people to the world beyond their community, and to understand the levels of support that are available. In the case of Sibonile School, it was important at the outset to examine the rights frameworks which support the inclusion of visually impaired young people in HIV/AIDS prevention efforts. It was also important to assess the potential levels of support for the project by the level of higher education authorities and parent bodies. Ultimately, developments need to be supported at this level in order to be sustained and it is important to assess whether advocacy is necessary at these levels to achieve objectives.

Similarly, in Amatole Basin the first contacts were made at District Management level through departments of Social Development, Education and Health. It was important to understand the orientation of decision makers within social service agencies to the needs of young people. It was also important to take stock of the realities of service provision, which are not necessarily in line with the orientation of higher level managers. Understanding the discrepancy between principle and practice allows one to understand where to focus activism and social change efforts. Unfortunately there proved to be a large discrepancy and this means that advocacy for better service provision is going to be an important part of developing this project. This need has not been successfully addressed, but analysis of the need to act at this level is important in setting goals for programme development.

It was also important to assess the access that participants had to information and the degree to which their orientation to HIV/AIDS was or was not influenced by mass media input. In both cases we found that mass media based educational interventions had effectively reached the participants, even those visually

challenged, but that most of the issues which they faced and needed to tackle to reduce risk of HIV exposure were not sufficiently addressed at the mass media level. This is a particularly important point to note. Educational interventions located within mass media forms of delivery are unidirectional – they do not allow for feedback or in-depth exploration of very specific individual, community and social problems. Furthermore, mass media approaches, of necessity, address an imagined homogenous target audience and are mostly not tailored to address specific needs and to develop particular capacities.

It is important to point out that mass media campaigns have a particular form of address that takes place as part of the backdrop to individual, community and social responses. Whilst this background level of information is important, and whilst it may stimulate a modicum of response, it is insufficient to directly mobilise or sustain response. If one were to imagine an individual, community or society's understanding of HIV/AIDS as slices of a pie, mass media interventions constitute only one thin slice of that pie. The remainder of the pie is made up of slices that relate to the immediate realities of peoples' lives as they interact with, or are affected by the disease. This includes their capacity to identify and deal with community and social problems, their interactions as individuals, families and communities, their exposure to direct experience of HIV/AIDS illness and death, their access to coping mechanisms and social support systems, amongst other things.

It is important to point out that mass media campaigns have a particular form of address that takes place as part of the backdrop to individual, community and social responses.

Given that this is the case, it is of concern that some mass media campaigns undertake evaluations to demonstrate that their activities are the causal driving force in evolving responses to the epidemic. Evaluation of such interventions is often conducted through internal agencies driven by uncritical and (perhaps unconsciously) self-serving data collection and analysis. Findings are often decontextualised from the broader experience of HIV/AIDS, or indeed the nuances and impacts of parallel interventions, but in spite of this it is commonplace to read evaluation reports that suggest that a particular attitude, belief or behaviour can be causally traced back to a particular mass media campaign. Nothing could be further from the truth and it is important to stress that individuals and communities are complex and multifaceted, and are not empty vessels into which one can pour information with a view to expecting a Pavlovian stimulus-response type relationship.

Perhaps the most foundational learning to be had from comparing these two projects, is that young people are not homogeneous in their needs and capacities. Programme development needs to begin with contextual analysis, and interventions and programmes need to be monitored and evaluated with a contextual framework in mind. Furthermore, the uniqueness of contexts and the specific needs may only emerge gradually, meaning that programme development must be open to being led by unfolding understanding.

In summary the following are important foci at each of these three levels of analysis:

- *Individual:* individual knowledge, attitudes, practices, self-efficacy.
- *Community:* social capital, communication patterns and networks, social groupings, beliefs, traditional practices, social hierarchies.
- *Social:* rights and legal frameworks, service provision, socioeconomic conditions, information access.

Mobilising participation in AIDS action

To the extent that young people's lives are determined (mediated) at the levels of individual orientation, community setting and social framework, it is important to engage in addressing the problems they face at each of these levels. There are usually stakeholders representing interests at each of these levels and it is important at the outset to identify these and to create strategies for engaging them.

Both projects were initiated at the social level in the first instance. Government officials and school authorities with relatively little appreciation of the contexts in question were approached in order to gain support for later engagement. As it happens, their later engagement proved difficult to secure in practical terms, especially in the Amatole Basin case. Participation may fluctuate and participants may be inconsistent, and it is important to understand what levels of commitment might realistically be expected at different levels.

In contemporary South Africa, in almost all domains of public service, there is an acknowledgement of the need for transformation of existing services and mobilisation of support resources. There is a widespread recognition of the need for community participation in the planning and implementation of services. But it is necessary to be very cautious about the capacity of young people to engage with services and agencies which are potentially an aid to their development process. The complexities and interests involved in changing the ways in which services are delivered may be quite entrenched and not easily changeable.

Advocacy is an appropriate tool for engaging resource and service provision, but advocacy is the power to influence socio-political processes, and it is difficult to establish a framework for advocacy in the early stages of a project. The research team, by virtue of their association with an established HIV/AIDS organisation, Cadre, were able to exert some influence which promoted support for the projects, but this influence did not extend much beyond the formative stages of the projects. In Amatole Basin, researchers were able to go directly to the District Management Office and elicit a framework of support for the project. This inter–action also allowed for large quantities of condoms and other information support materials to be procured. The residents of Amatole Basin would not necessarily have been able to do this independently. In the absence of an understanding of how the system works and in the absence of

significant community momentum it would be difficult to secure communication and credibility with relevant authorities. This suggests that strategies for advocacy be explored at an early stage of project development.

The public events (Launch and Open Day) worked at both community and social levels. They provided an opportunity for the community to come together in all of its parts to endorse the initiative. They also provided an opportunity of bringing the initiative to the attention of social level stakeholders (government officials, district management, other schools and communities). Whereas in *Pathways to action*, the problems of event-oriented campaigns were identified, it proved in these cases that where the events were part of an ongoing process they were very important catalysts to broader community involvement and a pretext for bringing the initiative to the attention of authorities and role-players at a social level.

The greater part of Amatole Basin project was conducted at the community level. Meetings, workshops, a public event, and community networking were used as primary means of creating a common purpose and vision for the project, and for integrating the range of perspectives represented. In the Amatole Basin project in particular, a new community structure was created to involve the community in analysis of the problem, and planning and implementation of a solution. In Sibonile, a group of three educators emerged as central to the continuation of the project over time and a group of 30 young people formed the core of the initiative. Both projects thus created new community groupings and structures, rather than simply relying on existing structures.

This is an important learning which calls into question how one should engage with communities of young people in mobilising AIDS action. As was pointed out in *Pathways to action*, existing groups (for instance, a soccer club) are likely to have as their central concern the interest that made them a group in the first place. In these two projects AIDS-specific social groupings were formed. In the Amatole Basin, the new structure was later brought under the umbrella of a broader community development initiative. But it was important that an AIDS specific initiative was formed in the first instance. Even though in its formation

it was necessary to defer to existing community structures, once it had formed and had a social identity and existence, it could be aligned with other existing groupings. By approaching it in this way it was possible, for example, to develop a credible community structure which had strong representation of young people, and this would not have been the case had the AIDS initiative been an outgrowth of an existing community body such as a soccer or drama club. Had the latter been the case the project would have never received the recognition and community support that it has and young people would not have taken centre stage.

Engagement of particular individuals has also been important in these projects. The formation of community structures depended, in the first instance, on the engagement of individuals who represented the newborn initiative before it became a group initiative. But even in the later stages, these individuals in both projects, were important in coordinating and promoting the projects. Ultimately the purpose was to engage all participants at an individual level, by making the project relevant and meaningful in their circumstances.

Individuals need to be motivated to be involved and appropriate forms of incentive have to be identified and addressed. These may range from incentives based on fulfilling personal desires (the need to: assume leadership and status roles; have one's efforts recognised; have fun; be creative; display one's talents; be appreciated at work; contribute to one's community, and so on) to material incentives.

It might be thought that the value of the project to the communities in question should have been incentive enough, but this kind of value takes some time to show itself. There are many ways in which we had to develop motivation at an individual level and we were not always successful. For instance, the interest of primary health care workers in Amatole Basin was not adequately secured and there were individual reasons for this. Simply put, the project worked against workers' interests because it would have placed an extra work burden on them and would possibly require inconvenience – for instance changing working hours to accommodate school-going people.

Hopefully, as the adolescent-friendly health services develop there will be sufficient support at district and community levels to create a sense of value for these participants. All participants must have a personal motivation for involvement, even if only at the level of feeling that it is good and meaningful to contribute to one's community. But before this could be relied on, it was necessary to build value in a range of ways, from providing particular participants with caps, red ribbon badges and small media items and providing cash incentives to cover the personal financial costs of involvement. Ultimately the status and appreciation that derived from leading the project and organising events, the recognition and admiration involved in performing or presenting, and the sense of meaning that came from being of value to the community proved to motivate personal involvement, but we definitely had to create motivations of many kinds as an interim measure in getting individuals involved.

In each of the projects it was shown that the interests of young people are served by multiple stakeholders, ranging from those who have custodial responsibilities towards them to those whose responsibility it is to deliver services that meet their needs. The process of involving the range of all stakeholders is bound to be less than optimal. In these projects, the research team encountered

teachers who perceived themselves to be already over-committed, health workers who had other priorities and people who were only too happy that someone else was addressing this problem as it relieved them of the burden of involvement. Also encountered were leaders who were interested in being nominally connected to the projects but who were not otherwise engaged in supporting it.

Participation fluctuated throughout both projects. Different groupings became active at different stages. Enthusiasm and interest waxed and waned, and at some stages it seemed that the Cadre project teams were the main driving force of the project. In this context a central concern was to focus on shifting responsibility for activities (and sustaining activities) to community participants, to the point that the Cadre team were able to withdraw with a sense that something was left in place that did not rely on their direct involvement.

The ways in which groupings of a community participate in projects such as these may inadvertently perpetuate part of the problem that the community is trying to address. It was found, for example, that the Launch Day in Amatole Basin followed protocols which expressed the dynamics of authority prevalent in the community. In many small and seemingly harmless ways, from seating arrangements to eating arrangements to procedure for the day, the prevailing authority structure was asserted. Whilst attempts were made to avert this and to maintain the youth led spirit of the project, this involved the risk of going against the standard practices of the community and a balance needed to be struck. Similarly it was necessary in setting up the project in the first instance to defer to the Traditional Authority. But ultimately the project needed to establish its own identity, which it did by having an independent organizing structure. Eventually this project led by young people was reconnected with traditional structures, but having successfully secured a place for young people in this aspect of community development, which would probably not otherwise have happened.

Special sensitivity was required in involving traditional healers and churches and to a certain extent problem areas had to be overlooked in order to build a project team. For instance, it was necessary to accept the pulpit-led notion of church participation, and to do otherwise may have undermined the involvement of key religious stakeholders. Ultimately if young people are to be

engaged through the church this needs to be problematised. (This concept is discussed below.) However, it was probably judicious to defer this to later in the project where the involvement of churches would hopefully be more securely established.

In the face of the need to win community participation it is sometimes necessary to bypass critical reflection on community and social processes, but at the same time it is necessary to be wary of entrenching some of the root causes of the problem whilst attempting to alleviate it.

In the face of the need to win community participation it is sometimes necessary to bypass critical reflection on community and social processes, but at the same time it is necessary to be wary of entrenching some of the root causes of the problem whilst attempting to alleviate it.

To transform situations it is necessary to think differently about them. Both of the projects were initiated through a process of contextual analysis, followed by a process of engagement and development of a plan of action. In different ways, young people were encouraged and even provoked into thinking about situations in new ways, or reflecting on issues in their own lives that they had never considered. It became apparent that when one starts to discuss and explore more important issues there is a quickening of interaction and a sense of involvement and excitement. This in turn may be used to generate ideas about action and commitments for action. In summary, what this means is that engagement must also involve a process of being open to understanding differently and this needs to be encouraged. Action needs to be premised on reflection and accompanied by ongoing reflection if it is to be anything other than a repetition of existing social practice.

The general dialogical methodology of Paulo Freire offers a particularly useful framework for bringing together action and reflection. This process involves reflecting together on problematic situations which are shared by a community of people. Understanding of issues which are close to the heart and mind does not come easily and it was found that there was a need to promote 'problematising'. Problematising refers to the process of identifying a situation as problematic in a way that leads to analysis and solution finding. An example of this in Amatole Basin is the issue of unquestioning and uninformed use of injectable contraception and the implications this has had for male orientation to HIV prevention. In Sibonile the boarding school environment and closed community were problematised to a certain extent. It is often assumed that we can know our situation best by virtue of our immersion in the day-to-day realities of our lives. Yet as suggested above, it is often exactly this immersion which prevents us from seeing the conventions, social practices, beliefs, assumptions and communication practices which structure our realities.

Finally, on the subject of engagement, it is necessary to talk about communication activities as they occurred in the projects. Whilst dialogue and direct interactive communication was foremost, it is almost important to review the role played by small media approaches. Small media products such as leaflets and posters provide basic information, but they also represent a tangible articulation of directed activity. They become part of the fabric of dialogue and interaction, and lend authority to the activities being conducted.

In Amatole Basin, Xhosa language HIV/AIDS leaflets and posters (developed as part of the national Beyond Awareness Campaign) were obtained from the district Department of Health in Grahamstown. Coordinators and others involved with the project were also provided with red ribbon pins, caps or T-shirts at various stages, and this further helped to legitimise involvement in the project. It is clear that such items were useful for supporting action at local

level. However, such media approaches were not only restricted to items derived from external sources. The making of media items such as posters, a permanent sign relating to the Launch and a wire mesh red ribbon, were all localised means of articulating the events at hand within the community context.

In both projects, folk media played an integral part in articulating HIV/AIDS issues and included slogans, plays and songs, all framed within the dialogic environment of a community gathering. All of these media forms were an important part of this initiative to build a communication culture around HIV/AIDS and to conceive this new force within the community.

Sustaining response

The process of establishing new social processes on a lasting basis requires some form of enduring framework to maintain the initiative over time, and the success of the projects depends in part on the extent to which this has been successfully achieved at all levels of engagement.

The projects are, in one sense, an attempt to reconceptualise HIV risk to children and young people as an environmental, social and cultural problem rather than specifically as a problem located within the individual.

At an individual level, personal pledges and mission statements were an important aspect of both projects; but these extended beyond the individual and provided opportunities for embedding action at a community level. In Amatole Basin the entire community went through an extensive process to create a 'mission statement' which was adopted in a specially created public event. In Sibonile school individuals adopted statements reflecting their chosen personal response to HIV/AIDS and publically expressed these. This public level of discourse allows for a broader location of individual pledges and commitments within the community.

Commitments made privately are not bound in place by anything more enduring than one's state of mind and immediate context, and it is important in developing social responses to consider ways of fixing these intentions so that they are maintained over time and situation. At the level of individual action there are many ways in which a person might bind themselves to courses of future action, including imposition of penalties on themselves for breaking an intention or pledge to action. Alternatively individuals might limit their exposure to situations which could lead them astray and undermine their intentions. Such strategies assist in turning an intention into an enduring action. Extending beyond individual mediation of action, is the exposure of one's commitments to others – for example, by telling friends and family members, or, as happened in the project sites, by making declarations to the wider community.

It is important to work with social expectations in anchoring intentions. Ultimately, values, norms and standards are an expression of social expectations. The social commitments made in these projects, and the trouble that went into creating contexts for this, went some way towards creating values and standards around AIDS response at a community level.

But ultimately commitments are also going to need recognition and support at the social level in order to continue to develop in the desired directions. In Amatole Basin the health promoting schools initiative and health services which

are better oriented to the needs of young people, are essential for further developing and sustaining the initiative. In Sibonile ongoing work with young people with disabilities needs to be entrenched through support of higher authorities, endorsement of the efforts of core individuals and groups involved, and appropriate allocation of resources. This kind of commitment is perhaps going to be the most difficult to secure and will ultimately determine whether these initiatives develop further or stagnate. This requires advocacy, networking and development-support skills and resources, which are currently not readily accessible to communities attempting to develop their capacities to respond to HIV/AIDS.

Conclusions

The Amatole Basin project involved a rural and impoverished community where existing frameworks for sexual enculturation have broken down, and have not been replaced by any real alternatives other than practices emerging out of 'trial and error'. In the situation of perceptually impaired young people it can be seen how learning to cope in a sheltered environment ironically makes the young person vulnerable to various forms of exploitation as they approach the edge of that environment. It has become evident that young people in such situations are in a sense trapped, and may not have the capacities to transcend the boundaries of what they know and what they are exposed to. That is, until they are invited to explore ways of transforming their worlds and until they unlease their energy and imagination on the static social arrangements that define their possibilities.

Through these two projects some progress has been made in discovering possibilities and problems associated with involving young people in transforming their orientation to HIV/AIDS. In the process of conceiving and executing these projects it has become evident that whilst we often think of young people as fluid and changeable, they occupy worlds which are to a large extent shaped by forces beyond their own control. Herein lies the most intractable problem we face as a society in orienting young people to HIV prevention.

The imagination, openness and aspiration which characterises the early years of life is constrained by harsh community and social realities, and lack of preparedness of young people to the challenges they face, or support for them in this. We cannot separate the challenge of responding to HIV/AIDS from the general development challenges facing young people trying to find a place for themselves in a world which may be quite unaccommodating and inhospitable.

Material circumstances must not be discounted as a factor influencing response to HIV/AIDS and this is true at many levels, notably the quality of family life, social capital, access to information and resources, freedom of choice and the sense that one has the capacity to mould the shape of one's world. Further, we have seen through these projects that the development of responses to HIV/AIDS requires support of various community and social services and unless these can be harnessed to care for the needs of young people, sustainable responses are hard won.

APPENDIX 1

AMATOLE DECLARATION (English version)

Masiphumelele – Silwa ingculazi

The Amatole community includes Tribal Authority, churches, traditional healers, traditional educators, clinic committee, village health workers and the residents of this community, young and old.

We, the community of Amatole Basin, meeting 7 September 2001 at Komkhulu Hall in the Amatole Basin, have adopted the following declaration:

Aware that lack of knowledge and communication, together with non-disclosure intensify the impact of HIV/AIDS in our community, and jeopardize chances of working together, providing mutual support and positive action within the community;

Recognise that this is not only a problem affecting the youth in our community, but is a burden carried by all equally, and that as the community, we have an important role to play in responding to the many challenges posed by the epidemic;

Recognise that a truly effective response to the epidemic requires partnership between all stakeholders, not only at community level, but also at the level of government, healthcare providers, other organizations involved with HIV/AIDS issues, and people living with HIV and AIDS, with the aim of improving prevention, education, care and support;

We hereby commit ourselves to working together in the ongoing search for solutions that will impact positively on this community and thus enable it to respond more effectively to HIV/AIDS.

We would like to see the death and destruction wrought by this disease come to a stop. We are aware that we all carry an equal burden in fighting the disease, and to this end, we agree to:

- Be a united community (adults and youth) and to work together in issues affecting the community.
- Educate and help one another.
- Encourage people affected by this disease to disclose.
- Support and love those known to have HIV/AIDS.
- Be supportive and partake in all AIDS-related initiatives that will benefit this community.
- Collect and share new information about HIV/AIDS.
- Try to reach those in the community who do not seem to view the disease seriously.
- Hold 'AIDS Awareness' programs where all will be encouraged to air their views, share ideas and educate one another around the issue.

- Find ways as a community to delay young people getting involved in sex so early.
- Respect that some young people choose to not have sex and not put pressure on them in any way.

We realise that it is a fallacy to think that aids is 'out there'. It is a shame to see the youth dwindling, and we commit to prevention and support efforts like the following:

- To discuss the issue in community gatherings.
- To continue with the condom distribution initiative, ensuring that condoms are always available at village level.
- To encourage all to carry and to use condoms at all times.
- We pledge to use condoms and to have one partner.
- We will go for testing when the facility is available.
- We agree to disclose our HIV status with the knowledge that we will have support from our community.
- We encourage all and their families to disclose HIV status when one has AIDS.
- We pledge to support, and never to gossip about or humiliate in any way, those who are known to have HIV/AIDS.
- We pledge to draw PWAs close and to encourage them to live positively. The community will deal severely with anyone seen to discriminate against them.
- We will preach and pray about AIDS at church, in schools and in concerts.
- We will encourage communication in families as we feel that this is an important area in AIDS/sexuality education.
- We have started holding inter-faith AIDS prayer services and will continue doing this.
- As people in the health services, we will ensure that we deal with people responsibly (e.g. use gloves and other sterile/protective gear when handling the sick).
- We pledge to work together as different sectors of the health services.
- We commit to use AIDS symbols in our workplaces as a visual sign of our unity and commitment (for example, on our clothes for work and church and school).
- We commit ourselves to maintaining and building upon this initiative.
- We commit ourselves to ensuring that our children grow up as an AIDS-free generation.
- We as youth commit ourselves to advise our peers and our younger brothers and sisters about responsible sexual behaviour and the dangers of HIV/AIDS.

We as the leaders of this community commit ourselves to:

- ensuring that the issue of HIV/AIDS is considered in all our work.

- effectively involve our people in designing action plans and implementing activities and programmes.
- work together with all stakeholders to maximise commitment, participation and leadership in response to the challenge of HIV/AIDS.
- provide the necessary support to our communities and strengthen their capacity to intervene in the challenge of HIV/AIDS.

Signed at Amatole Basin, 7 September 2001

REFERENCES AND USEFUL RESOURCES

Badcock-Walters P and Whiteside A. 2000. HIV/AIDS and Development in the Education Sector. DFID, Pretoria. www.und.ac.za/und/heard/papers/2000/sector.pdf

Bennett J, Thetard R, Msauli D. and Rohde J. No date. Strengthening community participation in health: Ideas from the Eastern Cape. The Equity Project, Bisho.

C A S E. 1998. Social security for people with disabilities, services provided for disabled people by national and provincial government departments: a Summary Report. CASE, Johannesburg.

Campbell C. 1999. Moving beyond health education: The role of social capital in conceptualising 'health enabling communities'. Unpublished paper, London School of Economics and Political Science.

Chalmers H, Stone N and Ingham R. 2001. Dynamic contextual analysis of young people's sexual health. Safe Passages to Adulthood Programme.

De Koning K and Martin M (Eds.). 1996. Participatory research in health: issues and experiences. National Progressive Primary Health Care Network, Johannesburg.

DOE. 1999. National policy on HIV/AIDS, for learners and educators in public schools, and students and educators in further education and training institutions. Department of Education, Pretoria.

DOH. 2000. A policy on quality in health care for South Africa. National Department of Health, Pretoria.

DOH. 2000. The Primary Health Care Package for South Africa—a set of norms and standards. Department of Health, Pretoria.

DOH. 2001. Developing and implementing an HIV/AIDS plan at district level. Department of Health, Pretoria.

Figueroa M, Kincaid D, Rani M and Lewis G. 2001. Framework and indicators for measuring social change process and outcomes. The Rockefeller Foundation and Johns Hopkins University Centre for Communication Programs, Washington.

Gillies P. 1998. Effectiveness of alliances and partnerships for health promotion. Health Promotion International, 13, 99-120.

Green S and Stone J. 1996.The Sexual abuse of children with visual impairments. British Journal of Visual Impairment, 14. www.qac.ac.uk/bjvi/vol14/bjvi142c.htm

Hawe P and Shiell A. 2000. Social capital and health promotion: A review. Social Science and Medicine, 51, 871-885

Hawe P, King L, Noort M, Gifford S and Lloyd B, 1998. Working invisibly: health workers talk about capacity-building in health promotion. Health Promotion International. Oxford University Press, London.

Jones H. 2000. Disabled Children's Rights and the UN Convention on the Rights of the Child. Disability Studies Quarterly, 20. www.cds.hawaii.edu/dsq/issues/2000/fall/pdf/06_children.pdf

Kelly K, and Parker W. 2001.Communities of Practice: Contextual mediators of youth response to HIV/AIDS. Beyond Awareness Campaign/ HIV/AIDS and STD Directorate/ Department of Health, Pretoria.

Kelly K. 2000. Communicating for action: A contextual evaluation of youth responses to HIV/AIDS. Beyond Awareness Campaign/ HIV/AIDS and STD Directorate/ Department of Health, Pretoria.

Lawson L..No date. HIV/AIDS and Development. SAIH/INTERFUND.

Leonard A. and Muia E. 1998. Community-Based AIDS prevention and care in Africa- Building on local initiatives. Population Council.

Meer S and Rodwell B. 2000. From crisis to development. Transitional National Development Trust, Pretoria.

Ntlabati P, Kelly K and Mankayi A.. 2001. The first time: An oral history of sexual debut in a deep rural area. AIDS in Context Conference: University of the Witwatersrand, April 2001.

Parker W, Dalrymple L. and Durden E. 2000. Communicating beyond AIDS awareness: A manual for South Africa. Department of Health, Pretoria.

SAHRC. 1997. Policy Paper #5: Disability. South African Health Research Council, Pretoria.

Sait W. 2000. Submission on the HIV/AIDS/STD Strategic Plan for South Africa with a focus on HIV/AIDS/STDs and Disability. South African Federal Council on Disability, Cape Town.

Schierhout G and Fonn S. 1999. The integration of primary health care services: A systematic literature review. Health Systems Trust, Durban.

Schneider M, Claassens M, Kimmie Z, Morgan R, Naiker S, Roberts, A and McLaren P. 1999. We also count: The extent of moderate to severe reported disabilities and the nature of the disability experience in South Africa: National Baseline Survey. Department of Health.

Schneider M. 2000. One in twenty. Youth disability: Selected findings from the national baseline survey. Development Update, 3, 56-67.

Senderowitz J. 1998. Involving youth in reproductive health projects. Pathfinder International, Washington.

Shakespeare D, Priestly M, Barnes C. 1999. Life as a Disabled Child: A qualitative study of young disabled people's perspectives and experiences. Disability Research Unit, University of Leeds, UK.

Stadler J, Collins T and Ngwenya S. 1999. Implementing adolescent sexual and reproductive health services in the Northern Province. Health Systems Development Unit, Johannesburg.

Stillwaggon E. 2001. AIDS and poverty in Africa: Prevention and treatment require a focus on overall health and development. www.comminit.com/TheDrumRole/sld-1992.html

UNDP. No date. Evaluating HIV and Development. UNDP. www.undp.org/hiv/publications/evaluation.htm

UNESCO/UNAIDS. 2000. A cultural Approach to HIV/AIDS Prevention and Care: Summary of Country Assessments and Project Design Handbook. UNESCO/UNAIDS.

White Paper on an Integrated National Disability Strategy. 1997. Office of the Deputy President, Pretoria.

WHO/UNICEF. 1994. Action for Children Affected by AIDS: Programme profiles and lessons learned. WHO/UNICEF.