

UNDERSTANDING AND CHALLENGING HIV/AIDS STIGMA



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A HIVAN PUBLICATION

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Understanding and Challenging HIV/AIDS Stigma is part of the HIVAN Community Booklet Series, an initiative which focuses on various aspects of HIV and AIDS, treatment, prevention and care within South African communities.

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Whilst all the above have contributed to the production of this book, we wish to emphasise that the statements made and the views expressed in the book are the personal views and responsibilities of the authors alone, and do not necessarily reflect the views of HIVAN or the funders.

Note: proceeds from the sale of these booklets will be allocated to the cost of extra print-runs and further issues in the booklet series.

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How can this book help in the fight against HIV/AIDS?

This book will help you to understand why so many people have such negative attitudes towards those who have HIV/AIDS, and their families. It shows how these attitudes - which are called stigma - undermine HIV/AIDS care and prevention, and cause great personal suffering and tragedy. The fight against HIV/AIDS and the fight against stigma have to go hand-in-hand: it is not possible to get rid of one without getting rid of the other.

At the moment those who most need to understand and tackle stigma sometimes have a limited understanding of what it is, how it is caused and how it can be addressed. Until this can be reversed, the HIV/AIDS epidemic will continue.

The aim of this book is to encourage individuals, groups and communities to think and talk about stigma and its causes, using their own first-hand experiences and then to develop ways to overcome it. Some anti-stigma programmes try to stop stigma by providing information about HIV/AIDS. On its own, this is not enough. In addition to receiving information, communities need to examine how stigma affects them in their particular situation, and what responses are possible and appropriate for their situation.

The information in this book comes from the experiences of two communities, one near Durban and the other in a rural area near Empangeni. The lessons from these two communities are used in this book as a starting point for other communities to begin to discuss their own experiences, and to engage in a process of critical analysis about the cause of stigma.

This book is based on the firm belief that responses and strategies for tackling stigma at a local level have to be built on communities' own understandings and experiences of the problem, and be guided by the solutions that they propose.

The book will be useful not only to communities of people who live in the same area, but also to health workers, religious groupings, NGO groupings, development agencies and so on - any person or group committed to the fight against HIV/AIDS, on which the problem of stigma has such a negative impact.

Note: To make the reading of this book easier, information obtained in the research appears to have been generalised. However, all information applies to the research samples only.

Introducing the concept of stigma

If you have AIDS you die twice because the first thing that kills you is being lonely when everyone discriminates against you, even your family members. The second one is the actual death.

(High School male)

This section aims to help you think about what stigma is, who is most affected by it and how people respond when they are stigmatised.

What is stigma ?

HIV/AIDS is a virus that is found in the body. Stigma is found in the thoughts of people and communities, when people believe that a particular illness, or something a person has done or feels, is shameful and brings disgrace on themselves, their family or their community. They believe that the person is bad and should be despised and avoided by the community.

There are many different types of stigma in societies, but in this book, stigma refers to all the negative thoughts and

feelings that people have about HIV/AIDS - about those who have it, their families and even about discussing it. Because of this stigma, individuals, families and even whole communities often discriminate against others in ways that cause great suffering. Stigma also undermines successful HIV/AIDS management.

A stigmatised person is someone who suffers because of stigma. Stigma can cause a person to lose their position in society and possibly even in their families.

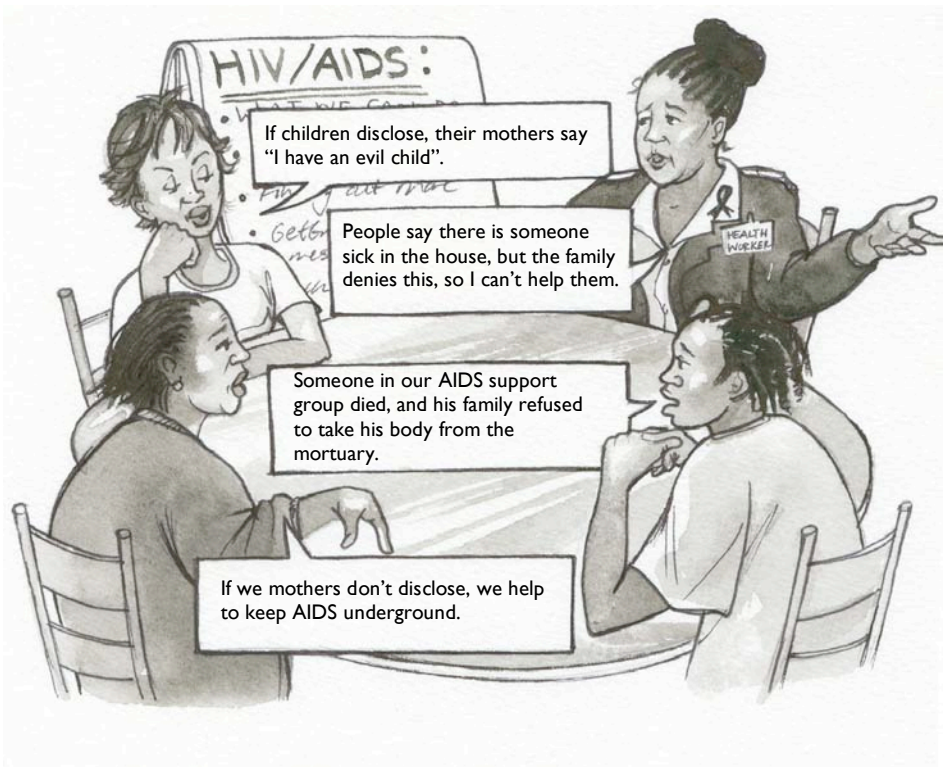
Who is most affected by the HIV/AIDS stigma?

People who are most seriously affected by the HIV/AIDS stigma are often those who were socially disadvantaged before they contracted HIV/AIDS. Women, youth, older people and the poor are often in this category of socially disadvantaged people. They also have the least power to resist or challenge stigma.

Even where HIV/AIDS affects members of more powerful groupings - men, or members of social elites with greater access to political or economic power - these people may end up being denied dignity and respect.

How do people respond to stigma?

Stigmatisation happens throughout communities. Here is a conversation about how the stigma of HIV/AIDS affects families.



This conversation shows that:

- Families are often frightened to acknowledge that anyone in their family has HIV/AIDS or has died of HIV/AIDS.
- Because of stigma, youth with HIV/AIDS may be afraid to tell their own mothers because their mothers may despise them.
- One way of trying to avoid stigma is to refuse to acknowledge that you or anyone in your family or even groups of people in your community have HIV/AIDS. But when families keep silent about HIV/AIDS they do not get the help that they need.
- If people do not speak out about HIV/AIDS and ask for help, the disease cannot be fought successfully.

So you can see that it will be very difficult to get rid of HIV/AIDS if the stigma that goes with it is not removed.

Stigma leads to denial

As you saw in this conversation, a very common response to HIV/AIDS is for people to deny that they have it, or that a family member has it, or even that it exists in a community. It is quite common for a dying person and their family members to deny that they have AIDS, even when everyone knows that they do.

Some people living with AIDS disclose to their families in indirect ways. There is a story about a man who, two weeks before his death, wrote to his family disclosing his status, rather than telling them face-to-face.

Denial is a form of protection from the isolation and disgrace that stigma brings upon those who have, or are associated with, someone who has HIV/AIDS.

Here are statements from people living in communities where people are dying of AIDS. All of them deny the existence of AIDS in the community in one way or another:

People of this community don't have AIDS - but people go to other places and bring it back here.

(Adult man)

A local guy disclosed his status on a TV programme recently. This guy has embarrassed all of us. I didn't ever think there would be a person from this community who would disclose his status in public. Anyway most people say that he was lying.

(Youth)

If a person who is always in the community gets sick, people don't regard them as HIV-positive. The only ones regarded as HIV-positive are these who went away from the community and then came back sick. Then people say it is AIDS.

(Young migrant worker)

When I told mourners at my brother's funeral that he had died of AIDS, people were angry with me. They said I had spoilt my brother's name.

(Adult man)

Denial is such a powerful response to HIV/AIDS that even those who acknowledge its existence often avoid using the word 'AIDS'. Even community health workers sometimes refer to HIV/AIDS as 'this thing' or 'this disease' or more generally as 'sickness'.

Taking action in spite of stigma

Sometimes stigma seems too big to fight. It takes a lot of courage to stand up against the views and attitudes of your community or your friends. But here are some stories showing that brave people are already doing this and succeeding. They have realised that they can make a positive difference to the suffering of others and to the prevention of HIV/AIDS.

- People living with AIDS are linking up with others who also have HIV/AIDS. Talking to someone who has the same experience and difficulties is a great comfort.



- Other people have found support by joining groups such as the Treatment Action Campaign (TAC), which raises awareness about how stigma increases the helplessness of people living with AIDS. TAC works hard to create a setting where no-one feels isolated or acted against.
- In the rural community that was studied, a group of mostly unpaid women have formed a group of community health volunteers. They work with tremendous dedication and selflessness to help the most desperate households. They often walk long distances from one homestead to another to give assistance and are prepared to help in any way, even with washing ill people and their bedding, and collecting wood and water for suffering families. These women always offer kindness and comfort even if they are not received in a friendly way from families who do not want to admit that they have an AIDS sufferer in their home.
- A growing number of individuals are starting to try and understand the way in which they either intentionally or unintentionally contribute to the problem of stigma. They are starting to look at the role that they can play in fighting stigma, even in the smallest ways. This can be done through the smallest of changes in how they think, feel and act in their own homes and neighbourhoods, schools and workplaces, on public transport and in all the many places where stigma exists and grows.

Stories like these can be used to help you to think of appropriate community-based action that can be taken to tackle the negative views and attitudes that are caused by stigma.

What causes stigma?

The fight against HIV/AIDS is also a fight against the stigma of HIV/ AIDS. In order to put an end to this stigma, it is important to understand what has caused it.

This section looks at the following causes:

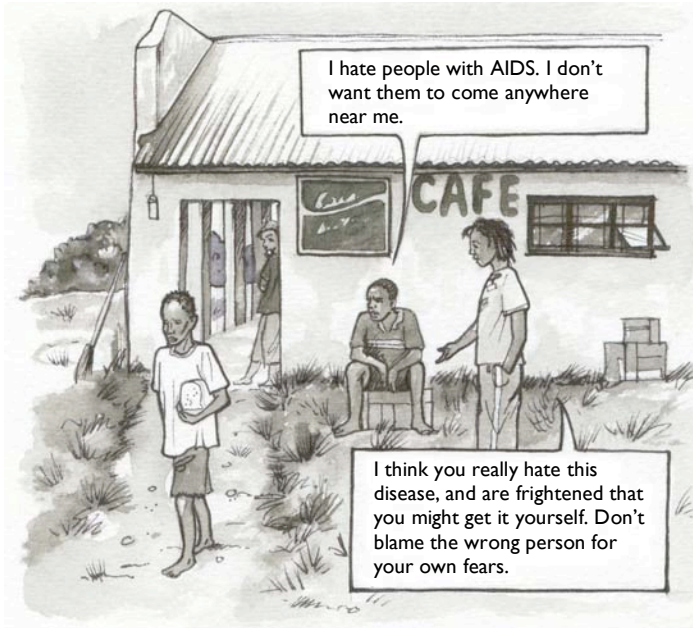
1. Fear
2. HIV/AIDS information
3. The fact that HIV/AIDS is linked to sex
4. Poverty
5. Not enough open discussion
6. Lack of HIV/AIDS services



Everyone has a role to play in getting rid of stigma, but clearly no person or group or community will be able to tackle all these causes alone or at the same time. Each group and individual needs to decide where they can best make a contribution. Where possible they should form alliances with others fighting stigma at other levels. But even when alliance building is not possible, every single individual has a role to play in trying to eliminate stigma from their own thoughts and feelings.

It is also important to facilitate peoples' awareness of the fact that they can make a difference by changing their own perspectives and actions.

Cause 1: Fear



The youth leader in this picture has correctly identified that the young boy who hates AIDS is really very frightened of getting it himself.

There are important reasons why people discriminate against people with AIDS. The starting point is that all human beings, no matter who they are, or where they live, suffer from the fear that something bad will happen to them one day. For people who see others dying of AIDS constantly, this general

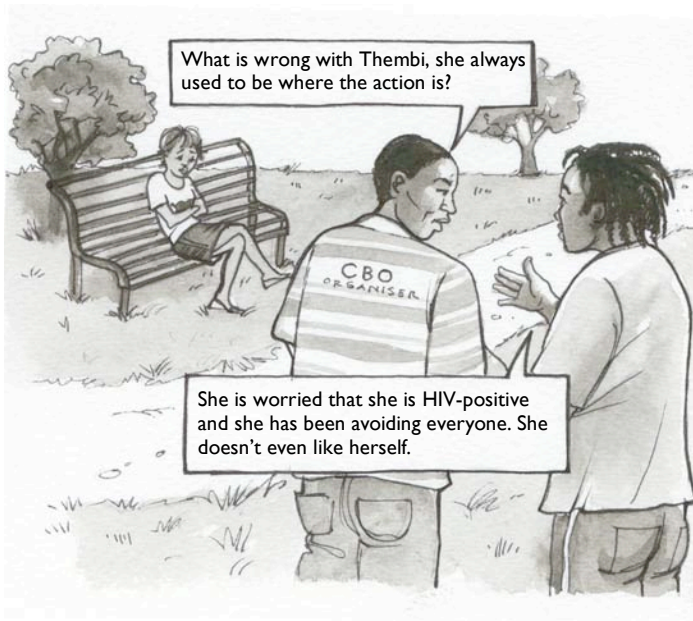
fear becomes more extreme. When they see or hear of people with AIDS, this immediately reminds them that they too might be at risk of contracting this terrible disease.

The fear of this possibility is so strong that people do not want to think about it. So they place this fear on those who remind them of the danger. The hatred that a person feels for the disease becomes a hatred for the person who has the disease. The boy in the picture has done this. This fear and hatred and anger take the form of stigma and discrimination against those with HIV/AIDS. This produces a false feeling of safety and security instead of fear.

How do people with HIV/AIDS respond to fear?

A number of things happen to people when all this negativity and fear is directed at them:

- They often deny that they have AIDS in order to stop being stigmatised. If they do this they will also avoid getting proper treatment.
- They may begin to hate themselves.
- They may stop seeing their friends and family at a time when they most need them.
- They become less confident and they think people are criticising them, even when this is not happening.



Thembi, in this picture, is already starting to avoid her friends even though she only thinks she is HIV-positive.

As will be discussed, one of the key steps in fighting stigma lies in creating support groups where people living with HIV/AIDS can get together and discuss the ways in which stigma undermines them, and gradually build up each others' confidence to withstand the discrimination they are exposed to.

Cause 2: The kind of information that people get

Information plays a big role in understanding HIV/AIDS. But too little information, or the wrong information, or confused bits of information can all bring about negative responses towards people living with HIV/AIDS. People who do have sufficient information often lack the confidence to use it to take appropriate action.

Lack of information

People are not well- educated about this disease. They have strange perceptions that they can contract the disease from even coming near such a person.

(Rural woman)

It's a shameful thing to have AIDS in this community. I think they would make a big gap between my desk and other learners' desks at school.

(Young boy)

These two quotes show that ignorance can lead to the isolation of people who have HIV/AIDS. People incorrectly think HIV/AIDS can be passed on through casual contact such as sharing plates or sitting next to someone in a taxi. This helps to promote the stigmatisation of HIV-positive people.

The first step in fighting stigma is to put people in touch with up-to-date and accurate information about HIV/AIDS including:

- How HIV is and is not transmitted.
- How HIV can be prevented.
- The difference between HIV and AIDS.
- How long people with HIV or AIDS can expect to live.
- The fact that people living with HIV/AIDS can be productive members of society.
- How to support and care for someone with HIV or AIDS.

This information needs to be shared in an interactive and participatory setting. An ideal situation would be a workshop where people can reflect, contest and come back and ask questions, or argue around information they disagree with or find unfamiliar.

Note: Information alone is not enough

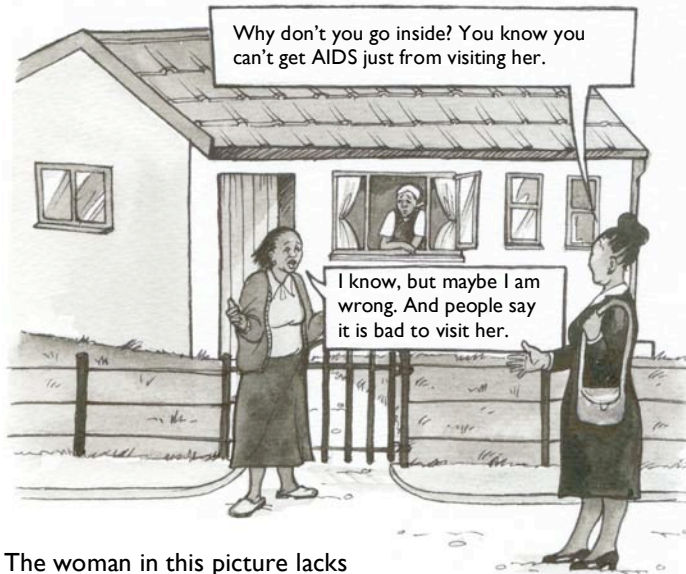
Some people may think that the solution to stigma is to provide more HIV-awareness programmes to teach people the correct facts about the disease. However, whilst ignorance is one cause of stigma, research has shown that just giving more information about the cause of the disease is not enough to reduce stigma. In many instances, stigma remains even when people do have the basic information about the cause of HIV/AIDS and how it is spread.

So, while it is important to move from ignorance to knowledge, information on its own is not enough.

Lack of confidence in information and how to apply it

Information can fail to help people in taking sensible action for the following reasons:

- People may not trust the information they have, even if it is correct.
- They cannot see how to take action on the basis of the information they have.
- Stigma has confused them and undermined their confidence in their information.



The woman in this picture lacks confidence in the information that she has, even though it is correct. As a result, she is unable to apply it appropriately by going into the house to visit her neighbour. She is also influenced by what "people say".

Conflicting information

If the information that people get conflicts with other information, this can cause confusion. For example, many people do not have easy access to hospitals, clinics or medical care. This is especially bad in rural areas. Their only source of health treatment are traditional healers, many of whom are skilled at advising people on how to strengthen their immune systems, and in giving psychological support.

However, some traditional healers say that HIV/AIDS is the result of bewitching. This conflicts with the medical information that people have, causing confusion and often leading to a denial of the real problem. It also promotes stigma.

These quotes show that medical information is often ignored when other reasons for illness are given. They also show how easy it is for this kind of non-medical information to cause stigma.

Saying that a person has AIDS is a shame to the community as a whole. It sounds better to say that someone has been bewitched.

(Rural woman)

People find it easier to say they are suffering from evil spirits than to say they have AIDS.

(Young man)

Accusations of witchcraft fly around easily in a community.

(Young man in learners' focus group)

If an improving household has a sick member they go to the traditional healer, who tells them they have been bewitched by their neighbour who is jealous of their success.

(Adult man)

Cause 3: Nowhere to talk openly

People keep saying that more information about HIV/AIDS is needed in order to fight stigma. Information is definitely important, but on its own it is not enough. Furthermore, even in isolated rural areas, people often have a surprising amount of information about HIV and AIDS. The problem is often not so much a lack of information, but the fact that people find the information they have difficult to apply in their own lives.

For example, women may not be confident about discussing HIV prevention with male partners. Young people may want to use condoms, but are frightened that their parents might find out when they go to collect them.

In such situations, it is important for people to have a place where they can discuss the doubts or fears they have with others.

In the picture below, the youth leader recognises the need to have a place where students can discuss the information they already have. Together, they need to be able to work through their doubts about its truth and its relevance to their own lives, and to talk about how to change their behaviour in the light of the information they have.

The Principal, on the other hand, thinks he has done enough by allowing information pamphlets to be distributed. This conversation also shows how different the views of adults are about the realities of their children's lives - and how these views contribute to making young people feel that they cannot talk about their confusion and fear about HIV and AIDS.



Until people feel safe and comfortable about openly discussing their first-hand experiences of AIDS with their families and communities, stigma will continue and the prevention of HIV/AIDS will be held back.

Cause 4: The fact that HIV/AIDS is linked to sex

This disease is still considered a shameful disease. People look down on those who have it. They say they have been sleeping around. Because of this people are frightened to disclose their status even to their family members. It becomes their secret.

(Community Health Worker)



A significant cause of stigma is the fact that in many communities, sex and sexual relations are regarded as something shameful that should not be mentioned or discussed. The young girl in the picture comes from a family who believes this. Because HIV/AIDS is transmitted by people having sex, it too is regarded as a shameful disease.

This presents the greatest challenge facing anti-stigma programmes. In fact, the stigmatisation of sex and of the sexuality of youth and women can be seen as the real problem rather than the stigmatisation of AIDS.

Why is there so much shame around sex?

Before looking at the sexual beliefs that support the stigmatisation of HIV/ AIDS, it is helpful to understand how power within communities and families contributes to the stigmatisation of sex and the sexuality of youth and women.

Taking action in spite of stigma

South Africa is a patriarchal society. This means that men are regarded as the heads of families and communities. Because of this, men have more privilege and power than women or youth, both in private and public life. Women and young people have second-class status, with men exercising power over them.

A key aspect of this power involves power to control or limit the sexuality of women and youth. The quotes below are examples of the power that men have over women and youth, particularly girls.

If we suggested condoms to our husbands we would be chased away from our homes. They say they have a right to sex because they paid cattle for us. They can demand anything from us and we have to oblige. If we refuse to have sex without condoms they will report us to our parents - and the old people will support our husbands, saying to us: 'Ha, we never heard of such behaviour'.

(Woman in rural focus group)

*(Interviewer:) Why do only boys play soccer and not girls?
(Mrs X, 55:) How can a girl leave the house to go and practise?
We would just forbid her and scold her, accusing her of going to see boys.*

The high levels of HIV/AIDS amongst youth, particularly young women, show very publicly that these groups are sexually active, despite male and adult attempts to restrict their sexuality and control their behaviour. Stigmatising people living with HIV/AIDS is a way of punishing those who "step out of line", and challenge the traditional control of adults and men.

The power of traditional authorities

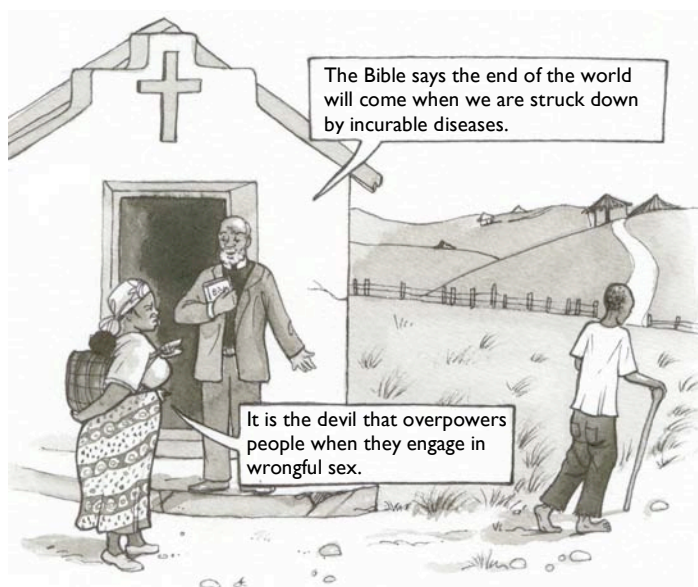
Traditional authorities also have power over the sexuality of young people and women. They, like the men in the community, are responsible for ensuring "acceptable" sexual behaviour in youth and women. And yet the existence of the AIDS epidemic shows up their lack of authority over the sexual behaviour of some of the people in the community. They have therefore reinforced the stigmatising of youth and female sexuality. Old-fashioned practices such as virginity testing have been reinstated, where girls who pass this test are rewarded with goods ranging from higher social status to virginity certificates.

Even well-intentioned leaders may contribute to stigmatisation by their public opposition to sex before marriage, which they refer to as 'bad behaviour'. With this kind of opposition, people are frightened to admit to having a disease linked with prohibited sexual behaviour. Families are even frightened to admit that one of their members has the disease.

The power of the Church

The Church teaches that sex should be conducted within a faithful marriage and that sex outside marriage is a sin. So there are strong links between sex, sin and immorality. The HIV/AIDS epidemic highlights how many unmarried people are sexually active and so it also highlights the way in which

many people ignore the Church's teachings. This shows that the Church has lost some of its moral authority and power. One of the strategies that some representatives of churches use to try to get back this lost moral authority, is to say that people with HIV/AIDS are guilty of sin and immorality and their behaviour may even lead to the end of the world! Here is a conversation between two people who have been influenced by the Church's attitude to HIV/AIDS.



To summarise the points made here about power, it can be said that stigma can be caused when authority figures - such as men, traditional authorities or the Church - feel the need to enforce their authority because it is being challenged. Where HIV/AIDS is concerned, part of the power of these three authority figures rests on their ability to control the sexuality of women and young people.



- The fight against stigma will not be won until people are aware of the power relations that keep stigma alive. Common beliefs about what is socially acceptable are often based on unequal power relations. Where possible people need to think about ways to challenge these power relations in their own lives.
- A key stage in preparing to challenge power relations is to develop critical thinking about how the stigma has started. What are the social roots of the stigma?
- When communities get together to think critically about stigma, they are often able to see the inequalities in social relations that contribute to stigma. Such community participation is a powerful weapon against stigma. It is just as powerful as information.
- Programmes need to include critical thinking about the way in which social institutions such as the Church, the family and the traditional leadership system do or do not contribute to stigma.

Note: Critical thinking involves analysing, questioning, criticising, discussing, drawing on experiences and arriving at conclusions on the basis of all this.

It is about:

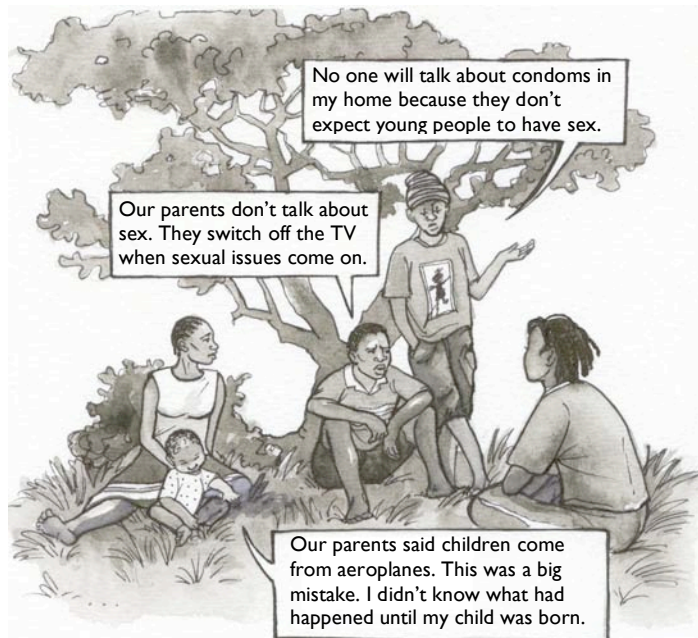
- Developing a common understanding of the way that social beliefs and conditions can damage the health and well-being of a society.
- Developing a collective vision for a better society and a belief that social conditions can be changed.
- Developing the confidence to fight some of the negative consequences of these social conditions.

This should ultimately lead to collective action.

Beliefs that support the stigmatisation of sex

The remainder of this section looks at beliefs that support the stigmatisation of sex, such as beliefs in the shameful nature of youth sexuality and women's sexuality.

Beliefs about the stigmatisation of sex



Sexuality means awareness of a person's sexual nature. As the conversation in this picture shows, parents often do not want to discuss anything about sex with their children. They will not acknowledge that their children may be growing into young people with sexual urges and sexual curiosity.

However, not all parents are like this. Look at the contradictory views about youth sexuality in these quotes:

If AIDS had been around when I was growing up, it would have spread as it spreads today. We had many girlfriends. Not two or three, but more than ten. We have no right to blame young people by saying they are not behaving themselves.

(Father in his early 40s)

Has your son ever told you he has girlfriends? (Interviewer)

Wow! Wow! He could never tell me that. Wow! There is no need for him to talk about that here.... I don't believe a parent must talk to their children about their love-life. This is how I grew up. It wouldn't be right for me to know my children have relationships. (Mother)

The father in the first quote is prepared to be honest about his own sexual behaviour in the past and can see that the youth of today are no different. This is the kind of view that encourages open discussion.

Parents who are not open about the subject of sex can never provide the support and information required to promote safe sexual behaviour amongst young people.

A companion booklet to this one (Supporting youth: Broadening the approach to HIV/AIDS prevention programmes) shows how failure to respect young peoples' rights to protect their sexual health, is part of a more general neglect of the needs and rights of young people in South African society.



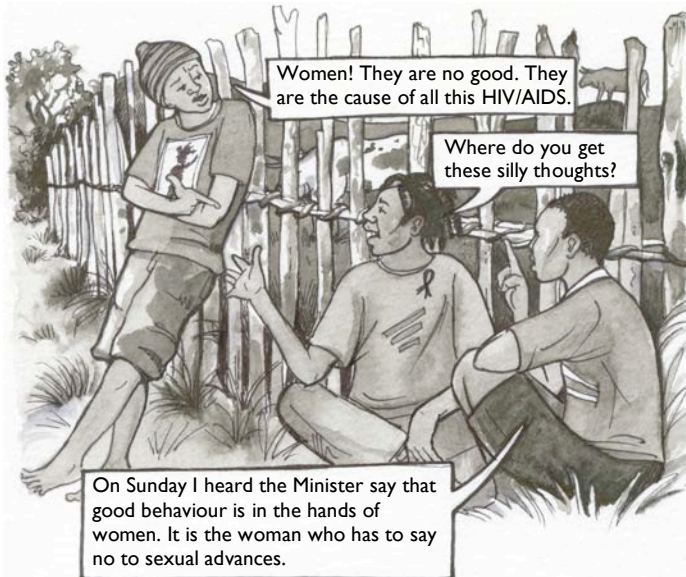
It is incorrect that youth of this generation are necessarily more sexually active than earlier generations. People need to be encouraged to think critically about this belief and to challenge it. The distinction between 'good' and 'bad' behaviour also needs to be challenged, and in particular the association of sex outside faithful marriage with 'bad' behaviour.

Beliefs about women's sexuality

Mother says that when you sleep with a boy you get a baby, he dumps you, and it's only afterwards that you regret that you ever slept with him. She says if you are a girl you must protect yourself against boys who will destroy your life.

(girl, 12-14)

There is strong denial that women, and particularly young women, have sexual desire and sexual relationships. Mothers often refuse to discuss sex in any way that is connected to their daughters' personal experiences of desire and relationships. They indirectly link sex with shame and danger, rather than accepting that their daughters are sexually active and teaching them how to protect themselves from STDs and pregnancy.



As the picture shows, the denial of young girls' sexuality is linked to a widespread belief that the weakness of women has led to the HIV/AIDS epidemic. This attitude is known as the 'demonisation of women', where women are viewed as being evil and not worthy of respect.

Under circumstances such as this, it is not surprising that young women try to hide their sexual activities. They are also less likely to try to find out more information about sexual health or to carry condoms. They often talk about sex as something that 'just happened' to them, as something they did not expect, and therefore did not prepare for.

However, the reality is that young people do have sex away from the sight of adults. Many girls want and enjoy sex as often as boys and as much as adults. But these young people have no support or guidance from their parents.

Cause 5: Poverty

Research has shown that the stigmatisation of people with AIDS is most severe amongst poor families. There are two ways in which poverty contributes to stigma.

Firstly, in a poor family the burden of caring for a person with AIDS can be almost unbearable. It almost always falls on women, who often do not know a lot about caring for a very sick person. As a result, they often become exhausted from the strain of trying to care for someone effectively.

The financial cost of caring for an AIDS patient is another factor that can cause great stress and can cripple households that are already very poor. This situation may sometimes lead to bitterness and resentment against the patient, and anger that 'they brought this sickness on themselves by their bad behaviour'.



An important part of fighting stigma is to mobilise local communities (neighbours, friends, volunteers) to assist carers and also to fight in every way possible for carers and patients to access whatever grants, health and welfare services and assistance is available. It is also important that carers are provided with knowledge and skills about AIDS and how best to care for an AIDS patient, and with necessary equipment for home nursing (gloves and so on).

There is a second way in which poverty contributes to stigma. Many communities are held together by networks of older women, who are united in their commitment to 'respectability'. These women provide very important survival networks that hold struggling communities together. They do not have wealth or education, but they are nevertheless revered within their community for the role they play in keeping their community 'respectable'. In their view, a community can lose respectability if some of its members engage in inappropriate sex.

Because they have little else, these women value their respectability highly and they stigmatise people living with HIV/AIDS as a way of emphasising their own dignity.

Cause 6: Lack of HIV/AIDS management services

This section draws together several of the causes of stigma already discussed (such as fear and poverty) and shows how these factors, combined with poor HIV/AIDS management and services, contribute to stigma.

AIDS care and prevention

The fear of HIV/AIDS is particularly great where there are not adequate health services. In many rural areas this is a big problem. Community clinics may visit once a month and hospitals are far away. A shortage of hospital beds means that people with HIV/AIDS are often treated and sent home again no matter how sick they are. It is also very difficult to apply for grants for people with HIV/AIDS or orphans. So, for very real reasons, people are afraid of catching the disease themselves or of having to care for someone. The section on Fear showed how this can easily turn to stigma.

As this quote shows, hospital staff can also be responsible for keeping alive the stigma of HIV/AIDS.

Hospitals often don't do proper counselling when they tell people they have AIDS, the nurses are badly trained, many are not dedicated. The nurses must stop calling people names, give them love so that their family members will also accept them.

(Health worker)

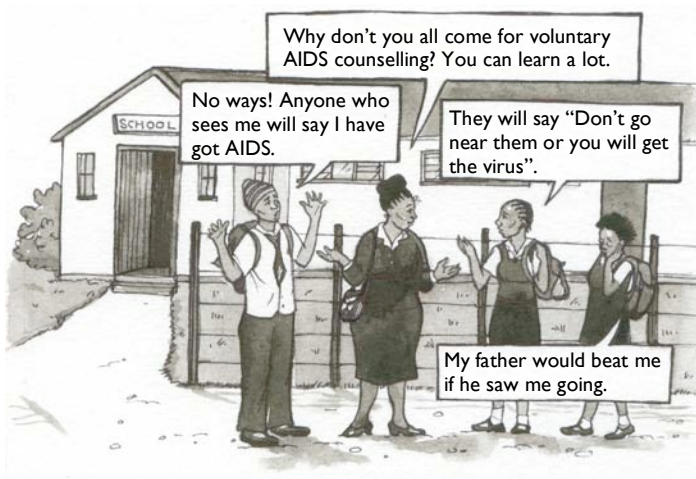
Even in the workplace, government employees such as nurses stigmatise AIDS patients by abusing them, or failing to treat them with respect.

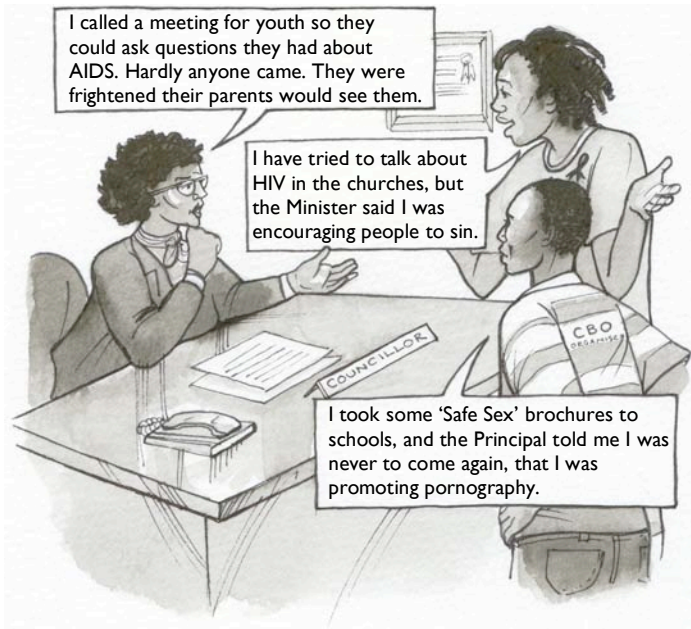
It is increasingly common to hear arguments that stigma will end when people living with HIV/AIDS have free and accessible treatment. There is no doubt that when people know that HIV/AIDS is not necessarily a death sentence, some of the fear and denial surrounding HIV/AIDS will end. However, treatment will not, on its own, be enough to eliminate stigma. The link between HIV/AIDS and so-called 'bad behaviour' will still exist and the disease will continue to be associated with shame and embarrassment.

How is stigma affecting the management of HIV/AIDS?

Stigma and the fear that accompanies it have a very destructive effect on HIV prevention, AIDS care and the social support that should accompany this epidemic.

The effect of stigma on HIV prevention





These two pictures are based on real responses from people. They say a great deal about the effect that stigma has on HIV prevention programmes and how stigma discourages youth from going for HIV/AIDS counselling or assistance:

- Youth are frightened that their parents might see them and punish them even if they go for counselling.

- They fear that people will think they have AIDS and are sinful and so they avoid all places that have anything to do with AIDS prevention or AIDS testing.
- Respected people in the community, like the school principal and the church minister, often promote stigma and therefore discourage HIV prevention programmes.

HIV prevention is also difficult for women if their husbands will not admit that they are HIV-positive. Mrs N told how she had become infected by her husband, a migrant worker working and living in Durban. He had many girlfriends and hardly ever visited her in her rural home. At these times, she felt that she had to have unprotected sexual intercourse with him, since she did not want him to accuse her of 'sleeping around' with other men. Her husband finally returned home when he was terminally ill, but even then refused to admit to her that he had AIDS. After his death, she decided to have herself tested at the local clinic and learned that she was HIV-positive.

If the husband of this woman had told her that he had AIDS and had agreed to use a condom, she would not be HIV-positive.



People are more likely to go for voluntary counselling and testing and take precautions in their sexual relationships if they see that people with HIV/AIDS are treated with kindness and care.

Those involved in HIV/AIDS management need to target men as a key group for HIV-prevention. This is particularly important, as there is a lot of evidence to show that many women throughout Africa who have remained faithful to their husbands get HIV/AIDS from their husbands.

The effect of stigma on AIDS care

Families hide the person away from the community once they discover they have AIDS. They take him away from the community and we end up not knowing what has happened to that person. They don't even allow him or her to go to the clinic or to seek out any help at all.

(Woman, 36, 'Youth leader')

People with AIDS who need care face a number of problems that are related to stigma:

- As the quote above shows, they are less likely to get the care they need.
- It is difficult for Community Health Workers to get people to apply for AIDS grants when they do not want to disclose that they have AIDS.
- It is possible that even when antiretroviral treatment is freely available, stigma will stop some people from coming forward to ask for it.

The effect of stigma on social support networks

***T**here are patients who are alone at home with no one to feed them. Their relatives run away from their sickness and they are left alone.*

(Clinic sister)

When people are sick and depressed, as those with AIDS often are, it is important to feel supported, loved and respected. Stigma deprives millions of people of this kind of support.

- The quote above shows how families sometimes abandon their own members rather face the stigma of being associated with a person who has HIV/AIDS.
- Community health workers say how difficult it is to care for and advise a patient who does not disclose.
- The strong anti-AIDS position taken by some churches, as well as their disapproval of sex, and their association of AIDS with sin, means that it is very difficult to raise the issue of HIV/AIDS in the Church. Even a Church Minister who had nursed his son until his death from AIDS was puzzled when asked whether he could use this experience as a basis for helping church-goers facing similar challenges. He responded very firmly that it would be impossible to raise an issue like this in the Church.

Moving forward from a position of strength

This book has looked at the way in which stigma contributes to the problems of HIV/AIDS prevention and care. It has shown how factors such as ignorance, fear, the sexual nature of AIDS, poverty and lack of access to health and welfare support, cause or contribute to stigma. These are complex issues that will not be sorted out by running support and awareness workshops only.

People are most likely to change their stigmatising attitudes:

- When they have sound and accurate **information** about HIV/AIDS.
- When they are provided with **social spaces** to engage in dialogue and debate about this information.
- When they take **ownership of the problem** of stigma. In other words, when they recognise that they must take responsibility for solving this problem.
- When they are helped to **think critically** about the social roots of stigma, and the ways in which these
- need to be challenged in order for change to be possible.
- When they have a sound **understanding of the ways in which community relations can make stigma worse**, and need for change in these relations if the problem of stigma is to be addressed.

- When they have the **confidence** that comes from realising that despite all their problems, they also have strengths.

The importance of these six points has been discussed in this book. They are repeated again here, because they form the basis for the way forward that is outlined in the remainder of this section. Organisers of anti-stigma programmes need to pay specific attention to ensuring that their interventions incorporate attention to each of these points.

Start by building on the strengths of people, not their weaknesses

People in deprived communities facing desperate circumstances have often shown that in order to survive they can be brave and creative. Nevertheless, because they are so overburdened by problems, they might have got into the habit of seeing themselves as helpless victims of forces beyond their control, rather than as courageous people with multiple strengths. They fail to acknowledge or value the courage and resourcefulness that it has taken to stay alive in conditions where many have died.

Although it is very important that people identify and name problems and their causes, it is also important that these problems are discussed in groups in ways that help people to identify their own or group strengths and abilities that they may

have overlooked because of all their problems. Putting people in touch with their individual and collective strengths is a key strategy for mobilising them to take on the challenges posed by a problem as complex as stigma.

How this can be done?

Some of the principles of a strengths-based approach are:

- It is participatory.
- There is an appropriate and 'safe' place for people to meet to break the silence and isolation that is associated with HIV/AIDS
- It highlights the positive roles that people are playing and the tremendous love and sacrifice of those who do help people with HIV/AIDS.
- It involves identifying the role that local communities are playing in either helping or obstructing people's ability to cope with problems such as HIV/AIDS and stigma.
- It involves working with participants to identify how they and their group can help develop a more supportive environment for the work of all those who provide support and care to PWAs families, Community Health Workers and so on.

People are most likely to take the challenge of solving problems such as stigma seriously:

- If they have a sense of 'community ownership' of the problem, and an understanding of the vital role they have to play in addressing it
- If they can see that treating people with AIDS with care and love and respect helps to reduce HIV/AIDS and its stigma
- If they have some personal reason for tackling the problem

This is most likely happen when:

- Community members really try and think through what it must be like to be an individual or family with AIDS.
- Everyone recognises that they face the risk of HIV infection.

Communities need to work out for themselves how they are most likely to encourage everyone to "own" the problem. Some suggestions for discussing this in a participatory way are:

- Share information that highlights the fact that AIDS is a problem faced by virtually every family in the country.
- Show that even if participants are not immediately affected by HIV/ AIDS, they may become directly affected in the future. For this reason, they have an interest in ensuring that proper support systems are in place for those people who do need help.
- Generate debate about the way in which stigma fuels the fear that is one of the greatest factors driving the epidemic.

- Generate discussion about the fact that the solution to this problem is unlikely to come from outside sources (health and welfare departments, NGOs), and for this reason it is vital for local people to develop their own responses to supplement this limited external help.
- Give examples of ways in which local people may already have started to develop local responses either as individuals or within any informal or formal groups they are part of.

Targeting specific groups for anti-stigma programmes

It will not always be possible to reach every member of a community and to include them in a participatory, strengths-based approach. Anti-stigma activists might decide to prioritise particular groups as a target for their efforts, aiming eventually to reach more widely and include more people.

The research that was done for this book found that the following groups should be the first targets for anti-stigma interventions: people living with HIV/AIDS, families caring for people with AIDS, faith-based organisations and partnership groups. These are discussed on the next page, but each community will have to decide about this, based on their own experience.

Supporting people living with HIV/AIDS

Starting support groups

When people who are part of a stigmatised group take collective action, this can have powerful social and political consequences. It can also strengthen individuals who are part of the group and help to build assertiveness.

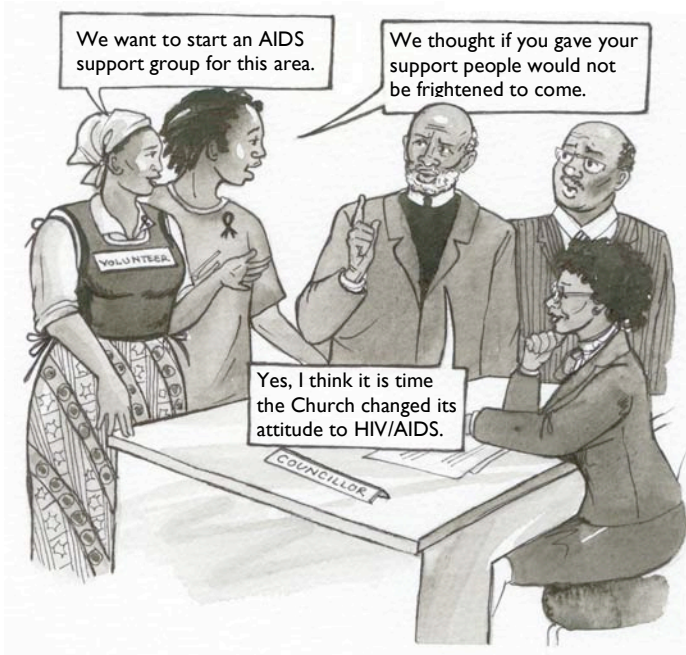
In South Africa, the 'Treatment Action Campaign' (TAC) has opened up the exciting possibility of collective action by people living with AIDS in South Africa. It has engaged in many high-profile campaigns to highlight the way in which peoples' lives are destroyed by various forms of stigma and discrimination. However, joining such a large and important organisation may not be the action of choice for all infected or affected people.

Other people have joined smaller confidential support groups, where infected or affected people can meet to share their experiences and support each other. Such people often say how much they benefit from being able to share their worries and gain various forms of advice, encouragement and practical assistance with others in a similar position.

Wherever possible, anti-stigma activists should facilitate HIV/AIDS support groups.

Some of the goals of such support groups could be:

- To create 'communities' of people with AIDS who can discuss ways in which they can help each other.
- For people to assist one another in making well- informed decisions whether or not to disclose, and who to disclose to.
- For people with HIV/AIDS to share skills and assist one another in accessing welfare grants or medical support most effectively.
- To begin to identify and challenge those who hold on to stigmas and who discriminate against people who have HIV/AIDS.
- To encourage people with HIV/AIDS to play as active a role as possible in challenging these stigmas and in improving the discriminatory social environment that they face.



Involve people with AIDS in HIV/AIDS management activities

A growing amount of emphasis is being placed on involving people with AIDS in various community-based HIV/AIDS management activities. However, this may be more possible in some communities than others.

Supporting families caring for people with AIDS

Supporting families caring for people with AIDS is another key aspect in the fight against stigma for these reasons:

- Poverty, lack of adequate health and welfare support and the burden of care on women already weighed down by other responsibilities, may lead to situations where families or caregivers unintentionally stigmatise the family member with AIDS.
- Training family members in a basic understanding of how HIV is transmitted or prevented, helping them access basic home nursing AIDS-care skills, helping families access grants and medical assistance, and mobilising neighbours and volunteers to provide relief from the burdens of care, can play a key role in reducing stigma in the household.
- Strengthening families' abilities to cope with the problem can also build their confidence in facing stigmatising attitudes or behaviours from those outside of the family.

Support for families is not only vital in relation to AIDS care, but also HIV prevention. Parents urgently need guidance in examining their attitudes to youth sexuality, in understanding how their denial of this phenomenon fuels the epidemic, and in supporting them to develop less harmful attitudes.

Each community would have to think of the most creative way of seeking to mobilise parents, taking into account local networks associated with schools, faith-based organisations and so on.

Working with faith-based organisations

Churches could play an important role in helping to reduce stigma and support people with AIDS and their carers. As you saw earlier, they have been slow to respond to the challenge of HIV/AIDS and some have even promoted stigma through their unrealistic attitudes to sexuality, and its link between sex and sin.

However, AIDS has personally affected numbers of church ministers and church members. This should be a basis for mobilising churches to become partners in community-wide anti-stigma initiatives. The challenge is how to persuade them to take the first step.

At the very least, it might be possible to organise churches to offer prayers and support to infected and affected individuals

and families. In fact, many church women's and prayer groups already do this, visiting households and praying for the sick, but generally disguising the nature of the illness they are praying for.

At best, churches could develop more sympathetic ways of:

- Providing affected individuals and families with supportive places of worship
- Openly accepting and supporting people with AIDS in congregations
- Mobilising women's groups and prayer groups to visit affected households
- Using religion as a channel for fighting stigma, by portraying anti-stigma as an essential part of good religious practice



Forming partnerships

Research has shown that community-led anti-stigma interventions often succeed if they form links or partnerships with outside leaders and organisations. The value of this is that information, skills and resources are shared and communities have a better chance of communicating their needs to more powerful groups.

The following are examples of possible partners for communities:

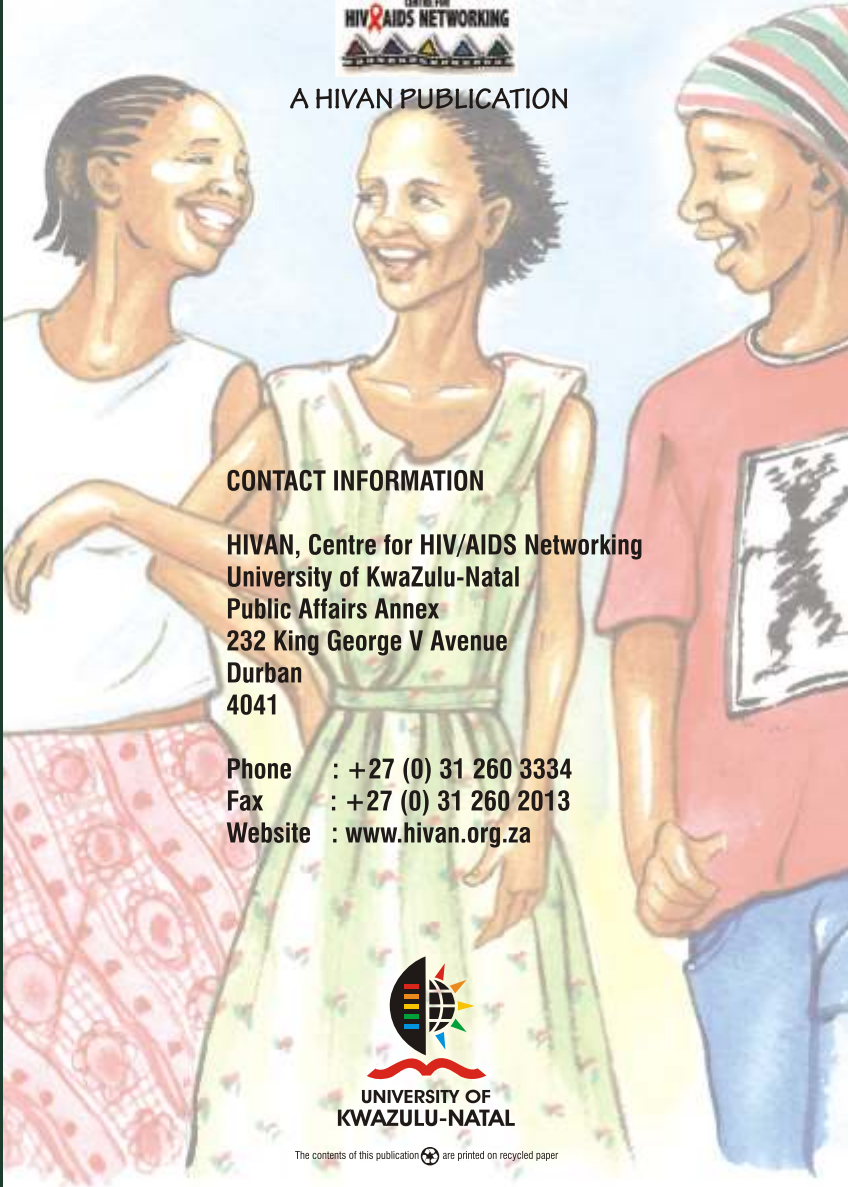
- Public sector organisations such as the Departments of Health and Welfare.
- Business, workplaces, CBOs and NGOs which are beginning to run anti-stigma programmes.
- Political, religious and traditional leaders, all of whom have a key role to play in the fight against stigma.
- Organisations such as TAC, which fight directly for the rights and needs of people living with HIV and AIDS at the national level.
- Organisations aiming to promote the empowerment of women, youth and the poor - groups who are all disproportionately affected by both the stigmatisation of sex and the stigmatisation of HIV/AIDS.

Where was the information in this booklet obtained?

The information in this booklet is drawn from two studies of community responses to HIV/AIDS prevention and care, carried out by the Centre for HIV/AIDS networking (HIVAN) at the University of KwaZulu-Natal. The first was a peri-urban community near Durban. The second was a deep rural area near Empangeni. These studies involved a total of 120 long interviews and focus groups with people drawn from a wide range of groupings. These included: people living with HIV and AIDS, carers, community health volunteers, local leaders, youth, male and female community residents, peer educators, school principals and teachers, NGO staff, traditional healers, doctors and nurses, social workers, church ministers, government officials and representatives of businesses and factories close to our research sites.



A HIVAN PUBLICATION



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