

# community conversations

Enhancing communities' capacity to respond to HIV/AIDS



"Starting where communities are"

The community conversations were held in Kliptown, Gauteng; Soshanguve, Gauteng; Mhluzi, Mpumalanga; Lerome, North West; Giyani, Limpopo; Galeshewe, Northern Cape; KwaMakhutha, KwaZulu-Natal; Thaba Nchu, Free State; Mthatha, Eastern Cape; and KwaLanga, Western Cape.

## Foreword Achmat Dangor CEO, Nelson Mandela Foundation

erhaps one of the unintended consequences of South Africa's remarkable political transformation was the gradual demobilisation of the community networks that had helped sustain people during the dark apartheid years. Obviously, as the role of liberation movements changed from "opposition" to "governing", local communities too had to make adjustments. After April 1994 it was no longer necessary for communities - defined as people living within more or less contiguous geographic areas - to mobilise



Achmat Dangor.

politically around the issues that affected their lives. They now had political parties that could represent their causes and articulate their aspirations. Yet, we need to ask whether South Africans, in that afterglow of the early miracle years, were unrealistic about what even the most ideal of democratic systems could deliver.

Let us consider the spread of HIV that led to South Africa being described as a "hyper endemic" AIDS country. HIV prevalence rates began to reach their "tipping point" in the late 1980s and the early 1990s, just as the country began to grapple with the more visibly burning issue of political transformation. When the latter reached its summation in 1994 and the impetus behind civil society organisation began to diminish, AIDS was already being driven into the background by stigma and discrimination. As the structured "community conversations" that characterised communal life fell into a lull, the AIDS taboo became a truly unspeakable subject. Only activist organisations kept it "on the agenda".

In 2007 the Nelson Mandela Foundation, in collaboration with a number of partners, initiated a series of "community dialogues" on HIV/AIDS. The results have been remarkable. Insights emerged into how the virus spreads and roots itself within local communities; how even the most well-intentioned, externally driven responses do not have the desired impact. Local knowledge, through memory and story-telling, came out into the open. The 2008 dialogues held in 10 community settings have since created a body of knowledge that policy makers, scientists and activists will certainly find useful. Most importantly, these dialogues have helped the local participants to confront that "unspeakable" presence in their midst: HIV prevalence and AIDS mortality. They now have the potential to be empowered and to act decisively.

In keeping with its vision of making a just society by promoting the vision, values and work of its Founder, Nelson Mandela, the Nelson Mandela Foundation intends extending this model of dialogue to address other critical social issues such as poverty, gender inequality and xenophobia.

We have had glimpses of how local communities, given "safe space", physically and intellectually, can be empowered to turn into grass roots reality Nelson Mandela's art of "listening and speaking, and getting others to listen and speak to each other."



Participants in one of the conversations fill the hall.

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A special thank you to Vodacom Foundation for the support of the community conversations 2008.

Special thanks also to the Nelson Mandela Foundation's implementing partners: Cool Ideas 247 (Pty) Ltd; Shoeshoe Mohaladitoe & Associates; and the Foundation's Dialogue team including Lee Davies, Sekete Khanye, Molly Loate, Naomi Warren and Mothomang Diaho.

4 COMMUNITY CONVERSATIONS









# Prevention is key

t the XVII International AIDS Conference in Mexico City in August 2008, the medical journal *The Lancet* held a symposium to launch a series of articles on HIV prevention. It turned out to be an extremely well-attended discussion, evidence of the widely held view that treatment is not the full answer to the HIV pandemic and that prevention is where the world's efforts should be focused. Currently, for every new patient on treatment there are two new infections. The key is to maintain treatment while implementing comprehensive prevention.

The journal itself (*The Lancet* 2008; 372:421-422) put it like this: "This systematic imbalance [between treatment and prevention] in clinical and public-health programmes is largely responsible for the fact that around 2.5-million people become newly infected with HIV each year. ... Countries need to develop context-specific national preventive



A member of the team taking notes during one of the sessions.

strategies, not off-theshelf slogans dreamt up by donors." It also suggested that: "Overall, HIV prevention has overly focused on individual behaviours. ... Prevention needs to embrace the political, economic, and social determinants of risk too."

Recent estimates indicate that sub-Saharan Africa faces significant gaps in prevention<sup>1</sup>. For countries where data was available, just 9.5% of women and 7.9% of men had ever received an HIV test and results. In sub-Saharan Africa, the face of HIV/AIDS remains that of women (Figure 1)<sup>2</sup>. Our intervention must ensure that socio-economic upliftment works hand in hand with prevention efforts.

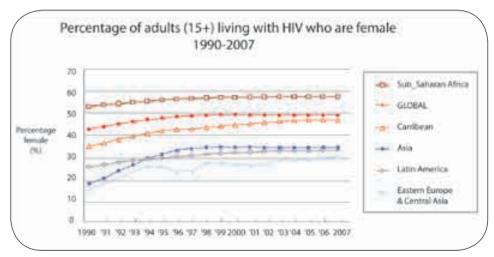


Figure 1: Percent of Adults Living with HIV who are Female by Region, 2007.

The global percentage of people living with HIV has stabilised since 2000. The overall number of people living with HIV, however, has increased as a result of new infections. Sub-Saharan Africa remains most heavily affected by HIV, accounting for 67% of all people living with HIV and 72% of AIDS deaths in 2007<sup>3</sup>. Preventing new infections remains the key to reversing the epidemic.

<sup>1</sup>WHO/UNAIDS/UNICEF, Towards Universal Access, Scaling Up Priority HIV/AIDS Intervention in the Health Sector, Progress Report; June 2008.

<sup>2</sup>UNAIDS 2008 Report on the Global AIDS Epidemic.

<sup>3</sup>UNAIDS 2008 Report on the Global AIDS Epidemic.

There are a number of issues that have been identified as key drivers of the epidemic in Southern Africa. These include high population mobility, inequalities of wealth, cultural factors, gender inequality, male attitudes and behaviours, intergenerational sex, gender and sexual violence, stigma, lack of openness and untreated sexual transmitted infections, and multiple concurrent sexual partnerships by men and women who use condoms inconsistently<sup>4</sup>.

For this reason, **expanded HIV prevention** (Figure 2), grounded in a strategic analysis of the epidemic's dynamics in the local context, is the sine qua non of getting ahead of the epidemic. An impressive range of states and individuals subscribe to the global consensus that effective HIV prevention requires locally contextualised approaches that address both individuals and social norms and structures and are grounded in human rights<sup>5</sup>.

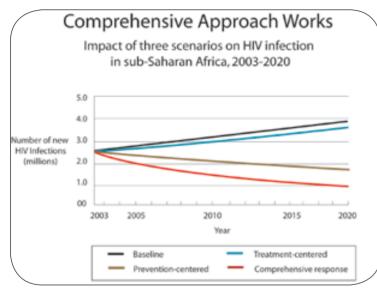


Figure 2: Comprehensive Prevention.

Effective HIV prevention programming focuses on the critical relationships between the epidemiology of HIV infection and the risk behaviours that expose people to HIV transmission. It also addresses the collective social and institutional factors, such as sexual norms, gender inequality, and HIV-related stigma, that will otherwise continue to fuel the HIV epidemic.

#### Why Community Capacity Enhancement?

HIV/AIDS in South Africa presents a major challenge to development. South Africa is experiencing one of the most rapidly progressing HIV epidemics in the world. The determinants of the epidemic cannot be explained only in terms of individual risk-taking



behaviour. The factors that cause it are to be found in the poverty and deprivation experienced by most South Africans. The challenges presented by the epidemic makes it advisable to rethink how best to support and extend communitybased care, as well as provide support for those infected and affected.

Community Capacity Enhancement (CCE) is based on the African concept of "*imbizo*",

These dialogues support communities in finding their own way to deal with HIV/AIDS.

when communities meet at the cattle enclosure or open area to discuss critical issues. Among the many HIV/AIDS campaigns and initiatives, CCE stands out as a people's participation approach. It focuses on people and their interactions, on their strengths and resources. It is based on the premise that all people have the capacity to respond effectively to a life-threatening epidemic. It is an approach that takes **cognisance of the socio-cultural dynamics of a community holding a dialogue with its own soul on the HIV/AIDS epidemic**. CCE builds on our capacity to respond to a crisis by giving communities tools with which to lead a dialogue and structure a credible response.

In the first article in *The Lancet* series<sup>6</sup>, 'The history and challenge of HIV prevention', the authors say it is only relatively recently that the world's HIV prevention efforts have begun to gather momentum, as the implications of the pandemic for development and security have become clearer.

"We now require an urgent and revitalised global movement for HIV prevention that supports a combination of behavioural, structural, and biomedical approaches and is based on scientifically derived evidence and the wisdom and ownership of communities."

The article on how to make behavioural strategies work better<sup>7</sup> suggests that "we need to get the simple things right. The fundamentals of HIV prevention need to be agreed upon, funded, implemented, measured, and achieved." It also talks about "aiming for many goals (eg, delay in onset of first intercourse, reduction in number of sexual partners, increases in condom use, etc)" and approaching them at many levels "(eg, *couples, families, social and sexual networks, institutions, and entire communities*)".

<sup>4</sup>Botswana's President Festus Mogae in his address to the 4th Annual ABMP meeting in Johannesburg, South Africa

<sup>5</sup>UNAIDS. Intensifying HIV Prevention: UNAIDS policy position paper

<sup>6</sup>Merson MD, O'Malley J, Serwadda D, Apisuk C 2008, 'The history and challenge of HIV prevention', The Lancet, vol. 372, no. 9637, pp. 475-488

<sup>7</sup>Coates TJ, Richter L, Caceres C 2008, 'Behavioural strategies to reduce HIV transmission: how to make them work better', The Lancet, vol 372, no. 9639, pp. 669-684

Efforts to change the behaviour of individuals are more effective when they pay attention to "the broader structural factors that shape or constrain individual behaviour, such as poverty and wealth, gender, age, policy, and power", maintain the authors. But these structural factors are related to each other and to HIV transmission in complex ways, and it is difficult to assess, compare or replicate efforts that take them into account.

Interestingly, confronted by such far-reaching and deep-seated historical conditions, the authors<sup>8</sup> conclude: "[T]he lesson to learn from the effectiveness of such efforts is that significant reductions in HIV risk and vulnerability can occur when *groups are enabled and empowered to come up with their own solutions.*"

In the final article of the series, the authors<sup>9</sup> say: "A quarter of a century of AIDS responses has created a huge body of knowledge about HIV transmission and how to prevent it, yet every day, around the world, nearly 7 000 people become infected with the virus. Although HIV prevention is complex, it ought not to be mystifying. ... **HIV prevention responses must be informed by an analysis of where the next 1 000 HIV infections are likely to come from in any given context.** 

"An impressive range of both individuals and states subscribe to the global consensus that *effective HIV prevention requires locally contextualised approaches that address both individuals and social norms and structures, and are grounded in human rights.*"

Speaking of societies where HIV incidence is high, like Southern Africa, the authors write: "What makes these societies unique from the HIV/AIDS perspective is that HIV transmission is far more diffuse than elsewhere, and occurs mostly within long-term and occasional heterosexual partnerships, often transgressing traditional concepts of high or low risk. Multiple vulnerability and risk factors (such as mobility, gender-based violence, or concurrent partnerships), which individually exist to an even greater extent in other regions (eg, low rates of male circumcision in Europe), converge to act synergistically in these societies. In other words, Southern Africa seems to be experiencing a perfect storm of HIV-related risks. Any explanation based on a single risk factor for this very high HIV endemicity ignores the realities of complex societies and human behaviour. A complex and diffuse epidemic should be addressed by an equally nuanced and multipronged response."

#### Marriage of approaches

In his closing speech at the conference in Mexico, co-chair and past International AIDS Society president Dr Pedro Cahn summed it up like this: "This conference is the first one in which progress has been reported both on ARV scale-up and prevention.

"But we have to keep in mind that we still have five new infections for every two patients reached by ARV rollout. And we know that even doubling the number of patients reached by these scale-up programmes would be insufficient to reach universal access.

In the words of Mike Cohen [Professor of Medicine, Microbiology and Public Health at the University of North Carolina-Chapel Hill], "this conference will be recognised as the one in which prevention and treatment got married. We look forward to the offspring, which needs to be the closing of the gap between where we are today and what we need to achieve."

#### Southern Africa is special

In a conference session<sup>10</sup>, UNAIDS executive director Peter Piot said: "Prevention is by nature long-term. That is one of the reasons that it is harder to get support for it, but also that it is so important that we are dealing with it now. ... Southern Africa is a special case when it comes to AIDS and also to HIV prevention. (Figure 3)

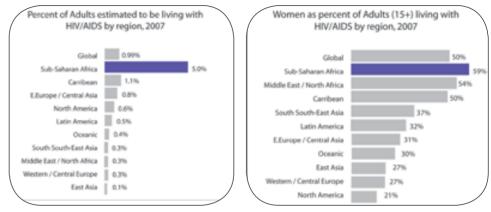


Figure 3: Percent of Adults Estimated to be Living with HIV/AIDS by Region, 2007.

"I do not believe in any technical fix for the epidemic in Southern Africa. ... This is an area where we have got to use every single intervention that has an impact. Where changing the social norms will be extremely important and where the leadership has to become far more forceful."

#### The answer lies within

It seems clear, then, the world's experts are thinking about the complexity of interrelated factors contributing to the spread of HIV – locally specific and broader factors – and the need for prevention efforts that take people's whole lives into account. Also, it is impossible to succeed with the treatment aspect of the struggle unless people know their HIV status.

The community conversations facilitated by the Nelson Mandela Foundation have met crucial points raised in *The Lancet*'s series, as indicated in italics in the summaries in this chapter. These dialogues are intended as a way for communities to find their own ways of dealing with HIV/AIDS – ways that take into account all the reasons that the virus has spread.

<sup>8</sup>Gupta GR, Parkhurst JO, Ogden JA, Aggleton P, Mahal A 2008, 'Structural approaches to HIV prevention', The Lancet, vol. 372, no. 9640, pp. 764-775

<sup>9</sup>Piot P, Bartos M, Larson H, Zewdie D, Mane P 2008, 'Coming to terms with complexity: a call to action for HIV prevention', The Lancet, vol. 372, no. 9641, pp. 845-859

<sup>10</sup>TheBody.com (August 6, 2008)

### Introduction Mothomang Diaho

Head of the Dialogue Programme, Nelson Mandela Foundation

he series of community conversations held by the Nelson Mandela Foundation in 2008 followed up a process that began the previous year.

In 2007, the Nelson Mandela Foundation and 46664 together held nine Youth Community Dialogues across South Africa. The dialogues encouraged young people (aged 16-24) to empower themselves in the effort to halt the spread of HIV/AIDS. Close to 5 000 youth were engaged in discussions around factors that put them at risk of HIV infection, including stigma, peer pressure and transactional sex.



Mothomang Diaho.

It became clear that the older and younger generations needed to talk and listen to each other more openly about HIV prevention and about caring for people who are infected and affected.

In the first booklet that recorded the youth dialogues, Nelson Mandela Foundation CEO Achmat Dangor wrote: "We intend ensuring that this first round of community dialogues will be repeated in many more communities and among many, many more young people throughout the country."

A lot of responses to HIV/AIDS to date have focused on raising awareness. Whilst there is value in this approach, efforts must also focus on communities taking responsibility and owning their own responses to the epidemic.

This year, the Nelson Mandela Foundation adopted an approach developed by the United Nations Development Programme, described in the chapter on methodology, called Community Capacity Enhancement (CCE). As the name suggests, this aims to develop the resources within communities to identify their problems and find their own solutions. One of its main elements is the concept of community conversations.

The methodology appears to fit many of the requirements of prevention efforts discussed at the latest international AIDS conference (see chapter on prevention).

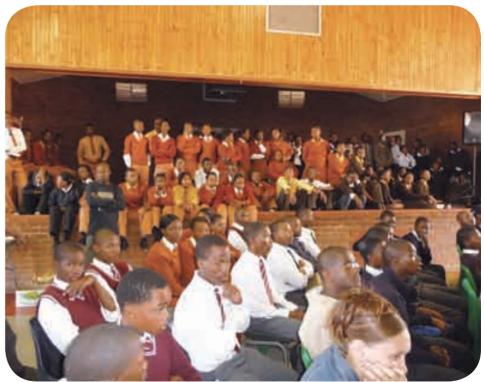
The Foundation held 10 community conversations in 2008, most of them revisiting the communities where the 2007 youth dialogues had been held. In total, about 6 525 people attended these events in 2008. There was a strong acknowledgement in these communities that the scale of loss through AIDS has become unbearable and that people

need to become more open about HIV/AIDS, more accepting of each other and more supportive. But it is also clear that there are still many challenges to overcome.

In this booklet, we record the way we approached the communities, what they said in the dialogues and how they are moving forward with their plans. We also hope to crystallise the lessons we have all learnt through this series.

We hope to continue building on these dialogues, supporting the communities' own efforts and documenting the progress they make. We also believe that the process should be scaled up as far as possible, using the partnerships we have begun to establish. That process will start with the next round of community conversations in 2009.

The Nelson Mandela Foundation would like to thank the Vodacom Foundation for its support of the 2008 community conversations.



Participants in the Galeshewe conversation.

### The methodology Community Capacity Enhancement

he methodology adopted by the Nelson Mandela Foundation for use in this 2008 series of dialogues was the United Nations Development Programme's Community Capacity Enhancement (CCE). As the name suggests, this aims to give communities the power to find their own solutions to problems that they themselves have identified. It is about an attitude – treating people with respect – as well as a set of activities.

Essentially, the methodology seeks to create an environment in which a healthy conversation can take place in a community, one where individuals can express themselves without fear. The origins, philosophy and practical elements of CCEP will be described below.

#### Deeper understanding

In a 2005<sup>11</sup> document, the UNDP explains how this approach evolved:

"The world is at a critical juncture in its response to HIV/AIDS. The last couple of years have seen an increase in treatment and access to medications. However, in many countries, prevalence rates are not declining. One reason why is that we are still struggling to address the underlying causes fuelling the epidemic's spread.

"The Community Capacity Enhancement programme, or CCE, is an integral part of UNDP's Leadership for Results programme and is based on a methodology known as community conversations. The CCE programme is aimed at dealing with the underlying causes of HIV/AIDS, be they power relations, gender issues, stigma or discrimination. Most community methodologies rightly focus on awareness-raising and discussion; CCE focuses heavily on interactive dialogue on the epidemic's deeper causes and, through a facilitated process, community decision-making and action.

"What became clear early on was the incredible understanding and response that came forth from communities once knowledge of the science and epidemiology of HIV/AIDS was shared. Communities immediately began to recognize for themselves the values and actions that would have to change if what they were hearing about this new disease was true. They reflected on how it spread and caused disease throughout the body and in other individuals. They identified which behaviours and sociocultural

<sup>11</sup>Gueye, M, Diouf, D, Chaava, T, Tiomkin, D, Community Capacity Enhancement Strategy Note; 2005.

practices would need to change if the epidemic was to be controlled.

"This awareness came about through a process called 'community conversations'. This series of facilitated dialogues contrasts with conventional approaches in which people are grouped together for awareness-raising lectures, often accompanied by the distribution of pamphlets or posters."

#### Human rights principles

"Community conversations promote human rights principles. Dignity of individuals





and families is preserved and enhanced in an environment that encourages compassion, acceptance and accountability.

"Stigmatisation, coercion and violence are avoided. UNDP has identified a core set of human rights principles that are guiding our response.

"These include equity, equality, non-discrimination, human dignity, nonviolence, participation, inclusion, accountability and responsibility." The report defines "community" as "a heterogeneous group of people living and/or working together, sharing norms, values and concerns, with common systems and structures for leadership, problem-solving and communication".

Above left: The streets of Thaba Nchu. Left: Audience members at the Galeshewe community conversation. The report says: "The aim is not just to have people discuss a problem they know something about. It is to provide a platform for people to think through all the repercussions of a situation. It is meant to help people analyse the way their individual values and behaviours, and those of their family and neighbours, affect people's lives and to discuss them with others. Community conversations create a space for mutual learning and result in new perspectives and creativity ..."

#### Steps in the methodology

Organisations using the CCE programme follow these steps in their work with communities:

- Identify local partners
- Enrol stakeholders and build relationships
- Prepare for implementation
- Hold skills-building sessions
- Facilitate community conversations
- Make follow-up support visits
- Document the approach
- Organise visits between programmes to exchange community experiences
- Hold resource network meetings for community conversations
- Host a national review, reflection and scaling-up meeting

#### Facilitation

This approach emphasised the importance of skilled facilitation in community conversations. In making sure that "all perspectives are heard and respected", facilitators must:

- Build relationships of trust and respect, and understand community values
- Identify and explore community concerns through strategic questioning
- Help the community to make its own decisions and plans
- Help the community to reflect on and review its agreements

Strategic questions are ones that cannot be ignored, and require thought before they are answered. They provoke without causing offence, and create options – there is no single reply. The answers go beyond "yes" or "no".

One way for facilitators to build trust with a group is to talk about significant events in the community's past and how challenges were overcome. Facilitators must also listen actively, showing that they have heard and respected what a person has said.

In their training and in their work in communities, facilitators are required to consider and ask questions like these:

- How do we reduce stigma and discrimination?
- How do we strengthen and expand community responses, building on the capacity within individuals, families and wider groups?
- How can community-to-community transfer be stimulated to help scale up the response to HIV/AIDS?

The facilitator's role is to guide communities in identifying and understanding the sociocultural dynamics that relate to the HIV/AIDS epidemic, and to empower communities to take action. They should not impose their own views.

They need to be sensitive to the challenges of working with communities and able to hold conversations around sensitive issues such as sexual behaviour. They must build a relationship of trust, understanding and respect with communities, which may view development interventions with suspicion.

Facilitators need to be able to guide and support groups and individuals who are confronting powerful emotions ranging from anger to grief and helplessness.

The CCE methodology involves documenting every step of the process – whether in written form or through forms such as photographs, songs and drama.

This series of community conversations was reported on regularly and reports were published on the Foundation's website, www. nelsonmandela.org.

(See the chapters on lessons learnt and reflections of the facilitators.)



Above and below: An important part of the session is discussing the challenges, and the setting of goals and action plans with the community.



#### **Case studies**

Community conversations have been used in countries that differ from each other socially, economically and politically. The UNDP says the approach works in all cases and can also be used to talk about issues other than HIV/AIDS.

One community conversation in Southern Africa dealt with the custom of "widow cleansing" – when a widow has sex with the men of her late husband's family to prepare her for remarriage. The practice can spread HIV infection. Through the conversation, this community agreed on another, non-sexual method of cleansing.

In another conversation in East Africa, the community discussed the practice of traditional healers who travel from one village to another, using needles and blades on multiple patients. The community decided to ban this practice.

A third example was a discussion in Cambodia about HIV/AIDS and contributing factors such as migrant labour, substance abuse and myths about condoms.

#### Social mobilisation

The conversations approach is based on the principle of meaningful participation and ownership. The concept of the conversation needs to be "bought" by the local stakeholders, from the tribal authority and municipal organs to community organisations,

Right: Participants engage with the conversations.





local media and other roleplayers. The process of enrolment is essential in ensuring that every stakeholder has a role to play and influences the outcomes of the conversation.

The conversation reconnaissance work begins with pre-conversations or mini-conversations to explore the dynamics of the area where the conversation is to be held. This phase engages local partners in determining who attends, which social drivers need to be examined further, which



A few of the participants of the Soshanguve community conversation.

cultural and social norms are likely to have an impact on the conversation and what obstacles may present themselves.

Ahead of a community conversation, the facilitation team engages in social mobilisation – activities to inform the community of the opportunity and encourage them to take part. This also involves forming partnerships with stakeholders such as local government, schools, churches, businesses and other organisations and groupings. Meetings of these stakeholders may be used as platforms to explain the idea of community conversations and invite people to attend.

A variety of media platforms are used, including distribution of flyers and posters in the area, interviews and stories on radio and television and in newspapers, and loudhailing in streets. (See Arts and Media, page 13.)

This 2008 series of conversations also held arts events prior to the main gathering, partly as a method of finding out what the community's concerns were and partly to advertise the conversation.

The Nelson Mandela Foundation called on Viva Hecate Production, an industrial theatre company, to present an updated version of its HIV prevention play.

#### Importance of introduction and ground rules

Every home, every village, every country has rules that govern the way individuals relate to each other. In the CCE methodology, the same holds true for the safe space in which a dialogue takes place.

When a community has gathered for a conversation, a facilitator first explains the occasion's purpose and vision. It is made clear that the conversation belongs to those who are there. The facilitator then asks those present to suggest their own ground rules for how people should behave at the event – for example, people should not be

interrupted while they are talking. These rules may be recorded and displayed where everyone can be reminded of them.





Top and above: Counting your losses. The stones on the cloth act as a memorial.

#### Counting your losses

"Counting your losses" is a powerful tool to use in a community conversation. It is an exercise which gives the community an opportunity to reflect individually on how HIV has affected individuals, family units and entire communities.

The exercise begins with asking the people who are gathered at a community conversation to remember family, friends and others they have lost through HIV/ AIDS. They are encouraged to think of households that are now headed by grandmothers or by children as a result of this loss of life.

The participants are then asked to take small stones from a supply brought by the facilitators, or from outside the venue. They will use these stones to represent the lost lives. The people file past a piece of cloth laid on the ground, placing the stones on the cloth as a memorial. A hymn may be sung while this is happening, and the participants may be holding hands. The atmosphere is quiet and respectful.

Afterwards, individuals are requested to reflect and share their feelings. This experience is the beginning of a healing journey for some of the community members; it provides a platform for sharing pain and experiences. It can be highly emotional, but the idea is that it is a safe and supportive place to express those emotions.

Sometimes this is where people disclose their HIV status for the first time, or talk about their regret and remorse, having infected other people with HIV or neglected sick people in need of support. They may speak of the burdens they carry as caregivers, or their fear of losing their own lives.

This may be where people realise that they can act to change the future and prevent further deaths.

#### Storytelling

Stories are about people and what they do. They are ways of understanding social life – its dynamics, influences and impact on individuals. Stories touch listeners in ways that theoretical presentations or statistics do not. Stories and proverbs are the ways that people were traditionally helped to understand their own actions and their impact on others. They can create a depth of understanding more quickly than by other means.

Asking people to create a story allows them to name their experiences in their own words and in spaces where the stories are listened to and respected. This in itself is transformational. Storytelling creates insight, discussion and change.

At a community conversation, the facilitators or a local storyteller create the



Participants in one of the conversations join hands.

beginning of a story which touches on issues that the community is faced with. The story must evoke emotional responses, must be challenging to the listener, and must encourage dialogue and engagement. The facilitator leaves the story at a "cliffhanging" point, where the community must take over.

The people attending the conversation are then segmented into groups such as older men, older women and youth, depending on the traditional, cultural or social dynamics of the area. This is done to create a safe environment for dialogue and individual expression.

The people then discuss the situation outlined in the story and put themselves in the places of the characters, answering questions about what they would do in those circumstances. In this way, their attitudes and concerns are revealed and they can debate different individual responses.

When the groups come together again, they share their thoughts about the story. This highlights the concerns of the community and points the way to what actions need to be taken. Facilitators record and display the points made where they can be seen, taking care not to impose their own views.

#### Action plan

The next step is to elect a committee from among the people present, to take those concerns and actions forward on behalf of the community. Usually, the committee is structured to represent sub-groups such as men, women and youth.

They make a concrete agreement about who will do what by a particular date, and continue to meet as the plan is carried out. The facilitation team gives this committee certain practical advice they will need to get started, but then tries to withdraw and let capacity develop within the community itself.

#### Arts and media

"Arts and media can be the vehicle for taking the voice of communities nationwide, which, in turn, will influence development practice, including the response to HIV/ AIDS. In addition, the arts and media sector will generate new metaphors and stories



that will become part of the culture, based on the vision of a future that people create for themselves and their children."

Using arts and the media is important in social mobilisation – getting people to attend and "own" the conversation – and in capturing and sharing what happens during and after the conversation.

Left: On air in Giyani's communiy radio station.



Above: Mural advertising the community conversation in Galeshewe. Below: Radio station involvement in the KwaMakhutha conversation.



# **Conversation series summary**

About the communities
 Mobilising communities
 Our community partners
 Counting your losses
 Storytelling
 Burning issues identified

7. Community action

he 10 community conversations held by the Nelson Mandela Foundation in 2008 are summarised in this chapter. We begin with descriptions<sup>12</sup> of each area where a conversation was held, then describe the general process of mobilising communities and list the local partners who were identified by the communities to help them in their efforts. We describe the CCE tools of counting your losses and storytelling, and share some of the reflections of people who went through these experiences at conversations. We pick out the burning issues identified by communities, note the factors that contributed to successful conversations, and list some of the typical action plans that community action committees made.

### 1. About the communities

#### Lerome

The village of Lerome was the first community conversation venue in 2008. At the 2007 conversation, the community had identified its challenge as being how to form partnerships with local structures to support young people in halting the spread of HIV.

Lerome falls within the Moses Kotane Local Municipality, in the Bojanala district of North West province. It is one of the 32 villages under the Bakgatla Bakgafela Tribal Authority. Lerome is a relatively poor village with a high rate of unemployment. It is surrounded by mines, which mostly employ men from outside the area.

Alcohol and drug abuse are a serious challenge to this community, leaving young girls vulnerable to abuse for monetary favours (transactional sex). There is anecdotal

<sup>12</sup>The population figures for the communities were found on www.salga.net and further information for the communities of Giyani, Galeshewe and Mhluzi were found on www.greatergiyani.gov.za, www.solplaatje.org.za, and www.middleburgsa.co.za respectively.

evidence that the HIV infection rate among young people in this community is high. There were 930 people who attended the 2008 conversation.

#### Mhluzi

Mhluzi is a relatively affluent township with 182 000 residents, adjacent to Middelburg in the Steve Tshwete Municipality, Mpumalanga. The province has a diverse economy built around timber, coal mining, agriculture, tourism and oil, but unemployment is evident too.

The 2008 community conversation coincided with the monthly queue for government grants, which made it clear that many citizens, young and old, depend on this source of income. There were 660 people attending the 2008 conversation.

The people of Mhluzi speak and understand many languages, including isiNdebele, siSwati, isiZulu, seTswana and sePedi. Their stated values of tolerance and compassion, however, are being strained by a new culture of substance abuse.

#### Kliptown

On June 26, 1955, over 3 000 representatives of resistance organisations made their way through police cordons to gather on a dusty square in Kliptown, Soweto, 40km south of Johannesburg. This was the Congress of the People, who met to draw up the Freedom Charter, an alternative vision to the repressive policies of the apartheid state.

Today, unemployment levels are high in Kliptown, especially within the informal settlements and among women and youth.

The community conversation in Kliptown, Soweto, was held in the same week and area as the Sixth Nelson Mandela Annual Lecture, given by Liberian President Ellen



A participant speaks in the Galeshewe community conversation.

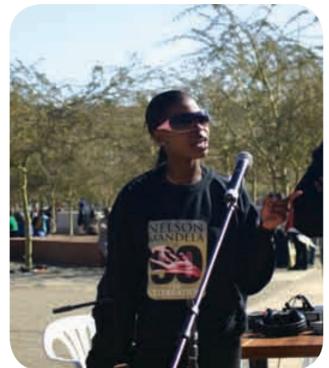
Johnson-Sirleaf and attended by 800 high-profile guests, including Mr Mandela. 320 people attended the conversation.

#### Thaba Nchu

The Motheo District in the Free State includes the communities of Bloemfontein, Botshabelo and Thaba Nchu. The urban centre of this district is Bloemfontein, which falls within the Mangaung Local Municipality.













The city controls trade and administration in the province and boasts a university, provincial government, military facilities and the Supreme Court of Appeal of South Africa.

Bloemfontein also claims its place in the country's political history, for it was here that the African National Congress was founded in 1912, followed by the National Party two years later. Today it is also known for hosting the annual Macufe Festival, a cultural mélange of music, dancing and drama.

East of Mangaung lie Botshabelo, South Africa's second-largest township, and Thaba Nchu, which was established in 1873. In the main, the region is peopled by Tswana- and Sotho-speaking people.

At 30.3%, the Free State province has the fourth-highest incidence of HIV infection in the country, with unemployment and migration just some of the contributory factors.

Various studies have produced conclusive evidence that migrancy plays a pivotal role in the spread of sexually transmitted diseases and HIV. This is due to the fact that migrant men are likely to have multiple sexual partners and to engage in high-risk sexual behaviour. Unique migration patterns have been noted for the Mangaung municipal area, in which 40% of the population is unemployed and 28% is HIV-positive (2005 figures from Mangaung Integrated Development Plan). 950 participants attended the Thaba Nchu conversation.

#### Giyani

Giyani, which falls within the Mopani District Municipality in Limpopo province, is geographically distant from economic centres. The town was the capital of the apartheidera bantustan of Gazankulu. Giyani Municipality, about 2 967km<sup>2</sup>, has 30 wards with a population of about 555 000, and 91 villages falling under traditional authorities.

Mopani District Municipality comprises four local municipalities that extend over approximately 10 000km<sup>2</sup> in the north-east of the province.

Key sectors of the local economy are manufacturing, trade, catering, government, finance, transport, communications and agriculture. However, 52% of the population aged 15 to 65 are not economically active, and poverty is prevalent. The labour force in Giyani consists of a small percentage of skilled and semi-skilled labour, and a large percentage of unskilled people. Giyani has a rich cultural history.

Health-care services are rendered in the district at family level, visiting points, clinics, health centres and hospitals. However, the referral system is not effective. Coverage is also a problem because of the large number of small settlements scattered throughout the district. Some people have to travel more than 40km to the nearest health services, though the norm is that people should not travel more than 5km to access such services.

Poor roads make health care even more difficult to access, and vehicles are subject to a lot of wear and tear. There is a shortage of health services staff, resulting in work overload and low morale. Lack of security has an impact on 24-hour service at clinics. Transport is also a problem and the bed occupancy is high at hospitals. These problems affect the quality of care. 380 participants attended the Giyani conversation.



Above: A scene in Giyani. Below: Abortion posters in Mthatha.



#### KwaLanga

Langa is a population that was driven away from an area called Ndabeni in Cape Town. In 1923 the Urban Areas Act was passed, forcing Africans to live in "locations". Ndabeni was overcrowded and the white middle-class residents of nearby Pinelands were keen that it be removed, so a new location named Langa was opened. The name literally means "sun", but it is derived from the name of Langalibalele, a Hlubi rebel imprisoned in Cape Town in 1874 after rebelling against the Natal government. Local residents refer to their township as KwaLanga, which will be the name used in this report.

KwaLanga is not new to struggle; it is one of the oldest townships in the country and faces the challenges of HIV/AIDS, alcohol and drug abuse, a high rate of school dropouts, poverty and teenage pregnancy, among other issues. The KwaLanga community conversation had the highest turnout of participants that numbered 1 100 people.

#### Galeshewe

The township is one of South Africa's oldest, established in the 1870s, and falls under Sol Plaatje Municipality in the Northern Cape. Like other townships, it was



Participants in Soshanguve.

designed as a labour reservoir to support the economies of cities – in this case, Kimberley – and the apartheid government did not provide adequate social or commercial facilities. Little consideration was given to the dignity of people and making it possible to maintain decent standards of living.

Though the diamond rush in Kimberley laid the foundation of the South African economy in its time, there is now an exceptionally high unemployment rate.

Galeshewe has a population of more than 103 000. Many of these people hold Christian beliefs and community/*ubuntu* values.

This was the home of the first General Secretary of the ANC, the celebrated writer Sol Plaatje. The PAC leader Robert Sobukwe lived here as well. The town's namesake, too, Kgosi Galeshewe, fought injustice in the 1870s, as did many other heroes of this place. 705 people participated in the Galeshewe conversation.

#### KwaMakhutha

Over the years KwaMakhutha was torn apart by violent conflict between the African National Congress (ANC), the Inkatha Freedom Party (IFP) and the apartheid-sponsored security forces (the South African police and defence force).

The community of KwaMakhutha has experienced a great deal of pain over the years. In May 1996, when no agreement









had been reached between the ruling party and the IFP, this increased tensions, leading to the possibility of elections not being held.

At that time, President Nelson Mandela called a meeting with King Goodwill Zwelithini, IFP leader Mangosuthu Buthelezi, ANC KwaZulu-Natal leader Jacob Zuma and traditional leaders in the province. Dialogue brought about a resolution, and peace and stability were restored in the province.

But political tension is not the only problem the area has faced. HIV infection is still on the rise in KwaMakhutha and most of those getting infected are young people, according to Sister Moganye at KwaMakhutha Clinic. She says the infection rate has increased since last year. There is a pressing need for behaviour change.

Ward Councillor Zithulele Ntuli says that "if one takes a drive around the township at 2am, one always finds crowds of people walking around from taverns as you would see children leaving the school premises after school". The KwaMakhutha conversation attracted 950 participants.

#### Soshanguve

The name Soshanguve is an abbreviation of the words Sotho, Shangaan, Nguni and Venda, which are languages spoken in this township. Situated about 45km north of Pretoria in Gauteng, the township was previously designated for migrant workers. It was established in 1974 on land scheduled to be incorporated into a Bantustan bordering on Mabopane in Bophuthatswana consisting of people who were to be resettled from Atteridgeville and Mamelodi.

It later became part of the City of Tshwane Metropolitan Municipality, and was the scene of riots related to poor service delivery in January 2006. Soshanguve is an extremely disadvantaged area with extensive squatter settlements around its periphery.

In their efforts to see a different direction taken in the struggle against HIV/AIDS, the women of Soshanguve took a daring step recently. Led by the chairperson of the Township Ladies Forum, Francinah Ndala, Soshanguve was one of the first and few townships in the country to participate in the community advisory group for microbicide clinical trials.

A few more than 230 people attended the conversation, and many of these were members of organisations already involved in HIV/AIDS work. About 62% of those present were adult women and there were only seven male youths.

Still, it was a powerful occasion, perhaps for the very reason that it was smaller and more intimate, and at least six people felt able to disclose their HIV status for the first time.

#### Mthatha

Mthatha is in the centre of the old Transkei region of the Eastern Cape. It falls under the King Sabata Dalindyebo Local Municipality and the OR Tambo District Municipality.

Nelson Mandela was born and grew up near Mthatha, in the villages of Mvezo and Qunu respectively.

The community conversation team that worked in Mthatha noticed that teenage pregnancy seems to be a major challenge here. Abortion services are widely advertised on the streets, indicating a demand. One of the young participants in the conversation spoke of many teenagers going to back-street abortion clinics without their parents' consent and paying R300 for a pill that induces abortion, which then happens at home with no supervision.

The high rate of teenage pregnancy suggests that the HIV infection rate may be high too.

There were 380 participants in the 2008 conversation.



Above: Streets in Soshanguve. Below: Participants in the Lerome conversation.



### 2. Mobilising communities

The series of community conversations around South Africa began in May 2008, a period for candlelight memorials in South Africa's health calendar. This provided an entry point for the first conversation, in Lerome.

In most of the communities, the social mobilisation team arrived weeks in advance of the planned conversation and set about making themselves "at home" – finding out as much as they could about the community, getting to know who was who, making contact with local people and organisations (including traditional leadership and municipal government) and getting a feel for the concerns and resources of the local people.

The team arranged meetings with representatives of the Health Department, mayoral offices, Speakers' officers and the like, to introduce the concept of community conversations and invite collaboration.

The aim was to start building a good relationship with local people, not one of "us and them" but one of mutual respect and trust. In many cases, local and provincial authorities and businesses provided practical support for the conversation, such as office space during the planning phase, public address systems, chairs, marquees and ablution facilities for the actual event, food for people who attended, transport to the venue and emergency medical services. Home Affairs services were sometimes available on site so that people could use the opportunity to apply for identity documents and register birth certificates.

To advertise the events and invite attendance, flyers were distributed and posters put up at high-traffic places like taxi ranks, trading spots, clinic waiting rooms, social grants queues, shebeens and shops. Radio and, where possible, other media such as television and newspapers were used to publicise the events ahead of time. As much as possible, airtime was negotiated so as to contain costs.

The team used any available opportunity to address local events and meetings, such as political, church, police forum and NGO gatherings, to inform people about the upcoming conversation. Loudhailers were also used in the streets.

Before the conversations, community members watched an HIV/AIDS awareness production and listened to poetry readings and music. The intention was to link community concerns to the content of the play and offer a space in which to talk about both.

In the 2008 the media strategy was to use mainly the local community radio stations, which are the most accessible and effective form of media with mass reach. The approach included planning, buying, and negotiating for interviews, live reads, current affairs and news spots.

The programme managed to secure various community radio stations, regional radio stations, and some commercial national radio broadcasters: Lesedi FM, Munghana Lonene FM, Motsweding FM and Umhlobo Wenene FM. This demonstrates the willingness of broadcasters to be partners and create exciting educational programming.

Good partnerships were created with some commercial regional radio stations like Tru FM, Igagasi and YFM. Some of the national broadcaster's radio stations granted a platform without requiring payment for the airtime. This was largely due to their understanding of the community conversations programme and its urgency. The local newspapers were the same in this regard.



Above: Workshop in Soshanguve. Below: Mobile Home Affairs unit.





### 3. Our community partners

#### Key partners identified through social mobilisation at community level

AIDS Law Project ANC Constituency Office ANC Parliamentary Constituency Office ANC Women's League ANC Youth League BloemWater Cape Town Tourism Cheshire Home Christian Youth Society Churches City of Cape Town Metropolitan Council City Managers Community Development Workers (a government programme) Community Health Centres/Clinics Community radio stations Correctional Services Department Department of Social Welfare & Population Development **District Municipalities** Education Department Elangeni Women's Development **Emergency Medical Services** Guga S'thebe (KwaLanga Tourism) Health Department Home Affairs Department Hospices Institute for Primary Health Isilimela Comprehensive School King Sabata Dalindyebo Municipality Special Programme King Sabata Dalindyebo Youth Advisory Centre KwaLanga Orphanage Langa Stock Farmers' Association Lerato Health Care Local AIDS Councils Local Municipalities loveLife Mayors' Offices

Ministers' Forum Municipal Communications Officer Napwa (National Association of People Living with AIDS) Nomzamo Orphanage Pfunekani Community Project Phila Sizwe Foundation Premiers' Offices Provincial Department of Health and **Environmental Affairs** Provincial Department of Social Development Radebe's Guest House SANCO (South African National Civics Organisation) Schools Siviwe Tours SOSHAD (Soshanguve Self Help Association of People with Disabilities) Soshanguve Pastors' Association Soshanguve Traditional Healers' Association South African Council of Churches South African National Defence Force Speakers' Offices **TB** Care Association The Red Cross Thola-Ulwazi Home Based Care Traditional leaders Transport Department Umthombo Wempilo HBC Ward Committees YMCA All individuals who participated in the community conversations

Please note that this list is continually updated and we apologise for any omissions that might occur.









### 4. Counting your losses

sing the counting your losses exercise, the facilitator tells the community that this is a respectful space in which to remember loss. He or she asks everyone to take as many stones as they need from a box provided, each small stone representing a life lost through AIDS, and file past a cloth on the ground, placing the stones on the cloth. As people do this, the facilitator may speak as follows:

"How can you make a difference? How long will this go on in silence? What has to be done to put an end to this? I have lost someone. I loved them. I won't be afraid anymore. One stone. One body. Remember to hold hands as a community, as a family, and grieve together. This is the safest space you will ever be in. Here, you are allowed to feel pain and loss. Each of us knows someone who has gone.

"Was I created to watch my people die? Is this what living is supposed to be about? Have I done enough? Can I ever do enough? I am an old woman and I've lost everyone in my family. If I don't stop it, who will? How long will we sing songs to bid farewell to those we love? How many times have I said sorry to my sister? How many children have I seen suffering without any food on their plates? How many stones do I have to put in front of my community? These are souls that I breathed with. They are no more. This is my reality.

"Let's have a moment of silence as everyone thinks about what we've had to go through, coming to the front. You picked up a stone, then another, and another. What is going through your mind? Have you remembered everyone? Let's think about love, let's think about loss. Let us think about our families, the people we have left at home. What is it that spreads this death? How can you support me? Let's talk to each other as family. We're here to pull each other through."

The participants are then invited to share their thoughts and feelings. These are some of the reflections recorded at this series of community conversations:

- "As the youth, we should ask ourselves, are we not next? I plead with you, let's be brave and get tested. Let's not worry about what people say. We must put an end to this!"
- "I feel touched; I lost my sister through HIV and it happened a long time ago when we didn't have enough understanding of it. She was afraid to disclose her status. I wish I knew then what I know now about HIV. Maybe I would've helped her understand what she was going through was just an illness just

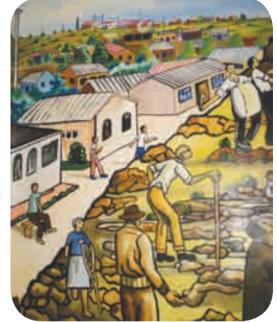
like any other. Now I have a cousin who is suffering from HIV. At least I know how to handle it better. Now I know better."

- "We were never told what my cousin was suffering from and her suffering was only disclosed after she had died and been buried. I wish we could all grow and understand that a sister or a brother with HIV deserves our love and care."
- "Let's condomise and be safe. Let's teach each other about this virus."
- "My brother's child, 11 years old, died of HIV. Just looking at the stones laid down while counting our losses, I feel pained. So parents, let us tell our children what we are suffering from, so that they can take care of us with caution. This young boy became infected with HIV while taking care of his mother who had AIDS. He

didn't know."

•

- "Most people are afraid of taking their treatment because people laugh at them when they go there.
  People are scared of testing. It's sad to see the stones there; our people are dropping like flies. The people we love are gone."
- "I've lost many relatives due to HIV, but now I'm happy that we can talk about HIV/AIDS. Back in the old days we used to be ashamed to talk about it. In the beginning when you were infected and disclosed to your parents they used to be disgusted and would isolate you because you had a virus. They felt that you would infect them if you used the same equipment in the house."
- "When I had to take stones to the front there, it made me ask myself who has to be next before something happens. Do I have to be infected before there's change? Or do I need to be an example? Or must I be the one to die first before



Above and below: Murals in Soshanguve and in KwaLanga.



there's change?"

- "A feeling of sadness comes over me. I didn't do anything for three people . I've lost. For the first time I am forced to acknowledge that these people suffered so painfully. As I speak now, last week I was burying my uncle and I did not help him enough."
- "When I had to pick a stone and lay it down at the front, I thought of my four • family members who were very dear to me. First it was my aunt who died. Then my two sisters who came after me. But the worst is the mother of my two kids. I feel bad that I did not manage to help them but I couldn't because they lived too far away. As men we are ashamed to cry, but it helps to let it all out. If you don't cry, you will fall down on the ground with pain some day."
- "When I took the stones to the front there, I remembered my cousin who died at nine months. His name was Mohau (meaning mercy). Mohau had not done anything wrong to deserve to die but the silence, the culture and our religion prevented us from talking in the family."
- "I am deeply touched by this experience. I know what it's like to lose someone you love. When it happened in my family I was called by my father, who lived



on the farm then. He was already dying and when he called me he was so sick he couldn't even get up to relieve himself. I had to go to the clinic to ask for diapers to help me take care of him. When I returned home it wasn't long before I had to get diapers for my mother too. I failed my grade 10 exams last year because I could not concentrate in class, worrying about coming back home to take care of my mother. I am asking myself: who will I take care of next? I was a bright student at school but I couldn't pass. I am hurting a lot."

• "When I came to the front, I did not know how many stones to lay down. So I had to pick only one stone, although I have seen many diminish in front of me. As I speak to you all now, I know 13 close friends and family who are bed-ridden. What hurts

the most is that people are afraid to disclose. How many times have I been told to condomise and the very same day or hour, I would go ahead and have sex without a condom. I am afraid I could also end up HIVpositive."

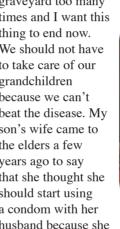
"I come from a very large ٠ family and I have watched them over the years disappear because

> of HIV. I have been to the graveyard too many times and I want this thing to end now. We should not have to take care of our grandchildren because we can't beat the disease. My son's wife came to the elders a few years ago to say that she thought she should start using a condom with her husband because she



Above: Stones placed during the counting your losses experience.

Below: Community members in the Soshanguye dialogue.





thought my son was fooling around. As the elders we told her to remember her vows and if she abstained or used a condom, she would be defying her husband. Her husband died from AIDS and she soon followed. This must be stopped."

- "When I had to put a stone at the front there, I felt sad and angry. I thought of my family members I have lost to HIV. My sister died last year. That's when I started wanting to know as much as I could about HIV and how to deal with it. Now I am not afraid anymore. I can actually teach others and encourage them to be strong. Now my nephew is positive, and I know how to assist him better. I would like to say to people who are HIV-positive, there's hope. Let's prevent a further spread of HIV."
- "Sometimes when I think about my life I feel miserable, I feel sad and I feel terrible. I cannot believe my past behaviour. The way I used to have a different girl every day. When I think about how many people I have infected, I feel ashamed. I would like to apologise to all of them. Right now I'm standing

Participants count their losses.

in front of my community saying that I am HIV-positive. I'm trying to break the stigma. Let us rectify the mistakes we've made. This is the first time I have talked about my status in public and I want to thank God for giving me the courage. A chance to make a change."

- "A lot of people are infected but they are afraid to come out because of the stigma. I see grandmothers and grandfathers coming to take their ARVs when I go for my medication. Let us not be ashamed."
- "It's quiet here; it feels like I'm in a funeral; it seems that people are heavy-



Above and below: Conversation participants.



hearted We are here because our children. fathers, mothers and families are dying because of AIDS. My nephew passed away recently and my Xhosa family said it was witchcraft. I asked what the symptoms were and immediately knew that it was HIV. I knew because I live among people who are infected with it. The time has come for us to come up with solutions to overpower this disease."

• "After counting my losses I felt angry. I feel we are letting HIVpositive people down by stigmatising them. Our family members are scared of disclosing their status."

• "It's painful digging into people's hearts because it brings back lots of memories that have been buried deep inside. As I was talking I saw faces changing and I saw people really expressing their hurt and anger." (Facilitator reflecting on counting your losses)

### 5. Storytelling

ach conversation used the CCE tool of storytelling, during which the facilitator outlines a story which the community can relate to. He or she then leaves it at a cliffhanging point and invites the participants to continue the story, putting themselves in the place of the characters and thinking about what happens next from all these different perspectives. This tool can help to identify people's values, concerns and beliefs (as well as misconceptions). It gives every person the power to express what they could do about a typical situation.

The story outline is usually about a young couple from "respectable", church-going families who are about to get married when the bride finds out that she is HIV-positive People are then asked open-ended questions about the story.

Adaptations of this story are often used in communities depending on the different circumstances. Here are three examples:

In the province of Northern Cape, in the Sol Plaatje municipality, there is a township called Galeshewe. In this township there live two families, the Modise and the Mthimkhulu families, who attend the same church. The Modise family has a daughter named Sarah, who is 21 years old and a student at the University of the Free State. The Mthimkhulu family has a son named Thabo who is 27 years old and works as a teacher in Galeshewe.

They are both loved in the community and have many friends. Sarah and Thabo have decided to get married. An announcement is made in the church and lobola (bridewealth) is paid. While arranging for the big day, Sarah gets sick and has to go to the clinic. The doctor tells her that she is HIV-positive.

On the campus of the University of Cape Town, Vuyiswa Nogam, an attractive young girl from a Christian family in KwaLanga, is invited by a friend to a "freshers' ball". There, she is offered a drink by Vuyani. She passes out as she hears the other girls chanting: "Akukho mntwomnt'apha, kuseKap'apha, thath' umntu uhambe!" (This is Cape Town; nobody belongs to anyone; take a person and go!) When she wakes up in the morning she's naked in a room full of strange boys and there are drugs present. She later takes a pregnancy test and, following the advice of the pharmacist, an HIV test. She finds out she's HIV-positive. She asks herself: What's happening to me? What about my future and education? Do I tell my parents? Do I confront Vuyani? Do I share this with my friend Xoliswa?

In the community of KwaMakhutha, we meet two families who serve in the same church. The Sithebe family is blessed with a son named Siyabonga who is 25 and studying to become a doctor like his father. The Mkhize family is blessed with a daughter, 21, named Slindile, who is in her first year of studying to become a teacher. Slindile and Siyabonga are engaged to be married. After their engagement celebration party, Siya heads back to Polokwane, where he studies at Medunsa, while Sli helps with the cleaning at the home. When she leaves for home in the evening, she is met with a great misfortune. She is raped by local boys whom she knows. She goes to the police station to report the matter and is advised to go to the clinic at KwaMakhutha to get checked. She is tested and is told that she is HIV-positive.

The responses recorded were a mixture of acceptance and rejection:

- "I would get together with other people who are HIV-positive and they would be able to help me deal with the virus."
- "It would be a painful for me to have an HIV-positive child but I would give her all the support she needed throughout."
- "I would commit suicide without telling anyone so that everyone would think it was something else like stress."
- "I would tell him so that we would go for testing and know our status together. I would take my Bible and pray and then tell my boyfriend. If he loves me he will accept me, but if he dumps me, he never loved me."
- "Let's take a realistic approach to this situation, people. I am a teacher, and my fiancée is at university. We met at church. I would ask her where the hell she got it from. Then I would tell her *gaan weg met jou VIGS*! (get away with your AIDS)"
- "I would first marry her so that she gets her chance at marriage like she wanted. Then I would immediately divorce her because I don't want to be married to a sick person. What will I do with a sick wife? She must give the many other girls out there their chance to marry me as well."
- "Marriage is not just about love, this woman has to bear children for me, and can't have a child with someone who is HIV-positive. I would kick her out."
- "I would call a meeting between the two families and if they agree to getting married, I would bless their marriage."
- "I would not tell my boyfriend. I would tell my parents, not my friends."
- "I would tell my husband to go for counselling because he's the one I'm facing the problem with."
- "I would go to the clinic to get information and accept my status."
- "I would first go to Siya and tell him so that we would go and seek help together. He would not like to hear what happened from other people, which would hurt him."
- "The truth is, as family members we will start pointing fingers at each other

as parents, saying 'your child infected my child'. That would be a waste of time though because it does not matter. As a parent I would support them. I would ask them to go for counselling and go to church."

- "They have to be honest with one another; the truth is they were unfaithful to each other."
- "If we had never tested, we would have gone ahead with the wedding, so let's accept it and go ahead with the wedding."
- "She's my child, she did nothing wrong. Anyone can get infected and it can



Above: Community discussions during the Mhluzi dialogue. Below: Members of the community at the Lerome event. happen in many ways. I would tell her that she still has a long life ahead of her."

• "As a neighbour, you could go to the family and say you understand what is happening and offer your support – for example, you could offer to remind Thoko to take her medicine at the same time every day, or offer transport to the clinic."

• "An honest traditional healer would advise you to go to a medical doctor first. It's difficult for traditional healers because they need money too."



### 6. Burning issues identified

Following the storytelling, concerns (burning issues) were raised and identified. The following are some of them:

Community	Issues
Lerome	<ul> <li>The Lerome community discussed the fact that poverty is driving HIV and AIDS, often by means of intergenerational and transactional relationships. Sexual abuse and incest were identified as serious problems. The high number of taverns in the area and the sale of alcohol to minors were also of concern.</li> <li>In addition to substance abuse, young people identified lack of self-esteem as a contributor to the spread of HIV, because it can make them susceptible to abuse and peer pressure.</li> <li>The misconception that HIV can be cured was discussed.</li> </ul>
Mhluzi	<ul> <li>The people of Mhluzi were particularly worried about substance abuse.</li> <li>Poverty was identified as the source of most of the temptations and challenges faced by the local youth. This gave rise to sexual relationships between generations.</li> <li>The number of liquor outlets and their proximity to other shops was a concern. It was felt that children were not safe going to the shops.</li> <li>Small children were seen playing in the street, supervised only by other very young children.</li> </ul>
Kliptown	The community of Kliptown brought up these issues as their strongest concerns: • Support for people living with HIV and AIDS • Communication within families; there is also a strong need for recreation in the area, especially for youth • Awareness building and information sharing
Thaba Nchu	<ul> <li>Parents should talk to their children about sex</li> <li>Moral degeneration</li> <li>People, especially the youth, must get tested</li> <li>Support – first at home and then in the community through support groups and other avenues</li> <li>The contribution of poverty to the spread of HIV and the problem of intergenerational relationships were also raised.</li> </ul>
Giyani	<ul> <li>The community agreed that their strongest concern was a lack of support. They said that their community needed to pull together and try to help each other if anything was going to be done about dealing with HIV/AIDS. They added that cultural beliefs should be utilised to create better communication between parents and their children, particularly about sex.</li> <li>There are still a number of misleading perceptions and practices in Giyani: some people believe that HIV is an automatic death sentence; a number of parents believe that they shouldn't discuss sex with their children; there is a shared sentiment among many of the young people that being HIV-positive should be punishable</li> <li>Young women in their teens are often "groomed" for marriage by their parents or a neighbour. Poverty, substance abuse and intergenerational relationships are also problems being experienced by the community.</li> </ul>

Community	lssues
KwaLanga	<ul> <li>The KwaLanga community brought up these issues as their strongest concerns:</li> <li>Encouraging more testing</li> <li>Support for people living with HIV and also people who are not infected, to encourage disclosure within families and community</li> <li>Substance abuse</li> <li>People who are infected are afraid of disclosing their status even to their families, for fear of being made laughing stocks. People are also afraid to be tested.</li> </ul>
Galeshewe	<ul> <li>Encouraging testing and counselling</li> <li>Encouraging disclosure</li> <li>Lack of support system</li> <li>Again, poverty and substance abuse were identified as creating vulnerability and risk.</li> </ul>
KwaMakhutha	<ul> <li>Disclosure</li> <li>Awareness building</li> <li>Information sharing</li> <li>Poverty and substance abuse were named again.</li> </ul>
Soshanguve	<ul> <li>Stigma</li> <li>Lack of support</li> <li>The need to encourage counselling and testing</li> </ul>
Mthatha	<ul> <li>Stigma</li> <li>Lack of support from families and community members</li> </ul>



Above: Posters advertise the community conversations in Galeshewe.

### 7. Community action

#### Action plan

At each conversation, the community elected an action committee representing adult men, adult women and youth. These committees were mandated to carry forward the burning issues identified and explored at the dialogue by drawing up action plans.

The implementing team shared the "five friends of planning" with the action committees: who, what, how, when and where.

WHAT	What do we want to do?
HOW	How are we going to do it? (What are the specific steps we need to take to accomplish our goal?)
WHO	Who (specific names) will be responsible for each step?
WHEN	When will each step take place? (Specific dates/times)
WHERE	Where will the action take place?

Most of the action committees' initial plans included meetings with local stakeholders – government departments, NGOs and so on – to introduce themselves. This would form the basis of further activities such as those listed below.

Some committees felt they needed extra support and training to empower them for their tasks. Examples of actions to be carried out:

- Explore what resources (organisations etc) are available in the community to provide care and support for HIV-positive people (Burning issue: lack of support)
- Improve the recreational facilities for young people (Burning issue: lack of healthy activities to build self-esteem)
- Organise a workshop to help parents talk to their children about sex (Burning issue: communication)
- Organise voluntary counselling and testing drives (Burning issue: knowing your status)
- Build awareness of substance abuse as an HIV risk factor (Burning issue: substance abuse)
- Paint a mural representing the community's concerns

Top right: Participants in the Mhluzi event. Right: Parents and elders in the Lerome conversation.





28 COMMUNITY CONVERSATIONS

### Case study Kliptown community conversation

he community conversation in Kliptown, Soweto, was held in the same week and area as the Sixth Nelson Mandela Annual Lecture and was attended by 800 high-profile guests, including Mr Mandela. The lecture was held at Walter Sisulu Square, which involved a lot of preparation for the community. This meant that awareness of a special event could have been heightened among local residents, but at the same time some confusion might have been created between the conversation and the lecture.

#### Social mobilisation



The implementing partner forged relationships with locally represented businesses: the supermarket chain Pick n Pay provided lunch for everyone who attended, the Maponya Group of companies paid for the marquee and 450 chairs, and Mhlophe Functions paid for 250 chairs. Walter Sisulu Square management offered the venue, Kliptown Visitors' Centre, at no charge.

The municipality was engaged with the help of the ward councillor. Meetings were held in advance of the event with the Department of Health, the Mayor's Office, Walter Sisulu Square Management, the Gauteng Legislature and the Speaker's Office. Community-based

Participant in the Kliptown conversation.

organisations, non-governmental organisations and other groups involved in the arts, sports and culture were brought together at a meeting where the programme was explained.

Posters and loudhailers were used in the township to publicise the event.

One group of women who arrived at the event said they had heard about it from their ANC branch. Some of those present were members of groups (Youth AIDS and Persevere Until Something Happens, or PUSH) already working in the HIV/AIDS field or in community care, eg in hospice work or helping the elderly or youth. Some of the people who arrived said they did not know what the event was all about.

Youth AIDS falls under the Society for Family Health and its members are young people (under 21) who are trained to work in schools as peer educators. They distribute government condoms and the emphasis of their message is on delaying young people's first experience of sex.

PUSH is based in Eldorado Park, near Kliptown, and focuses on behaviour change, care and support.

The event started late because of a fairly poor turnout (about 200-300).

The media showed a good deal of interest in the conversation, probably partly because of the connection with the Annual Lecture and Mr Mandela's 90th birthday celebrations generally. Soweto TV promoted the conversation, and tickets to the Annual Lecture were given away to listeners. Two interviews were done on YFM, on the popular presenter DJ Sbu's breakfast show – one to promote the arts day and one about the conversation. There were also interviews on Thetha FM (covering a large area as far afield as Vereeniging and the East Rand) and Jozi FM. *Pimville Urban News* devoted a full page to an article about the conversation the week before it was due, and foreign media were present at the event itself.

On July 11, before the community conversation at the Kliptown Visitors' Centre, media briefing was held for the journalists who attended. It was explained that there were parts of the conversation that should not be filmed or photographed, so as to give people privacy. Participants might become emotionally overwhelmed while sharing their personal stories, or even reveal their HIV status for the first time. Their safe space should be respected and protected.

#### The conversation

The event was opened with a song and prayer. There was a short welcome address by the ward councillor. Then a facilitator broke the ice with an amusing story and explained the purpose and vision of the day. "The purpose of today is to address challenges that we are faced with. We want to sustain local action. We know our problems and why the pandemic is spiralling out of control, so we need to identify challenges and come up with an action programme. The answer lies within us. Listen to the facilitators and participate. Today we are saying HIV/AIDS *uzowuzwa umoya* [will feel the wind – ie, we will make an impact on HIV/AIDS]."

He explained how the CCE programme was designed to encourage dialogue in communities so as to address issues that affect those communities. "The idea is to explore community perspectives on how we live, how we respect people, how we support each other, what we can do among ourselves to address challenges." He said the focus would be on HIV and AIDS and that this was a safe space in which people could talk.

Another facilitator told the people who had gathered in the marquee: "You are going to be in charge of everything that's going on. I would like to applaud all of you who have come." He also told an amusing story to help people relax and then got them to make the circle of chairs smaller.

#### Setting the ground rules

A facilitator then helped those present to come up with their own ground rules for the conversation, and asked everyone whether they accepted those rules. She got a volunteer to draw a picture for each rule and these were stuck up on the marquee to remind everyone.

The rules were:

- Respect each other
- Maximum participation
- Speak so we can all understand
- Keep cellphones silent
- Active listening, no talking on the side
- Listen without prejudice

What followed was an exercise in everyone getting to know each other. "We have to know each other's strengths and weaknesses so that we can handle each other better. We must also know where to draw the line because we all come from different backgrounds and we have different personalities. I want us to get to know each other better and we are going to do this by turning our seat and talking to the person behind us. Ask them who they are, what their interests are and how you can support them."

Some of these interests and needs were shared, eg "we want antiretrovirals to be available" and "we want low-cost housing". Everyone was asked to tell the person next to them that they loved and cared for them, and to hold their hands.

#### Counting your losses

The facilitator then started the "counting your losses" exercise. He gave examples from all over the country of individuals with problems related to HIV/AIDS, such as children who have to go to school and then find a way to feed their siblings or look after



Above and below: Community conversation in Kliptown.



sick parents. He said this was a respectful, graceful space in which to remember loss.

He asked everyone to take as many stones as they needed from a box provided, each small stone representing a life lost through AIDS, and file past a cloth on the ground, placing the stones on the cloth.

Afterwards, people shared their thoughts and feelings. A hospice worker said she had seen a lot of suffering. She spoke of a friend who had not disclosed her HIV status until she was dying, and how shocking it had been to see a person "reduced to something else". "When I came to the front to drop the stones, all those thoughts of her lying in her death bed came back to me. I didn't know much about HIV/AIDS then, so after her death I started learning more about it." Now the worry was that the woman's daughters would meet the same fate, through resorting to *ukuphanta* (a slang word for hustling).

The woman appealed to people to know their status. "Getting infected is really easy but a lifetime of living with AIDS isn't, so let's stand together and eradicate the stigma attached to it. Know your status; spread the word, not HIV."

#### Storytelling

A poster was put up with the title or theme of the story: *Rea gola rea bona* – growing and learning. The facilitator introduced the fictitious Madonsela family:

Bra Joe (56), a bus driver and the family breadwinner; his wife of 25 years, Sis' Fikile, a housewife; their son Bafana, a BCom student at Wits; and their daughter Thoko (18). Thoko is the main character. She is in matric but not doing well at school and her attendance is poor. There are other worrying signs, like valuables going missing at school. Thoko has been moody and talking back at her father. Something is obviously wrong. Eventually, in desperation, the family goes to Baba Khumalo, the local inyanga (traditional healer). Meanwhile, Thoko goes to visit a friend for the weekend, where she collapses. The family fetches her and takes her to a doctor, who refers her to hospital. Tests are done and Thoko is kept in hospital overnight on a drip. The family comes back the next day and sees the doctor to discuss the problem. The doctor says there is a high concentration of toxins in Thoko's blood – it seems that she has been taking drugs. Also, her kidneys are failing and she is HIV-positive.

Having strategically set the scene, the facilitator asked everyone to think about the following questions:

- What would you do if you were Thoko?
- What would you do if you were her parents?
- What would you do as her friends and classmates?
- What would you do if you were her neighbours or in her community?
- And if you were a traditional healer?

The group was divided into three circles to answer these questions, and then reported

back to everyone. Here are some of the responses:

- "The family must stand together and pray for Thoko."
- "She should go to the local clinic for counselling, get her CD4 count and get anti-retroviral drugs."
- "Thoko should apologise to her family for not talking about her problems."
- "Her father should ask himself what went wrong and learn from his mistakes something went wrong because he didn't know his daughter."
- "Friends and classmates should learn a lesson and should go for voluntary counselling and testing, as well as advising and supporting Thoko."
- "They should support her and learn from her mistakes it could have been them in this situation."
- "Community members should try to claim their area back from drugs."
- "The healer should tell Thoko to get treatment from a clinic and fight with his or her ancestors!"
- "You can take traditional medicine, but allow six hours in between that and ARVs."

#### Identifying burning issues

The facilitator condensed the community's concerns into three main needs: communication, support and information. (See table of burning issues page 26).

#### Action committee

A facilitator explained that an action committee would be formed and would meet the next day, with the local ward councillor, to discuss a way forward.

Volunteers came forward and were voted on. The committee comprised a young woman, a young man, and an older man and woman.

The people were tired by this time and the conversation was concluded with a vote of thanks by a community development worker and a free meal provided by a Pick n Pay, Kliptown.

#### Following up

The following week, the facilitator reported that all the action committee members had arrived for their meeting the next day, except for one, who had to attend a funeral, and the councillor. Another young woman who had been at the conversation also arrived to see if she could help, and she will be an ad hoc member of the committee.

"The enthusiasm was still there," said the facilitator. The facilitators helped the committee to come up with an action plan using the "five friends of planning": who, what, how, when, where.

The team decided to set up a meeting with local government representatives by July 31, to discuss how the committee could get more support. They were going to push for more recreational facilities for Kliptown and look at getting organisations like loveLife involved.

#### **Kliptown reflections**

"[The conversation] is a good idea – some of us come from the rural areas and only see HIV-positive people on TV; we aren't exposed to them. We want to hear from the horse's mouth, not from TV or the radio. In Limpopo, where I come from, we don't have community centres and they don't talk about HIV/AIDS. There is still a lot of stigma attached to it. I think that the more we talk about it, the more aware we will be. We have become so familiar with AIDS that when someone suffers from it we just say 'it's part of life, what can we do'. We live recklessly; even though we hear about it we continue to have unprotected sex. Some of us go for an HIV test, but you can't take your partner everywhere so it all boils down to trust."

"I came to hear what people are going to say to us. As a concerned citizen I want to know what other people think."

"I saw the poster and it has the photo of Tata [Nelson Mandela] so we came here. If it was anyone else we wouldn't have come here. Our main concern is that there are certain questions we want to ask. We need to have a branch of the Nelson Mandela Foundation in Kliptown. It would mean that we get proper facilities. We'll be off the street, out of crime. That's really our heart's desire."



Above, below and below left: The community conversation in Kliptown.

"I saw the posters and just decided to come."





### Kliptown arts day

n July 10, the day before the conversation, as part of social mobilistion, an open-air arts day was held at the Walter Sisulu Square in Kliptown. The square is a large public space near a taxi rank and shops, and on the day was being decorated with huge banners for the Nelson Mandela Annual Lecture.

Early arrivals were a group of children whose music teacher had read about the event in the Pimville newspaper and knew there would be a play about HIV/AIDS. The young musicians played a few numbers to get the arts day started. Passers-by started to pause and about 100 to 150 eventually stayed to watch – some of them very young, unsupervised children.

The play was set in a fictional radio station. First there was a "drama serial" called Let him go about a "sugar daddy" figure putting pressure on a girl who is impressed by his money and the flashy things it can buy. The show then crossed to a "reporter on the scene" in Kliptown, who reported back on the community having problems with violence and drugs. A "message from the sponsor" followed, about fighting crime, drugs, violence and xenophobia. "Fight poverty by believing in yourself and being yourself. ... I don't need alcohol or drugs to make me who I am," said the "Super Confidence" character in this slot.

The tone of the play is humorous but it aims to get people to start "breaking the silence" around critical social issues like HIV/AIDS, crime, drugs, alcohol abuse and rape. The audience is also encouraged to "celebrate ideas" like non-racism, gender equality, and self confidence. It emphasises the notion that knowledge is power and protection against HIV/AIDS.

After the performance, an ex-convict and prison gangster spoke to the audience, saying he was a "true reflection" of what was in the play. He said he had started smoking at a young age, went on to drugs and alcohol, was exposed to crime and then starting committing crime too. He was eventually convicted of armed robbery and sentenced to 18 years in jail. He got involved in prison gangs – "I was a disaster" – but came to realise that happiness and respect come from within. With the help of a benefactor in Australia, he was released early and his message was that there are people out there who are willing to help, who provide others with hope – that "we can make a difference, people of Kliptown".

A group of young hip-hop musicians performed next. Some of the members came from troubled backgrounds and their producer said he was trying to help them stay away from crime through the medium of music.

> Top right: The Viva Hecate production. Right: Walter Sisulu Square in Kliptown.





### Case study Soshanguve community conversation

n November 2007, the Nelson Mandela Foundation held a youth dialogue at Galala Community Hall in Soshanguve. More than 300 young people (aged 16 to 24) attended and talked about factors contributing to the spread of HIV in the township. They spoke



of alcohol and drug abuse, limited recreational facilities, prostitution and "sugar daddies", lack of communication between the generations, lack of knowledge and

Left: A facilitator during a dialogue session. Below: Community conversation in Soshanguve.



training, denial, sexual experimentation, and stigma. Some spoke of the need to engage youth in different, more creative ways so that they paid more attention to messages about HIV/AIDS. The need to build self-confidence and self-esteem also emerged as a theme.

On August 27, 2008, the Foundation returned to Soshanguve to hold a community conversation involving a wider spectrum of people. What they found was a community divided over the political shifts that were happening at a national level. The result was that the venue was moved four times because people did not want to work with each other – and the conversation was eventually held in a Catholic church, where the priest made it a condition that no mention should be made of condoms.

A few more than 230 people attended, and many of these were members of organisations already involved in HIV/AIDS work. About 62% of those present were adult women and there were only seven male youths.

Still, it was a powerful occasion, perhaps for the very reason that it was smaller and more intimate, and at least six people felt able to disclose their HIV status for the first time.

#### Social mobilisation

The team arrived in Soshanguve on August 18, 2008 to prepare for the conversation. Because they were working on another conversation too, they had only a week to activate all the elements of social mobilisation. They used traditional tactics such as attending meetings of existing groups and distributing posters. Soshanguve Community Radio and Tshwane University of Technology Radio broadcast 10-minute interviews publicising the event. Contact was initiated with government departments, church organisations, health projects and the ANC office. The short time available meant that not all requests made to the municipality and other stakeholders could be processed ahead of the event, but at least the contact was made and should benefit the action committee in future.

#### The conversation

An HIV/AIDS co-ordinator from the City of Johannesburg welcomed those who had come to the conversation: "Please feel free to converse in any language that you are comfortable with. We are here to engage with the community of Soshanguve on issues of HIV/AIDS and to come up with possible solutions to your problems. We are all

important in this house and we are all going to make a difference."

The facilitator respected the church's ground rule, saying "Every house has its rules and condoms are a big issue for the church." However, this was a challenge in a discussion about an epidemic where prevention is the only "cure".

The background to the event was explained thus: "We are facilitating a series of dialogues hosted by the Nelson Mandela Foundation. We seek to tap into what exists and we believe that the answer lies with the community. We know what fuels HIV infection in our communities, we know why people are dying. We know that we don't want more people dying of HIV/AIDS, so we take care of ill people.



Above: Community conversation in Soshanguve. Below: Church mural in Soshanguve.

"We want to hear what you as an individual think of the HIV infection rate and other things. We want to allow people to talk about themselves. We are here to participate - the Foundation is based on the legacy and ideals of Nelson Mandela. that no idea is useless and that every voice must be heard. We are here to share ideas and talk about our community. We are not going to preach; we want to have a conversation.



"We need to get to know each other, so turn to someone on your left or right, tell them your name and surname and ask them what they like about living in Soshanguve and what they would change if they had a chance to change anything about Soshanguve."

#### Storytelling

The order of sessions was changed, with the storytelling taking place before "counting your losses".

The storytelling was introduced like this:

"While growing up we listened to stories told by our grandmothers and these stories helped us make decisions. Now we watch 'soapies' on TV and they also teach us lessons and help us make decisions. Basetsana Kumalo [a former beauty queen, now a business woman] once said, 'We know we are beautiful – we are just enhancing our beauty by wearing make-up.' So we also acknowledge that Soshanguve has power – we [the facilitators] are here to enhance that power."

The story followed the "master plot", where a young woman discovers just before her wedding that she is HIV-positive. Many of the comments that followed suggested an accepting and caring attitude among the participants.

#### Counting your losses

The "counting your losses" session followed, facilitated in a way that highlighted the importance of speaking out.

In a quiet but emotional atmosphere, people told stories of losing family and friends to AIDS-related diseases. Some spoke about the suffering they had experienced at the hands of the community once their positive HIV status was discovered; others disclosed their own positive status for the first time during the dialogue; while some asked for forgiveness, knowing that, by remaining ignorant of their status, they had infected others.

#### Soshanguve reflections

- "We don't have facilities in our community. Things don't happen here they all happen in Johannesburg and we are always the last to hear of things. Some people in this community use sex as entertainment and they get infected with HIV."
- "Today's dialogue is a great idea for us, the youth, to come and dialogue about pressing issues in our community and get solutions to those problems. We are grateful for the people who are here to offer us advice it's great because we will now have a clear idea of where we are going. I think the root causes of HIV in my community are: peer pressure, pessimism, sexual coercion, low self-esteem and transactional sex."

- "Poverty also plays a big role in the high HIV infection rate. Some of the youth can't accept poverty so they have unprotected sex though they know that it will lead to HIV/AIDS. They focus on the negative, not on what they can do to change the situation at home. I also think that the media must be blamed for the HIV infection rate because the youth see lovemaking on TV and experiment with it. We need positive media that will not mislead and brainwash the youth, media that will portray reality."
- "After counting my losses I felt angry. I feel we are letting HIV-positive people down by stigmatising them. Our family members are scared of disclosing their status."
- "When my sister passed away HIV/AIDS was perceived as a disease that only promiscuous people got. So I decided to equip myself with knowledge and I learned as much as I could about it. I learnt about the enemy (HIV) and now I have tools to deal with it."
- "Let's celebrate this life and know that we can make a difference, let's know that life is a journey and it isn't over until we beat this thing. Sometimes we feel miserable, especially when we think about the decisions that we have made and issues related to HIV/AIDS. I'm not happy that I'm infected and I'm not proud of it. I'm glad that someone called me to order and I am proud that I am spreading the word about HIV. I am trying to break the stigma around HIV and I'm rectifying my mistakes by doing so. This is my first public disclosure."
- "I am HIV-positive but I told myself that I will fight this disease. I am a mother of three and everything I do, I do for my children. I tell myself each day that I will survive this. I have a two-year-old son and he is the reason that I go on every day. Whenever I look at him, I know that everything is possible. I know now that HIV is a normal sickness like high blood pressure or sugar diabetes. Community! Do not point fingers at us without knowing your status."
- "You don't know where the virus comes from, you don't even know when and how you got infected. No one knows the second, date or place. It's not nice being HIV-positive, people look down on you and say bad things about you. People came and asked for help from me, the same people who threw stones at me because I was gay and HIV-positive, because we now had one thing in common and that was HIV, and we aren't going to let it beat us. I am positive and I'm living large. For you to feel good you must accept and disclose your status."
- "If I said I knew why HIV is spiralling out of control I would be lying. From my findings I gather that people are trapped in traditions; they would rather go to traditional healers than go to hospital and get help. Traditional healers can't see what you are going through. Consult doctors, then go to the healer to satisfy that traditional need. One other thing is that males tend to turn a blind eye and women end up fighting this battle alone."
- "The fact that people came to the dialogue shows that we as the community acknowledge that we have a problem, we care about where we live and we have been motivated to bring about change."



Above and below: Participants in the conversations in KwaLanga and Soshanguve.



## Refining our approach

The Nelson Mandela Foundation continuously embraces the spirit of inclusiveness by engaging our implementing partners and stakeholders in open dialogue. Together we critically evaluate our work and highlight concerns we need to address, in this case to strengthen the community conversation process. We consult our stakeholders and ask them to question our approach and we share lessons learnt. Most importantly, as requested by the methodology and our Founder, we listen.

"I have always endeavoured to listen to what each and every person in a discussion had to say before venturing my own opinion." – Nelson Mandela

# Lessons learnt from implementation

The Nelson Mandela Foundation and its implementing partners met on September 8, 2008 to discuss the process of the conversations to date and what could be improved or built on. What follows are points made by various people at the meeting

#### Social mobilisation



An audience reflects on the issues raised in the dialogues.

There are two main aspects to social mobilisation: **first is support from stakeholders** and **second is attendance at the conversation**.

A target of 800 participants was set to attend each conversation. On average, 400 actually arrived. We need to think about how mobilising large numbers of people creates problems with the size of venues and manageability of the process. Convincing men to attend the community conversation continues to be a challenge. There are few organisations consisting specifically of men, so there's no "captive audience" to work with.

As a facilitator you must blend in, meet a lot of people and decide who will be walking beside you, no matter whether it's an ordinary person or someone influential. You have to support the locals but not take the lead. The community needs to see that it's a local initiative, not outsiders telling them what to do.

The importance of keeping records of all meetings cannot be stressed enough, especially records of commitments and promises made.

Political stability is critical for effective social mobilisation. When the country's political wall has cracked, at local level the wall falls down. People may not want to work together, for example a Speaker and a Mayor. We have to understand the politics but stay above it.

Sufficient forward planning must be done in order to ensure the work of social mobilisation does not have an impact on CCE facilitation of the conversations.

We have learnt that when planning community conversations it is imperative to be aware of all community activities, such as pension pay day, because a clash of activities can result in reduced reach and impact of the conversation.

There must be sufficient planning to ensure loudhailing can be done successfully, that equipment is available and a local community member of influence is available to get the message across in the local language.

Action plans made to tackle the burning issues raised by communities do not always coincide with councils' funding cycles; there is a possibility that implementation of plans could be delayed by a lack of resources.

The word "conversation" itself is difficult for some people to pronounce and understand.

A review of the design of the promotional material (posters, flyers, murals) should be considered. We need to move away from bland artwork and colours to something more vibrant. Consideration of the placement and distribution of this material needs to be reviewed to avoid vandalism.

We need to continue harnessing the great relationships we have developed with community radio stations.

Sufficient planning is required to cement relationships with partners in the time available.

An opportunity exists now to link community development workers with community action teams (CATs) and the plans from the conversations.

Working with existing structures on the ground, including the Departments of Health and Social Development and NGOs, has established great partnerships and support. The name Nelson Mandela sometimes creates expectations because of a perception that the NMF is wealthy, and this can result in reduced financial support by partners. Yet political support from the ANC has been good thanks to the Nelson Mandela connection.

Criteria for action committees need to be clearly understood by the members of the CATs. Facilitators should spend time with each member explaining the role the community has nominated them for and they should clearly understand the role. If they feel they can't do it, the community will select other members.

#### Who are the key stakeholders at local level?

- The municipality, and especially the Office of the Speaker, because all the departments are represented in this office and the Integrated Development Programme is located here. Approaching the Speakers to be champions of the conversations would be an advantage as they are in charge of public participation and they bring agendas to the municipality.
- Local AIDS Councils (statutory bodies)
- The health services, which provide information about HIV prevalence
- Civil society structures involved with HIV/AIDS (faith-based organisations, community-based organisations, etc)
- Business sector

#### Media engagement

Community radio stations rely heavily on revenue and there's a perception that the NMF has a lot of money, but we did manage to negotiate reasonable rates for advertising.

News items from press releases gave us the best coverage as people actively listen to the news and it has credibility and impact.

Radio interviews with community members and facilitators took place, but we need to measure the impact of these interventions. Radio DJs have been trained in HIV issues for previous dialogues, so we must remember that capacity does exist in the media and we can use it to enhance the programme.

Where local newspapers belong to a national stable, it's hard to get them involved as partners. A logistical issue is that print deadlines are not always in line with the conversation programme.

We need to review our media strategy, to answer questions such as these: Do we want an aggressive media campaign to draw the masses or something that deals more with the issues? Should we be partnering with a media outreach institution, so we have more in-depth, detailed and informative media intervention? Should have more live reads and prepackaged promotions which take the pressure off the DJs?

#### Arts Day

Combining the industrial theatre play with the conversation created constraints in the implementation of the methodology. It was clear that we needed to locate the play within schools and on a separate day: young people love it. But there is still a battle to link it to

the conversations conceptually. What is performed in the play and what is discussed in the conversation are not necessarily the same thing, and different people attend. The CCE tools do not allow for a discussion of the issues raised in the play; issues are raised by the community and not identified externally. The content is not linked and the audiences aren't the same; you enter the conversation in a different frame of mind. We realised that the script opened issues but there was no space created for these to be addressed and internalised by the audience. How can we counteract misconceptions that are raised? We have a lot of room for growth in the media and arts element of the CCEP as a whole.

#### Storytelling

The story should be adapted for local content and incorporate relevant messages. Do we want messages in the story that change behaviour, that create awareness or that address the conditions behind behaviour? What do we leave in the story to address the conditions that act as a barrier to change?

Facilitators will continue to tell the story until community members are trained to do so. Using an untrained local storyteller, the messages can be lost.

It is very important to localise the story in content and language. The benefit of returning to the same communities is that we can now adapt the story to include the burning issues that have been identified, enhancing the sense of ownership and belonging.

The story needs to trigger action, for example if only 10% of people know their



Participants in the breakaway groups at a community conversation.



A facilitator learns from a member of the community.

status, what are we trying to achieve? What do we want individuals to go and do? We could put into the story the triggers that push you into making changes, therefore the story must encourage testing. What conditions serve as a barrier for people to access those services? After the Lerome conversation, 30 people went and got tested at a clinic that usually saw only a handful of people in a day. In Giyani, 34 got tested. The impact of a well thought-out story can result in immediate individual action.

#### Identifying burning issues

The most debilitating burning issue raised at all the conversations is that of stigma. The one thing that is raised by most people living with HIV/AIDS is "stop discriminating against us". Stemming from stigma are other burning issues raised, including lack of care, support and compassion; lack of disclosure; and cultural beliefs working against openness. People are afraid to test and can't get support.

We still find a lack of information among people, and the information they do have does not make them change their behaviour.

In peri-urban areas, misconceptions spread like wildfire.

Awareness through communication tends to be one-way; it's not fed by what's happening on the ground. In Giyani, 13-year-old girls who have been initiated are married to 30-year-olds; in Lerome the issue of incest was mentioned. There is no message that speaks to these particular issues. Generic messages can be dangerous!

#### Action committees

There's a great need for the committees to be given support. They have to be involved with stakeholders who are sometimes reluctant to get involved. We find two challenges: the action committee doesn't carry the same weight with stakeholders as the Nelson Mandela Foundation does; and everyone needs training to build their capacity.

#### NMF's actions from the lessons learnt in implementation

- Training a cadre of 40 facilitators: two identified by each community (22), 15 as social mobilisers and documentation specialists, and three CCE quality control supporters November 2008
- Plans for 2009 community conversations will allow for full engagement of the CCE methodology, from relationship building to review and reflection. This will include the use of all tools, such as the transect walk.
- Development of a participation model of monitoring and evaluation framework to measure the true impact of the conversations December 2008 to June 2009
- The NMF will embark on roadshows to all communities to engage the municipalities. In addition there will be partnership enrolment at a national level; we will also be enrolling the community partners and stakeholders working in prevention at an advisory level January to March 2009
- The actors used will be trained in the methodology. The play will be focused in schools in and around the communities, with a CCE facilitator from the community available to facilitate a session after the play. Thus the conversation will be enriched by co-ordination with the awareness campaign.
- Mobilisation of partners to ensure there are testing facilities at every conversation in 2009
- A consultative process focused on our media intervention, the story and the messages it sends will be scheduled in February 2009.
- Use of the latest mobile technology, namely SMS messages and a mobiwebsite, to stay in contact with facilitators, CATs, stakeholders and partners is being developed and piloted at present. This will be our main communication tool with the communities and we plan to be utilising it fully by March 2009.
- A need has been identified for facilitators and the community to have access to counselling; we are therefore engaging the services of an organisation whose networks across the country will perform this function. We are also approaching the national Department of Health in this regard to ensure that national helplines are aware of the community conversations and can cater for demand. This will be in place by the first community conversation of 2009.

### **Consultative forum**

On October 30, 2008 the Nelson Mandela Foundation held a consultative forum at their offices in Houghton to discuss Community Capacity Enhancement (CCE) and to point to the way forward for its community dialogue programme. The Foundation invited facilitators and stakeholders who had been involved in the 2008 community conversations, as well as representatives of other organisations that might be interested in the methodology, and potential funders.

#### Welcome by NMF CEO

Nelson Mandela Foundation CEO Achmat Dangor welcomed the forum participants. "When we reviewed the impact of the conversations," he said, "what struck us was the absence of dialogue at community level. Since 1994 we have relinquished our need to participate in the life of the country. It has become just a matter of voting or not voting. This is creating a dangerous void where policymakers often don't understand what communities need. In the 1980s, we had a rich and vibrant civil society. These dialogues have shown us we need to rekindle that spirit at community level."

Speaking about what it is that creates social cohesion, Dangor said: "Poverty, gender inequality and mistrust will militate against it. The Nelson Mandela Foundation is hoping that what will come out of this workshop is thoughts about how the Foundation can use AIDS dialogues to stimulate discussion generally.

"Look at Khutsong [a South African township that has been the scene of violence and protest over the issue of provincial boundaries]. If there had been a meaningful community dialogue there might have been a different response. It is important for communities to have a say and to be taken seriously. We won't resolve AIDS until we start addressing broader issues in society that have an impact on it."

#### The Lerome experience

Phillimon Monyeki and Councillor Thomas Manganyi, both from the Moses Kotane Municipality, a partner in the Lerome conversation, were present and their contribution was acknowledged. Paddy Nhlapo, CE of Cool Ideas 247 (Pty) Ltd, said that the level of support provided by this municipality had been excellent; office space and human resources had been provided for the community conversations team and they were guided in matters such as how to approach traditional leaders. The Office of the Mayor had assured the team that their efforts would be sustained.

"We were sceptical at first," said Cllr Manganyi, "but the young team injected a good work ethic and passion. The conversation has made people far more comfortable to talk about issues of concern to them – unlike other methods. Other communities also want to form part of this initiative. The experience has strengthened us. We learnt a lot – like what it means to make a difference in someone's life by engaging and listening rather than by assuming we know what people want. We are building on this process."

"I learned a lot," said Monyeki. "What was good was getting people to solve their own problems. After the community conversation we elected a team of 10 members and we met on the second day. The mayor promised a budget for our programme and asked for a costed plan for the whole year. We had to draft a programme and train people."

Nhlapo added that Lerome had served as a pilot and that stakeholders such as mayors were keen to participate in the conversations once they had a clearer idea about how it had worked in practice.

Diaho said that the Foundation planned to visit each municipality in the conversation series to discuss taking the process forward.



#### Why Community Conversation?

#### Experience of community conversations

Mothomang Diaho, Head of the Dialogue Programme, outlined the thinking behind the community conversations, saying that the idea of people getting together to talk about issues is not new but it is exciting to revive it.

### Organisations at the Consultative Forum:

#### 46664

Cool Ideas 247 (Pty) Ltd **Flow Communications** German Technical Co-operation (GTZ) Helen Suzman Foundation Independent Consultants JHPiego Key Change Music Khomanani Local AIDS Council (Lerome) National Department of Health Newstart **Nelson Mandela Foundation** Provincial Council on AIDS Chairperson (Lerome) **Public Health Agency** Shoeshoe Mohaladitoe and Associates Soul City The Olive Leaf Foundation Tsabo-Tsonga Consultancy CC **Tshikululu Social Investments** United Nations Development Programme (UNDP) **Viva Hecate Productions** 

Shivaji Bhattacharya, a senior policy advisor at the United Nations Development Programme, also spoke about the development of the methodology and practical experiences of using it elsewhere in the world.

"HIV is something we often believe is 'outside', 'out there', happening to others," he said. "This CCE methodology moves us from that to 'I' – I am part of the issue, part of the solution."

The reason HIV/AIDS is so difficult for people to talk about, he said, is that "it distils itself to sex and death". Human responses to those concepts include shame and fear, therefore there is a tendency to stigmatise and discriminate against people living with HIV/AIDS. The result is silence and denial.

"We need to move out of that space of silence and

denial into one of dialogue," he said. "That requires a process of introspection. To move out of that state, we need hope and belief that this is not the end. Then we will be open to ideas and get a deeper understanding. That in turn leads to action."

Giving people information is of limited value because everyone interprets information differently, according to what they already know, he said. It is better to consult with people. "The ultimate destination of the methodology is self-mobilisation – 'what I can do'."

Bhattacharya spoke about the process of change: a cycle of building relationships, identifying concerns, exploring concerns, decision-making, action, reflection and again building relationships.

He spoke of working in a village in India where the locals, a community of basket weavers, told development workers what they thought they wanted to hear. There was a "them and us" division. The outsiders then tried the community conversations approach, starting by sitting with the weavers and trying to weave baskets themselves. This showed the local people that they had knowledge and skill of their own which the outsiders did not have. It was the start of building a relationship. Bhattacharya also made the point that information and change should flow in both directions – findings at community level should move up the ladder to service providers and policy makers.

He said community conversations can achieve the following:

- an understanding of the HIV/AIDS epidemic
- social cohesion in a changing environment
- self-development
- redefined social contracts (such as gender relations)
- a pool of resources and leadership
- bringing the voices of people to policy and back again
- capacity building in civil society.

He gave examples of changes that had occurred at a personal level through community conversations, such as an Ethiopian man saying that circumcising his first daughter had been a mistake and that he would not force it on his second daughter.

Taking questions from the floor, Bhattacharya noted that it is important to build flexibility into any strategic plan for community conversations. Funders and donors have to accept this.

The need for research to track the changes in communities over time was discussed, as this would be a concern of funders. The point was raised that the concerns and decisions of communities should be recorded at conversations, by facilitators and by community members.

In answer to a question about donors wanting their branding at community conversations, Bhattacharya said the Paris Declaration on aid, signed by governments and donors, was clear: the donor does not own a programme – the people do. "We are the servants of the people. The more foreign the intervention, the more you will be blocked – though politely treated," he said. "If you want to see change, don't put up banners. Everything after the community can have your branding on it."

John Muir, of the organisation Olive Leaf Foundation, supported this stance, saying that branding does not create a safe space. "We're proud of where we're from, but it doesn't allow free dialogue – it shows that there's money attached."

Olive Leaf Foundation, an international faith-based organisation, used to be focused on rapid outcomes of its interventions, he said. Funders wanted results fast. "But the CCE methodology says you're no longer in charge of the time frame." The organisation realised it was being arrogant, paternalistic and controlling, telling people what their



Participant in the consultative forum.

problem was and how they should solve it. "We realised that as an organisation we have to listen and observe before we speak. CCE used to be a programme within the organisation; now it is becoming a philosophy for the organisation."

He outlined the steps (7 A's) towards communities becoming "HIV/AIDS competent": awakening; awareness; acknowledgement; ability; analysis; action; amplification. "CCE gives us the vehicle to get there."

After a history of people being dehumanised in South Africa, said Muir, and after AIDS having the same effect, "CCE starts to re-humanise people".

As seen in cases like Khutsong and the xenophobic attacks in South Africa in 2008, "people are frustrated because their voices are not being heard", said Muir. "The [anti-apartheid] struggle was about saying 'you matter'."



Above and below: Participants in the

#### Learning through doing

Participants attending the forum were taken through the "counting your losses" and storytelling processes as if they were participating in an actual community conversation.

The 180 stones available to represent lost lives were used up well before all 42 people at the workshop had filed past the memorial cloth. "Whose problem is AIDS?" asked Nhlapo. "Where are we heading as a country if we are picking up more stones all the time?"

People then shared their thoughts and feelings about the exercise. One person said she knew so many people who had died as a result of AIDS, she could probably have used all the stones herself. She said she



had been working in the HIV/AIDS field before her mother and two aunts had died, but "I did nothing. I feel I should have done more. I ask myself: what should I have done? Today I am promising myself to do more – to do everything in my power to make a difference, starting with myself, so that I don't count more stones."

"I feel angry," said another participant. "It didn't have to be that way. Things could have worked differently. My aunt didn't say anything and we only knew why she had died when we found her medical records. We weren't open to her so that she felt she could say something. I am angry when I see the way my cousins live because they have lost their mother."

"For me it was a reawakening," said another. "I took more than seven stones for very close friends."

"I was a little conflicted," said one. "The memory was quite unsettling. I put down stones for my grandmother and aunt. We had to be silent about it because of issues around age and sex. I also put down stones for friends. The silence continues to bother me – silence about women in same-sex relationships – we still can't talk about it in our country."

"The first stone was for my uncle," said a participant. "I was working for a bank at the time he got ill, and it seemed I was the only person he could talk to about it. He wouldn't say what his condition was but asked for money for medicine. When the family went to visit him, we found he was being ostracised, living in an outside room. At his funeral, the picture of him on his coffin looked exactly like me. I thought at the time: 'that's not going to happen to me'. I thought about the dignity he had lost. The latest person I know who has tested positive is a friend's younger sister, who is pregnant. I went to her house and everyone was crying because they expect her to die. If only I'd thought 'it's not going to happen to me because I'm going to do something' – not 'because I'm lucky'. I believe we each have the answers within us."

A participant said: "I'm an agent of change through the CCE programme. I see all this transformation but it doesn't happen in my family. I appeal to you: let's go all out. People have the capacity to change – let's facilitate it."

#### **Burning issues**

A facilitator shared some of the burning issues identified at the 10 community conversations:

- lack of support
- poor communication between parents and children and lack of parental involvement
- stigma and discrimination
- · lack of self-esteem, often originating in poverty
- incest
- abuse of customary practices, such as rushing girls through initiation so that they are "ready" to be married
- "sugar daddies" (transactional sex)
- substance abuse
- lack of recreational facilities

#### Discussion

People at the forum who were not familiar with the CCE method had an opportunity to ask questions.

**Q:** Do you follow up on conversations by working with segmented groups, such as young girls?

A: People at conversations are divided into breakaway groups in which they can feel comfortable to discuss things. Also, the community action team (CAT) that is elected represents men, women and youth. These CATS are coming for eight days of training in November 2008 and it is hoped that their work in their communities can be linked to municipal programmes.

Q: Do you go into a conversation to discuss pre-identified issues or are you neutral?

A: The issues of concern come from the community itself. The social mobilisation team also goes to the local clinic, to the taverns, and so on, and spends time in the community before the conversation to get to know what their concerns are.

Q: How are communities identified as candidates for a conversation?

A: On the basis that other organisations are not very active there or that projects there have failed.

Q: Does a community have access to the research done there?

**A:** In this CCE methodology, the community has the capacity to document every step of what happens. The facilitators should help them decide how to do this. The media should also be there to hear what people say.

**Q:** What happens to the facilitators who have to hear all these stories from communities?

A1: We recognise there are difficulties for facilitators. Community change champions are ordinary people with their own baggage. The programme will make sure they get support. Let's look at where we can partner.

**A2:** I've discovered that the process is healing for the facilitators as well as the communities. You become part of the community. Among all the CCE tools, there is none so punishing as counting your losses. Sometimes you don't know what to do.

**A3:** When I started working with CCE as a facilitator, I thought I had healed [from my own losses], but I realised I hadn't. Now I have healed and I can do more than I thought I could.

A4: The facilitators support and debrief each other. I think it would be good to have a retreat because there is burnout.

#### Closing

"You're here because we saw the potential for partnership and we want to start a social movement," added Mothomang Diaho, Head of the Dialogue programme. "The next step in the community conversations series was a facilitation training workshop for the community action teams, with a practical conversation session in Soshanguve."

NMF CEO Achmat Dangor closed the workshop by saying that there should not be a dichotomy between communities and authorities. "We should bring in the police, the councillors and so on as partners – they share the same problems of scarce resources."

He said he hoped that the Foundation and its partners could begin to identify policy issues that could be addressed at a macro level.

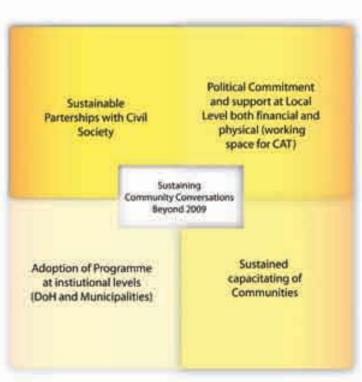
#### Reflections on the forum

"We were very impressed. It's a good approach when the community owns it." – Sina Eckhoff, GTZ.

"Community conversations pose a challenge to professionals, forcing them to ask how they can respond to the HIV/AIDS pandemic. It is important for institutions to collaborate instead of competing." – Mthetho Tshemese, clinical psychologist and consultant to Soul City

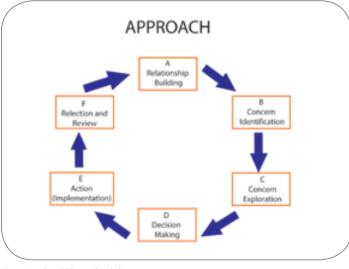
"This methodology reminds us of the old ways of doing things, when men used to sit under a tree and converse ... There is a link between HIV/AIDS, poverty, education and social welfare and we can't isolate these from each other." – Mercy Makhalemele, Tsa-Botsogo Consultancy

What we ask of you



## Training of facilitators

he first step in training facilitators in the CCE methodology is to build their relationships with each other, thus creating an environment in which they can trust and learn. Each records the profile of a partner and the challenges they face in their communities. The exercise is designed to support the development of self-esteem, self-confidence and tolerance.



Steps in the CCE methodology.

They go on to form rules and a code of conduct to govern them while in the training workshop, to create an atmosphere of harmony and coexistence. These rules are formulated in the form of pictures so that they are explicit to everyone. Every home, community and society has rules about their day-to-day activities and how people relate to each other.

The next exercise is one of taking stock. Trainee facilitators share what they have done to address HIV/AIDS issues in their communities. They look back at what has been done well and what still needs to be done better to halt the spread of the epidemic.

They then think about and share experiences about socio-cultural aspects of HIV/ AIDS and how they link to trends in their country. This is also an opportunity for them to identify misconceptions about the spread and "cure" of HIV/AIDS.

Documentation is an important skill for facilitators to acquire. Events, processes and outcomes around community conversations must be recorded as they happen and be as close to verbatim as possible. It is important to use the words the community used in talking about issues and concerns. Documentation provides the basis for decision-making and effective reviews. In their training, facilitators are exposed to this function of recording a community dialogue and are shown how documentation can help them personally as they record their daily activities and the changes in their own behaviour.

Each community conversation begins with time to reflect and share experiences. Reflection is not an easy process or a well understood concept, so facilitators are trained to understand and practise it. Rather than recapping what has happened, reflection is about looking within oneself, critically questioning oneself and listening for answers from within. It helps a person get in touch with their own feelings and values – the first step in planning a response to a situation.

Facilitators are taken through all the steps and tools in the community conversation methodology and shown how they interconnect:

- Relationship building
- Respecting and acknowledging community experiences, norms, values and perspectives
- Concern identification
- Strategic questioning and active listening
- Concern exploration
- Deeper examination of identified concerns, underlying factors and related issues

#### - Decision making

Community identifying what needs to be done to address concerns

#### - Action implementation

• Prioritisation of concerns, implementation of set activities

#### - Reflection and review

• The training then reviews the difference between facilitation and teaching, and how a conversation can address power relations. Participants are taken through different scenarios of facilitation; they see how sitting with the audience (rather than standing in front of them like a lecturer) allows more freedom of expression, mutual learning and a sense of belonging.

Ken Wilber's "four quadrants" methodology is an analytical tool that can be used to explore the relationship between intentions and values on one hand and actions on the other. It helps in understanding the HIV/AIDS epidemic by examining the origins of actions. The quadrants are a way of seeing any reality as a whole and also as part of a whole, and seeing it from within and from outside.

Facilitators are taken through how social capital manifests itself in society and is linked to behavioural change. In past training sessions, facilitators have come up with these as examples of ways of understanding social capital:

- co-operation
- · something that creates unity and respect
- a way of developing trust
- a way of bringing people together, through things like sports and burial societies
  unity and love

It has also been defined as "the value and co-operation created through social human relationships or networks".

The training includes exercises to develop competence in:

- **strategic questioning**: formulating questions which solicit information and perspective in a community conversation
- historical timelines: exploring the meaning of events in people's lives and the effects of such events in creating cohesion in a community
- active listening: closely following what is being said and giving feedback to the speaker using verbal and non-verbal expressions; demonstrating respect for what the speaker is saying; weakening relationships based on power and guarding against discrimination against those perceived as without power or social status

Facilitators are introduced to the idea of the **transect walk**, a tool that allows community members to explore and rediscover familiar surroundings. It is an opportunity to focus on realities and resources that are often overlooked or taken for granted. Participants look out for possible entry points for action on HIV/AIDS – for example, community gathering points, deserted and potentially dangerous places, places like taverns and truck parking spots.

They learn about how **power relations** work in daily life among individuals and in broader groups. Power relations affect the way people respond to HIV/AIDS. Trainee facilitators are asked to sit in pairs, one silently on the floor and another on a chair, talking. They then talk about how this makes them feel.

They also discuss the way **language** and **images** influence behaviour and attitudes. For example, language can discriminate and damage self-esteem. They learn to consciously use language in ways that bring people together rather than creating rifts.

Another important part of the training is **teamwork** and **team building**: communication, co-ordination and appreciation of individual roles in team activities. Facilitators are taught to develop skills in:

- the use of **storytelling** to encourage dialogue
- the "**five friends of planning**": what, how, who, when and where (used to help communities act to address their challenges)
- **preparing for a field trip** to facilitate a conversation (setting an agenda, assigning roles and responsibilities)

Trainers of facilitators are expected to reinforce their skills by attending community conversations.

The quality of a facilitator's work is observed in conversations, judging by criteria such as:

- presentation and style
- how the voice is pitched
- body language
- alertness and being in the present
- application of the tools that demonstrates an understanding of their purpose
- encouraging participation by all present
- maturity in handling disruptions
- poise to resonate calmness and concentration
- · controlling dialogue to achieve set objectives
- managing time
- liaison with other facilitators
- sensing unease on certain topics
- toning down language that may be offensive
- creating harmony in situations where communication breaks down
- capturing information in detail
- supporting other team members

After every community conversation the team have a debriefing session and reflect on things that went well and things that require improvement. **Skills refinement is an ongoing process.** 



Facilitators spend some time together before the conversations start.

## Facilitators' reflections

igh demands are placed on the facilitators who work at community conversations. It is a personal journey of transformation for them as well as for the communities and individuals they work with. They must have factual knowledge about HIV/AIDS and be able to work in teams and with partners such as local government. They are called upon to control and hold the attention of large groups of people without being prescriptive. They must be sensitive to other people's perspec-



tives and elicit information respectfully. It is also important to capture this information reliably. They must be able to manage highly emotional situations and empower people to make decisions and take actions as a community. What follows are the reflections of some of the facilitators after the series of community conversations.

#### Lesego Mooketsi

I have been a facilitator for the Nelson Mandela Foundation since 2007 and was involved in the Youth in Dialogue series. Previously I worked as a social mobilisation officer and trainer for Napwa. I received training in CCE and got excited about it. Being trained changes you: you learn methods like the transect walk and you know that you are there to help the community find their own solutions. This is the difference: you let people take control. You see people getting excited about this and enjoying a conversation and not wanting it to end. Some people who didn't want to be part of it before they saw it then want to join in.

I have to change so that other people can change. Why should they be prepared to change if I am not? People must look at me and see the new Lesego.

When you're trained, your objectives become clearer and you see how you can help people change in lots of ways – not just in behaviour relating to HIV.

Sometimes you come out of a conversation having listened to other people's experiences and you feel like your problems are nothing in comparison. I lost my mother to HIV/AIDS, but when I hear a young child who has to care for sick parents, it helps you heal your own troubles. And you see that HIV/AIDS is everyone's problem,

not someone else's problem. This starts to make more sense.

It hurts to see people not taking HIV seriously. What do they need to make them take it seriously? Sometimes, conversations do this for them – until then they were avoiding things, shielding themselves and closing doors. The conversation allows them to heal. It really makes a difference. People can open up in a safe environment, share their feelings and decide to take action.

There's still a lot that needs to be done. Sometimes it makes me sad – to see that we haven't done enough yet. If we had knowledge, we wouldn't have stigma and a lack of care. But then you feel determined to do more than you have done before.

#### Motlatsi Lekhuleni

I started working with the NMF this year as a facilitator. For me at the beginning it was just a job that I took because I needed to earn a living, but as time went by it became more than that. It became my life. It made me look into myself and I realised that I needed to change before I preached change to other people. What has been moving for me has been the "counting your losses" exercise. This exercise has challenged me and it drove me to make a personal decision to change my life.

For me, all the community conversations touch you in their own different ways. The one conversation that stands out for me though would be Soshanguve.



Facilitators join hands before a conversation.



Above and below: Facilitators during the storytelling sessions.



There was a lot of politics involved and we didn't have many resources, but we made something with the little we had and many people publicly disclosed their status for the first time.

#### Thabane Tsagane

This is a very informative venture. The concept isn't yet known by communities around South Africa but I believe that as soon as people understand how this concept operates then it will run on its own. It's a really good programme and I feel that it's able to reach its objectives. Once people are able to grasp this concept then we will see the results.

I thought that breaking through would be difficult because the moment you mention

"conversation", people interpret it in different ways. People are sceptical and are afraid to talk (I noticed this when we were doing social mobilisation). I became accustomed to people's reception and decided to educate people and help them understand the concept of community conversations.

I didn't expect people to confront their issues so enthusiastically. I was surprised at how open they would become after the "counting your losses" exercise. It's as if after that session they really grasp what the programme is about. They just come out spontaneously and become more open about issues. During social mobilisation you can become disheartened and think that people won't come, but at the conversation things change and it makes you feel that the time given was too short to get the community's issues.

I have learnt that if stigma and denial were dealt with earlier on and people were given information about HIV/AIDS, then we would be in a better position in terms of new infections. I have also learnt that people are willing to face this pandemic and work against it – the lack of resources is preventing them from doing so.

I can't single out one thing that drives HIV. But what I can say is that in most communities we went to, we found alcohol was a big problem. People drink; and when they are drunk they become less resistant to having unprotected sex. Alcohol plays a huge role and it makes people forget to abstain and condomise. In the shebeens and taverns that we visited during the social mobilisation period we found a lot of young girls, some as young as 12, and in our culture a woman succumbs to the man no matter how old he is. So we need to have strict control over the selling of liquor, because we observed the same pattern in all the communities. These shebeens sometimes host ladies' nights and this is where they become drugged without them knowing – their drinks get spiked.

There are other underlying factors, such as child-headed families. In instances where the mother is away, there is no one to take care of the family, so the girl child looks for the easy way out and that is getting a quick buck from these older males.

To solve the problem of HIV in this country, I feel that sex education is needed. South Africans rely a lot on what the government can do rather than what they can do to help themselves. In most communities we discovered that there is a lot of transactional sex going on between older men with money and younger girls. So we need to educate adult males because they are economically independent and their money gives them an opportunity to exploit younger girls. They lure these girls into drinking and infect them with HIV. So we really need to think about our moral values and what we can and cannot do.

A community conversation facilitator needs to have strong communication skills and be able to understand the dynamics of each community. A facilitator needs to know the politics of a community so as to be able to understand the key issues of that community.

What stood out for me as a highlight of the conversations was the openness that people had once they were given an opportunity to talk. When someone says "I have lost so many people to HIV/AIDS" and speaks from the heart, that really touches me. Again, when people pledge to help their communities in every way possible in this fight against HIV/AIDS, that shows me that people are ready to help and give back to their communities.

#### Thabang Xaba

These conversations have educated me so much and taught me to understand other cultures and backgrounds. I have grown emotionally. I have also learnt a lot about the way people perceive HIV/AIDS.

At first, when I heard the word "conversations", I pictured a gathering where people debated issues affecting their communities. As I helped facilitate the conversations, I realised that they are something totally different: they are about us trying to make people realise that they have the potential to fight AIDS; and we follow up, so it's not all just talk. We gave the communities the opportunity to take ownership of their own issues.

Being in those communities made me see that the HIV prevalence rate can be brought down – the communities came up with strategies on how to do this. We created a platform; they came up with solutions themselves.

What stood out for me was the fact that there's a lot of stigma attached to HIV, despite so much awareness having been raised about it. Lots of people aren't comfortable to disclose their status because they get stigmatised.

From the community conversations I learnt that it's possible to beat AIDS only if we commit ourselves and engage with people on the ground. We need to change our attitudes so that we can come up with solutions to this pandemic.

One of the skills that I think a facilitator must possess is humility – it really goes a long way. Communication is also essential. These skills combined will enable a facilitator to deal with people and their different cultural backgrounds.

For me personally, the Soshanguve conversation stood out because the room was full of people and over 50% of them were HIV-positive and they didn't know that about each other before. So after that conversation they established relationships and they are now helping each other. They discovered each other's status through the conversation and they now talk to each other.

Personally, the conversations have made a great impact in my life. We go to the communities thinking that we will educate but we end up being educated. The conversations have changed the way that I look at life in general and I am now able to adjust to environments, be they rural or urban. I now relate better towards people because I was forced to leave my comfort zone and learn more about other cultures; and I am grateful.

#### Lesley Nkosi

Community conversations this year were more intense and demanding for all of us than the Youth in Dialogue sessions last year. Firstly, as facilitators we were trained in this effective methodology which taught us to facilitate action and encourage ownership of the process in the communities we visited. We had to be what we preached. We had to maintain intense mental vigour and be driven to want to see those results.

Deepak Chopra once said: "To change the printout of the body you must rewrite the software of the mind." Personally I have always been of the belief that the Achilles' heel in HIV lies in the mental and emotional attitude of those affected by it. It was the most enlightening experience to literally observe a positive mind shift every time I was in a conversation.

First our own migration as facilitators, from just doing a job to being compelled to be more emotionally and mentally mature. Praying more, reading more, caring more, listening more, being more humble, loving more, giving more, the list is endless. But there was also the fascinating and immediate shift of people in communities from hopelessness and dreary disempowerment around HIV /AIDS to realising that the answers really lie within each one of them. It was like watching people move their eyes away from seeing only dark shadows around them to seeing the beauty of the sunshine. "Sometimes life's shadows are caused by our standing in our own sunshine." – Ralph Waldo Emerson

For me the truth is the CCE programme empowered not only the facilitators but also the identified communities, allowing them to take more ownership of the community conversation process; starting with organising their events, to unreserved participation during their conversation events, and then on to embracing a leading role in the process



Facilitators prepare before one of the community conversations.

of change after their conversations were through by way of community action teams partnering with existing local stakeholders.

This time, I had the greatest confidence that we were on the right track in bringing change. Community conversations brought a lot of hope to communities changing more than just issues around HIV/AIDS. I witnessed the most conservative community



Below: Participants share their feelings about loss.

members embracing change and taking action following conversations.

The tools selected were powerful and effective, compelling community members as well as facilitators to concede their own shortfalls in committing to change while allowing everyone to feel safe to open up and talk about their weakest qualities without fear of victimisation or being alienated.



In Soshanguve, we witnessed young people open up to their own community, saying that even though they had been aware that they were infected with HIV, they had still gone out to infect other people. I saw them turn around in the same breath and say they were going to change and protect others. In fact they campaigned to be selected as community action team members.

In Giyani, an incredibly conservative and tribal community where shame and stigma in local villages drives people who are infected to desperate denial of HIV/AIDS and blaming witchcraft instead, I was approached by a tribal chief who said to me that he wanted to take the lead and be more involved in changing the attitude of the people in his village. He was going to make sure that conversations were directed strictly at HIV acceptance and empowering the minds of his people.

In Lerome, talking about incest was taboo, until the community conceded in the conversation that by ignoring that it was rife, their children were victimised. This could only be achieved through the CCE methodology's storytelling tool, which allowed the community to face the skeletons in their closet without feeling accused or disempowered. Although it's still a difficult issue, the community of Lerome took a bold step in admitting that it was a problem they could no longer ignore. It was most humbling to see young and old come together and admit that something was wrong.

In KwaMakhutha, we prayed before the conversation began. I had already learned a few tricks about embracing the universe and allowing the divine power within to take over. The most powerful tool in CCE for me has to be "counting your losses". I loved using the historical timeline to bring across the realisation that we have triumphed through adversity before.

And as we were paying respects to our loved ones we had lost to the fear of HIV, I could see an old man standing in front of his community, with tears trickling down his cheeks as he was confronted by how much had been taken from him. During reflections, he realised that he was not alone, his community felt his pain; they were not laughing at him for raising useless children. They too were going through the same challenges. The process was intense yet effective.

Another healing reflection was a local municipal leader who said that he needed to change his attitude towards women. He said that despite having buried many friends and family, and even though he was nursing eight of his friends who were suffering from opportunistic infections at that moment, he still neglected to use a condom every now and then. He confessed to not caring enough and vowed to protect himself and those he loves. No amount of money can buy such humbling experiences.

I personally went through a journey of empowerment and enlightenment by being involved with the community conversations at many levels.

Through my participation with CCE, I have acquired invaluable skills to enhance my own life for a long time to come. I have experienced spiritual fulfilment at an individual level. I now expect more from myself than I did before.

"What the soul knows is often unknown to the man who has a soul. We are infinitely more than we think." – Kahlil Gibran

### About the Nelson Mandela Foundation

#### Centre of Memory and Dialogue

he Nelson Mandela Foundation is a not-for-profit organisation established in 1999 to support its Founder's ongoing engagement in worthy causes on his retirement as President of South Africa. The Foundation is registered as a trust, with its board of trustees comprising prominent South Africans selected by the Founder. The Nelson Mandela Centre of Memory and Dialogue was inaugurated by Nelson Mandela on September 21, 2004, and endorsed as the core work of the Foundation in 2006. The Nelson Mandela Foundation, through its Nelson Mandela Centre of Memory and Dialogue, contributes to the making of a just society by promoting the vision and work of its Founder and convening dialogue around critical social issues.

#### **Dialogue for Justice**

The Dialogue Programme of the Centre of Memory and Dialogue aims to develop and sustain dialogue around Mr Mandela's legacy. It is committed to building on the history, experience, values, vision and leadership of its Founder to provide a nonpartisan platform for public discourse on critical social issues. Achieving community participation in decision-making, even at policy levels, is prioritised.

The Dialogue Programme aims to perpetuate and re-invigorate the culture of engagement using the example set by Mr Mandela of inclusive and open dialogue for which South Africa is famous.

Drawing on the rich traditions of transformative dialogue, problem-solving and social renewal that made possible South Africa's remarkable transition, the Dialogue Programme:

• Aims to facilitate greater understanding and awareness about the problems faced by people, particularly in South Africa and Africa, and the possible solutions available to them

• Utilises comprehensive methodologies to promote dialogue between stakeholders

• Convenes result-oriented stakeholder dialogue on key social issues identified through continuous engagement with partners



Living the Legacy

#### Memory for Justice

Memory resources documenting the life and times of Nelson Mandela are to be found in an extraordinary range of locations, both within South Africa and internationally. The Memory Programme provides a unique facility which:

- Locates, documents and ensures the preservation of these scattered resources
- Collects and curates Mr Mandela's personal archive
- Promotes public access to these resources and fosters dialogue around them
- Ensures that all initiatives in the name of Nelson Mandela are true to his legacy

Memory is not an end in itself. Its significance lies in its use. The Memory Programme seeks to reach both global audiences and those systemically disadvantaged within South Africa by:

• Undertaking outreach programmes, including travelling exhibitions, books, a comic series, and internships

- Ensuring web-based access to information through its web portal
- Supporting digitisation initiatives designed to broaden access to resources
- Facilitating research by individuals and institutions

"We believe that the vehicle for sharing memory effectively, for growing it, and for engaging it in the promotion of justice, is dialogue. We actively open our memory work – on the life and times of Nelson Mandela, the events and the people he influenced or was influenced by – to debate and discussion, and we draw on this memory work in convening dialogue on critical social issues that present a threat to justice in society."





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