

# Helping Ourselves: Community Responses to AIDS in Swaziland

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## Foreword

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In March 2005, a Joint Mission of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and UNAIDS, led by Dr Peter Piot (Executive Director, UNAIDS) visited The Kingdom of Swaziland to see some of the community-based HIV programmes that have been developed there. In a country severely affected by the epidemic, these community programmes represent innovative and inspirational methods for supporting people infected with and affected by HIV, particularly orphaned and vulnerable children.

The Joint Mission visited the community of Mambatfweni in Manzini region where community initiatives are based on several interconnected elements:

- building a community KaGogo social centre to coordinate efforts to respond to the epidemic and its impacts;
- establishing a system of Neighbourhood Care Points to feed orphaned and other vulnerable children, teach them basic life skills and give them care and support within the community;
- reintroducing traditional community Indlunkhulu fields to help grow food for the sick and vulnerable;
- establishing community support structures for people living with HIV;
- providing psychosocial support programmes; and
- strengthening community outreach services.

Mambatfweni is not unique in developing these community efforts. Similar community-based initiatives are being rolled out and scaled up across the country and have become the foundation stones of the national response in Swaziland, now facing (in 2005) the highest recorded prevalence in the world.

Following their visit members of the Joint Mission suggested that these inspirational community-based activities should be documented as part of the UNAIDS Best Practice Collection of publications to highlight the innovative methods adopted and to learn from those experiences. This report describes some responses of two different communities in different parts of the country.

## Abbreviations and acronyms

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AIDS	Acquired Immunodeficiency Syndrome
AMICAALL	Alliance of Mayors' Initiative for Community Action on AIDS at the Local Level
CANGO	Coordinating Assembly of Non Governmental Organisations
DPMO	Deputy Prime Minister's Office
E	Emalangen (Swazi currency plural of Lilangeni)
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	Human Immunodeficiency Virus
MOE	Ministry of Education
MOH & SW	Ministry of Health and Social Welfare
NCP	Neighbourhood Care Point
NERCHA	National Emergency Response Council on HIV and AIDS
RHM	Rural Health Motivators
SIPAA	Support to International Partnership Against AIDS in Africa
SWAGAA	Swaziland Action Group Against Abuse
SWANNEPHA	Swaziland National Network of People Living with HIV and AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
VCT	Voluntary Counselling and Testing
WFP	World Food Programme
WHO	World Health Organization
UNICEF	United Nations Children's Fund

## Summary

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*“If we do not honour our past  
We lose our future.  
If we destroy our roots  
We cannot grow.”*

*Swazi proverb*

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It is clear that AIDS is now a crisis of such magnitude in Southern Africa that a “business as usual” approach cannot continue. There is a clear need to experiment with new and creative initiatives to mobilize whole communities in the response to the epidemic. Swaziland, experiencing the highest recorded HIV prevalence in the world in 2005, is implementing new and innovative measures, based on traditional practices that are rooted in communities.

This Best Practice document records information gained through wide-ranging consultative meetings and site visits to two Swazi communities—Mambatfweni in Manzini region and Mambane in Lubombo region. The writer interviewed many key people involved in the community initiatives in both these communities and observed the process in action. A number of visits to social sites were also undertaken, including to Neighbourhood Care Points, KaGogo social centres, community fields, facilities and services.

One of the most visible impacts of the epidemic for households and communities has been a dramatic increase in the number of orphans and vulnerable children to approximately 69 000 today—a number that is predicted to rise over 120 000 or approximately 15% of the population by 2010. Many of the community initiatives documented in this report seek to mitigate the impacts of the epidemic on these children and to give them hope for the future.

Existing Swazi culture is being strengthened and deepened to mount an effective response to AIDS. The practices and policies adopted, whilst being Swazi-specific in some cases, may also serve as an inspiration to other countries facing similar problems. This document considers whether some of the innovative and practical experiences of Swaziland can be replicated elsewhere; and attempts to assess some strengths and weaknesses of these community based initiatives.

The report outlines case studies of some of the community-based HIV programmes that have been developed in Swaziland. It considers:

- how and where the community initiatives came about;
- the aims of the programme or project;
- the target population (how and why it was chosen);
- how the programmes were developed and where expert/specialist advice comes from;
- how and where decisions are made;

- the range of people involved in the programme or project and what kind of skills they have;
- partnerships;
- budgeting and funding;
- what impact the programme/project is having and how it is measured (monitoring and evaluation); and
- the lessons of experience—successes and failures; problems encountered and how they have been handled.

The initiatives outlined in this report have been lifeboats to communities facing apparently overwhelming and insurmountable odds. Instead of leaving people feeling helpless and hopeless, they have given communities a sense of hope for the future and ownership of the solutions.

Every community is unique with different strengths and weaknesses. The experiences of the two communities documented have varied considerably, with some of these initiatives establishing firmer roots in one community but not the other. Additional difficulties, such as the deepening drought and worsening food shortages, are having a direct impact on community efforts to establish and maintain these initiatives

Much has been achieved in a very short time, but many challenges remain. What is not in doubt is the communities' commitment to doing what they can to help themselves.

With all of these practical initiatives, whether providing psychosocial support, or the community working together to provide care points for orphans or to grow additional food for vulnerable children, the impetus comes from the community itself. This 'bottom up' approach enables community initiatives to blossom and empowers people at local level to identify the problems for themselves. Support provided by Government and international partners enables these local initiatives to flourish and become sustainable.

Without support from Government and donors, however, these innovative and inspirational efforts may be seriously undermined by a fifth consecutive year of drought and consequent food shortages that face Swaziland, and the region of Southern Africa as a whole.

Food shortages are also threatening to undermine the impressive rollout of antiretroviral treatment that Swaziland has managed to achieve so far. People cannot take these drugs on empty stomachs and there are people who currently cannot get onto treatment programmes because they have no food.

Communities such as Mambatweni and Mambane, with little more than hopes and ideals to sustain them, have shown their determination to mobilize to respond to the threats posed by AIDS and deal with its devastating consequences as best they can. They have made progress but the advance of the epidemic has not yet been reversed. Support from Government and external sources is needed to ensure that community volunteerism does not dwindle because people are hungry and, as a result, unable to sustain these innovative and inspirational initiatives.

### siSwati Names and their English meaning

Umphakatsi – Chief's residence and headquarters of the community

**Indlunkhulu** – traditional Chief's homestead

Indvuna – Chief's assistant

**Inkhundla** – Constituency Centre

**KaGogo** – traditional Grandmother's hut, now refers to a place of refuge within the umphakatsi.

**Lihlombe lekukhalela** – "A shoulder to cry on" community members that are trained to protect children and support those abused.

**Lutsango Lwa boMake** – traditional organization for married women.

Tigodzi – parts of a chiefdom (sub-chiefdoms) equivalent to a ward in urban areas

Lutsango LwakaNgwane – traditional women's regiment

**Tinkhundla** – Constituencies

**Umcwasho** – cultural practice aimed at preserving chastity among girls.

## Introduction

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### The Kingdom of Swaziland – Facts and Figures

Population:	1 096 000
Capital City:	Mbabane (71 000)
Currency:	Emalangeni
Languages:	siSwati, English
Religions:	Christian, local beliefs
Land Area:	17 364.4 sq. kilometres (10 789 miles)
Regions:	Hhohho, Lubombo, Manzini and Shiselweni.

### Profile of the Epidemic in Swaziland

HIV Prevalence recorded in antenatal clinics

1992	3.9%,
1994	16.1%
1996	31.6%
1997	34.2%
2000	38.6% <sup>1</sup>
2004	42.6% <sup>2</sup>

- The first AIDS case was reported in Swaziland in 1986.
- The King declared AIDS a “national disaster” in 1999.
- Swaziland has a population of just over a million people, and about 200 000 are estimated to be HIV-positive.
- There are currently about 26 000 cases of AIDS, of whom about 50% are receiving free antiretroviral medication from the Government with support from the Global Fund<sup>3</sup>.
- It is estimated that by 2010 there may be as many as 120 000 orphans.

<sup>1</sup> NERCHA- Draft National Multisectoral HIV/AIDS Monitoring and Evaluation Systems Operation Plan.

<sup>2</sup> Ministry of Health and Social Welfare 8th HIV Sentinel Sero-Surveillance Report.

<sup>3</sup> NERCHA

The epidemic is having a catastrophic effect on the country. Few families remain unaffected and over 50% of hospital beds are occupied by AIDS patients<sup>4</sup>. When hospitals can no longer cope, patients are sent home to be cared for by family relatives and community.

The loss of economic output and the social and economic disruption caused by the epidemic is impossible to quantify with any degree of accuracy. It is estimated that the annual rate of growth in the Swazi economy fell from 2.6% in 2003 to 2.1% in 2004<sup>5</sup>. Almost 70% of the population is already living on US\$ 10 per month<sup>6</sup> and the burden of looking after the sick and dying people is driving many more people deeper into poverty.



*It's estimated there will be at least 120 000 orphans in Swaziland within the next five years*

Declining household food security is due partly to erratic weather patterns, partly to a decrease in arable land, and partly to HIV and the deaths of productive members of society. Self-sufficiency in food has declined from 60% to 40% over the past three years with little prospect of recovery in the near future<sup>7</sup>. Poverty, hunger and death combine together to have a massive impact on the lives of children and on other vulnerable members of society.

One of the most visible effects of the epidemic for households and communities has been a dramatic increase in number of orphans to approximately 69 000 today—a number that's set to rise to about 120 000 or approximately 15% of the population by 2010.

It is telling that there is no 'western' concept of orphan in Swazi culture. Traditionally a child whose parents had died would be cared for by the extended family, but now the numbers of orphans and vulnerable children are overwhelming the capacity of the extended family to cope. Elderly grandparents or relatives who are left to look after orphaned children when parents die from AIDS-related illnesses, often simply do not have the energy or means to grow enough food.

## **Why is HIV prevalence so high in Swaziland?**

There is no straightforward answer to this complex question says Derek Von Wissell, the National Director of Swaziland's National Emergency Response Council for HIV and AIDS (NERCHA). "There's no easy answer...but what I would say is that Swaziland is not unique. It's probably just ahead of the game. We may be just five or ten years ahead of other countries unless they do something drastic to slow the epidemic down."

Amongst the reasons cited for Swaziland's high infection rates are:

- a breakdown of traditional norms and values in a strongly moral society that has been buffeted by colonialism, consumerism and the throwaway culture,

<sup>4</sup> Ministry of Health and Social Welfare

<sup>5</sup> Swaziland's Ministry of Finance budget statement of 9 March 2005

<sup>6</sup> Draft Monitoring and Evaluation Plan for Swaziland OVC national Plan of Action, 2005.

<sup>7</sup> ECHO, "Humanitarian assistance to vulnerable groups in Lesotho and Swaziland affected by combined effects of drought and HIV/AIDS."

- a high degree of mobility—men go to work in the mines in South Africa to earn money; there is also easy internal mobility with people having homes in the rural areas and the towns, there is a pattern of men being able to move freely and establish relationships outside their families;
- a scientific reason for the high rates of infection: recently infected people have very high viral loads which may ensure high transmission rates, so in a polygamous society such as Swaziland, where people have many concurrent partners, infection spreads rapidly (polygamy is widely practised at all levels of Swazi society, although less common than it once was due to the expense involved; although the formal practice of polygamy is in decline, an informal network of multiple concurrent partners has often replaced it).

The situation facing Swaziland is probably set to get worse before it gets better. But recent statistics show a faint glimmer of hope, with a slight drop in the new infection rate for those aged between 15 and 20<sup>8</sup>.

## The national response to the epidemic

Since December 2001, Swaziland's national response to the epidemic has been coordinated by the National Emergency Response Council on HIV/AIDS (NERCHA). NERCHA is mandated by the Government of Swaziland to translate the National Strategic Plan for HIV/AIDS into a programme of action, and to ensure that coherent and comprehensive services for prevention, care and support, and impact mitigation are delivered to the people who need them. The Council is also responsible for monitoring and evaluating such responses and meeting the finance and administrative needs of the national response.

The National Response's work is guided by six basic principles.

1. The Response must be national—Swaziland is faced with a generalized epidemic, thus the country as a whole should be mobilized to respond effectively to AIDS.
2. The use of local solutions—solutions to the problem can only come from within the country. There are many social, economic and cultural issues that differ from country to country and each country has to find its own model.
3. It was decided not to create a new bureaucracy to deal with AIDS, but to widen and deepen existing and accepted structures that are viable if their capacity can be increased.
4. Because the epidemic is so widespread and universal, services must reach everyone in every part of the country. Equity of services and goods to all orphans throughout the country is a very important concept.
5. Community Involvement is the foundation of the country's response to the epidemic. It is extremely important for the communities not just to participate in the programmes but to own the programmes. The community must internalize the response.
6. Sustainability—whatever is done must be sustainable by the community with minimum external support.

<sup>8</sup> Ministry of Health and Social Welfare 2002, 8th HIV Sentinel Sero-Surveillance Report.

UNAIDS supports the Government of Swaziland in implementation of the “Three Ones” principles:

- One agreed AIDS action framework that provides the basis for coordinating the work of all partners
- One national AIDS coordinating authority
- One agreed monitoring and evaluation system.

Swaziland has embraced the “Three Ones” principles and is working towards their implementation. A new Strategic Plan is currently being drawn up, but unlike the first Strategic Plan, which covered a five-year period, the new Plan will run for three years from 2006–2008 in recognition of the fast changing nature of the epidemic in Swaziland and the challenges posed by changing social needs..

### **Formulating policies to care for children orphaned by AIDS**

Perhaps one of the biggest challenges facing Swaziland is how to care for the thousands of orphan children. Swaziland’s Draft National Plan of Action for Orphans and Vulnerable Children<sup>9</sup> defines an orphan or vulnerable child as someone less than 18 years of age who falls under one or more of the following categories:

- a child whose parents or guardians are incapable of caring for him or her;
- a child who is physically challenged;
- a child living alone or with poor elderly grandparents;
- children living in a poor child-headed household; or having no fixed place of abode;
- children lacking access to healthcare, education, food, clothing, psychological care and/or having no shelter to protect them from the elements;
- children who are exposed to sexual or physical abuse, including child labour.

In the past, it has often been difficult to define exactly who is an orphan or who is vulnerable, and to accurately collect data on such children. A child may be a ‘double orphan’ (i.e. both parents are dead or absent) or a single orphan (one parent dead or absent). Vulnerability is sometimes loosely defined as economically vulnerable, sometimes sexually vulnerable or at risk of exposure to HIV, abuse or exploitation. However, under the new National Action Plan for Orphans and Vulnerable Children, a Children’s Coordination Unit will be established under the Ministry of Health and Social Welfare to coordinate all interventions to protect the rights of children.

Recognizing that orphans and other vulnerable children have a right to protection, to food, to health and to education, Swaziland’s National Plan of Action for them aims primarily to achieve the following.

- Ensure that orphans and vulnerable children have access to shelter and are protected from abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.
- Ensure that vulnerable individuals and households are able to produce or acquire adequate and appropriate food to meet their short and long term nutritional needs.

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<sup>9</sup> 2005

- Provide improved access to basic health care services.
- Ensure universal primary education and support to orphans and vulnerable children in secondary schools<sup>10</sup>.

## The community response

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*“Swaziland is just like a tree. If we want things to work properly, we need to concentrate on the trunk. Then the branches will survive.”*

*Chief Siphon Shongwe, Minister of Health and Social Welfare.*

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The Kingdom of Swaziland is divided into 360 Umphakatsi or Chiefdoms, in both rural and urban areas. The Umphakatsi are the social structure closest to the people and the body that rural households will first turn to when they need assistance. In Swaziland a community is a defined area and number of households under the auspices of a Chief whose appointment is confirmed by His Majesty the King.

Many rural Swazi communities have been hit hard by the epidemic, because when people living in the city fall sick with HIV-related illnesses, they often return home to their rural communities to be cared for. In addition to undertaking the often demanding tasks of caring for those infected with HIV, the community is also left to look after orphans when parents die. “People here are dying in big numbers. It’s something that’s not been seen before in this country,” says James Xaba an elder in Mambatfweni community. When his own daughter died it had such a big impact on his family, he says. Her four children came to live with him temporarily until their father, who was working in South Africa, could care for them, but he never came. James lives with a disability and finds it difficult to look after his grandchildren.

To begin with, people like James struggled on their own but it soon became obvious that the community would have to work together in order to look after the sick and dying, and to feed all the orphans and vulnerable children. Many community initiatives started with individuals helping to feed the orphans around them, because they could see the scale of the problems and felt moved to try to do something about it. Now the Government, supported by partners and agencies, has moved to formalize and support some of these initiatives.

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*“The way to get things done is to go to the people”*

*Prince Masitsela, Regional Administrator of Manzini Region*

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This report focuses on community responses in two communities in different parts of the country. It considers how six different innovative community initiatives have evolved and been strengthened through support from Government and other partners and it documents their successes and challenges.

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<sup>10</sup>Draft monitoring and evaluation plan for Swaziland OVC National Plan of Action

## A tale of two communities



### Mambatfweni, Manzini region

Mambatfweni is a large community, in the heart of maize growing country, about an hour and a half's drive south west of the Mbabane-Manzini corridor. The road follows the Ngwempisi River, which is almost dry in places now and the landscape is one of rolling hills and forest, dotted with scattered homesteads. There are about four thousand homesteads in the community and on average six to seven people living in each household<sup>11</sup>.



View of Mambatfweni

Fairly large fields surround each household, lying fallow at the end of September, waiting to be ploughed in preparation for the planting season. Farming here is mostly mechanized, and relies on either privately owned tractors or machinery hired from the Ministry of Agriculture and Cooperatives Extension Office in the local settlement of Mahlangatsha, where the community's nearest clinic, shop and police post are also to be found.

<sup>11</sup> According to John Ntlalintjali, Mambatfweni Council of Elders.

Drought is not so much of a problem here as it is in Mambane and other parts of the country, although the area is prone to severe hailstorms that damage the crops. The farmers also complain that because cultivation is so mechanized, the inputs (seeds, fertilizers etc) are very expensive.

Princess Ncoyi has been Mambatfweni's Acting Chief for five years<sup>12</sup>. She was born in the community, but since her marriage, she has moved to another community in the Manzini Region. Despite her absence much of the time, she's been a driving force behind the mobilization of Mambatfweni. She has been known to do manual work in the Indlunkhulu fields herself to demonstrate through her leadership that the community needs to work together all of the time.

### **Mambane Community, Lubombo region**

Mambane community is one of the most remote, poorest and driest parts of Swaziland and has been badly hit by recurrent drought in recent years. The road to the community runs along the ridge of the Lubombo Mountains, looking down on the verdant green of the sugar plantations in the lowveld on the right. On the left, beyond the mountains, lies Mozambique. During the civil war in Mozambique this area played host to thousands of refugees from across the border.

Chief Mvimbi Matse's appointment was confirmed by the King about seven years ago. He estimates that Mambane has about 875 households, with an average of about 10 people per household. The number of orphans and vulnerable children has doubled here in the last three years, from 260 in 2002-2003, to 675 in 2004-2005. He estimates that by 2010 there could be between 1000 and 1250 orphans in the community.

Chief Mvimbi Matse says that HIV is a serious problem in Mambane and that he's trying to encourage people to check their status. He attended a workshop for Chiefs in the year 2000, which tried to create awareness, but regrets that often when he calls community meetings, few people come.

The Chief has recently appointed a new Indvuna (Chief's Assistant) and Badlancane (Governing Council). The Council members say their workload has increased with accelerating poverty and hunger and the growing number of people who are sick and dying.

The community is suffering the fifth consecutive year of acute drought and there is no water. Food shortages are becoming more serious by the day and a growing number of people are coming to the Umphakatsi asking for the Chief's assistance.

With the deepening drought, a high proportion of households are forced to draw water from unprotected and unclean sources. Only 36.5% of households have piped water; 6% get their water from dams, 21.6% from rivers, 28.1% from springs, 3.8 % from wells and 2.4% from 'other sources'. Over half of the households do not have access to sanitation and many people are well outside the Government's stated aim of having health services within a 10-kilometre radius<sup>13</sup>.

<sup>12</sup>She will stay in the position until the young boy that has been appointed by the King is old enough to take over.

<sup>13</sup>S.P. Kunene, Ministry of Health and Social Welfare, Malaria Unit.

## Neighbourhood Care Points

***Neighbourhood Care Points (NCPs) have been established to provide day-to-day support to orphaned and vulnerable children, and enable them to be cared for in the community.***

Swaziland's preferred policy is that orphaned and vulnerable children should be cared for in their communities, since institutional care is both anathema to Swazi customs, and would, in any case, be too expensive given the numbers involved. As a result an extensive network of Neighbourhood Care Points (NCPs) have been established in many communities.

At each Neighbourhood Care Point, a group of caring people (who are volunteers but chieftom approved) provide a place where vulnerable children can come every day for a hot meal, have opportunities to play with other children, and get non-formal education and psycho-social support. There are currently about 415 Neighbourhood Care Points in Swaziland, with over 33 000 children registered in them.

Mambatfweni has 13 Neighbourhood Care Points within the community, and the Manzini region as a whole is fairly well serviced by a network of centres. Lubombo region, by contrast, has approximately 220 Neighbourhood Care Points in 31 communities but Mambane currently only has one functioning centre, based at the KaGogo centre.

The initial impetus for the Neighbourhood Care Points came from individuals within the community and was community driven. The initiative started in the Hhohho region where some women realized the scale of the orphan problem around them and started looking after children in their own homes or under a tree, contributing food from their own households. "There are a lot of women in the communities who are motivated from the heart to support the children in the community. Yes they are facing a lot of challenges, but despite all these challenges, a lot of them will still wake up and make sure they provide for the children," says Thembi Gama, NERCHA's National Coordinator for Impact Mitigation.

A group of women in the Mambatfweni community came together to discuss the growing numbers of orphans in the area, and decided to try and set up a project to support them. In September 2003, they were informed that NERCHA could supply maize to feed the children and they received 80 bags of maize and some water tanks. The women were responsible for deciding how the maize should be distributed and initially gave rations to children to take home, but they soon realized that the rations were sometimes not reaching younger children in child-headed households and that many of the children were starving. As a result, they decided they should cook food for the children at a central point, so that the children would have a hot meal, this was especially important for children living with grandparents who could not cook for them. Providing a hot meal also had the social benefit that children could come together to eat. Other people in the community would contribute vegetables or sugar or whatever they had to spare. The elderly and people taking antiretroviral drugs are also given some food by Neighbourhood Care Points.

Rose Mdluli, a volunteer Care Worker at Gugwini Neighbourhood Care Point, says that the women had heard about Care Points that had been established in the Hhohho region and they asked for training from the Deputy Prime Minister's Office. After receiving training, they decided to establish a Care Point in one of the women's household; this was eventually moved to a central venue because of the growing number of children. They received some

building materials and two large cooking pots from UNICEF. The community came together to build a simple mud hut with a corrugated iron roof that would serve as the Neighbourhood Care Point.

UNICEF noticed this activity, and helped people to mobilize and scale up what they were doing. “The idea was to create a Point close to the children,” says Pelucy Ntambirweki, UNICEF’s Programme Coordinator. A massive mobilization campaign then started around the issue, coordinated by the Deputy Prime Minister’s Office, which became the office responsible for rolling out and establishing Neighbourhood Care Points in communities throughout the country. Meetings were called with Chiefs, local leaders and women to work together and share experiences<sup>14</sup>. Care Workers were trained to understand the trauma the children go through when they lose a parent. They were shown how to care for the children, how to keep them clean, how to prepare food for them and to teach the children how to look after themselves.

Volunteer Care Workers from Mambatfweni also travelled to the Hhohho region to see the work there for themselves. They were particularly impressed by the kitchen gardens they saw, providing vegetables for the Neighbourhood Care Points, and decided they wanted to establish gardens in Mambatfweni too. The Moya Centre (a local nongovernmental organization) using funds from Swaziland Post and Telecommunications Corporation helped them fence the gardens to keep goats and chickens from eating the crops; each child was given their own plot to grow vegetables. Most Neighbourhood Care Points in Mambatfweni have now estab-



*Children have been given their own plots to grow vegetables*

lished vegetable gardens, or expanded those that existed before, and these gardens serve the dual purposes of providing additional food for the Care Points, and teaching the children how to grow their own food. Many children whose parents had died had nobody to show them how to cultivate crops. Each child is given their own plot and expected to come everyday to water the vegetables—a task they do with notable enthusiasm, proud of the food that they grow for themselves.

There are currently about 1500 volunteers looking after 33 000 children in more than 415 Neighbourhood Care Points throughout the country. Volunteers are selected by committees that have been established within the communities. The work is done on a rota basis, but because volunteers receive no payment for the work they do, it can sometimes be a struggle. Many of the care workers are themselves poor, needy or sick, and often have orphans to care for at home as well. At a community meeting of care workers in Mambatfweni, more than half of the women present had lost family members to AIDS in their own households, and most were also caring for orphans at home in addition to their own children.

<sup>14</sup>Funding was obtained from the European Commission Directorate General for Humanitarian Aid (ECHO) to support the initiative in two regions, and this provided training for caregivers.

Initially UNICEF supplied the community with cooking pots and food. Eventually the communities supplied the food or it was grown in the vegetable gardens. But with successive years of drought it became clear that many communities needed more support to sustain the initiative. Many needed supplementary supplies of food from the National Disaster Task Force under the Deputy Prime Minister's Office. Others needed clothing for children who had little or nothing.

The Neighbourhood Care Points also needed water and sanitation, and ECHO (European Community Humanitarian Aid) funding provided for the provision of water tanks and gutters, which UNICEF distributed. It also provided for the construction of pit latrines. All the construction work was done by the communities themselves, with technical support from the Deputy Prime Minister's Office and partners.

Coordinating Committees at Chiefdom-level are responsible for identifying orphans, drawing up a list of those needing assistance and giving the list the stamp of authority. But in poor areas experiencing drought and food shortages, it can be hard to determine who qualifies for help: suddenly everyone is an orphan.

Vester Simelane, a Care Worker with Susane Neighbourhood Care Point in Mambatfweni, says care workers live in the community and they know who the orphans are. If a parent dies, after the funeral the care workers will discuss with the family whether a child should be looked after at the Neighbourhood Care Point. "There are so many funerals," she says. "The numbers of funerals are increasing, especially of young girls who leave young children with their grandmothers when they die. When that happens, you find the grandmother is quite old and is unable to feed the children or to go to the fields to grow some food, so that's why the care point became very important."

## **Neighbourhood Care Points as early childhood development centres**

Neighbourhood Care Points have changed and adapted with time and are now becoming more like early childhood development centres. The age range of children at most care points is from six years upwards; many of these children have never been to school. In the early days of Neighbourhood Care Points it soon became clear that there was an urgent need for informal education, so that the children could then be integrated into mainstream education. UNICEF provided literate caregivers with a "School in a Box" kit, which contains wall charts, alphabets, books, pens, pencils, rubbers and a ball. "This was a major breakthrough," says Pelucy Ntambirweki, UNICEF's Programme Coordinator. "Suddenly more kids came to the NCP, not just because they were hungry but because they wanted education. The NCPs made the vulnerable visible. The statistics now had a face and challenged the Government to do something about it."

## **Linking the Neighbourhood Care Points to Mainstream Education**

Neighbourhood Care Points have highlighted the numbers of children who currently fall outside the formal education system, and are an effective means of directing children into school education.

In December 2004, the Government announced it would give bursaries for orphans to attend school, and now pays E 400 (approximately US\$ 60) per child directly to schools. School enrolment has gone up dramatically as a result. The number of children from Neighbourhood Care Points attending formal school had reached 1258 by June 2005<sup>15</sup>. Caregivers are now also

able to challenge head teachers about why a child is not attending school. The constitution of Swaziland mentions the need to provide free education at primary level.

The Ministry of Education anticipates another huge increase in pupil numbers once the planned policy of universal primary education is implemented in 2006, in accord with the Millennium Development Goal targets. Swaziland is trying to phase in the policy gradually so as to avoid overwhelming the educational system. Expansion of teacher training is already underway, but the double problem of the 'brain drain' and teachers themselves falling sick and dying of AIDS-related illnesses continues to undermine efforts to expand teaching capacity.

The challenges faced by schools are very different from those they faced ten or 15 years ago, and the school curriculum is being adapted to reflect those challenges. Agriculture, for example, although already part of the school curriculum, becomes even more important in a situation where children have nobody at home to pass on to them the knowledge they need to grow food for survival<sup>16</sup>.

Feeding schemes have been established in many schools to ensure that orphans and vulnerable children get at least one meal a day; the Ministry of Education would like to see two meals a day being provided.

### **Feeding vulnerable children**

By far the biggest need at the Neighbourhood Care Points is food, and this need is becoming more and more critical as the impact of five years' of successive drought is hitting communities. World Food Programme (WFP) is committed to supporting the Care Points and the volunteers who run them by providing 'food for work' rations for about four carers at each Care Point. Each ration is enough to feed five people so that the care workers can also feed their own families. WFP has been trying to get a minimum package for these centres and schools, and to determine what they need. CANGO, a consortium of local nongovernmental organizations, has also been working with Neighbourhood Care Points through the national Food Security Consortium, assisting in food distribution for vulnerable populations.

Such efforts are aimed at strengthening and supporting Neighbourhood Care Points in vulnerable communities such as Mambane. In the Lubombo region, 99% of Neighbourhood Care Points are entirely dependent on food distribution, because the communities are struggling to feed themselves, let alone the vulnerable. When food is not available Neighbourhood Care Points cannot function.

### **Making the vulnerable visible**

Each Neighbourhood Care Point is tasked with keeping a register of children; this helps to capture key information about orphaned and vulnerable children in areas where little or no data existed before. Better information has enabled Government and donors to target assistance and shape programmes where they are needed most.

"The NCPs have been a beautiful entry point for service provision. Services can now be taken from national and regional levels to the community," says Pelucy Ntambirweki

<sup>15</sup>DPM's office: Child Protection network meeting minutes, June 2005.

<sup>16</sup>The Government is receiving support from UNESCO to adapt the curriculum. The EU has also provided funding of €20 million to the Government of Swaziland for a programme addressing: basic education (access equality etc.); early childhood education; special needs of disabled children; and skills development and technical skills.

of UNICEF. For example, many children did not have the birth certificates and documentation necessary to enrol in school and get access to Government education bursaries. Now these are issued in the community and, as a result, there has been a significant increase in the number of children eligible to receive bursaries. Similar efforts are now being made with marriage and death certificates.

Neighbourhood Care Points have also created an entry point for other partners and initiatives such as WFP's food distribution programme, FAO's assistance with vegetable gardens and UNAIDS supported care and prevention programmes for HIV.

Some children attending Neighbourhood Care Points have serious health issues and some are also HIV-positive. In many communities there are now plans for outreach health services to be taken to the Care Points rather than children having to go to clinics, which can be some distance away and difficult to reach. "The NCP's make our work easier because the children are now together," says Andreas Zwane, the clinic nurse at Mahlangatsha, the nearest health services for the people in Mambatfweni.

### **Bringing the community together**

Neighbourhood Care Points have also brought together communities in other ways; some have also established adult literacy classes<sup>17</sup> that meet in the afternoon. Others have established income-generating projects and credit schemes to buy things such as salt and cooking oil, or to buy school uniforms and other necessities for orphans. Often, the women meet in and around the Neighbourhood Care Points in the afternoons, and the Care Points have become a focal point in the community.

Care givers from the 13 Neighbourhood Care Points in Mambatfweni have also, with assistance from Government, nongovernmental organizations and partners, set up a credit and savings scheme. They have been taught how to organize the groups and manage the money; there are currently 120 members in four savings groups. The joining fee is (Swaziland currency Emalangeni) E10 (approximately US\$ 1.48) and each member subsequently contributes E10 a month or more. They are then able to borrow money from the group to fund income-generating projects; they pay back the initial loan with 20% interest. The savings schemes have proved very popular with the women and they look forward to receiving their dividends at the end of the year.

### **Visit to Ngumane Neighbourhood Care Point**

Wearing a broad rimmed straw hat and a bright blue overall, Hlobsile Shabangu is stirring maize porridge in enormous black pots outside the simple mud hut that serves as the Ngumane Neighbourhood Care Point. As she straightens her back to wipe the smoke from her eyes, she looks down from the hill to stunning views of the valley below.

This Care Point, one of 13 in Mambatfweni, was established by Hlobsile and three of her neighbours in July 2004 and now feeds 53 children from 11 homesteads daily. To begin with they provided the food themselves and when they didn't have enough they asked other neighbours to help. She says many of the children who go to school come back hungry because they have had nothing to eat all day. The volunteers cook for the children five days of the week, but there's nothing at the weekend.

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<sup>17</sup>with help from Sabenta, a Swazi nongovernmental organization.

“It was not that easy”, says Hlobisile “but it became easier when neighbours started helping with the feeding. The children feel good when they eat together. When they come and don’t find food, they really feel very bad and go back very sad.”

Behind the hut is a small fenced garden where the children are proudly watering the vegetables they grow to eat. There are carrots, lettuce, cabbage and beetroot; Hlobisile says they grow enough to sell some vegetables so that they can buy matches, salt and new seedlings. The garden is funded by Swaziland Posts and Telecommunications Corporation (SPTC). Water for irrigation comes from a nearby stream and is piped to a tank, constructed for them by the Ministry of Agriculture and Co-operatives, so irrigation is not the problem here that it is in many other parts of the country.

Ngumane Neighbourhood Care Point is now assisted by UNICEF and ECHO funding, and the care workers have received corrugated iron, clothing for the children, a “School in a Box” kit, and some food.

## Neighbourhood Care Points in the cities

Neighbourhood Care Points are not just a rural phenomenon; they have also been established in urban areas. At Gigi’s kitchen on the outskirts of Manzini, mealie porridge and beans and fresh oranges are distributed to the children every day and schooling is also provided there.

## Neighbourhood Care Points incorporated in the second National Multisectoral Strategic Plan for AIDS

Swaziland is currently drafting a new National Strategic Plan for AIDS for the next three years<sup>18</sup>; Neighbourhood Care Points are going to be key resources in the national response. The National Plan of Action for Orphans and Vulnerable Children also envisages Neighbourhood Care Points as an important structure for providing care. They will also play a crucial role in the Government’s planned policy of decentralizing services to community level, which is due to be implemented soon.

## Challenges

There is no doubt that the Neighbourhood Care Points are working hard and meeting many real needs in many communities, but clearly they face many challenges as well.

- There are currently about 415 Neighbourhood Care Points in Swaziland, with over 33 000 children registered in them. By 2010, it is estimated there may be 120 000 orphans and vulnerable children in Swaziland. Ninety more Neighbourhood Care Points are currently planned; most of them in Lubombo region, but these alone will not be enough to cope with a trebling of the numbers of orphans in need of care.
- The Neighbourhood Care Points give valuable assistance to vulnerable children, who need help, but it also sets them apart and in some communities this accentuates stigma.
- Orphans and vulnerable children have sometimes been taken in by other families or relatives, and the distinction between a child who can attend a Neighbourhood Care Point and the other children in the homestead who cannot attend can be problematic.

<sup>18</sup>In contrast to the five-year period which the previous Plan covered

- Access is not always possible: some vulnerable children are excluded from the Neighbourhood Care Points because they don't meet the criteria set by the community or may live too far away from the care point to walk there every day.
- Food delivery at many Neighbourhood Care Points is irregular and insufficient; these difficulties are exacerbated in times of drought and shortage, when everybody is suffering and there's no spare food to give the vulnerable.
- The Neighbourhood Care Points are dependent on volunteers. They have big hearts but many also have problems in their own families. Sometimes they are sick themselves, and with the deepening drought and food shortages, there's often little spare food or energy left for the orphans. UNICEF hopes that money may be made available through the Global Fund to help fund the caregivers. WFP is providing food for work/training (not just for the volunteers but their families) and it hopes that this would also help with incentives. The hope is that ultimately the Government will take this up and, with funds from the Global Fund, be able to provide a "dollar a day" for the services, time, and generosity of volunteers.
- Neighbourhood Care Points started as a response to try and help destitute children, but have become permanent institutions even though they cannot provide adequate schooling facilities.
- The informal and voluntary nature of Neighbourhood Care Points' origins persists in many cases. This can result in a lack of integration of children into the established and formal educational services. Monitoring of some Neighbourhood Care Points activities might help encourage them to link more closely and consistently with existing service provision.
- Training of caregivers can be expensive and needs constant renewal since there is high turnover due to lack of incentives.

### **Summary of achievements**

- Above all, the Neighbourhood Care Points have made orphans and vulnerable children visible within the communities in which they live, and brought people together to find solutions to the challenges they face.
- Neighbourhood Care Points have given communities a sense of empowerment and hope for the future.
- Neighbourhood Care Points provide a cost-effective, stable and caring structure for children who otherwise would have nothing, enabling them to come together daily with other children in a safe environment to eat, learn and play.
- Neighbourhood Care Points have become channels for non-formal and formal education and prepare children for schools.
- In times of drought and food shortages, Neighbourhood Care Points enable emergency food to be distributed to needy children effectively and efficiently. Children are also being taught how to grow food for themselves and reduce dependency on others.
- Neighbourhood Care Points have influenced national policies and provision of services, providing a focal point for support to communities.

## Indlunkhulu Fields

***The reinvigoration of Indlunkhulu fields, a traditional practice that had largely lapsed, whereby a Chief allocates land for the community to grow food for vulnerable members in the chiefdom, has been another innovative community response to the situation in Swaziland.***

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*"I believe the orphans of my area should be looked after by the people of that community, and not somebody else. We cannot say we are helping them if we are uprooting them to somewhere else.... I am against institutional care of kids on principle. Even if the parents have passed away they still have a resource in the land—we can sustain these kids of ours in the community, using community resources and land. I strongly believe that as a community, we can solve most of the problems, provided we are given the financial support."*

*Chief Siphon Shongwe, Minister of Health and Social Welfare*

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In late September, Swaziland is enveloped in a haze of smoke as fields are burnt to clear the way for the new planting season. The rains usually start in October, but for the past five years, erratic rainfall, combined with the devastating impact of HIV on productivity, have left a growing number of people unable to grow sufficient food.

It's estimated that Swaziland needs 142 000 tonnes of food annually to feed itself, but it is anticipated that only 80 000 tonnes of maize will be available in 2005<sup>19</sup>. Some 200 000 people (almost one fifth of the population), mostly in the dryer lowveld of the east and south, are facing problems of food security. In the past, drought-prone areas or those growing other cash crops such as sugar were able to buy maize from highveld, but now the whole country is facing severe shortages, and in some regions there's a serious threat of starvation.

Traditionally, any stranger to the community or person in need would go to the Imphakatsi or chiefdom to be fed and accommodated, but in modern times this tradition had largely died away. The growing numbers of orphans and destitute children, combined with the desire to keep these children in the community, has led to the revival of the traditional practice of Indlunkhulu fields.

In Swaziland, all land is owned by the King, and the chiefs act as custodians of the land on behalf of the people. A Chief is regarded as the father of his people so if the head of a family has died, Swazi custom dictates that the children have to be looked after by the Chief. According to Swazi culture, whoever has plenty is bound by custom to send something to Indlunkhulu. The fields are ploughed and harvested by the community and the crops are used to feed people who seek help from the Chief.

The concept of Indlunkhulu not only provides additional food for the needy, it also revives the practice of people working together and helping each other, and it could become a conduit for better practices in agriculture, by introducing new methods and seeds to people.

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<sup>19</sup>Ministry of Agriculture and Cooperatives



*NERCHA has provided silos for communities to store food from Indlunkhulu fields*

The reinvigoration of Indlunkhulu fields programme started in 2002, and NERCHA facilitated a process of consultation with traditional leaders and the Ministry of Agriculture and helped to mobilize the communities. In the first year NERCHA and the Ministry of Agriculture and Cooperatives anticipated working with 100 chiefdoms, but the response from the communities was so positive, almost twice as many wanted to participate. Now about 350 chiefdoms are working under the programme, 320 of them in rural areas and the rest, working through AMICAALL<sup>20</sup>, in urban areas. NERCHA also provided

funds for Ministry of Agriculture and Cooperatives to procure silos for communities to store food from Indlunkhulu to be distributed to needy members of the community.

### **Mambatfweni's experiences**

Mambatfweni was one of the first communities in the country to rekindle the concept of Indlunkhulu fields, with the Chief allocating land for the first fields in 2002. The community has wholeheartedly embraced the concept and, as previously mentioned, the Chief has been instrumental in reviving the concept of Indlunkhulu, often taking part in the cultivation of the fields herself to set an example through her leadership.

To begin with yields from Mambatfweni's Indlunkhulu fields were good, with about forty 50-kilogram bags of maize being produced in the first year. "It was enough in 2000 because the orphans were not very many," says John Ntjalintjali, a member of the Inner Council. "But now it is not enough because the numbers are growing daily. So the community is in serious trouble this year." In 2005, the Indlunkhulu fields only produced two bags of maize and the community as a whole is suffering, he says.

The food shortages in Mambatfweni have been caused not so much by drought as by adverse weather conditions and heavy hailstorms that damaged crops. Late arrival of seeds and fertilisers also caused problems in 2004-2005, and there were no contingency plans for the anticipated shortages in 2005-2006. These problems have been reported to the Ministry of Agriculture and Cooperatives and the community is hoping for further assistance from NERCHA and other partners in order to supplement and sustain the initiative. The Inner Council has also requested more land from the Chief to grow food for the growing numbers of orphans, and at the time of writing this document they were awaiting a response.

Mambatfweni's Acting Chief, Princess Ncoyi, says community initiatives such as the Neighbourhood Care Points and Indlunkhulu fields have been very important in enabling the community to look after the 430 orphans and vulnerable children in the area. She says the

<sup>20</sup>Alliance of Mayors' Initiative for Community Action on AIDS at the local level.

community now needs support to make these initiatives work better and to ensure that the mobilization is a continuous process, adding, “People get fatigued because they have their own problems.”

### **Mambane’s experience**

In Mambane, the community is suffering more acutely from the effects of the drought. Food shortages are becoming more serious by the day and more and more people are coming to the Umphakatsi asking for assistance. The Chief has allocated land for one Indlunkhulu field but the yields have so far been poor and completely inadequate to meet the needs of the community.

### **Challenges**

- The biggest challenge to the Indlunkhulu fields programme is that of deepening drought. Many communities such as Mambane have no water for irrigation of individual or communal fields, and when everyone is hungry, there’s simply no capacity to make special provision for orphans and vulnerable children. The situation is critical in that there is no drinking water in these areas, and although NERCHA through the Global Fund has provided tanks for each Umphakatsi, it is a challenge to provide adequate and regular supplies of water to communities.
- The success of the Indlunkhulu fields also depends on receiving inputs such as seed and fertiliser on time, and tractors being available to plough the land. Without these the community cannot cultivate the Indlunkhulu fields.
- The success or failure of initiatives such as reviving Indlunkhulu fields is largely dependent on leadership from Chiefs. Some Umphakatsi do not currently have an appointed Chief. Another problem sometimes encountered is Chiefs not often resident in the community, making it difficult for them to provide consistent leadership.

### **Summary of achievements**

- The reinvigoration of the practice of Indlunkhulu fields providing food for the needy has also revived the practice of people working together and helping each other in time of need.
- The concept of Indlunkhulu fields enables communities to be more self-reliant instead of depending on outside help, and as a result gives them a sense of ownership and commitment to assisting those in need.
- Working together as a community to grow the crops and involving children who are beneficiaries in the process transfers agricultural skills and knowledge to those whose parents have died.
- Community participation in the distribution of the crops grown ensures that the process is transparent and trusted, and that the food goes to those identified by the communities themselves as requiring assistance.
- With effective support from Agricultural Extension Officers, Indlunkhulu fields can become a conduit for better practices in agriculture, by introducing new methods and seeds to people.

## KaGogo Social Centres

***KaGogo social centres (or grandmother's houses) have been built in each community to provide services and coordinate the response to the growing numbers of orphans and vulnerable children. They are new initiatives based on a revival of traditional ways.***

Traditionally the role of the Chief has been as caretaker to the people, looking after their welfare, but in recent times many of these duties and customs had largely died out. Now the traditional practices are being revived to strengthen the community's ability to cope with the impact of AIDS epidemic. The KaGogo centres and Indlunkhulu fields are therefore new initiatives based on traditional ways.



*The new KaGogo centre at Mambatfweni*

KaGogo social centres (literally grandmother's house) have traditionally been a part of every homestead and are a place of refuge or a neutral place for discussing family matters and resolving disputes. Now they are being revived as a way of mobilizing and empowering communities in the response to HIV. KaGogo social centres are located in each chiefdom, near the Chief's Umphakatsi, and serve as a nucleus for impact mitigation, prevention and care and support efforts and are being used to revive old traditions of psychosocial support.

All the KaGogo social centres have been built by the communities themselves who provided labour and local materials. NERCHA and the Global Fund provided financial and technical contributions. The estimated cost of each centre is US\$ 10 000.

Construction of the centres began in 2003 and the KaGogo programme has made a massive amount of progress in a very short time. So far 50% of the centres have been completed nation-wide, and a further 30% have been constructed up to roof level. Some KaGogo social centres were constructed in less than two months. Participation and ownership of KaGogo social centres by community members was a key element in their success. Mobilization brought all the players on board and working as a team. Communities have been enthusiastic about the centres, because it was a familiar concept, and they understood why the KaGogo social centres needed to be revived in the era of AIDS.

Clearing the sites for the construction and access roads was sometimes a problem for communities, but the Land Development Unit under the Ministry of Agriculture and Cooperatives went as far as diverting machinery from other projects to assist them. Water was another issue and the Ministry of Public Works and Transport assisted.

With the deepening drought and food crisis, NERCHA is coordinating efforts to distribute emergency food through the KaGogo social centres. The food is stored at the centres and community coordination committees oversee the distribution. The communities themselves select these coordinating committees, use the KaGogo social centres for meetings and are tasked with collating basic data about orphans and destitute children.

It is envisaged that the community KaGogo social centres will eventually be able to provide other essential services for orphaned and vulnerable children, whilst enabling them to continue living in the community they belong in. For example, the KaGogo social centres can be used for pre-schooling and non-formal schooling, both for children and adults. However, although the Government is keen that KaGogo social centres should be expanded as centres for non-formal schooling, it is not envisaged that they should become an end in themselves. Instead they will prepare children for school and channel them into mainstream education.

### **Mambatfweni's KaGogo social centre**

The KaGogo social centre in Mambatfweni was one of the first to be completed in the country. It is solidly built out of local stone and has a neat, thatched roof and a large, airy veranda where meetings are held. There is a cooking area to the back, and four small offices and a filing cabinet for storing data collected on orphans and vulnerable children and others who are needy in the community.

The KaGogo centre is used frequently for community coordinating meetings to manage Mambatfweni's response to the epidemic, coordinate the activities of the Neighbourhood Care Points, select caregivers and Rural Health Motivators volunteers, and to oversee the distribution of food assistance. It is situated in a central location within the community and a grain storage tank has been placed next to it for crops from the Indlunkhulu fields.

### **Mambane's KaGogo Social Centre**

Mambane's KaGogo centre is built in the same basic design as the one in Mambatfweni and doubles up as the Neighbourhood Care Point—the only one in the community. Under the thatched veranda about 40 children are sitting on plastic chairs doing sums in shared, well-thumbed maths sheets. The children range in age from seven to 17 years. They are provided with two meals of maize porridge and bean soup a day, that is, mid morning snack and lunch, with support from WFP.

Lungile Matse is one of the volunteer teachers and a caregiver at the Neighbourhood Care Point. Recently widowed, and with five children of her own to care for, she still finds time to come to the Care Point every morning, five days a week. There were 89 children registered at this Neighbourhood Care Point, but now they have 83 because six have already gone to school. The rest—although of school age—get their only lessons here. Lungile and the other volunteers have received some training, and they teach maths, siSwati and English using work sheets and books provided by UNICEF. The education they provide here is supposed to be for children of primary school age who haven't had the chance to go to school, but several of the children attending are older.

A chart on the wall shows that 18 of the children have no parents or are 'double orphans'. Twenty-three have only one parent and 42 are classified as 'vulnerable'. The community coordination committee decides who should come to the Neighbourhood Care Point and the carers say that a lot more would like to come but live too far away or are too young.



WFP provides food

Mambane is divided into seven areas, and the community would like to see a minimum of seven Neighbourhood Care Points being set up so that children don't have to walk such long distances for food, but for the moment this is the only Care Point they have.

WFP has provided all the food to the Mambane Neighbourhood Care Point since July 2005. "Other hungry children come here looking for food" says Busisiwe Mazibuko, another of the caregivers. "But we only have enough to give the children here. It's very hard to turn the other children away but we can't

feed more." She says they have been trying to grow vegetables for the Care Point, but water is scarce and they don't have enough seeds.

Busisiwe has two children of her own and is looking after her neighbour's four orphaned children as well. Her children are at school but the orphans do not go to school. Although the Government pays the fees for orphans and vulnerable children, she says the money is not enough. The school charges E 500<sup>21</sup> (about US\$ 76) but the Government bursary pays only E 400, so children who cannot pay the difference are sometimes excluded.

More than 30% of the children in the Lubombo region are currently not receiving any education<sup>22</sup>. The introduction of free universal primary education, which the Government is hoping to implement nation-wide in 2006, will therefore be a huge challenge. Teachers already have classes of 70 or more pupils and there are concerns that the quality of education will be further compromised by an influx of new pupils. There is also a shortage of teachers and many are sick and unable to work properly.

Mambane's primary school is only a few hundred yards down the road from the KaGogo social centre and Neighbourhood Care Point and is also a recipient of WFP food. It cooks two meals a day for the children. Water is scarce here; the only source is a blue tank of rainwater that is kept under lock and key most of the time.

Acting Head Mistress Thembisile Nxumalo keeps a chart on her wall, which shows that out of the 416 children enrolled at the school, 253—over half—are classified as orphans or vulnerable children: thirty three children are double orphans, 103 have only a single parent and 117 are classed as 'destitute'.

The school committee, composed of the Inner Council of umphakatsi members and the Inkhundla Development Officer, decide which children should be classified as destitute. The committee meets once a year and there are so many cases to be considered, it usually takes them a week to get through them all. "It's a huge challenge" says Thembisile Nxumalo. "Many of the children have performance difficulties because they are hungry and have problems at home."

<sup>21</sup>Swazi Lilangeni

<sup>22</sup>Lubombo Region Education Office

The school has now set up a health club to teach children how to protect themselves from HIV and to try to raise awareness.

## Challenges

- The community-based responses to HIV, such as Neighbourhood Care Points and KaGogo social centres are largely dependent on the office of the Chief. As part of the Government's proposed decentralization policy to be implemented in 2006, there is a provision for an official Clerk to be appointed to build capacity for the communities at the KaGogo social centres<sup>23</sup>, but limitations of human capacity may prevent local initiatives making optimal progress.
- Communities who have a resident Chief seem to be making more progress than communities with non-resident chiefs or without a Chief at all. The process of appointing a Chief may take quite some time and this appears to be something of a continuing problem in the Manzini region.
- The KaGogo social centres are intended for the use of the whole community, but if they are used to house Neighbourhood Care Points, as is the case in Mambane, this restricts the use of the centre for other activities and meetings.

## Summary of achievements

- The KaGogo social centres have made enormous progress in a short time, with construction taking place across the country.
- KaGogo social centres provide a formal and physical centre for coordinating community initiatives and a forum for discussions and meetings about how to respond to the epidemic's impact.
- Communities have enthusiastically embraced KaGogo social centres. Because the communities have provided the labour and much of the materials for the construction of the KaGogo social centres, they feel a sense of pride and ownership in the building and how it is used.
- The centres are responsible for collecting basic data about the orphans and vulnerable children within the community, and this is helping to shape national policies and responses to AIDS.
- The KaGogo social centres can provide an entry point for other services, such as community outreach and food distribution (both from the Indlunkhulu fields and emergency food distribution in times of drought).
- The KaGogo social centres are also now regarded as the coordinating centre of community interventions such as the Neighbourhood Care Points and are expected to keep data on orphans and other vulnerable people in the community. There are also plans to deliver other services at the decentralized level, using the KaGogo social centres as a gateway.

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<sup>23</sup>NERCHA is hoping that further funding will become available through the Global Fund to enable one person to be at the KaGogo social centre on a daily basis so that service delivery can really get started.

## **Community-based initiatives for People Living with HIV**

*Innovative community-based initiatives have been put in place to provide services and support to people living with HIV*

### **Peer support, counselling and home-based care**

In Swaziland, as in many other African countries, the increasing numbers of terminally ill people challenges the provision for hospice care. Traditionally, the extended family would care for anyone needing assistance, but since the advent of AIDS, families are no longer able to cope alone. Institutionalized hospices would be both expensive and an anathema within Swazi culture, so some communities have established systems for peer support, counselling, and home-based care for people living with HIV.

The counsellors and carers are all volunteers selected by the community, and are allocated a certain number of households to visit on a regular basis, to provide care and support, report any specific problems back to community health workers and umphakatsi.

In some cases ‘backyard gardens’ have been established with the support of FAO, where vulnerable households are given a small plot of land to enable them to grow vegetables and assist with basic nutrition.

### **Rural Health Motivators**

Rural Health Motivators are volunteers who are selected by the community coordination committee to deal with all health issues, not just those related to HIV. They have existed for many years, but their role and responsibilities have increased enormously as a result of the AIDS crisis, and goes far beyond the role originally envisaged by the Government.

There are currently 4500 Rural Health Motivators throughout the country. They are equipped with a basic first aid kit and are expected to make home visits and care for sick people, take them to hospital when necessary and make sure they take their medicines at home. If there are problems in the community they report back to the nurses at the clinic and get advice on how to deal with problem situations. They offer HIV counselling and show people how to care for patients. They also prepare food for them and administer DOTS<sup>24</sup> treatment for patients with tuberculosis and directly observe the drugs being taken for six months.

Galina Simelane is one of 30 Rural Health Motivators in Mambatfweni. She says they were chosen for their ability and character to care for the sick and dying at home. They receive a small allowance of 100 Emalangeni or approximately US\$ 15 a month for their work (unlike the caregivers at the Neighbourhood Care Points who are entirely voluntary). She says the HIV epidemic has greatly increased their workload. To begin with, each health worker had about 40 households to visit, and although that has now been reduced to 20 households, the work involved is just as much because they have so many sick and dying to care for. Often the Rural Health Motivators use their own personal resources—money, food, clothing—to care for people in need. In some households they take over the role of bathing and cooking for ailing patients to enable children to go to school.

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<sup>24</sup>WHO's internationally recommended Directly Observed Treatment Strategy for Tuberculosis.

In an effort to improve basic health supplies at community level, containers are placed outside each Inkhundla (constituency) in the country to provide Rural Health Motivators with basic equipment such as gloves, disinfectant, soap and adult-sized nappies to give to AIDS patients who have diarrhoea. Mambane's nearest container is 14 kilometres away, however, Rural Health Motivators complain that it is time-consuming and expensive for them to get there as they usually have to go at least four times a month and it costs E 20 a trip for transport.

Rural Health Motivators receive training from the Ministry of Health and Social Welfare on the transmission of HIV, how to care for people who are sick and dying, how to protect themselves and how to dispose of condoms and other hazardous waste safely. After receiving training, the health workers call a community meeting so they can pass on what they have learnt to the community as a whole. .

Also as part of their work, the Rural Health Motivators encourage people to go for voluntary counselling and testing, and address issues of stigma and discrimination. With the rapid rollout of antiretroviral treatment throughout the country in the past year, they are also key resources helping to ensure that people take their drugs properly and consistently. They also discuss prevention and treatment of sexually transmitted infections, which are a big problem in many communities such as Mambatfweni.

Outside the Inkhundla (local administration) offices in Mambatfweni is a container which has been supplied by NERCHA and is now being used as an AIDS office and a storeroom for supplies for Rural Health Motivators from 11 neighbouring Umphakatsi or chiefdoms. Gcinile Vilakati is a volunteer who looks after the container three days a week. She says the NERCHA container has helped the Rural Health Motivators great deal, and proudly shows off the boxes of disinfectant, nappies, soap, plastic sheeting and gloves. But she says the supplies need to be more consistent. Right now she has no condoms. "The ones we have finished. We are waiting for new supplies." She does not know when new supplies will arrive, adding: "It's a problem."

Rural Health Motivators also work closely with the community coordinating committee that distributes food to orphans and vulnerable children and with the Neighbourhood Care Points to ensure the children get proper health care and nutrition.

Lizzy Ntjalintjali, a Health Motivator in Mambatfweni says they also talk to people about traditional healers and advise people to take their own razor blade when they go for treatment. People are now carrying their own razor blades she says, and the Rural Health Motivators have also conducted training sessions with traditional healers.

Rural Health Motivators are often the first line of reporting for suspected cases of child abuse and investigate any cases that are reported to them. They offer counselling and in some cases may refer the child for further professional counselling.

Most of Rural Health Motivators are women, although there are a few men doing the work. It can be culturally difficult for women to talk to a man about health problems or to wash or take intimate care of a male patient.

## What it costs

- The Ministry of Health and Social Welfare's Public Health Unit in Mbabane has a budget for training Rural Health Motivators and paying their monthly allowances of E 100 per month (approximately US\$ 15).

- There are about 4500 Rural Health Motivators throughout the country, and the total budget for allowances is E 450 000 (approximately US\$ 68 854).
- The Public Health Unit also conducts pre-service training for Rural Health Motivators lasting 10 weeks, with funding from NERCHA and the Global Fund. The total budget for training nation-wide is E 725 000 (approximately US\$ 110 933).

Refresher courses are constantly needed and training is a continual process. “Many Rural Health Motivators have died, so we need to train new people all the time,” says Thandi Mndzebele of the Public Health Unit. She says, “Last week alone there were 13 deaths of Rural Health Motivators reported in the Hhohho region, so RHMs need to be constantly replenished.”

### **Promoting adherence to antiretroviral therapy**

With the rapid roll out of antiretroviral therapy (ART) currently taking place in Swaziland, these community-based initiatives are also well placed to ensure drug treatment reaches those in need and helps to promote adherence to the drugs by patients. Antiretroviral drugs are now available free of charge in Swaziland. Approximately half of the 20 000 or so people who need them urgently have started taking them in 2005. It is hoped the rest will receive drugs within the coming months. Despite this progress, there’s still a long way to go. Currently, back-up services such as CD4 testing are centralized at the national level and are not available in the regions. People still have to travel long distances to get treatment and long queues at facilities are frequently a problem.

### **Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA)**

SWANNEPHA is a national network made of about 46 different groups of people living with HIV and was formed following a study conducted with the assistance of the Ministry of Health and Social Welfare, SIPAA, NERCHA and UNAIDS in March 2004. In November 12, that year, SWANNEPHA was launched by the Prime Minister, and on 21<sup>st</sup> of March 2005, the National Secretariat came into being. It was officially opened by the Hon. Minister of Health and Social Welfare, Chief Siphon Shongwe and Dr Peter Piot, the Executive Director of UNAIDS during his visit to Swaziland.

SWANNEPHA supports groups of people living with HIV in the communities of Mambafweni and Mambane, and other communities throughout the country, providing guidance and training at a local level. “We have been able to give people living with HIV a voice,” says Thembi Nkambule, SWANNEPHA’s National Coordinator, “As a result, we have been able to influence some policies such as the National Strategic Plan and gender policy. We have also been able to assist groups in developing their proposals for funding through NERCHA/Global Fund and mobilize resources so that we have a collective voice.” The main concern of people living with HIV in Swaziland is stigma and discrimination and most people are afraid to come out in the open.

Most of the proposals they receive from members are for income generating projects, so SWANNEPHA has developed a booklet to assist groups in drawing up business plans. A draft strategy plan, due to be finalized in the coming months, has also been drawn up and workshops on treatment literacy are being organized in conjunction with the Ministry of Health and Social Welfare.

SWANNEPHA is now asking for free treatment of opportunistic infections because most of its membership cannot afford treatment. The organization is also campaigning for better treatment literacy so that people can understand the issues around treatment.

Some of SWANNEPHA's members in communities such as Mambatfweni and Mambane work as volunteers at the Neighbourhood Care Points or are themselves involved in home-based care, and Thembi Nkamule believes this helps to challenge stigma and discrimination. "The community-based responses are helping even more people to come out about their status because they feel that's where they can get assistance."

One of the biggest challenges for many people living with HIV, especially in rural communities such as Mambatfweni and Mambane, is that they cannot take the drugs on an empty stomach but often they do not have enough to eat. WFP is giving food to patients receiving antiretroviral treatment in areas where food shortages are particularly acute, such as Mambane. Elsewhere, some of SWANNEPHA's members are benefiting from food grown in Indlunkhulu fields, and other community-based initiatives, although this falls far short of what is needed. It can also be difficult to ensure patients receive the necessary assistance if they do not want to be identified as being HIV positive, fearing stigma and discrimination.

WFP is working with SWANNEPHA and AMICAALL to get food to about 20 000 people and their families, and also trying to set up "food for work" programmes for stronger people in the community. This can be a difficult concept, because people are often reluctant to work for something that they see someone else getting for free.

Joseph lives in Mambane now but used to work in the mines in neighbouring South Africa, until he became sick and was retrenched. "Our young people go there to work and come back here and die." He's surprisingly open about his HIV status and the fact that's now receiving antiretrovirals. "I am one of them," he says and adds that he knows of about 45 others who are receiving the drugs. He started in February 2004 and says, "It has made an enormous difference. I used to be so sick and was in and out of hospital." He believes people who are positive, like him, should speak out about their status, to set a good example to the community and break down stigma and discrimination.

But food is a problem, he says. WFP gives him six kilograms of corn soya a month so that he can take the drugs, but he says he cannot eat food when his wife and children have none, so he shares his rations with his family and they barely last a week.

Joseph would also like to see Mambane becoming "an exemplary community" and would like to encourage the whole community to test for HIV at the same time so that they all know their status. They could then carry cards to protect those who are not infected, he suggests. "If everyone tested," he says, "it could remove some of the stigma and we can care and support those who are infected and it would mean that children who are negative have a reason to stay that way."

Mambane's Chief did invite the mobile testing services to visit the community in 2004 and he and his family were the first to be tested, setting an example to the rest of the community for HIV testing. Some women in the community would like the mobile VCT clinic to come back to continue the process that was started last year. "Any time we are ready," one of the women, "but it's the men who are reluctant. Women do check, but it's useless unless men do the same."

## Challenges

- Stigma and discrimination against people with HIV is still a problem in some communities, preventing some people who need assistance from disclosing their status and, as a consequence, getting the help that is available.
- Although peer counselling and home-based care provide support to people living with HIV, carers and counsellors have few resources at their disposal. It is hard and emotionally draining work. Many carers may themselves be sick, and so new volunteers need to be constantly recruited.
- It may be difficult for volunteers to oversee effective adherence to antiretroviral treatment if patients do not have sufficient food to take the drugs consistently.

## Summary of achievements

- Community-based care for people living with HIV enables people to be supported by people who know them well and can respond more appropriately to their specific needs and circumstances.
- Community-based care can help to break down stigma and discrimination, as more people disclose their status when they see the care and support being given to others.
- Greater openness can help to create greater awareness about prevention and treatment options.
- Existing community-based support structures have been useful in the rapid rollout of antiretroviral treatment because they can be an effective method of ensuring drug adherence at household level and alerting Rural Health Motivators to any potential problems.

## Psychosocial Support Programmes

### *An innovative programme of psychosocial support has been developed at community level to try to address the multiple challenges facing the growing population of orphans and vulnerable children*

Many communities in Swaziland are transforming themselves in response to the AIDS epidemic. But for thousands of orphans growing up in such difficult times and without adult care or supervision, their opportunities for growth, development and education may be severely adversely affected. There is now a growing recognition that unless something is done, the long-term consequences could threaten the future of communities and perhaps even the social structures and stability of the country as a whole. As a result, many communities have implemented a programme of psychosocial support to try to address the enormous challenges they face. Given the link between social conditions and cognitive and emotional health, this psychosocial support programme uses a holistic approach to address the interaction between children's emotional, social, mental, physical and spiritual development and the factors that affect these.

Bereaved orphans are often traumatised by their experiences of caring for sick parents and seeing them die, and from struggling to look after their remaining family and property. They may also find themselves marginalized and excluded from their communities due to the stigma associated with AIDS. Psychosocial support for children made orphans by AIDS is recognized as a crucial component of orphan care in Swaziland.

### Reviving traditional Swazi customs

The Kingdom of Swaziland is a very traditional society, with complex social structures and allegiances to His Majesty the King, and to the Chiefs as his representatives at chiefdom level. Historically, Swazi society was organized into age-related Royal Regiments, for women, men, boys and girls, which mobilized people for ceremonial functions such as the Umhlanga (or Reed) dance and to play their traditional roles within the Chiefdoms. These traditional structures are now being revived as an innovative and effective response to the HIV epidemic.

### Lutsango IwakaNgwane

Lutsango IwakaNgwane is a women's "regiment", one of several traditional Swazi regiments<sup>25</sup> established by the late King Sobhuza II before independence in 1964. The word means 'an enclosure' in siSwati, and all married women automatically become members. Lutsango's main role is to mobilize women for ceremonial functions and to train them for their traditional roles in Chiefdoms. Lutsango members are the cultural custodians and teach children traditional songs and dances, how and when to wear traditional clothes, how to pray and worship, and teach the girls to cook and how to behave. From the outset the regiment was expected to take on a care and nurturing role and be responsible for transferring good cultural practices and behaviour from one generation to the next. That role has now taken on an enhanced importance as AIDS has decimated families and communities.

A programme of training for Lutsango care mothers has been developed and is being delivered through a network of national and regional Lutsango offices established with assistance from NERCHA. The volunteers are trained to care for HIV-positive children, in basic life skills

<sup>25</sup>The others are Tingatsha regiment for boys, Timbali regiment for girls and Emabutfo regiment for men.

such as nutrition and hygiene and in HIV education and prevention strategies for children<sup>26</sup>. In line with Swaziland's preferred policy of looking after orphans in their own communities, local Lutsango members are assigned to orphaned households to ensure that the children can stay in their parental home, are protected from abuse and exploitation and are cared for by community members who are known to them. Where possible, a relationship is established with a child before the sick parents die, to try to ensure an element of stability and continuity.

Lutsango also teach girls to cook and, with support from FAO agricultural packages, to grow crops. Some areas have been successful, but in drought-affected areas such as Mambane, these initiatives have so far had only limited success. Lutsango also supports women with income-generating projects and has developed a curriculum for courses training the women in fiscal and social development, as well as mental and emotional development. Forty graduate facilitators have been recruited who visit 17 chiefdoms a week. Training in the Lubombo and Hhohho regions is almost complete<sup>27</sup>.

It is also envisaged that even if women can not read and write they should start collecting data on the households they are responsible for—personal data about the child, the child's health and immunizations, on relatives and the community as a whole. "It's demanding work," says Mrs Katamzi, Lutsango's national coordinator for the AIDS programme. "The poverty is terrible. On the first and second visit, the women take what they can to the children. But they have little to give themselves and many say they cannot bear to go visit the children and be able to give them nothing. But where we have already been we make a difference."

Khanyisile Mndzebele, is a volunteer of Lutsango in Mambatfweni. She has received some training in psychosocial support and says she is responsible for visiting six homesteads, where there are eight children. "We become second parents to the children," she says. "As the children begin to trust us, they open up to us."

All this work is done on an entirely voluntary basis and, whilst much has been achieved in a relatively short time, "We are not going to be able to cope," says Bella Katamzi. "Men also have to be included because we cannot cope alone."

## Getting men involved

The men's traditional regiment, Emabutfo, has also been enlisted in the community response to HIV.

Recognizing that historically many of the outreach services in Swaziland have been targeted at women, and that little work has been done with men, NERCHA is now trying a new approach and starting a programme aimed at men<sup>28</sup>.

In Swazi culture, when an animal is slaughtered, the Chief calls the men together to eat the head and other parts. NERCHA is now hoping to develop this traditional occasion into a forum where men feel free to talk, and messages about HIV can be communicated to them through drama performances, followed by a discussion. "This has been very successful where it has taken place," says NERCHA's National Director Derek Von Wissell, "The only problem is that it is very slow to set up. But where it has taken place the dialogue has been very good and

<sup>26</sup> Although national coordination of the programme is conducted through NERCHA, which receives financial support from the government of Swaziland, the Chieftancy committees manage Lutsango's work at the local level.

<sup>27</sup> In Hhohho there are 94 chiefdoms, in Lubombo 48, Manzini 109 and Shiselweni 127.

<sup>28</sup> With funding from ECHO.

people have really been learning from it—especially targeting multiple partners as a message. We are targeting men and it empowers them because they go home with knowledge. We are not telling them what to do.”

### **Umcwasho: Encouraging abstinence**

Young girls are also organized into age-related traditional regiments (Timbali), and the revival of the traditional Swazi practice of wearing tassels (Umcwasho) as a way of promoting and protecting abstinence, has proved popular with some young people. Traditionally the tassels were worn for a specific period, after a Chief asked a particular age group to abstain from sexual activity. Any man found violating a girl wearing a tassel is fined.

The boy’s traditional regiment Tingatja, also promotes abstinence amongst its members. These regiments have experienced a resurgence of interest and popularity amongst young people seeking personal guidance during difficult times.

### **Building Partnerships**

The Church Forum on HIV/AIDS is also working to support initiatives to provide psychosocial support at community and grassroots level. The Swaziland Church Forum believes its main task is to bring hope, to help people get over traumatising experiences, to get on with their lives and be productive. “You can live a certain amount of days without food or water,” says Bongani Langa, the National Coordinator of the Church Forum on HIV/AIDS, “But you can’t live a minute without hope. The advent of HIV and AIDS has challenged people’s hope.” He sees one of the Church’s primary roles as being the entity that brings back hope to the people and helps communities get over these traumatising experiences. The church can bring people together to share these experiences so that together they can find ways to move on and be productive in spite of what has happened.

The churches in Mambatfweni collect food from members through tithes and the community decides who needs help. Orphans and the elderly receive food and the NCPs also benefit. They have also asked the Chief for land so that the Churches can grow food themselves. Mrs Ellinah Maphalala, a lay Minister of the Church of God of Prophecy says they bring “hope, soap, clothing and food” to the sick and dying.

Pastors in the community also preach abstinence and provide counselling to children who have lost their parents. The Reverend S. Hlophe of the Jericho Church in Zion says they also try to speak out about wrong beliefs about AIDS and invite people who are knowledgeable about HIV to address their congregations.

There are many different churches and faiths within the community, but the challenges they faced have encouraged them to work together and set aside their differences, says Olgate Ntjhalintjhalali, a pastor with the Holy Apostolic Church of Zion. Eight church leaders came together in 2002 to form a committee to collect money for orphans and now they have a combined treasury to administer the funds.

With all of these practical initiatives, whether it is for psychosocial support or the community working together to provide care points for orphans or grow additional food for vulnerable children, the impetus comes from the community itself. This ‘bottom up approach’ enables community initiatives to blossom and empowers people at local level to identify the problems for themselves. Support provided by Government and international partners enables these local initiatives to flourish and become sustainable.

## Involving Businesses

Many businesses throughout Swaziland came together in 2001 to form The Business Coalition against HIV/AIDS (BCHA), to coordinate the private sector response to the epidemic. Working closely with the Government, unions and urban and rural communities, BCHA helps to facilitate and fund the work being done by existing nongovernmental agencies in accordance with the National Strategic Framework. BCHA is currently helping to develop an educational and AIDS awareness programme for migrant workers, especially in communities such as Mambane which have a high proportion of migrant and transient workers.

Some larger businesses have also initiated innovative fund-raising schemes to support community initiatives. The Swaziland Post and Telecommunications Corporation, for example, organizes a popular annual football tournament, which raises money to support, amongst other things, the fencing of kitchen gardens for Neighbourhood Care Points in Mambatweni and other communities. Without such fencing many of the gardens would not be viable because goats and other animals would eat crops. Money is raised both from the sale of tickets to the tournament, and from a telephone voting system whereby the public decides which of their favourite teams will participate in the tournament. The publicity surrounding the event, and visits by football stars to Neighbourhood Care Points in the communities, also helps to raise awareness about community initiatives and HIV prevention messages.

## Challenges

- By far the biggest challenge to continuing to provide high-quality psychosocial support will be the predicted rapid growth in the number of orphans and vulnerable children requiring assistance.
- The increasing burden of providing psychosocial support to a growing number of orphans and vulnerable children will strain volunteerism and make sustainability of the initiative problematic.
- The psychosocial trauma experienced by some of the orphaned and vulnerable children, many of whom have cared for sick parents or have watched them die a painful death, can be profound and may be beyond the capacity of volunteers who have little formal training.
- To have maximum benefit traditional customs and volunteerism need further support from trained psychosocial professionals.
- Women are doing much of the psychosocial work, as well as the home-based care. The cultural constraints of working with men and older boys mean that the women can only do so much. Getting more men more involved is essential and will be a challenge.
- Orphans and vulnerable children can be difficult to define and identify. Sometimes parents abandon their children with elderly relatives whilst they go the city to try to find work. Lutsango has put in a lot of effort into trying to educate and persuade people to be responsible for their own children, through radio programmes and community meetings. It would like to see legislation put in place that will enable parents to be traced and forced to take responsibility for their own children.
- So far psychosocial volunteers have been more concerned with pre-adolescent children than adolescent ones, so there has been little emphasis given to teaching the

children about HIV in a systematic way. Training for counselling on sexual behaviour is planned for the next phase.

### **Summary of achievements**

- Traditional Swazi customs and structures within society have been effectively harnessed and adapted to face the challenges posed by AIDS and to help alleviate the impact of the epidemic on orphans and vulnerable children.
- An effective and far-reaching network of psychosocial support has been established based entirely on volunteer efforts.
- Psychosocial interventions from familiar and established traditional organizations, such as Lutsango, which have ready access to families and women in particular, are acceptable and effective.
- The psychosocial support that organizations such as Lutsango can provide at community level complements and supports other community efforts such as Rural Health Motivators and Neighbourhood Care Point care workers.

## Community Outreach Services

***The Government of Swaziland, with support from its partners, is trying to strengthen the availability and coverage of community outreach services at local level in response to the AIDS epidemic.***

With the rapid increase of the number of people living with HIV and devastating impacts of the epidemic, there has been increased demand for community outreach services at community level. These include:

- Public health outreach
- Rural health initiatives
- Child protection services
- Legal education services
- Prevention of mother-to-child transmission programmes.

## Plans for Decentralization

The challenges posed by the AIDS crisis and growing numbers of orphans and vulnerable children to be looked after by communities have also contributed to a wholesale reappraisal of the structure and delivery of Government services in Swaziland.

Swaziland has had a centralized system of Government since independence in 1968 but is currently preparing to decentralize Government planning and budgeting, using a bottom-up approach to address the economic, social and political challenges at local level. Cabinet approved the decentralization policy. It is hoped it will become law in 2006 and plans for a national framework for implementation are being drawn up. Decentralization will still need national planning and a national framework, but local economic plans will be consolidated first in regional and then in national plans.

Acknowledging the scale of the problems that communities face, the policy of decentralization is predicated on the belief that more participation at local level will ensure better analyses of their problems, and that the mobilization of resources to support local initiatives and the solutions will be more sustainable and innovative. The aim is to create an enabling environment for communities such as Mambane and Mambatweni to start planning for themselves and for Government to start listening to ideas from the 'grass roots'<sup>29</sup>.

## Using the KaGogo social centres for outreach services

It is envisaged that outreach services will be able to use the newly built network of KaGogo social centres to reach communities such as Mambane that are currently not being served. Service delivery mechanisms would then become much easier because there would be a central point where a nurse can provide the services and people can go. The idea is to take the services to the people, rather than the other way round. The programme is still at the planning and trial stage, but it's hoped it will be scaled up nation-wide in the near future.

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<sup>29</sup>UNDP is committed to supporting the decentralization process in line with the Millennium Development Goals for poverty reduction by 2015, and works in partnership with the government in sharing experiences and best practices to build up the capacity of local government.

Ultimately, the hope is that other services, such as home-based rehabilitation and hospice care, can also be delivered in this decentralized way at community level. Mambatfweni's acting Chief says it is her dream that one day hospice care can be provided within the community to people who need it.

The hope is that service delivery mechanisms for prevention, treatment and impact mitigation of HIV will complement and be supported through government decentralization. The aim is to give people greater access to and control of their own resources and determine what they want to do as a community.

## **Public health outreach**

The Government's policy is that no one should have to walk more than eight to ten kilometres to get to the nearest clinic. It also aims to build one clinic a year, but the reality currently falls far short of the Ministry of Health and Social Welfare's goals.

The AIDS epidemic has had a profound impact on the health sector throughout Africa, and Swaziland is no exception. The migration of health workers to neighbouring South Africa and rich countries, and the loss of trained staff to AIDS have seriously undermined capacity to deliver basic health services at all levels. Although everyone suffers when this happens, rural communities, such as Mambane, which fall outside the reach of what limited health services there are, feel the effects even more.

In Mambane the epidemic is having severe effects, but the nearest hospital or voluntary counselling and testing services are at the Good Shepherd hospital at Siteki, approximately 40 kilometres away. There are sometimes long queues of people waiting for antiretrovirals, and sometimes they have to go back home without their supplies. The nearest clinic is at Tikhuba, about 15 kilometres away. Transport is scarce and expensive.

Outreach services visit the community once a month to provide preventative and curative services, but the nearest outreach point to Mambane is at Skokomane, which means people have to walk or travel about 12 kilometres to get there.

At the Public Health Unit at Siteki staff members complain that outreach services suffer from a shortage of nurses, transport and drugs. They only have one vehicle, if it breaks down, the outreach clinic may not take place on the allocated day. In an effort to overcome such shortcomings, the Public Health Unit works hand in hand with community Rural Health Motivators in the community of Mambane. They alert the Public Health Unit to any problems and remind people when the outreach services are due to come each month.

## **Legal education services**

Another innovative aspect of community outreach services, supported by NERCHA, is a programme of legal services and education. The legal outreach services are provided by a local nongovernmental organization which has mobile officers and a vehicle that travels round the regions, visiting communities such as Mambane and Mambatfwene on a regular basis, using the offices at the KaGogo social centres. The unit deals with issues such as property inheritance, and the registration of births and deaths. These are truly important issues because e.g. if a child does not have a death certificate for a parent he or she cannot access the government's education grant to go to school. It also deals with questions of how a child inherits from its parents, whether the current legislation is adequate and how it can be enforced.

This is still a very new programme, and lessons are being learnt from it, but communities have welcomed it and it is being seen as the start of a more decentralized legal service delivery. Some cases that have come to light will be taken up by University of Swaziland and the Law society with a view to pursuing them as test cases in the courts.

### Prevention of mother-to-child transmission

Prevention of mother to child transmission ‘plus’ (PMTCT Plus) is a new programme of training at community level, supported by UNICEF and other partners, creating a support structure in the community for women who are pregnant. Trained community Rural Health Motivators talk to pregnant women about how to prevent transmission of HIV to their babies and are very much involved in the efforts to prevent mother to child transmission. They encourage women to visit the clinic for testing when they find themselves pregnant so that they can access drugs to prevent the virus being transmitted to the unborn baby.

The programme has been tried out in certain communities, and has yet to be evaluated, but funding for further expansion is currently an issue.

### Child Protection Services: Providing a Shoulder to Cry on

There’s a Billboard at the edge of the Manzini-Mbabane highway with a smiling picture of a pretty little girl. The caption reads “Do not touch: We care.” It is symptomatic of the determination to improve child protection in Swazi society.

A reported increase in the incidence of child abuse is among the most disturbing aspects of the epidemic. There have been some reported instances of children becoming HIV infected as a result of rape. It has been suggested that one of the driving forces for this is a persistent belief that if an infected person has sexual intercourse with a virgin he or she will be cured of HIV. Other factors found in all societies around the world such as family breakdown, poverty, unemployment, drunkenness and drug taking also play a part.



*“Do not touch”*

NERCHA is working in partnership with, the Swaziland Action Group Against Abuse (SWAGAA) to support community initiatives against abuse. SWAGAA is a local nongovernmental organization set up to campaign against sexual and physical abuse and to support and counsel victims. The focus is very much on supporting what communities such as Mambatfweni and Mambane are already doing for themselves.

Nonhlanhla Dlamini, SWAGAA’s Director, says there is a strong link between sexual abuse and the spread of HIV. “In the past a child belonged to the community, and everybody took responsibility for that child—every parent in the community was your parent. But a lot of what we had in the community has been distorted because of the break up of extended families due to HIV and urban migration.”

Accurate statistics are hard to come by but SWAGAA believes abuse is taking place on a scale never seen before in Swaziland. “People were not very open about it,” says Nonhlanhla. “It was not until we started creating awareness that people started to speak out.” SWAGAA has a programme of sensitising children, to be aware of issues of abuse and encourage them to speak out. The Ministry of Education has also set up a hot line to report abuse. In 2004, 1555 cases were reported. In approximately one third of cases teachers were reported to be the main abusers, and in another third, parents<sup>30</sup>.

The legal framework to deal with such cases has been relatively weak up until now, but Swaziland is in the process of introducing stronger child protection legislation and establishing an effective child protection network of key professionals.

## Shoulders to Cry on

In Mambatfweni and Mambane, as in other communities throughout the country, women have formed Lihlombe Lekukhalela (“Shoulders to Cry on”) committees, and volunteers have been appointed within each community and trained to recognize and deal with child abuse cases. The Lihlombe Lekukhalela are selected by and known in their communities so have the confidence of their neighbours. They are the first referral if there are problems or suspicions of child abuse.

## Community Child Protectors

Each community also has also appointed Child Protection Officers who deal with cases of child abuse. They work under the guidance of the Deputy Prime Minister’s Office and in partnership with ‘Save the Children’ organization. The information on child abuse cases is then fed to the quarterly meeting of the Child Protection Network at national level. The Protection Officers also visit schools to talk to children and encourage them to report any cases. The establishment of Neighbourhood Care Points and KaGogo social centres have greatly helped community care workers such as the Child Protectors and the Lihlombe Lekukhalela, as well as national bodies such as SWAGAA, by providing local facilities to coordinate efforts. They have also made it easier to identify and deal with cases of sexual and physical abuse by providing an entry point and a place where children are gathered together, rather than hidden behind closed doors.

At Mambatfweni the Neighbourhood Care Point caregivers said they had come across many cases of child abuse, beatings and emotional abuse. They said rape was rare in the community, but it was common for children to be beaten and physically abused. Part of their role as care givers is to intervene in families and discuss the problems. One care worker described a case in which the father was abusing the child. She intervened and arranged for the child to live with an aunt, “She’s doing well now.”

## Community Police

The communities of Mambatfweni and Mambane have also established a system of volunteer community policemen, who are chosen by the communities themselves, to tackle crime and to keep the peace. They are also the first point of reference in child abuse. There are 11 community police in Mambane, including several women such as Ncamsile Gumedze and Khetsiwe Matse. Since many of the men are often away working on the sugar plantations, the

<sup>30</sup> Child protection network meeting minutes 13-15th June 2005

community policing in Mambane has largely become a task for the women. Khetsiwe is only 22 and, used to have a job as a security guard in the main commercial city, Manzini, but when she fell sick she lost her job. She has now come back to the community, where she is happy to volunteer her services as a community police officer.

The community police patrol at night and carry knives and knobkerries (sticks). Part of their role, says Ncamsile, is to disperse groups of boys at night, because “that’s when thefts and other trouble starts”. They see their primary role as the moral guardians of society and to prevent situations arising that could contribute to the spread of HIV. Every Saturday they report problems to the Umphakatsi and cases of rape or child abuse are reported to the local police station. The incidence of rape and child abuse in the community has reduced since the appointment of the community police.

### **The legal response to child abuse**

Greater awareness of the problem of child abuse at community level, and more proactive efforts to address them through the efforts of volunteers working as community police, child protectors or Lihlombe Lekukhalela have resulted in a substantial increase in the number of cases coming into the public domain. This has had a direct impact on national policies.

About 55% of the cases handled by Swaziland’s Director of Public Prosecution involve sexual offences. Many children have been unable to give evidence or to confront the perpetrators; this resulted in a high number of acquittals. In an effort to try and strengthen the legal response to the growing number of child abuse cases, in 2002 the Chief Justice decided to build a children’s court. New legislation passed in 2005 allowed use of intermediaries and the use of a separate court linked by CCTV, so a child’s evidence can be seen in main court, but the child can not see the court. The lawyers question the child through the intermediary who tries to put the questions in a relaxed and child-friendly way, so that the child is comfortable giving evidence. Training of intermediaries began in February 2005 and the first successful case soon followed with a four year old child giving evidence against a 65 year old man that led to a subsequent conviction.

A survey of the incidence of child rape, conducted by SWAGAA suggests the inauguration of the children’s court and the surrounding publicity may have led to a reduction in the number of cases. Currently, all cases of rape are dealt with under common law, so there is also a need for stronger legislation to deal with issues of rape and sexual abuse or domestic violence against women generally. The Director of Public Prosecution’s Office has worked with nongovernmental organizations such as SWAGAA and relevant Government ministries and agencies (Education, Health, the Deputy Prime Minister’s Office, Police) to come up with comprehensive legislation to deal with these issues. A draft bill containing provisions concerning HIV has been drawn up and it will soon become law.

Under the new legislation it will be an offence for people knowingly to infect someone with HIV. The proposed legislation will also make it illegal to marry a child under 18 without consent, and prohibits the traditional practice of widow inheritance (where a man automatically inherits his deceased brother’s wives) without a woman’s consent. Thus the legal response is an interesting mixture of old and the new—some traditional practices are being revived and others discouraged or being made illegal. Efforts have been made to identify traditional practices that seem to be related to the spread of HIV and to address these within the legal framework so that no one is forced into risky behaviours without consent.

## Challenges

- With the rapid increase of the number of people living with HIV and the deepening impacts of the epidemic, the demand for community outreach services at community level has increased beyond current capacity to deliver such services.
- Outreach health services and other services are themselves struggling to cope with AIDS attrition of essential staff, and have insufficient financial or transport resources to deliver services on a regular and effective basis.
- As a result, many vulnerable and isolated communities, such as Mambane, currently receive little or no public health outreach services, child protection or legal education services.

## Summary of achievements

- The Government of Swaziland, with support from its partners, has recognized these challenges and is trying to strengthen the availability and coverage of community outreach services at local level in response to the AIDS epidemic.
- The construction of KaGogo social centres within communities has resulted in an effective mechanism for more efficient delivery of outreach services to communities and has helped to coordinate the services and to collate essential data for effective interventions.
- Likewise, the Neighbourhood Care Points have made the most vulnerable children and orphans visible and enabled care workers to channel requests for assistance through the KaGogo centres to the relevant outreach services, so that assistance can be effectively targeted to children in need.
- The outreach services can work hand in hand with community care workers and health volunteers to ensure that a holistic and consistent approach can be developed.
- The community initiatives complement and strengthen regional and national outreach services, and are increasingly becoming the cornerstones of the national response to HIV.

## Conclusion

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All of the community initiatives outlined in this report depend upon a high degree of community participation and mobilization. It is hard to imagine what the situation would be like without such community-based activities and interventions. They have given communities such as Mambatweni and Mambane a sense of self-reliance and ownership of their responses to HIV. Participation at local level ensures better analysis and ownership of problems, better mobilization of resources to support their initiatives, more sustainable and innovative solutions, and less reliance on outside assistance.

These innovative initiatives have also empowered the communities in Mambatweni and Mambane to look after orphaned and destitute children themselves rather than depending on outside help. They have also fostered a realization that children orphaned by AIDS are a challenge for the whole community, a challenge that is here to stay for the foreseeable future.

There's no doubt that the community initiatives outlined in this report have been lifeboats to communities facing apparently overwhelming and insurmountable odds. They have given people in Mambatweni and Mambane a sense of purpose and ownership, and above all a sense of hope that something *can* be done.

But just as they have got those lifeboats afloat, and are struggling to get survivors into them, yet another problem is threatening to engulf them—the food shortages and drought facing the country and region as a whole. Without food, the community initiatives and volunteer efforts outlined in this report will be hard to sustain. Food shortages are also threatening to undermine the impressive rollout of antiretroviral treatment that Swaziland has managed so far. People have agreed to be tested, have been counselled and are now receiving antiretroviral treatment, but in order to take the drugs they must have a sustainable supply of food. Some people can not currently get onto treatment programmes because they have no food.

Most of the initiatives outlined in this report concentrate on impact mitigation and care and support rather than prevention of new infections. They are the result of impressive and massive mobilization in the communities studied. However, the most effective responses to HIV work across the continuum of prevention, treatment and care. Communities will become exhausted by the effort if impact mitigation is not combined with more effective prevention strategies as well. Providing antiretrovirals is usually effective in improving the quality of life of people living with HIV but it is certainly not a complete answer. The future depends on people changing behaviour and preventing new infections, especially amongst young people and children.

## Lessons Learnt

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The initiatives outlined in this report have given communities such as Mambatfweni and Mambane a sense of self-reliance and ownership in their response to AIDS, and illustrate a number of ‘Best Practice’ lessons that could be replicated and adapted within Swaziland and beyond.

- Participation at local level ensures better analysis and ownership of problems, better mobilization of resources to support their initiatives, more sustainable and innovative solutions, and less reliance on outside assistance.
- These innovative initiatives have also empowered communities to look after orphaned and destitute children themselves rather than depending on outside help, and fostered a realization that children orphaned by AIDS are a challenge for the whole community and one that is here to stay for the foreseeable future.

Reinforcing traditional structures such as the KaGogo social centres, the Chiefdoms, and Indlunkhulu fields, gives both Government and donors a better structure with which to work and to gain access to those who need assistance most.

- Some of these programmes are new, but others are based on old, traditional ways of doing things, that are now being revived and strengthened. People understand and accept these traditional ways, so they have become effective vehicles for mobilizing community responses.
- The role of the chiefs is central to the success of these community initiatives. Engaging traditionalist Chiefs and giving them special support as needed enables agencies better to know who is in need of assistance in the community and to provide help more effectively and efficiently.
- Communities that develop successful responses to HIV are less likely to contribute to the continuing stigmatization of, and discrimination against, individuals living with HIV.
- Good management structures and effective communication between communities and agencies is valuable in furthering the work of both parties.
- The proposed decentralization of Government should enable donors and nongovernmental organizations to work more directly with the communities on the initiatives they have started.

## Annexe 1: Useful Contacts for Further information on community initiatives in Swaziland.

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Joint United Nations Programme on HIV/AIDS  
UNAIDS Country Coordinator  
P.O. Box 261, Mbabane, Tel: 404-2301, Fax: 404-9931

### **Attorney General's Office**

P.O. Box 546, Mbabane, Tel: 404-2807

### **Business Coalition against HIV/AIDS**

P.O. Box 72, Mbabane, Tel: 404 0768 or 404 4408, Fax: 4090051  
Email: [bcha@business-swaziland.co.sz](mailto:bcha@business-swaziland.co.sz)

### **Coordinating Assembly of NonGovernmental Organizations (CANGO)**

Tel: 4044721/4049283  
Email: [Cango@africaonline.co.sz](mailto:Cango@africaonline.co.sz)

### **Church Forum on HIV/AIDS**

Tel: 6118457

### **Delegation of the Commission of the European Union**

P.O. Box A36, Swazi Plaza, Mbabane, Tel; 404-4769, Fax: 404-6729

### **Department of Immigration**

P.O. Box 372, Mbabane Tel: 404-2941

### **Department of Labour**

P.O. Box 198, Mbabane, Tel: 404-3521

### **Department of the Treasury**

P.O. Box 38, Mbabane, Tel: 404-2041

### **Deputy Prime Minister's Office**

P.O. Box A33, Mbabane.

### **Good Shepherd Hospital**

P.O. Box 2, Siteki Tel: 3434133, Fax: 3434003

### **Lutsango**

Senator Isabella Katamzi, President,  
P.O. Box 211, Malkerns M204 Tel: 5503114, mobile 6130497

**Ministry of Agriculture and Co-operatives**

P.O. Box 162, Mbabane, Tel: 404-2731

**Ministry of Commerce and Industry**

P.O. Box 451, Mbabane, Tel: 404-3201 Fax: 404-3833

**Ministry of Education**

P.O. Box 39, Mbabane, Tel: 404-2491

**Ministry of Finance**

P.O. Box 443, Mbabane, Tel: 404-8145

**Ministry of Foreign Affairs**

P.O. Box 451, Mbabane, Tel: 404-2431

**Ministry of Health and Social Welfare**

P.O. Box 5, Mbabane, Tel: 404 4239

**Ministry of Justice**

P.O. Box 924, Mbabane, Tel: 404-6010

**Ministry of Public Service and Information**

P.O. Box 170, Mbabane Tel: 4040 3521, fax 404 5379

**Ministry of Tourism, Environment and Communications**

P.O. Box 2652, Mbabane Tel: 404-4556

**Ministry of Works**

P.O. Box 20, Mbabane, Tel: 404-2321

**Manzini City Council**

P.O. Box 418, Manzini Tel: 505-2481

**Mbabane City Council**

P.O. Box 1, Mbabane Tel: 404-2611

**National Emergency Response Council on HIV/AIDS (NERCHA)**

P.O. Box 1937, Mbabane Tel: +268 404 1703/8

Email: [www.nercha.org.sz](http://www.nercha.org.sz)

**Prime Minister's Office**

P.O. Box 395, Mbabane Tel: 404 2754, Fax 404 4073

**Public Health Unit**

P.O. Box 1119 Mbabane, Tel: 4045270 (telefax), 6067800 cell  
Email: ruralhealth@swazi.net

**Registrar of Companies**

P.O. Box 460, Mbabane Tel: 404-3041  
Save the Children  
P.O. Box 472, Mbabane, Tel: 40425573, 4045181, Fax: 4044719

**Swaziland Business Growth Trust**

Embassy House, Mbabane Tel: 404-4705

**Swaziland Post & Telecommunications Corporation**

P.O. Box 125, Mbabane Tel: 404-2341

**Small Enterprises Development Company**

P.O. Box A186, Swazi Plaza, Mbabane Tel: 404-3046

**Swaziland Action Group Against Abuse (SWAGAA)**

P.O. Box 560, Matsapha, Tel: 505 7514, Fax: 505 2899,  
Email: swagaa@realnet.co.sz, www.swagaa.org.sz

**Swaziland network of people living with HIV and AIDS (SWANNEPHA)**

Tel: 4042578/6172674  
Email: swannepha@africaonline.co.sz

**Swaziland Chamber of Commerce**

P.O. Box 72, Mbabane, Tel: 404-4408

**Swaziland Industrial Development Company**

P.O. Box 866, Mbabane Tel: 404-3391, Fax: 404-5619

**Swaziland National Archives**

P.O. Box 946, Mbabane Tel: 416-1276

**Swaziland Sugar Association**

P.O. Box 445, Mbabane, Tel: 404-2345/6

**United Nations High Commission for Refugees**

P.O. Box 83, Mbabane, Tel: 404-3414 Fax: 404-4066

**United Nations Development Programme (UNDP)**

P.O. Box 261, Mbabane Tel: 404-2301/3, Fax: 404-5341

UNAIDS

**United Nations Children's Fund**

P.O. Box 1859, Mbabane, Swaziland Tel: 404-3725, Fax: 404-5202

**World Food Programme**

P.O. Box 3748, Mbabane Tel: 409 9001, Fax 404 7880

**World Health Organization**

P.O. Box 903, Mbabane, Swaziland Tel: 404-4268, Fax: 404-4566

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together ten UN agencies in a common effort to fight the epidemic: the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its ten cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials



## UNAIDS • BEST • PRACTICE • COLLECTION

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact-alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

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The Kingdom of Swaziland now has the highest recorded HIV prevalence in the world, and this southern African country faces enormous challenges, particularly when it comes to looking after the thousands of children orphaned by the epidemic. However, much inspirational work is being done at community level to put in place structures and programmes to stem the flow of infections and mitigate the impact. Some of these programmes are new, but others are based on old, traditional Swazi ways of doing things, that are now being revived and strengthened.

This Best Practice report examines two different communities, Mambatweni and Mambane. It looks at the strengths of the initiatives, notes some of the challenges overcome and considers what support they need in order to sustain these efforts. The practices and policies being followed, whilst being Swazi-specific in some cases, may also serve as an inspiration to action in other countries facing similar problems.

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