The STRATEGIES FOR HOPE Series produces and distributes books and videos that promote good practice in HIV/AIDS work by civil society organisations in developing countries, particularly in sub-Saharan Africa.

Founded by ActionAid in 1989, STRATEGIES FOR HOPE is a project of Teaching-aids at Low Cost (TALC), UK. The Series has produced sixteen books, four videos and the Stepping Stones training package. These materials are used for information, training, planning and advocacy purposes in over 160 countries.

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JOURNEYS OF FAITH

Church-based responses to HIV and AIDS in three southern African countries

by Gideon Byamugisha, Lucy Y. Steinitz, Glen Williams and Phumzile Zondi
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Gideon Byamugisha
Lucy Y. Steinitz
Glen Williams
Phumzile Zondi

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NOTE: In most cases the real names of people quoted or mentioned in this book have been used, with permission from those concerned. In some cases, however, names have been changed to respect people’s wishes for confidentiality.

PREFACE

Journeys of Faith describes and analyses innovative HIV/AIDS programmes carried out by churches and other Christian organisations in Mozambique, Namibia and South Africa.

This book is the sixteenth in the Strategies for Hope (SFH) Series, which was established by ActionAid in 1989 and is now a project of Teaching-aids at Low Cost (TALC). The SFH series, while not a faith-based organisation, has always recognised the importance of spirituality and of religious institutions in promoting good health and coping with illness. Nowhere is religious faith of greater relevance than in responding to the daunting challenges of the HIV pandemic.

Journeys of Faith describes how several churches and Christian organisations in three southern African countries have responded to the challenges of HIV/AIDS with imagination, courage and commitment.

The organisations and individuals whose work is described in Journeys of Faith were actively involved in checking and revising the book. The views expressed in the book, however, are entirely the responsibility of the authors.

We are deeply grateful to the five church organisations, and the UNAIDS Intercountry Office for East and Southern Africa, who provided the financial assistance needed to make this book a reality. Any views expressed in the book, however, are the responsibility of the authors.

Glen Williams
(Series Editor Strategies for Hope) 1 June 2002
Chapter 1: Introduction

Faith is the mainspring of the soul. Through faith, our aims, desires, plans and purposes are translated into physical, social, economic, political, artistic and spiritual achievements. Over the centuries, positive religious faith has stimulated individual and collective actions for the improvement of people, collectively and individually, in many different spheres of life. History also abounds with instances of religious faith, applied negatively, bringing untold suffering, injustice and evil into the world.

For many centuries, religious faith and spirituality have been major resources in promoting health and well-being and in helping people to cope with the impact of diseases. This is especially the case in Africa, where religious beliefs play a major role in shaping people’s personal identities, thought patterns and perceptions of disease, and the decisions they make which affect their health.

Faith communities* in Africa therefore have the potential to play a pivotal role in determining how individuals, families and whole communities respond to the HIV epidemic, which is the greatest health and development challenge facing the continent today. Indeed, in many African countries, churches and other faith-based organisations** have been very much to the fore in developing and spreading innovative and effective responses to the HIV epidemic. Strategies such as home-based care, counselling, peer education and community-based support for families affected by HIV/AIDS have been pioneered and developed by Christian health programmes and other faith-based organisations in many African countries.

Religious faith can also play an important role in promoting safer sexual behaviour and in motivating large numbers of volunteers involved in HIV/AIDS care, support and prevention activities. Moreover, the personal testimonies of many people living positively and productively with HIV reveal a deep reliance on inner spiritual resources for strength and willpower.

Yet by and large, the responses of faith-based organisations in general, and of churches in particular, towards the global HIV epidemic have generally lacked sufficient urgency and commitment. This is especially so in the field of HIV prevention, and in combating the stigma, denial and discrimination that are often attached to HIV/AIDS. The main reason for this failure has been the association, in the collective mind of many members of faith communities, of HIV/AIDS with immoral sexual behaviour.

Many church leaders in Africa – and elsewhere in the world – regard HIV infection

* We define a ‘faith community’ as the people who belong to a particular religious faith or who espouse a set of similar spiritual beliefs.

** We define a ‘faith-based organisation’ as an institution, association or group formed by people of the same religious affiliation. Within the Christian tradition (the focus of this book), faith-based organisations include - but are not limited to - churches and church-affiliated men’s and women’s organisations, youth groups and Sunday schools, as well as church-based non-governmental organisations, social welfare bodies, schools and health institutions, and both national and international church organisations and networks.
simply as the consequence of individual sin. People already infected with HIV are exhorted, therefore, to repent of their sins and to pray for healing through faith. HIV prevention is reduced to a simplistic emphasis on returning to ‘traditional’ moral values and standards of sexual behaviour. Unfortunately these judgmental attitudes have had the effect of reinforcing denial and secrecy on the part of people who know they are HIV-positive or believe themselves to be. This, in turn, undermines efforts to mitigate the impact of HIV/AIDS and to prevent its further spread.

In recent years, however, growing numbers of secular leaders at global and national levels, and among international agencies, have come to appreciate the unique potential which churches and other faith-based organisations have for preventing the spread of HIV and helping communities cope with the impact of the HIV epidemic. Growing numbers of religious leaders and institutions, especially at international level, have realized the urgency of exploring new ways of responding to the huge challenges of HIV/AIDS. Yet most faith-based organisations still lack the information, attitudes and skills, as well as the appropriate policies and strategies, for taking their rightful place in the global fight against the HIV epidemic.

Journeys of Faith describes how church groups, organisations and individuals have mobilised themselves to take collective action in response to the HIV epidemic. In the course of their work they have encountered indifference, scepticism and outright opposition. Yet they have been sustained by their Christian faith and encouraged by the support they have received from many quarters, especially from people infected or affected by HIV/AIDS. Their experiences are a rich source of inspiration and practical guidance for churches and other faith-based organisations looking for a ‘road map’ to translate their religious convictions into effective action against the HIV epidemic, and in support of people living with HIV and their families.

The Orphan Haven consists of a nursery and a pre-school held Monday to Friday and a club for school-aged children held every Saturday and during school holidays. It began in February 2000, with just 16 pre-school children. Two years later, 60 children were attending the pre-school and 10 babies were being cared for in the nursery. Over 100 children aged between 7 and 18 attend the Saturday Club.

Most of the children attending the Haven have lost both parents, and their guardians make no payments for any of the services provided by Tumelong. There are six children, however, whose parents pay a small monthly fee and also make a contribution towards the bus fares. These are not orphans but local children who...
There are no household amenities such as piped water or electricity. Most of the households are headed by women, many of whom are aged grandmothers looking after their orphaned grandchildren and sometimes other orphans as well.

The Orphan Haven is run by six women staff, including a pre-school teacher and a social worker, and a group of women volunteers. Joyce Sibasa, for example, comes to the Haven several times a month to help with the day-to-day running of the centre. She paints, washes toys and cleans the buildings. Several other grandmothers and guardians also come to the Haven to help with tasks such as washing clothes and preparing meals.

‘Place of faith’, consisting of the Orphan Haven, a health centre, a hospice (see box page 11), a home-based care project, a rape crisis centre, a primary school, a youth centre, a nutrition project, two centres for disabled people and several income-generating activities.

Tumelong is not a traditional mission station, with its activities concentrated on a single site with a large church in the middle. On the contrary, the different parts of the mission are scattered throughout Winterveldt and the neighbouring townships, and the projects it supports blend in with those of local communities. Tumelong staff work closely with several local churches and other community organisations. They have a particularly close working relationship with the health centre run by the Catholic Sisters of Mercy in Winterveldt township.

The land in and around Winterveldt is owned mostly by absentee landlords, and local people are unable to buy the land on which their houses stand. There are no household amenities such as piped water or electricity. Most of the households are headed by women, many of whom are aged grandmothers looking after their orphaned grandchildren and sometimes other orphans as well.

The Orphan Haven is run by six women staff, including a pre-school teacher and a social worker, and a group of women volunteers. Joyce Sibasa, for example, comes to the Haven two or three times a month to help in the kitchen by peeling and chopping up vegetables, doing the washing up and other odd jobs. Several other grandmothers and guardians also come to the Haven to help with tasks such as washing toys and cleaning the buildings.

A joyful place

The Tumelong Orphan Haven has two main aims. Its first aim is to provide orphans with holistic care – emotional, social, physical, intellectual and spiritual. Its second aim is to

Joyce
Grandmother and volunteer

Joyce Sibasa has two grandsons - five-year-old Katleho and seven-year-old Kgathiato - attending Tumelong Haven five days a week. The boys have been living with her since their mother died in Tumelong Hospice three years ago.

“My daughter had been sick, on and off, for a long time. The Tumelong people used to visit her. When she went to stay in the Hospice, my grandsons came to stay with me, and when she died they just stayed on. I’m their only relative, so where else were they going to stay?

“But I couldn’t look after them properly. I’m not in good health myself, and I’ve only got my old-age pension to support us all. I managed to look after the boys for over a year, but really I wasn’t coping at all well. Then two other ladies from Tumelong came to see us, and they said the boys could come to this Haven place every day, and without paying! They would even get picked up by bus every morning and brought home in the afternoon.

“I’m very, very happy with the Tumelong Haven, and so are my grandsons. They’re well looked after there. They get food and clothing. They’re also learning to read and write, so they won’t have problems when they start school.

“What I also like is that they are learning hymns and choruses, and they are even learning to pray. My daughter wasn’t a church-goer so they weren’t learning those things before. Now they even pray at night, before going to bed.

“I like coming to the Haven to help out in the kitchen now and then. The work’s not too hard and I get to meet people and make new friends. For me, it’s a good day out.

“What I’m worried about now is how I can support the boys when they start school. Kgathiato should have started already, but I have no money for his uniform, shoes and the school fees. I’m hoping that Tumelon can help there as well.”

The mission

The Haven is part of Tumelon Mission, established in 1939 by the Anglican Diocese of Pretoria to provide relief and support to families in and around the sprawling township of Winterveldt. About 1 million people now live in Winterveldt and seven nearby townships, mostly in make-shift shacks that are bitterly cold in winter and swelteringly hot in summer. The area has an unenviable reputation for crime, violence and extreme poverty.

True to its Tswana name, Tumelon is a joyful place, consisting of the Orphan Haven, a health centre, a hospice (see box page 11), a home-based care project, a rape crisis centre, a primary school, a youth centre, a nutrition project, two centres for disabled people and several income-generating activities.

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The outdoor playground equipment at the Haven is popular with the children.
provide grandparents, neighbours and other orphan caregivers – most of whom survive on precariously low incomes – with some respite from the daily demands of looking after young children, some of whom still suffer from the emotional and social effects of losing their parents to AIDS.

When the Tumelong executive committee realized the need for a place to bring infants and pre-school children during the day, they made an appeal to the local community for a building. Only one organization replied positively – the Catholic Church in Klipgate township, where a building previously used as a creche had been standing unused, for several years. Tumelong gratefully accepted the offer, but there was still a lot of work to do.

“When we first came here,” recalls Tumelong programme manager, Mary-Anne Carpenter, “the grass in the yard was shoulder-high, and there were rat droppings and cobwebs all through the building. It took us three months to clean it all up, and we added an extension as well.”

The Haven now consists of a huge hall, two large rooms, a kitchen, a pantry, toilets and a bathroom. The local Catholic and the Lutheran churches have contributed furniture, playground equipment and toys for the children. Another donor has provided funds for a tube well, which is ingeniously connected to a roundabout. Whenever children push the roundabout – regardless of the direction in which it moves – water is pumped up into a storage tank, high above ground level. The water is cleanable, not only for the kitchen, the toilets and the bathroom, but also for the large vegetable garden which provides much of the food used in the children’s midday meal.

“The Haven is a noisy, joyful place. The 60 children attending from Monday to Friday are given two snacks, and a cooked breakfast and lunch, every day. They are encouraged to express themselves through drawings, paintings and making models and pictures with scissors, glue, cardboard, cloth and other materials. They take part in organized play therapy, and use the outdoor playground equipment with great enthusiasm. They also acquire simple literacy and numeracy skills, so that when they start school they are not at a disadvantage compared with children from better-off backgrounds. In addition, they learn Christian hymns and prayers, taught by staff and volunteers from a wide range of Christian denominations.

“Children attending the Haven are given regular medical and dental check-ups, and are taken to a nearby clinic for vaccination, but none are tested for HIV. Six babies have died since the Haven began, and HIV was probably the cause of most of these deaths. A two-year-old boy who almost certainly is HIV-positive is currently being looked after in the nursery. Since no suitable relatives can be identified to foster the child, a Tumelong staff member is looking after him at home.

Most children come to the Haven because their mother or (less often) father is staying at the Tumelong Hospice. Some begin attending the Haven even before the parent’s death. Others are referred to the Haven by Tumelong’s two home-based care teams, its own health centre, or by other health centres, hospitals and social welfare institutions.

An average of five to eight new children are referred to the Haven each month, but not all can be accepted because of a lack of transport to bring them. At the end of 2001 there was a list of 50 children waiting to be admitted. Satellite Havens have been started at two other townships, which now receive almost 100 children twice a week. When more caregivers have been trained, these centres will operate five days a week.

The Saturday Club

On Saturday mornings, and also during school holidays, a totally different scene takes place at Tumelong Orphan Haven. Over 100 children of school age arrange, mostly by bus, some on foot, to start with a breakfast of porridge or bread and jam with three, then sing a hymn or a chorus, followed by prayers led by a member of staff. The group then splits into two – those aged 16 and over, and those below 16. The older group discusses whatever topic they have chosen for the day, which might be drugs, sex, pregnancy careers, food gardens, self-image, and management of stress and anger. Discussions are led by a Tumelong staff member. The younger children meet separately for their own discussions on similar topics, and for activities such as painting and drawing. There is also an opportunity for children to seek help with their homework from staff. A cooked lunch and snacks are served, and outdoor games are played in the afternoon.

Tumelong staff also carry out grief and bereavement counselling, on a one-to-one basis, with children who have recently been orphaned. Social worker Patience Nqoko explains: “We start by asking whether they understand why they are here. Did they go to the graveyard to bury their parents, and did they understand all that? Usually they’ve been living with their mother only, and we know her from the Hospice or the home care team, or both. We ask if they’ve looked at the items in her memory box and read her memory book. Did they understand those things, and would they like to tell us about them?”

“Sometimes the child will say ‘oh, I’ve seen that box but I haven’t looked at it’. So we encourage them to go through the box and to read the book, and to treat them as their treasure. Next time they come we’ll talk about the contents, which leads them to talk about their parents. We also ask them if they are happy where they are staying now and whether they are feeling any stigma at school or in the community.

“Very few parents are honest enough to call their children in and say ‘I’m dying of AIDS. They might say they have TB or pneumonia, but not HIV or AIDS. But they might write about having HIV/AIDS in the memory book, so the first time the child learns for sure that his or her mother died of AIDS is when they read it in..."
the Tumelong staff are, why they do certain things, which families are eligible for food parcels and school bursaries, and how long Tumelong will continue to assist orphaned children.

For most orphans, living conditions at home are at best basic, often harsh. In cases of extreme poverty, Tumelong’s home-based care teams provide families with blankets, second-hand clothes and a monthly food parcel. In 2001, for example, Tumelong distributed 300 blankets to the children attending all three orphan havens; 15 children received school bursaries and 10 families were given monthly food parcels. Tumelong helps families to start home food gardens rather than providing many families with food parcels, as this mobilizes caregivers in the household and is less likely to create a sense of dependency.

Providing this kind of family support requires considerable resources, many of which Tumelong is able to mobilize locally through the memory book, which can be difficult for them to cope with.”

The home environment
Tumelong’s commitment to orphans extends beyond the Haven, into the communities where orphaned children live. Staff try to establish a relationship with the guardians or relatives of all the children attending the Haven. Says Patience Ngoko:

“... There’s no written contract between Tumelong and the guardians, but we expect them to be involved in the child’s growing up, to know what’s happening with the child, for example, whether the child is ill or not. If we want to take the children on an outing, we expect them to know about that and to sign consent forms.”

In addition, a meeting of guardians, relatives and Haven staff is held once every three months. This is an opportunity for staff to report on latest developments, such as donations received, the numbers of children attending the Haven, and any deaths that might have occurred. The guardians and relatives ask questions about who the Tumelong staff are, why they do certain things, which families are eligible for food parcels and school bursaries, and how long Tumelong will continue to assist orphaned children.

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Tumelon
The Government of South Africa’s Department of Social Development has a programme to provide foster parents with a monthly allowance for orphaned children. Unfortunately, the bureaucracy involved in fostering a child is extremely difficult and time-consuming so very few people are able to claim this allowance, even when they do take foster children into their families.

**Staff attitudes and ethos**

The Tumelong Orphan Haven has demonstrated both the value – and the viability – of non-residential care, in a Christian context, for orphans and other children made vulnerable by HIV/AIDS. Although few of the staff of the Tumelong Orphan Haven are professionally qualified, all take part in a range of in-service training activities which serve constantly to upgrade their skills and maintain high morale.

Every second Friday, for example, nursing sisters from a Catholic hospital in Pretoria come to provide professional guidance and support, and to do health check-ups of the children. Experts from other professional institutions also visit regularly to provide training in areas such as pre-school education, and identifying and coping with physical and sexual abuse in children. It is also important for maintaining a high level of staff morale are monthly outings to recreational centres, which help everyone to “de-stress” and enjoy one another’s company.

Most importantly, all staff at the Haven have a Christian background and their faith helps to strengthen their motivation to carry out their work, for which they receive only modest material rewards. Social worker Patience Nqoko believes that the Christian faith which

A few kilometres down the road from the Orphan Haven stands Tumelong Hospice, also part of the Anglican mission. The parents of many of the children attending the Haven have spent their final days here.

Most patients are referred to the Hospice, which has 21 beds, by one of Tumelong’s two home-based care teams. Other patients are referred by local clinics and hospitals, or have heard about the Hospice by word of mouth. Some suffer from cancer, many from advanced TB, but most have HIV/AIDS.

“Looking after dying people is stressful, yes, but I really love my job,” says Vivienne Msiza, in-patient supervisor of the Hospice.

In the two years between January 2000 and December 2001, the staff of Tumelong Hospice nursed a total of 323 patients, of whom 238 died in the Hospice. Yet this is not a morbid, depressing place. On the contrary, it has a reassuring atmosphere of peace and calm, broken occasionally by laughter.

The entire staff of Tumelong Hospice consists of lay people. A team of 18 community health workers (CHWs), all trained in palliative care, looks after patients around the clock. A doctor and a nurse - both volunteers - visit two or three times a week to carry out examinations, write prescriptions, and provide staff with professional guidance and support; they are also constantly on call in emergencies.

A team meeting is held once a week to enable staff to discuss problems, give one another mutual support and upgrade staff skills through in-service training sessions.

The Tumelong social worker visits the Hospice to provide advice and practical assistance with problems such as making a will, planning for children’s futures, and funeral arrangements. She also helps the family to understand legal and administrative processes such as inheritance rights and orphan grants from government. Hospice staff encourage patients to keep a memory box of items such as family photos and favourite possessions, and to maintain a memory book about their lives, which their children can treasure and use in the future.

The Hospice provides all its services free of charge, and family members are encouraged to visit their loved ones. If the family cannot afford transportation, the Hospice can provide assistance. If the family of the deceased person has difficulty meeting the costs of the funeral, the Hospice can provide financial support for the coffin, the undertaker’s charges and the grave site.

Spiritual support is an important part of the life and activities at the Hospice. An Anglican chaplain visits fortnightly to hold services and to pray with patients. A nun from the Sisters of Mercy visits patients at least twice a week to do spiritual counselling. Individual patients are also visited by priests, pastors or traditional healers, depending on their particular faith background. The staff are also ready to give spiritual support: “I offer to pray with the patient, or to read the Bible with them, and most of them are very glad to do that,” says Vivienne Msiza. “But we don’t force anything on them. If they believe in our ancestors,” she adds, “I just pray silently for them and hold their hand.”
the staff share also makes a difference to the quality of the care which they provide to the children attending the Haven.

“I think the fact that this is a place which is faith-based keeps us on our toes. It makes us want to do things as well as we possibly can.

It’s not just a matter of ‘OK, at the end of the month I’ll get my pay’, as though we were working only for money. This is an Anglican Church project. It’s a service to the community we live in, so we’ve got to answer to our own consciences for the work we do here.”
THE STRATEGIES FOR HOPE SERIES

Including Journeys of Faith, the Strategies for Hope (SFH) Series consists of 16 book titles, four videos, and the Stepping Stones training manual and video. Since 1989, production of SFH materials has amounted to almost 900,000 books, over 13,000 videos and over 9,000 training manuals. All SFH materials have been published in English, most in French and Swahili, and some in Portuguese. Please see order form overleaf. Please note that English editions of several book titles are now out of print. SFH materials published before 2002 and still available in English are:

**BOOKS**

No. 5: AIDS ORPHANS: A Community Perspective from Tanzania (1991, revised 1993)
No. 9: CANDLES OF HOPE: The AIDS Programme of the Thai Red Cross Society (1994)
No. 11: BROADENING THE FRONT: NGO Responses to HIV and AIDS in India (1996)
No. 15: OPEN SECRET: People facing up to HIV and AIDS in Uganda (2000)

**VIDEOS**

HIV/AIDS COUNSELLING: the TASO Experience (30 minutes); re-release of Part 2 of the video “TASO: Living Positively with AIDS” (1990)
THE ORPHAN GENERATION: Community-based care and support for children orphaned by AIDS (50 minutes, including 10-minute programme, “These are our Children”)
UNDER THE MUPUNDU TREE: Community-based home care for people with HIV/AIDS and TB (35 minutes)
OPEN SECRET: People facing up to HIV and AIDS in Uganda (40 minutes)

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