PHOTO: TALLULAH PHOTOGRAPHY

The future of the Soweto Home-Based Caregivers Co-operative in AIDS-ravaged South Africa is in question. *by Roberta Staley*

As Thandeka Ndlovu describes her life, she barely mouths the words, requiring you to cup your ear and bend close to hear.

It isn't that Ndlovu is being secretive. Classmates at Lekang Primary School in Soweto, South Africa, already know the Grade 4 student is HIV-positive as well as an AIDS orphan. More likely, a bold articulation of her situation might prove too much for her already heavily weighted shoulders to bear. "My father killed himself when he found out he was HIV-positive; I was six," says Ndlovu, dressed in a worn, maroon-and-yellow-striped school uniform. "My mother died in hospital. She was HIV-positive; I was seven. I had an HIV test

The Soweto co-op's office, meeting room and kitchen is contained in this pre-fab building.

(*below*) **Life is a struggle for Thandeka Ndlovu, who is HIV-positive.**

LIFELINE SOWETO

when I was eight; I was positive. Now, the other children don't want to play with me. They don't want to talk to me. I feel sad. Very, very sad."

Ndlovu, who has a shy, gentle smile and short hair, was born 11 years ago in Soweto, a city of 3.5 million just 20 km from Johannesburg, the industrial hub of South Africa. (She contracted HIV from her mother at birth.) Soweto is best known as the heart of the anti-apartheid movement against racist white rule, which ended in 1994. Today it is arguably the heart of the global AIDS pandemic. About 20 percent of Soweto's population, or 700,000 people, have HIV-AIDS, while 35 to 38 percent of pregnant mothers test positive for the virus, according to South African government statistics. Nationally, 5.8 million are infected; the South African Medical Research Council reports that the virus causes 71 percent of deaths among those aged 15 to 49. Worldwide, 33.2 million people are HIV-positive – 25 million have died since 1981.

South Africa appears to be losing ground to the virus, but these devastating statistics don't reveal the often-unheralded efforts made by

individuals, the community and international NGOs to bring healing and comfort to those afflicted with AIDS.

Ndlovu and her three older siblings live with their grandmother Maria Ndenki. The family survives on Ndenki's old age pension, which is equivalent to about $125 a month. Even basics like soap, not to mention school fees and books, are beyond Ndenki's budget. "My granny doesn't have any money," Ndlovu says. Since her parents' deaths, some of Ndlovu's small but vital needs have been met by the Soweto Home-Based Caregivers Co-operative (SHBCGC), an organization that cares for HIV-AIDS patients convalescing – or dying – at home. As some of SHBCGC's patients have succumbed to AIDS, workers have maintained links with the orphaned children, helping out when they can with financial and emotional support and monitoring their well-being and progress at school and at home.

The desperate need for basic care and public education – from administering drugs to bathing and feeding patients and distributing condoms – has driven SHBCGC's growth. With a staff of nearly two dozen, SHBCGC now attracts workers in their 20s who are cultivating careers in healthcare. This is a positive progression from the co-op's modest beginnings in 1998 when a handful of middle-aged women with basic Red Cross training formed a loosely organized group of volunteers to care for those suffering HIV-AIDS-related diseases like tuberculosis, meningitis or pneumonia.

The SHBCGC is a model of palliative care for Soweto; it and similar organizations play an increasingly important role in the care and treatment of Soweto residents with HIV-AIDS. While physician care and the administration of anti-retroviral drugs (ARV), which reduce the effects of HIV and decrease the viral load, are key, these strategies are complemented by home care, says Dr. Alan Karstaedt, director of the infectious disease division at Chris Hani Baragwanath Hospital. Bara, as locals call it, is the sole hospital serving the city's 3.5 million population. Only the most severely ill patients are admitted. Even seeing a doctor at the hospital's HIV-AIDS clinic can be challenging: it is only open three days a week and people begin queuing hours before it opens, Karstaedt says.

Shortly after the SHBCGC was formed in 1998, the Canadian Co-operative Association (CCA) began helping out, providing training in co-op development. The Canadian International Development Agency (CIDA) has also assisted, giving the group funding in 2001 for a prefabricated trailer to serve as an office, meeting room and kitchen, says Mabel Mashego, who is responsible for SHBCGC's office finances as well as fundraising. The dozen or so caregivers at the time were also given a stipend of 500 rand a month, equivalent to about $75, adds Mashego, seated below an office poster displaying photos of mouth lesions in HIV-positive children.

CCA focused on building capacity at the co-op, providing training in strategic planning and project management. But there was almost total dependence upon the Canadian partners to pay salaries and office expenses. In 2004, the SHBCGC was urged to focus on fundraising. The first project, undertaken by Mashego and two other caregivers, was making and selling food at an international summit being held nearby. That brought in 4,600 rand, or about $675, sufficient to cover just one week of expenses at SHBCGC. Mashego says the co-op also received a 20,000 rand donation, equivalent to about $3,000, from a casino.

Despite CCA efforts to train workers in capacity building, office management, democratic decision-making and fundraising, the organization teeters on the financial brink. The contract with the CCA has finished and SHBCGC, which has an annual budget of 250,000 rand, will run out of money by summer, Mashego says.

Early last month Rev. Marian Lucas-Jefferies, a former nurse who has worked with AIDS New Brunswick, returned to Canada from an intensive one-week assessment of the co-op on behalf of the CCA. While in Soweto, Lucas-Jefferies set up new fundraising and sustainability strategies. But the best way to ensure the co-op's continued existence, she believes, is accessing South African government funding for palliative home-care. To qualify for this funding the co-op must undergo an audit. However, the co-op cannot afford to pay for one.

The story of home-care delivery in Soweto is more positive for another cooperative, the Soweto Retired Professional Society, which created a small hospital in 2004 called Footprints Hospice. The hospice administrators consist of a group of 10 retired nurses, all over the age of 60. These nurses are accomplished in their field and include such people as project coordinator Nada Mayekiso, who is famed as the first black nurse to head

the Baragwana Nurses College. This group has inspired local backing from church and community in a way that the SHBCGC has not managed to do. For example, local stores donate groceries, blankets and linens for the hospital beds, says 67-year-old administrator Auntlate Tindleni.

We need to make sure that [the Soweto Home-Based Caregivers Co-op] continues its work, because its work is so valuable. ▸ Rev. Marian Lucas Jefferies

Footprints moved into a newly renovated building a few months ago and now boasts four wards with 24 beds and an annual operating budget of 1.5 million rand. Patient information, from drug regimen to health status, is computerized. At least 60 of the 300 patients admitted so far to the hospice "to die" have been discharged back into the community after regaining their health with a combination of love, care and ARV drugs, says Tindleni. The South African government subsidizes five beds, but administrators have been forced to seek operating funds elsewhere with great success, getting DeBeers Consolidated Mines and FirstRand Bank to donate generously. DeBeers has stipulated that its grant is to be used to cover salaries; auxiliary nurses receive 2,000 rand a month while senior nurses receive 4,000 rand, which is nearly $600 a month. (While better than the wages at SHBCGC, it is still a modest salary.) Tindleni notes that caregivers are also encouraged to work towards a professional nursing degree.

At one point, it was suggested that SHBCGC join forces with Footprints. However, the fit between the two is tentative at best, says Lucas-Jefferies. She points out that Footprints, as a co-op, cannot act as a charity, and there are fears that SHBCGC would consume Footprints' operating funds. "What is Footprints going to get besides good feelings about partnering with the home-based caregivers?" Lucas-Jefferies observes, adding, "Small contracts with the SHBCGC might be a good way to start building a relationship."

Other organizations such as the CCA and CIDA that have supported SHBCGC in its growth are not charities either and cannot be expected to support the co-op forever. However, even home-care organizations in Canada find it impossible to exist without government assistance, says Lucas-Jefferies, who will be submitting recommendations to the CCA on what it can do to help ensure the co-op's continued existence. "We need to spend extra time and energy making sure that the SHBCGC comes up to snuff to qualify for South African government funding," she explains. "We need to make sure that this co-op continues its work, because its work is so valuable."

To a shy, HIV-positive 11-year-old at Lekang Primary School with no parents, the value of the Soweto co-op is immeasurable. "The workers come and visit me and if I have a problem, we sit down and talk," says Ndlovu. For this young girl and hundreds of others like her – be they adults, teenagers or other children – the co-op is more than just a valuable service. It is a lifeline. E