

Building Community-Based Partnerships to Support Orphans and Vulnerable Children

As the growing number of children losing parents to AIDS overwhelms fragile social safety nets, many believe that strengthening community-based efforts is the only hope for building effective, sustainable support systems for orphans and other vulnerable children.

MaTsepo* likes her work as coordinator of a support group in Soweto, South Africa, because she can help comfort women like herself who are learning to live with HIV. But she still has questions about the virus and how it will affect her own life.

One question looms larger than all the others. MaTsepo takes a deep breath, then says: "Both of us -- me and my husband -- are HIV-positive, and our youngest one is three years old. When I'm going to die, what about my children? Who is going to look after my children?"

It is a question that haunts many parents. More than 32 million adults -- including about 15 million women -- were living with HIV at the end of 1999, and almost 13 million had already died of AIDS.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations Children's Fund (UNICEF) estimate that by the end of 1999, more than 11 million children younger than 16 had lost a mother or both parents to AIDS. According to the United States Bureau of the Census, more than 7 million of those children live in the 34 countries worst affected by HIV/AIDS in Africa, Asia or Latin America. And in the next ten years, the total number of children orphaned by all causes in those countries will rise from 15 million to at least 24 million, largely as a result of AIDS deaths.

A Long-Term Problem

The number of orphans will continue to soar -- regardless of the success of current HIV prevention efforts -- as the tens of millions of people living with HIV/AIDS today fall ill and die over the next decade.

"Even if HIV incidence were to level off tomorrow, you'd still have an increase in the number of orphans and children affected by HIV/AIDS for at least ten to 20 years to come," said Sara Bowsky, a technical officer with Family International (FHI), which is working with community-based organizations in six countries to strengthen support for orphans and other vulnerable children. "The impact of the epidemic will linger for decades."

In Zambia, for example, the number of orphans is projected to peak at almost 1 million in 2014, and orphaning is likely to be a serious problem for another 30 years or more.

Today most AIDS orphans live in sub-Saharan Africa, and nine out of ten live in 19 African countries. In many of these countries, the percentage of all children who are orphans has risen from about 2 percent to 7 percent or higher as a result of HIV/AIDS. By the year 2010, one out of every three or four children in Botswana, Burkina Faso, Malawi, Rwanda, Tanzania, Uganda, Zambia and Zimbabwe will be an orphan.

Most countries in other regions of the world are just beginning to see increases in orphaning. The number of orphans in Asia can be expected to skyrocket as the growing number of people living with HIV in this populous region -- more than 4 million in India alone -- begin to die and leave children behind.

A Second Chance

Behind the staggering statistics are children. Children like Keith in Zambia, whose comfortable, happy world collapsed after his father died when he was 12. His father's relatives took all the family's property, leaving Keith's mother with nothing.

The family struggled to stay together. But eventually Keith was sent to a children's town (orphanage) in the capital city of Lusaka, while his mother and two sisters were taken in by maternal relatives in their home town of Ndola.

Keith excelled in school at the children's town, scoring well enough on a highly competitive examination to qualify for secondary school. But no one was able or willing to help him further his education. He ended up on the street, where he took to heavy drinking and theft.

Keith's experience is not unusual. But he is more fortunate than most orphans, because he was rescued by a social worker from a project called CINDI (Children in Distress), which is run by Zambia's Family Health Trust (FHT). CINDI gave him counseling and helped him go back to school. Keith still feels bitter toward his father's relatives, but he is working hard and getting good grades. He hopes to use his academic abilities to build a better future for himself and his family.

"Keith's story shows how a combination of factors -- death, hostile cultural practices, street life -- can negatively impact a young life," says Elizabeth Mataka, executive director of FHT. "But it also shows that when they are given a chance, all is not necessarily lost to these children."

Vulnerable Children

The basic needs of orphans -- food, shelter, clothing and medical care -- are painfully apparent. Studies have found that orphans are more likely to be stunted in their growth and less likely to be enrolled in school than children living with both parents. Poor nutrition and limited access to health services put orphans at increased risk of starvation, illness and death.

Without nurturing from a loving parent or guardian, children's emotional development may be stunted as well. Children in Zimbabwe told the staff of the Families, Orphans and Children Under Stress (FOCUS) Programme run by Family AIDS Caring Trust (FACT) of being neglected, ostracized and abused. "No one wants to live with us," said one. "They always complain about us staying with them." Another child lamented: "When I was beaten, I thought that if my parents were here, then things would have been different."¹

Children living in child-headed households, on the street, or with families who regard them as an

unwanted burden are particularly vulnerable to neglect, abuse and exploitation. Those subjected to sexual abuse or exploitation are at increased risk of becoming infected with the virus that killed many of their parents.

Such problems can begin long before children lose parents to HIV. In households where a parent or parents are suffering from AIDS, older children are often responsible for supporting their families and providing care. Children of all ages struggle with the pain of losing a parent and the stigma of living in a family touched by HIV/AIDS.

Efforts to help children may inadvertently add to that stigma by singling out those orphaned by AIDS. They also may miss some of the most vulnerable children, according to John Williamson, senior technical advisor to the United States Agency for International Developments (USAID) Displaced Children and Orphans Fund.

"At the community level, it's really important that we don't just target our efforts and our resources to children who are orphaned by AIDS, or even just to orphans," he said. "Our job is to help the community look at who they're most concerned about."

On the Front Lines

As AIDS claims the lives of more and more adults, the traditional safety net for orphans -- the extended family -- becomes stretched to the breaking point. Nongovernmental organizations (NGOs) sometimes step in to provide food, clothes, health and social services, school fees and even housing. But there is growing recognition that such small, intensive service delivery programs can help only a fraction of the children and families who need them.

Many who have been working with orphan programs during the past decade say we must look within communities for solutions.

"Communities have always had to deal with vulnerable children and orphans," Bowsky said. "Our responsibility is to figure out from the communities what they need and how we can support and strengthen their traditional ways of caring for orphans and vulnerable children."

Williamson came to this realization nine years ago while assessing orphan support needs in Uganda. Members of the assessment team assumed that government and NGO officials were at the forefront of the response to the orphan problem there, but that perception was reversed when they visited villages in Rakai and Masaka districts.

"We realized that the front line was the families and communities," Williamson said. "And what the rest of us could do was going to have significance largely to the extent that it made it easier for families to cope, made it easier for communities to support the families and the vulnerable children."

Community-Based Programs

Most programs for orphans and vulnerable children (OVC) aim to strengthen the ability of families and communities to support and nurture those children. They strive to keep siblings together and children within their extended families and communities, using institutional care -- which is more expensive and far less likely to meet children's developmental needs -- as a last resort.

FACT's program in Zimbabwe's Manicaland Province is praised for its ability to motivate community volunteers and support orphans and vulnerable children at a relatively low cost. As FACT expanded FOCUS from a pilot project serving 300 households in one community to a program for 2,800 households in nine communities, the annual cost per family served fell from US\$ 44 to \$9.

The core of the FOCUS Project is its "community visitors," volunteers who identify and visit vulnerable children, determine how to meet their needs using community resources, and distribute donations of food, blankets, maize seed and fertilizer to the most needy households. The volunteers visit each of these households at least twice a month to offer emotional and material support.

Widows in Zambian communities are also volunteering their time to visit and support orphans and vulnerable children. These "widow's clubs," sponsored by the FHT's CINDI Project, provide transitional material assistance to child-headed households to help siblings stay together in their communities. In addition to giving the children food and plots for gardens, they pay for vocational training for the eldest child in a family and school fees for the younger children.

FHT facilitates the community mobilization process, provides training, and links widows' clubs and other community-based organizations to sources of funding and credit, but the volunteers do the rest. In fact, CINDI's guidelines require that the majority of officeholders in participating organizations be women whose lives have been affected by HIV/AIDS. "When people directly affected by the problem are involved, their motivation is clear and unquestionable," Mataka noted.

Another "CINDI," the Children in Distress Network in South Africa's KwaZulu Natal Province, coordinates the diverse efforts of local NGOs and government agencies to improve the lot of orphans and vulnerable children. These programs include early childhood education, outreach to identify street children and reunite them with extended or adoptive families, support for small group homes in communities, and recruitment and training of foster parents for children believed to be HIV-positive.

Members of South Africa's CINDI say that belonging to this network gives them opportunities to share resources and ideas and enhances their credibility with donors. The services offered by each organization in the network have been strengthened by collaborative efforts to provide material assistance, collect statistical information, train child care workers and advocate for policies that protect children's rights.

Expanding Community Responses

What these and other successful projects have in common is their emphasis on community members identifying their own priorities and responses. Examples of such community-initiated responses include

cooperative child care centers, community schools that offer free education, and communal gardens to provide food for needy families.

Increasingly such activities are being linked to HIV/AIDS prevention and care services. OVC projects may enlist nurses who provide community-based AIDS care in efforts to register and monitor vulnerable children. Students involved in HIV/AIDS prevention clubs in schools sometimes raise money or repair houses to help their schoolmates.

As volunteers and project staff develop a deeper understanding of the needs of vulnerable children, they begin to address more complex issues, such as child protection and emotional well-being. Providing counseling by trained counselors is beyond the means of most community-based projects, but volunteers and other members of the community can help children cope with the trauma of losing a parent.

Some community groups organize sports, youth groups and cultural activities to give orphans opportunities to interact with other children and outlets for pent-up emotions. School programs educate students about how HIV/AIDS affects families and encourage them to support each other. Volunteers and teachers can also be trained to recognize signs of emotional distress and talk to children about their problems.

Often adults can make a big difference simply by listening to vulnerable children. A key finding of the 1999 evaluation of the FOCUS Programme was that children felt the volunteers often overlooked them, speaking only to the adults in their households. As a result, the project was not addressing what the children considered their major problems: stigmatization and sexual vulnerability.

Heightened awareness of the potential for exploitation and abuse of all kinds, leading to community action to protect children, has been an unexpected result of community mobilization for many OVC projects.

Williamson saw this happen in urban communities in Zambia, where Project Concern International had mobilized community members to support vulnerable children. "People said they had begun to intervene in situations where, in the past, they would have said, 'That's a family thing, it's not our business,'" he explained.

In one community, for example, community members pressured a man who had abandoned his family to return household goods he had taken and to continue supporting his children. In other communities, people have reported cases of abuse to the authorities or convinced traditional leaders to protect the property rights of women and children.

A growing number of community-based projects are beginning to advocate at the community, district and even national level for policies to protect and support children. For example, two CINDI branches in Zambia's Eastern Province successfully lobbied for exemption from school fees for orphans and vulnerable children in their districts.

Generating Income

To promote self-reliance and more sustainable responses, donors often require communities to commit their own resources before providing limited funds for OVC support activities. Many communities have started income-generating activities such as raising poultry, tailoring and gardening to earn money for direct aid to needy families or to strengthen the finances of families affected by HIV/AIDS before they become destitute.

The most promising approach to shoring up household income appears to be providing small loans through village banks. Borrowers have used these loans to start their own enterprises, such as market trading, charcoal making and honey production.

Many microcredit experts had said such programs would not work in communities ravaged by HIV/AIDS. They believed the default rate would simply be too high.

The success of village banks supported by the Foundation for International Community Assistance (FINCA) in Uganda and Malawi has confounded these expectations, with loan repayment rates of 99 percent. Although FINCA does not target households affected by HIV/AIDS, 75 percent of the Ugandan participants recently reported that they were caring for orphans.

Taking Time

Many NGOs are struggling to move from direct service delivery to more community-based approaches to OVC support. This transformation can be difficult because the pace of community mobilization often runs counter to the natural instinct to respond quickly when children are suffering.

"People get very anxious to do something fast," Bowsky said. "But there's no quick fix."

The importance of taking the time to involve beneficiaries and other community members was brought home to Bowsky when she talked to a group of HIV-positive women who belong to one of 12 Hope Worldwide support groups in Soweto. Hope staff had initially identified healthcare, jobs, child care and support for education as group members' main needs.

But many of the women felt paralyzed to take advantage of such services because they were unable to disclose their serostatus. "How can I do anything if I can't tell my child I'm dying of AIDS?" one woman asked with tears in her eyes.

In response to these concerns, support group coordinators are working with group members to address disclosure and planning. Some of the women are keeping memory books with journal entries, photos and other keepsakes for their children.

Mobilizing Communities

For its new OVC project with FHI, Hope Worldwide has already begun involving community members. Project staff (many of whom belong to the support groups) have mapped each of the 12 areas of Soweto covered by the project to identify individuals and groups that could contribute to the project, opportunities to link with related programs, and community resources for OVC support.

The next step will be to hold focus group discussions with many of the people identified during the mapping exercise to begin assessing the needs of orphans and vulnerable children and forming community groups to respond to those needs.

Focus group discussions will also be used as both assessment and community mobilization tools in the new USAID-funded Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children (SCOPE-OVC) Project in Zambia. Participants in the process will develop their own criteria for determining which children are vulnerable, then use those criteria to identify children and households in need of support.

CARE International and FHT will facilitate community mobilization and capacity building, with technical and financial support from FHI's Implementing AIDS Prevention and Care (IMPACT) Project. Beginning in four districts and gradually expanding to nine, SCOPE's community mobilization officers will support local OVC committees and link them with similar committees at the district level.

Community mobilization officers will also work with community members to develop their own monitoring and evaluation plans. FHI's Bowsky provided technical assistance to design a plan that would capture the data needed to assess the results of SCOPE while giving communities the freedom to choose and measure their own indicators of progress.

Examples of evaluation indicators communities might consider include the number of children placed in or returned to school for at least one term, the number of children who had been living in institutions or on the street who have been reintegrated into communities, and increased economic resources in households with orphans or vulnerable children.

"The key is that not every community is going to have the same indicators," Bowsky said. "We have to allow community members to look at their own priorities."

Bridging the Gap

Monitoring and evaluation are particularly important for OVC programs because no one has ever attempted to meet the needs of so many orphans before. Many questions remain about how to bridge the immense gap between the need and the response.

In just one of the most affected countries -- Zambia -- volunteer groups, churches and NGOs assist only about 7 per cent of the children who need help.

"There are a lot of very good, relatively small and modest responses," Williamson said. "But how to go

from there to something that even begins to match the scale of the problem is where we're really struggling right now."

Experience to date suggests that simply expanding successful programs may not be the answer.

"Often we seem to hit some kind of ceiling with community mobilization programs," Williamson explained. "When you try to develop a single program beyond a certain size, then the community ownership gets lost."

Instead of "scaling up," many programs are looking at "scaling out" by sharing their methods and lessons with other groups. FACT, for example, has decided against further expansion of the FOCUS Programme, but has helped several groups in Zimbabwe and at least three organizations in other African countries start community-based OVC programs.

As the number of organizations and individuals involved in OVC support grows, it will become even more important to stitch together the patchwork of projects and services for vulnerable children. Structures such as the networks of village and district orphan care committees being developed in Malawi and Zambia can help coordinate the efforts of various groups. They can also encourage broader participation in OVC programs from all sectors of society -- from businesses to churches to government agencies.

Sharing the Burden

Everyone recognizes that communities cannot tackle the problem alone, particularly as even more adults succumb to AIDS. FHT's Mataka believes that communities must advocate for government policies that are more supportive of vulnerable children and their families -- such as laws to protect the inheritance rights of women and children and removing financial barriers to education -- and for more resources to improve woefully inadequate social welfare and health services.

Effective support for vulnerable children requires access to sound healthcare, education, social services, economic opportunities and HIV prevention services, yet health and social welfare budgets are shrinking in the countries where these services are most needed. Donors are beginning to commit more funds to OVC support. But the international community has yet to face the implications of an epidemic that will kill tens of millions of adults and, in some countries, orphan more than one-quarter of all children.

While recognizing that communities should not be expected to shoulder the entire burden of supporting those children, Mataka and others agree that communities must lead the response if it is to be effective -- and sustainable.

"If we don't strengthen and support the families and communities, the numbers are simply going to overwhelm any kind of possible service response," Williamson concluded. "It's not going to be business as usual as far as development work in these communities that are seriously affected by AIDS."

-- Kathleen Henry

* MaTsepo's name has been changed to protect her privacy.

References

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Talking to the Virus: A Mother's Story

I was diagnosed in 1996. I had a problem with herpes, so I went to the clinic. They did an RPR test [for syphilis] and it came back negative. Then they did an HIV test. I didn't have any problem with the test -- it didn't concern me.

So they did the test. After two weeks I went back to fetch my results, and they were positive. I was shocked. I felt so much pain and fear -- I thought the person who gave me my results must hate me or something.

My emotions were intense. I didn't cry, but something was happening inside me -- I don't know what. Gradually this intense emotion became more manageable. I wanted to be ready to tell my boyfriend, so I had to deal with it.

After six months, I told my boyfriend. He told me, no problem. If I have HIV, then he is also positive. I think he knew before me, but I'm not sure.

There was no support group and no place where I could go and get education about HIV and AIDS. And I was not even interested, because I think I was in the denial stage.

In 1998, I was pregnant. In the hospital they told me that the baby was not sitting in the right position, and they decided to admit me. After three weeks, they found out that the baby was not gaining weight. The weight was going down, and I had high blood pressure, so they decided to do a Cesarean section.

It was then that I realized that HIV is there, because I met other women at the hospital. They were pregnant with HIV, and we

talked.

I learned that there are drugs which are helping people to live longer. Unfortunately, it's not everyone who has access to them, and they don't work for everyone.

After Rose was born, we were in an AZT study. I took AZT for six months. But later, when I moved to Johannesburg, I was not able to go back and get the drugs, and I could not get into another study.

My daughter Rose was so small. She was in an incubator. After two weeks, she weighed 1.9 kg. [kilograms]. They wanted to give her to me when she weighed 2 kg. But on Good Friday, they decided to give me Rose. They said that if she's not gaining weight -- if she's not at least 2 kg -- I must bring her back.

By that time I was starting to fight with Rose's father. Things were not going right. But I went to his house, and Rose did recover.

We were fighting a lot because I think Rose's father was in denial, and he didn't want to hear anything about HIV and AIDS. After three months, I came here to Johannesburg to my family so that they could help me with Rose.

I stayed here with my mother's sister. I was not breastfeeding Rose. I had to buy formula milk, food and clothes, and there was no money. I was struggling a lot, and there was no food in the house. I used to look at my child and cry.

I think that this stress is what brought on the symptoms. I had severe diarrhea, and I thought I was going to die. I didn't even have money to go to the hospital. But even though I had diarrhea for three months and I was not eating well, I did not lose weight. That's why I think it was stress, not the virus.

I took Rose to a special clinic to get her immunizations. The sister there told me that Rose was not gaining weight, and why? I kept quiet for the first visit. The second visit, I decided to tell the sister. I spoke with her in private, and I told her everything. I told her that I am living with HIV, and there is no support from Rose's

father, and I don't have money to buy milk. She told me that she would give me the milk and the soup for my child.

She took me to the Hope Worldwide support group in Chiawelo Clinic. I found a counselor there, and she talked to me. She said every day when there is a support group, I must come there and be involved and talk with them about my problems so that I can relieve stress.

There were food parcels there. And I was happy that there was food there because I was asking myself when I was going to eat after that. So I was happy, especially to see that there were fruit and vegetables there.

The second time, they told me that there is a support group every day in Jabavu Clinic.

People were saying that this place is for people who've got AIDS, so I was so scared to come here. But I did come, and I received training in maternal and child health, STDs [sexually transmitted diseases], and HIV and counseling. I met other women here, and we talked.

I found women who have been living for a long time with HIV. And I felt like no, it's not me alone. We really talk, and the counselor is always here for us. I talk to her about other things, not HIV only.

After some time, I was no longer afraid of coming here. I'm fit, I'm fine, and nobody can see that I have HIV.

Through my involvement with the Hope project, I sometimes forget that I am HIV-positive. Because we have the support group. We make peanut butter and cushions to sell, and we're also doing a garden. So all those things keep you busy.

They tested my daughter for HIV when she was one year, five months, and she was okay then. When she was 23 months they tested her again because she had pneumonia, so they felt the first results were false negative.

I felt like I needed to do the test because she was not gaining

weight. I used to look at her and think she was getting smaller and smaller. I just told myself that she's positive, and that's it.

Then when they told me she was negative, I was so happy! I wanted to tell everybody, even people who didn't know me. I wanted to tell each and every person I met.

Rose goes to the creche [child care center] now, and I'm able to feed her with the money I earn working for Hope. The salary helps, but it cannot cover everything. I have to go to the HIV clinic once a week, and the fee has increased. Then I have to go to a private chemist for medicines, and I have to pay for public transport. We are living at my grandmother's house, a family of nine in three rooms. I sleep in a shack at the back of the house with my daughter and my younger sister.

So it's still tough, but right now I am the happiest I've ever been. One of the things that really helped me was to disclose to my sister four months back. My counselor also helped with that. I said, "I think I should tell my sister about my status, because somebody in my family must know about this." So she said to me, "Okay, you can come with her here and talk to her."

I was afraid and wanted my counselor to break the news for me. But she's not the one who's supposed to talk for me.

My sister did come, and I did break the news to her, and she was fine with it. I wanted somebody in my family to know because when I get sick or something happens to me, I have to know who will take care of Rose.

My father left me when I was four years old, and my mother when I was 12. After turning 18, I started realizing that I needed my mother more than anything.

Sometimes I think that one day I'm going to die, and I start to cry. I'm starting to read the books that will help me, and I'm seeking advice on how to plan for Rose's future. I want to be strong with that.

Rose is too young now, but I will definitely tell her about my HIV

because I don't want her to go through what I did. Every time that I pray, I pray to God that he keeps me alive until my daughter is ready to listen to what I want to tell her.

But if I'm not here by that time, okay, I'll leave a memory book for her to read. So that if she decides to be involved with boys and things like that, it's her decision, but my job will be done. I will have told her everything.

I have already planned how I am going to start with her. That is the thing that keeps me going, because I've told myself that I'm not going to die now. I'm not going to let HIV destroy me.

That's why I always talk to it. I say, "I know virus, you are in my body. You have to be friends. I know that you are stronger than me, but this is my body. You have to give me some time to live so that I can see my daughter growing."

This is the story of a 24-year-old South African woman living with HIV in Soweto, Johannesburg. Her daughter's name has been changed to protect their privacy.