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Rising to the Challenge

Health Policy Initiative
Helps HIV-positive
Teachers Tackle Stigma
and Discrimination in
Kenya

Kenya

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Stigma and discrimination have been stumbling blocks in Kenya’s national response to the HIV epidemic. Self stigma and fear of being stigmatized have kept many people living with HIV (PLHIV) from disclosing their HIV-positive status or seeking the treatment, care, and support they need to live positively. Perceptions that HIV is a death sentence, a “sinners” disease, and other misconceptions have fueled stigma and discrimination and discouraged those who do not know their status from being tested for HIV.

While HIV-related stigma is a challenge throughout Kenyan society, it has rendered certain groups particularly vulnerable. Members of particular professions, such as

teaching, have been acutely stigmatized because of their positions of trust in the society. Teachers living with HIV have been wrongfully dismissed, interdicted (officially barred from performing their teaching duties), or forced to resign their posts because of their status. They have also been denied transfers and promotions and been ridiculed and stigmatized by students, fellow teachers, and the community at large. At the post-primary level, access to HIV counseling, testing, and treatment services has been limited and levels of stigma are extremely high.

Recently, this situation has begun to change, in part, due to the efforts of networks of teachers living with and affected by HIV. With assistance from the USAID | Health Policy Initiative, teachers have come together to support and educate each other about HIV, encourage each

other to seek treatment, and advocate for their rights. The project has provided training and financial support to strengthen and expand the Kenya Network of Positive Teachers (KENEPOTE). It has also helped facilitate the formation of a new network to support PLHIV, fight stigma and discrimination, and raise awareness of HIV at post-primary educational institutions—the Kenya AIDS Network for Post-primary Institutions (KANEPPPI).

Learning to Live Positively

KENEPOTE helps HIV-positive teachers combat stigma and mobilize communities

KENEPOTE, Kenya’s first network of HIV-positive teachers, was founded in 2003 by two primary school teachers, Elsa Ouko and Margaret Wambete. Since then, KENEPOTE has expanded across the country and become an influential advocate for the rights of HIV-positive teachers. The network has also become an active force in mobilizing communities to fight HIV-related stigma and increase care and support for orphans and vulnerable children (OVC).

KENEPOTE’s mission is to improve the quality of life of HIV-positive teachers; strengthen their capacity to act as advocates fighting stigma and discrimination in the education sector; enhance their productivity at work; promote greater involvement of PLHIV (GIPA) and increase HIV-positive teachers’ involvement in local and national decision- and policymaking bodies; and promote access to high-quality care, support, and treatment. Since 2003, the network has blossomed. It now has more than 4,000 members across all eight provinces and more than 50 grassroots support groups.

Advocating for Teachers' Rights

KENEPOTE members use advocacy skills to fight stigma and discrimination

The POLICY Project, predecessor to the Health Policy Initiative, was instrumental in facilitating the formation of KENEPOTE. The project helped the network hold its first national forum and draft its first operational plan. Since 2006, the Health Policy Initiative has continued to build KENEPOTE's institutional and technical capacity through training, technical assistance, and financial support. The project has trained KENEPOTE members on leadership and network management, community mobilization, advocacy, stigma and discrimination, OVC care and psychosocial support, treatment literacy, GIPA, palliative care, life skills training for OVC, proposal writing, and monitoring and evaluation.

In March 2008, the Health Policy Initiative provided technical support to KENEPOTE for the drafting of a new constitution, which was ratified at a national delegates' conference in June 2008. Under the new constitution, KENEPOTE is governed by a steering board, which includes the National Coordinator and nine provincial coordinators (Rift Valley is served by two coordinators). The provincial coordinators supervise district coordinators who, in turn, coordinate the activities of the support groups. KENEPOTE is in the process of officially registering as an independent NGO.

In addition to providing trainings directly to support group members, the project has also trained KENEPOTE trainers who are able to provide ongoing capacity building to their fellow network and support group members.

The project's training has strengthened KENEPOTE as a network, helping it gain recognition and enabling it to successfully advocate for the rights of HIV-positive teachers.

As a result of the network's advocacy efforts, many teachers who had been dismissed or disciplined because of their HIV status have now been reinstated. HIV-positive teachers are also beginning to receive promotions and recognition in the workplace—something that was virtually unheard of just a few years ago.

KENEPOTE members have gained national and international recognition for their efforts. The network is recognized by and works in close partnership with the Ministry of Education, Science, and Technology (MoEST) and the Kenya National Union of Teachers (KNUT)—two of the most powerful actors in the education sector. One of the network's top officials, Jemimah Nindo, was appointed as Senior Administration Officer in charge of advocacy and counseling at the Teachers Service Commission (TSC) AIDS Control Unit—the first time that an openly HIV-positive teacher has held such a position at the commission. Network members also sit on Constituency AIDS Control Committees and participate in the Joint AIDS Program Review and are advocating for involvement of PLHIV in Constituency

BOX 1

KENEPOTE Vision and Mission

Vision

KENEPOTE aspires to create an environment where teachers with HIV and AIDS will be free from fear, shame, denial, stigma and discrimination; to avoid further spread of HIV and re-infection; to have access to information, education, care, treatment, and support for its members, orphans, and vulnerable children; and to uphold the dignity and professionalism of teachers and to ensure that this is not compromised regardless of status so that teachers continue to serve as productive agents of change in the community and beyond.

Mission

To build the capacity of its members in advocacy for the reduction of stigma and discrimination and protection of rights of HIV positive teachers, orphans, and vulnerable children; increase access to psychosocial support services and skills to teachers; and prevent further spread of HIV and AIDS in collaboration with other stakeholders—such as faith-based organizations (FBOs), public, private, and civil society organizations—by bringing about positive changes in attitudes and behaviors in communities.



Elsa Ouko and Kephers Khejeri—founders and National Coordinators of KENEPOTE and KANEPPI, respectively.

“A change begins with one person. It begins with you... You will start as one person, but one day you will help the whole world.”

—Elsa Ouko
National Coordinator, KENEPOTE

Development Fund (CDF) Committees. Moreover, the network’s model has already spread beyond Kenya’s borders, and is being replicated in Uganda, Zambia, and Cameroon.

In 2006, KENEPOTE’s advocacy efforts led the TSC to draft and adopt a sub-sector policy on HIV/AIDS that emphasizes GIPA principles. Furthermore, at KENEPOTE’s insistence, TSC has also adopted a policy that all trainings conducted by TSC must include a session on stigma and discrimination reduction and psychosocial support conducted by KENEPOTE members.

Mobilizing Communities

Through training, KENEPOTE members engage grassroots

The Health Policy Initiative and KENEPOTE worked together to design a community empowerment mobilization curriculum, which network members used to conduct community-level trainings on antiretrovirals (ARVs), treatment literacy, nutrition, stigma reduction, and positive living. The trainings reached more than 2,000 people across four provinces and the community response was overwhelming.

KENEPOTE National Coordinator, Elsa Ouko, described the scene at one such training:

“We only budgeted for 100 people, but 200 people came. Then I told them, ‘Where will I get food? My God! I only invited 100 people!’ They said, ‘We don’t want food. We only want this education. It has never come to our locality. Please allow us to be trained’.”

In the end, community members contributed food for the extra participants, and KENEPOTE was able to train all 200 people.

KENEPOTE’s enhanced capacity has had a profound impact on the lives of its members and their communities. The number of teachers seeking voluntary counseling and testing (VCT) services and antiretroviral treatment (ART) has increased and more teachers are speaking openly about their HIV status. Several members of KENEPOTE’s Kombewa support group credit it with saving their lives (see pages 4–5). Support groups have also increased access to VCT and ART in their communities. For example, after a community training, the health center in Kombewa began offering ARVs for the first time.

According to Caleb Ochieng’—the leader of KENEPOTE’s Kombewa support group—teachers who have been empowered by the group have gained the confidence to reach out to help others, creating a multiplier effect that has spread beyond the teachers themselves. Ms. Ouko, described this, saying that the groups have “made the teachers become role models in the community; because other people within the community realized that ‘If a teacher can accept this status and go around and speak about



Changing Lives

In Kombewa Community, KENEPOTE's Impact Is Deeply Felt

When it was founded in 2005, KENEPOTE's support group in Kombewa, a town in the Nyanza region, had 16 members. Since then, the group has grown to 43 members (23 men and 20 women) and become a beacon of hope and a source of much-needed support for its members and the wider community.

As people living with HIV, members have felt the sting of stigma and discrimination from healthcare providers, fellow teachers, students, community members—even their own family members. After a stigmatizing encounter with a clinical officer, one teacher was discouraged from returning to the local health center and waited for months before seeking HIV testing in a private clinic.

Several group members first sought HIV testing after an encounter with the KENEPOTE group. "It was through this group that I even made it to a health facility," says one such member. Like so many

others, when he learned that he was HIV positive, he thought that his life was over. He stayed at home, alone, without seeing anyone. That was when Caleb Ochieng'—the leader of the Kombewa support group—came to see him. "He came to my home and talked to me and then took me to the hospital," the man says. "From there, he got me into this [support group]. And from the group, I was empowered and even ready to talk about my status. And I have managed to empower so many people."

Another member, a young woman, also credits the support group with saving not only her life, but the life of her husband as well. She discovered her status in 2005 after meeting with one of the support group members. "I got encouraged by [her]. She became my friend and I opened up to her... So I learned my status." The young woman describes how hard it was for her to disclose her status to her partner, who had not gone for testing. "It was so difficult for me to start medication



"I'm very happy to be associated with these members because, without their support, I don't think I would exist."

—Member of KENEPOTE's Kombewa support group

Above: Member of the Kombewa support group shares her story, expressing gratitude for the group that helped her gain the confidence to live positively. Top left: Caleb Ochieng', leader of the Kombewa support group.

or disclose to him, because I couldn't know how he would react." That was where the support group came in. "Now, having joined the group, I got the capacity. I got the knowledge, and I became bold and I opened up. .. and I'm happy to say that, through me, my partner is surviving now. Because last year... he was almost dying... but because of my strength and the support from members he is working, he is taking his ARVs... I'm very happy to be associated with these members because, without their support, I don't think I would exist."

Most members of the Kombewa support group have been trained on stigma and discrimination reduction, community mobilization, OVC care and support, strategic planning, and monitoring and evaluation. Through these trainings they have been able to fight stigma and discrimination in their community, begin providing care and support to OVC, and encourage other teachers and community members to seek testing and treatment.

One teacher describes how she has used her training. "After getting training, it empowered me to go and train the community where I teach. And from there the parents have come up. They have told



Several members of KENEPOTE's Kombewa support group gather in front of the resource center at a local primary school.

me, 'Madam, you have helped us.' Some of them are now accessing ARVs, some of the parents and their children are also accessing ARVs."

"Our group has helped this community a lot," one member says. "Because we accepted that we were positive and, after accepting, we've been sensitizing from home where we live up to school... So our hands have spread to the whole community."



Member of the Kombewa support group smiles as he relates how the support group and its leader, Caleb Ochieng', helped save his life.

Support group members acknowledge that their work is not without challenges. A few members have become less active as they have had trouble balancing their teaching duties and family responsibilities with participation in the group. Others have been discouraged by the lack of direct financial support for the group's activities.

Stigma and discrimination will not disappear overnight. But here in Kombewa, KENEPOTE's support group is slowly turning the tide—and changing lives in the process.

it—and even go to church!—then why am I not accepted?’” This has encouraged others to come forward to seek counseling, testing, and treatment services.

Ms. Ouko emphasized the importance of grassroots trainings. “Community-level training is very important. There is a need at the grassroots level. People are still ignorant about HIV. People are still thirsty for knowledge.” She also explained how cost effective the network had found this type of training to be. “For the money for one training in a hotel where you take 40 or 50 people, you will reach even 600 people at the grassroots level. And you shall have changed somebody’s life down there.”

Caring for Vulnerable Children

KENEPOTE members mobilize communities in support of OVC

OVC must overcome multiple obstacles to gain access to education. Limited financial resources, the burden of caring for family members affected by HIV, and stigmatizing attitudes toward OVC often prevent them from attending school, even at the primary level. Primary school teachers are uniquely knowledgeable and well positioned to advocate for OVC’s right to attend school. With training from the Health Policy Initiative, KENEPOTE has also begun to advocate for OVC rights, provide psychosocial and other direct support to OVC, and mobilize greater community awareness of and support for their needs.

KENEPOTE has broken new ground in this area by reaching out to parent-teacher associations (PTAs) to help OVC overcome barriers to education. In August 2008, the network trained 53 PTA members from nine districts and three provinces (Nairobi, Nyanza, and Western) on implementation and advocacy for increased access to treatment, care, and support for OVC in schools. The trainings revealed a lack of knowledge among PTA members that had contributed to insufficient support for OVC in schools. Participants came up with workplans outlining how PTAs and OVC guardians would work together to support the well being of OVC. When KENEPOTE returned to monitor the impact of the trainings, they found that participants had formed groups bringing together guardians, PTAs, and teachers at the school level to address the needs of OVC.

Ms. Ouko was struck by the fact that participants designed approaches that were tailored to fit the local environment and culture. “They came up with their own approach of how to help these children,” she says. “What we got in Nyanza was not what we got in Western. They were coming up with their own approach that suits their culture and which is also comfortable with them... It was very successful.”

KENEPOTE also reached out to OVC directly, providing life skills trainings for those between the ages of 14 and 17 in three provinces. For many OVC, this was the first chance they had ever had to share what they were going through. The training highlighted the need to form more psychosocial support groups for OVC themselves.

BOX 2 KENEPOTE Achievements

- The number of teachers nationwide who have openly disclosed their HIV status has risen significantly since 2003.
- Levels of stigma and discrimination in schools are showing signs of abating, as teachers have shared their personal experiences with the school administration and with their fellow teachers.
- Advocacy by KENEPOTE led to a reduction in the number of disciplinary cases brought by the Teachers Service Commission against HIV-positive teachers.
- Advocacy by KENEPOTE also led to the development and adoption of a customized HIV workplace policy at the Teachers Service Commission.

Reaching Higher

KANEPPI brings advocacy and support efforts to post-primary institutions

While KENEPOTE has been serving HIV-positive primary school teachers since 2003, until recently Kenya lacked a network to support teachers affected by HIV at the post-primary level. With a boost from KENEPOTE and the Health Policy Initiative, the Kenya AIDS Network for Post-primary Institutions (KANEPPI) was established on August 7, 2008.

While KENEPOTE's members are mostly primary school teachers, KANEPPI aims to support teachers and the wider academic community (including students and non-teaching staff) at post-primary institutions. Kenya's post-primary educational institutions include a broad range of teachers' colleges, universities, technical institutions, and secondary schools. The new network aims to both champion the rights of HIV-positive and affected teachers and to spark a stronger HIV response at these institutions. The network's efforts include raising HIV awareness among students, fellow teachers, and other staff, as well as fighting stigma and discrimination. KANEPPI welcomes the participation of non-teaching staff, making the group an eclectic mix of professors, doctors, and lawyers, as well as administrative and custodial staff.

In many ways, KENEPOTE catalyzed the formation of KANEPPI. In 2005, after learning of his HIV-positive status, Kephers Khejeri, KANEPPI's founder and coordinator, joined KENEPOTE in search of support. He found it difficult to feel comfortable in the network, however, as most of the members were primary school teachers and he was a university lecturer. The context he was living and working in was drastically different from the other members, and the members themselves felt uncomfortable with him. Mr. Khejeri began reaching out to other teachers in secondary schools and colleges.

Elsa Ouko was appointed as an advisor for KANEPPI. Mr. Khejeri and Ms. Ouko traveled together across the country to mobilize support for establishing a PLHIV network for post-primary institutions. As they traveled, they saw that there was a great need for such a network. Many lecturers confided their HIV-positive status to the pair and asked for support.

In 2008, Mr. Khejeri, along with three other professors, approached the Health Policy Initiative for assistance. The project began supporting mobilization efforts in preparation for the launch of the new network. The project's backing enabled Mr. Khejeri to travel to more universities and post-primary institutions, where he addressed both teachers and students. After his talks, many students would come forward and ask to access VCT services.

Following KANEPPI's launch, the Health Policy Initiative trained the network's 53 members in policy advocacy, network formation, stigma and discrimination reduction, and consultation. The project also enabled KANEPPI representatives to meet with the Country Coordinator of the President's Emergency Plan for AIDS Relief (PEPFAR) in September 2008 to help the network understand PEPFAR programs in Kenya and forge linkages with other PEPFAR-funded agencies. In January 2009, the project sponsored a workshop for KANEPPI to finalize its constitution. Members ratified the constitution, formed the institutional structure, and elected officers. The network also drafted a workplan to guide its activities in the coming year.

The Health Policy Initiative also helped facilitate a television appearance for KANEPPI's National Coordinator. Mr. Khejeri was interviewed by the national television network, KBC. The response to the program was tremendous. The station received so many calls from teachers that they could not handle them all during the one-hour program. So, the studio asked Mr. Khejeri to remain. He continued to answer calls off the air. "I was called

"University students are also lacking role models...I remember going to one class, and I told them 'look at me carefully'...and then I told them I'm HIV positive and I'm a lecturer. And the whole hall was quiet. You could even drop a pin and hear it falling... After I had finished, they demanded that 'we want to go for VCT'."

—Kephers Khejeri
National Coordinator, KANEPPI

by teachers from all over Kenya,” he recounts, “about 205.” The strength of the response to Mr. Khejeri’s interview demonstrates the extent of the need for the support KANEPPPI is offering.

KANEPPPI continues to mobilize additional members from different universities and tertiary institutions and to create awareness. Since March 2009, the coordinator and 10 other members of KANEPPPI have visited the University of Eastern Africa, Baraton; Moi University in Eldoret; the United States International University in Nairobi; and Eldoret Polytechnic in Eldoret. Network branches have been set up in the campuses visited and the network plans to reach all middle-level colleges and all universities in Kenya.

The Way Forward

Both KENEPOTE and KANEPPPI are providing much-needed support to teachers themselves. They are also tapping into the leadership role

of teachers in society to mobilize community responses to HIV and help protect and nurture OVC. Both networks continue to grow rapidly and to gain organizational strength and skill. In the coming years, KENEPOTE aims to continue its advocacy efforts on behalf of teachers and students, as well as expand and build the capacity of its community-level support groups. KANEPPPI plans to continue its own expansion, reaching out to new educational institutions and diversifying its resource base.

In a recent article in Kenya’s *Daily Nation* newspaper, Ms. Ouko described how the two networks plan to work together to tackle the challenge of HIV:

“As I fight HIV at the primary school level, [KANEPPPI] fights it in the higher institutions of learning. We meet somewhere in the middle and together, squeeze and suffocate the virus within the education sector.”

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