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Haba Na Haba

Technical Bulletin

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Spotlight On…

Working with Communities Toward Elimination of Pediatric HIV and AIDS

Photo credit: James Pursey

Expectant mothers attend a group HIV education session at a Malawi antenatal clinic

Community participation is an important contributing factor toward achievement of the Foundation's goal of virtually eliminating pediatric HIV and AIDS. A number of studies have indicated that involving communities in health service delivery can contribute significantly to improvements in health-seeking behaviors, retention in care, and adherence to treatment.[1-6] Community support may positively affect those living with HIV through increasing access to health education, care, and psychosocial support.

continued

Welcome!

Welcome to the Elizabeth Glaser Pediatric AIDS Foundation's technical bulletin, *Haba Na Haba!*

This publication provides a dynamic forum for the routine sharing of technical information and promising practices across the Foundation as well as with our extended family of partners and other like-minded organizations around the world. Each issue of *Haba Na Haba* highlights a topic of particular importance to the Foundation. The highlighted topic for this issue is **Working with Communities Toward Elimination of Pediatric HIV and AIDS**. We hope you enjoy the information presented, and we invite you to stay tuned for the next issue, which will bring you the latest exciting news from across the hall and across the ocean!

What Does *Haba Na Haba* Mean?

The name of the bulletin, *Haba Na Haba* ("little by little"), is borrowed from the Swahili proverb ***haba na haba, hujaza kibaba*** ("little by little fills the pot") and was chosen to reflect the often incremental nature of progress in our field. As the experiences described on the following pages demonstrate, the smaller efforts of every one of us are the essential "ingredients" for mounting a strong and united global response to HIV and AIDS.

Feedback is welcome from all readers, and contributions are accepted from all Foundation staff. Please send your questions, comments, or content submissions to techbulletin@pedaids.org.

Spotlight On… *(continued)*

Meaningful engagement of people living with HIV has augmented the health sector's ability to address the holistic needs of children and adults living with and affected by HIV.[3,4] Additionally, there is a shortage of health-care workers in many of the countries where the Foundation works; engagement of communities can ease the workload of HIV health service providers.[7,8]

The World Health Organization (WHO), Joint United Nations Programme on HIV/AIDS (UNAIDS), and United Nations Children's Fund have advised organizations involved in scale-up of prevention of mother-to-child transmission of HIV (PMTCT) service delivery to develop effective mechanisms to engage communities and establish better links between health facilities and local communities.[9] WHO's strategic vision for eliminating pediatric HIV specifically states that the institution is committed to promoting increased community participation (including that of male partners and community health workers) for support and delivery of PMTCT services.[10] To strengthen the role of civil society and the private sector, the Global Fund for AIDS, Malaria and Tuberculosis has introduced the routine inclusion of strengthening community systems through a Global Fund grant process.[11] The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) strategic plan (2010–2015) states that PEPFAR activities must be responsive to the breadth of needs experienced by people living with HIV, their families, and the communities that are hardest hit by the epidemic.[12]

Over the last decade, the international community has made rapid progress in expanding the coverage of services to prevent the vertical transmission of pediatric HIV. Between 2004 and 2010, the global percentage of HIV-positive pregnant women receiving antiretroviral drugs (ARVs) to prevent vertical transmission increased from 7% to 53%.[5,6] Despite this success, sociocultural factors such as low health literacy, poverty, HIV-related stigma, limited health infrastructure, gender norms, and traditional practices can present complex challenges to the delivery and expansion of HIV prevention, care, and treatment services. Involving influential community members—such as community leaders, mothers-in-law, and male partners—in HIV prevention, care, and treatment services can mitigate these challenges.

Promoting a Focus on Community Needs

Individual behavior is often heavily influenced by broader socioeconomic, cultural, and environmental factors.[13,14] The socioecological model* recognizes that successful activities to promote health, including efforts tied to the elimination of pediatric HIV and AIDS, involve not only individual behavior change but also policy development, economic support, and organizational and environmental change.

*This construct is based on the Social Ecological Model, as described by McLeroy et al.[8]

According to this model, interventions are more successful if they operate within most, if not all, levels of influence outlined below[15]:

1. Intrapersonal factors—characteristics of the individual, such as knowledge, attitudes, behavior, perceptions of self, risk, and skills.
2. Interpersonal processes—formal and informal social networks and social support systems, including family, work groups, and friendships.
3. Institutional factors—social institutions with organizational characteristics and formal and informal rules and regulations of operation.
4. Community factors—relationships among organizations, institutions, and informal networks within defined boundaries.
5. Public policy—national, district, and local laws.

HIV programs can target health-care services through these levels to comprehensively address the needs of people living with HIV. PMTCT and pediatric HIV interventions should be based on an understanding of the local context and culture, and be attuned to the dynamics that drive the local epidemic at these five different levels. Examples of how the Foundation's country programs and its many partners can better address the needs of communities at different levels of influence are described in more detail below.

- **Addressing health-seeking behaviors at the intrapersonal level.** Social norms, cultural practices, and local traditions can influence individual knowledge, attitudes, behavior, and perceptions of self risk. These influences can hinder early diagnosis and treatment adherence among people living with HIV. For individuals newly diagnosed with HIV infection, community-level interventions can be tailored to address the initial feelings of helplessness, social isolation, and status denial, as these vulnerabilities may be shared by specific risk groups in the same community. For individuals on treatment, interventions that promote a supportive community environment, such as family support groups, can enhance self-efficacy, and in so doing, promote treatment adherence and retention. *Turn to page 18 to read about how the Foundation is supporting the use of community counselors to improve uptake and retention of PMTCT services in Côte d'Ivoire.*
- **Enhancing a supportive environment through interpersonal interventions.** In many of the settings in which the Foundation works, most of the care HIV-positive individuals receive often occurs at the household level. Household members and primary caregivers, particularly the caretakers of children on treatment, need information, caregiving skills, and emotional support. For example, in many of the settings where the Foundation works, male partners and mothers-in-law hold decision-making power regarding health service

Box 1. Overview of the Foundation's Community Initiative

The Foundation recently launched a community initiative to strengthen existing community approaches in the countries it supports. The aim of this initiative is to promote increased documentation, knowledge sharing, and capacity building as regards evidence-based, community-oriented interventions. The initiative will support country programs and the Foundation as a whole by focusing on the following:

- Increasing uptake of HIV care and treatment services and prevention of vertical transmission
- Retaining women, children, and families in prevention, care, and treatment programs
- Enhancing treatment adherence among women, children, and families
- Enhancing the psychosocial well-being of people living with HIV

Outputs include a literature review and an accessible inventory of existing community-related tools and resources that have been used, adapted, or developed by the Foundation's country programs to support community-level implementation.

For questions or suggestions related to the Foundation's community initiative, please contact Lola Walker at dwalker@pedaids.org and Alana Hairston at ahairston@pedaids.org.

Box 2. Global Policies on Community Involvement and Ownership of Health Services

The importance of involving communities at all stages of planning, implementation, and management of health services is recognized by numerous international accords, including the Declaration of the Alma-Ata International Conference on Primary Health Care (1978),[17] the Ottawa Charter for Health Promotion (1986),[18] and the Declaration of the Paris AIDS Summit (1994),[19] which advocate for greater involvement of people living with HIV in research, policy, and service delivery.

The Bangkok Charter (2005)[20] emphasizes that well-organized and empowered communities are highly effective in determining their own health and are capable of making governments and the private sector accountable for the health consequences of their policies and practices.

Most recently, UNAIDS *Treatment 2.0* guidance[21] highlights strengthening community systems as an important pillar of HIV programming within this next-generation approach.

Monitoring and Evaluation of Community-Based HIV/AIDS Programs: Sharing Experiences at the Foundation's First Global Monitoring and Evaluation Conference

Juan Seclen (jseclen@pedaids.org) and Lior Miller

At the Foundation's first global M&E conference in Nairobi, Kenya, M&E staff from the Foundation-supported Uganda program presented the work that the new Strengthening TB and HIV/AIDS Response in the South-West Region of Uganda (STAR-SW) project is undertaking to identify appropriate community indicators for prevention of vertical transmission, HIV care and treatment, and TB interventions (read more about the STAR-SW project on page 27). The presentation emphasized that community-based monitoring systems should be aligned with ministry of health strategic information systems in order to avoid parallel structures. A key message of the presentation was that it is critical to engage community service providers to determine their own data needs and how to meet those needs.

Kenyan representatives spoke about their four years of experience monitoring community-based efforts using a Foundation-developed monthly reporting tool, the Community-Facility Linkage Activities Report (CFLA). The purpose of the CFLA is to assess and monitor client outcomes, capture the multiple dimensions of adherence, close information gaps in existing data collection tools, and incorporate local perspectives on adherence and psychosocial support. By using the CFLA, the Foundation's Kenya program has been able to document improvements in community-facility linkages and the effectiveness of these efforts in improving client outcomes.

For more information about these presentations, please contact Juan Seclen at jseclen@pedaids.org.

access among pregnant women and children living with HIV. Social networks composed of individuals living with HIV (e.g., family support groups, associations, and networks for people living with HIV) can also successfully provide support to HIV-positive individuals and household members. *Turn to page 23 to read about the Foundation's efforts to ensure the sustainablity of support groups for people living with HIV in Kenya.*

- **Influencing structural barriers through work with local institutions.** Traditional kinship as well as religious and social institutions serve powerful functions as community gatekeepers and as the generators and enforcers of social norms and belief systems. National health policies and regulations can sometimes serve as barriers to community-level service provision. Program implementers can collaborate with local institutions such as local governments, community and religious leaders, and community health committees to reduce structural barriers that affect the uptake of services and retention in HIV care and treatment. *Turn to page 11 to read about how the Foundation is working to increase male partner involvement in PMTCT through sensitization of village AIDS committee members.*
- **Increasing ownership of health services and health outcomes by communities.** Efforts to enhance the consumer's voice in service delivery and planning can help ensure that HIV programs are more patient centered. Where this systematically occurs, it can help improve patient satisfaction and increase patient willingness to remain in chronic care. *Turn to page 21 to read about how the Foundation is involving community members in the provision of HIV care and support for children living with HIV in Zimbabwe.*
- **Advocating for supportive policies.** Supportive policies for children, women, and families living with and affected by HIV, as well as policies that support effective HIV service-delivery models, are necessary to scale up and sustain PMTCT and pediatric HIV care and treatment. Such policies should be employed at the local, district, and national levels. It is also important for people living with HIV to be involved in the development and implementation of these policies. *Turn to page 15 to read about the Foundation's partnership with civil society organizations in Lesotho to support community–health facility linkages.*

Challenges to the Sustainable Scale-up of Community-Based HIV Services

To date, a number of challenges have hindered the effective scale-up of community-based models of client care and support. Limited research, monitoring, and evaluation of major community health interventions provide an inadequate understanding of the factors that contribute to the effectiveness of community-based HIV programming. More targeted efforts to quantify these numerous factors are needed. In the

absence of conclusive evidence, community-based interventions are sometimes perceived as overly complex, ineffective, and unsustainable. Formalized technical oversight of community care providers is often limited, and national policies supporting formal roles for lay community workers are nonexistent in many countries or are often poorly funded where they do exist.[16] The recent emergence of widespread support for global elimination of pediatric HIV and AIDS provides a critical opportunity to systematically address these challenges.

The Foundation's Commitment to Supporting Community Involvement

Since 2002, the Foundation has supported innovative models of community involvement to prevent vertical HIV transmission and provide care and treatment to people living with HIV. More recently, the Foundation has begun increasing its investments in this area to further strengthen the capacity and expertise of its country programs and its numerous partners in implementing, monitoring, evaluating, and researching community-focused interventions. This issue of *Haba Na Haba* showcases the Foundation's experiences in a variety of settings to illustrate how community approaches are helping the Foundation reach its goal of virtual elimination of pediatric HIV and AIDS.

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KEY RESOURCES: WORKING WITH COMMUNITIES

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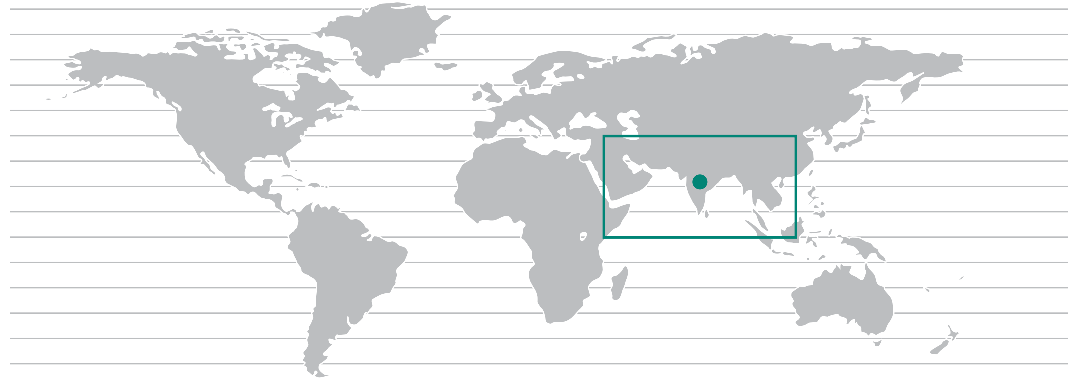
Country Program Notes



INDIA:

Reaching Rural Women with Integrated ANC and PMTCT Services

Purnima Madhivanan (pmadhivanan2@gmail.com)

Clients being greeted at the entrance of the Project *Kisalaya* mobile ANC clinic

The Foundation-supported India program began in 2002 and as of December 31, 2010, had provided more than 763,000 women with HIV counseling and testing. The program, referred to in India as the EGPAF Consortium, is made up of eight NGO partners and is the second-largest provider of PMTCT services in the nation after the government program. The EGPAF Consortium works primarily in the private sector in the four high-HIV-prevalence states of Andhra Pradesh, Karnataka, Maharashtra, and Manipur. In 2007, the Foundation granted an International Leadership Award, sponsored by Jewelers for Children, to Dr. Purnima Madhivanan for the project described here.

Background

Each year, 27 million women give birth in India, nearly 49,000 of whom are living with HIV.[1] While India has the highest burden of pediatric HIV infections in South Asia, only about one in five HIV-positive pregnant women currently receives antiretroviral medicines (ARVs) for treatment and PMTCT.[2] According to the Indian government's National Family Health Survey, only about 43% of women living in rural areas had three antenatal care (ANC) visits prepartum, and even fewer, 31%, gave birth in health-care facilities.[3] This is particularly troubling since the Indian National AIDS Control Organization (NACO) estimates that 60% of those living with HIV are located in rural areas, home to roughly half of India's population.[4]

Efforts of the government's National Rural Health Mission have led to increased health-care service availability in rural areas, yet large disparities still exist between urban and rural uptake of HIV testing and PMTCT. According to the National Family Health Survey of 2005–2006, urban women between the ages of 15 and 49 were almost twice as likely to have received HIV voluntary counseling and testing than their rural counterparts.[5] Finding cost-effective interventions for India's hard-to-reach rural populations poses a major challenge for national policymakers and nongovernmental organizations (NGOs) working to eliminate pediatric HIV and AIDS.

Pilot Project for Integrated Service Delivery and Community Health Education

Project *Kisalaya* (Sanskrit for "Tender Shoot") was designed as a pilot project to deliver integrated ANC, HIV treatment, and PMTCT services to rural Indian women in Karnataka state. *Kisalaya* began in 2008 with financial support from the Foundation and consisted of a multilevel intervention combining local health worker training, community education, and delivery of integrated ANC and HIV/PMTCT services to 144 rural villages in the rural Mysore district of Karnataka.

During the three years of the program, *Kisalaya's* outreach workers and medical staff trained almost 500 community members and community health workers on maternal health care, HIV, and PMTCT. The training was based on a World Health Organization PMTCT training package, which was translated into the local language of Kannada and adapted for low-literacy populations.[6] Trainees helped mobilize communities to ensure that pregnant women in each village attended community education sessions and the mobile ANC clinic. Additionally, 77 auxiliary nurse-midwives and 126 social health activists from the government's National Rural Health Mission received this training, which strengthened stakeholder cooperation and support for the program.

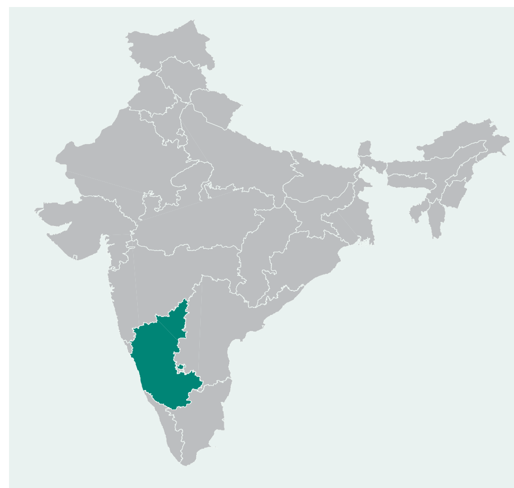


Figure 1. Karnataka state in India

Project staff conducted 141 community education programs, reaching more than 5,000 community members (including nearly 900 men). Typically held in community venues, the meetings involved presentations on birth preparedness, the importance of institutional deliveries, risks during pregnancy, and PMTCT. To promote participants' interest, the programs also included theater, role-playing, visual presentations, interactive games, and a quiz show with prizes.

The mobile ANC clinic was operated out of a converted bus equipped with an electrical generator, a stat laboratory to deliver a full range of ANC tests (including hemoglobin level, blood sugar, hepatitis B, syphilis, HIV, urine albumin, and bacterial vaginosis), and medications. The clinic was operated by 14 staff members, including doctors, nurses, counselors, laboratory assistants, and outreach workers. Women were examined and counseled in a private area of a community venue. Blood samples were collected, packed in coolers, and transported back to a central laboratory facility for processing. Within three days of each clinic visit, counselors returned to the sites to deliver test results, carry out one-on-one post-test counseling, and provide referrals for clients with high-risk pregnancies or those in need of PMTCT services and HIV treatment.

Over the course of the program, 1,675 (76%) of the 2,211 pregnant women in the catchment area accessed services at a Project *Kisalaya* mobile clinic. All 1,675 women were offered HIV testing and counseling, and 1,639 accepted these services (97.9%).

Challenges and Lessons Learned

The training of both staff and community members was a key component of Project *Kisalaya*, making possible the delivery of antenatal and HIV/PMTCT care to thousands of rural women who previously had little

» *continued on pg. 25*

CAMEROON:

Using Partner Notification to Identify and Refer People Living with HIV for Care and Treatment

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The Foundation currently supports PMTCT services at 434 health facilities in 6 of Cameroon's 10 regions through its in-country partner, the Cameroon Baptist Convention Health Board (CBCHB), and in collaboration with the Cameroon Ministry of Public Health. Since February 2000, the Foundation-CBCHB partnership has reached over 530,000 women with critical PMTCT services and has tested more than 519,000 women for HIV. In addition to PMTCT, the Cameroon program implements 88 adult and 6 children's psychosocial support groups, an infant and young child feeding program, a women's health program, youth health and education, and contact tracing.

Background

The effectiveness of partner notification as a strategy to reduce the spread of sexually transmitted infectious diseases is well documented.[1,2,3] In 2007, CBCHB piloted a partner notification program targeting HIV-positive youths in the North-West region of Cameroon. This area of Cameroon was chosen because of its high adult HIV seroprevalence of 8.7%.[4] The program, Extended Forum for Care, emphasizes the importance of identifying people living with HIV, both at health facilities and in their communities, and referring them for care and treatment. As of March 2011, CBCHB trained 58 health advisors who were employing the partner notification strategy in the North-West and South-West regions of Cameroon.

Recruitment and Training of Health Advisors

Health advisors are selected from among members of CBCHB staff (HIV educators, laboratory technicians, clinical nurses, and faith-oriented community leaders), as well as members of support groups for people living with HIV. Advisors are trained on a range of topics, including client counseling and interviewing skills, ethical issues (e.g., confidentiality), fieldwork techniques (including safety and sensitivity to cultural issues), and HIV rapid testing; advisors are also trained to follow the Extended Forum for Care's standard operating procedures, as well as standard data collection and contact tracing tools. Three-day group training sessions are followed by on-site practical orientation courses on partner notification techniques, facilitated by the Extended Forum for Care training committee. Refresher courses are organized twice a year.

Partner Notification Services

The notification program is currently operating in nine CBCHB health facilities (three hospitals and six integrated health centers) in the North-West region and two in the South-West region of Cameroon. Clients are offered a choice of three partner notification services: provider referral, client referral, or contract referral.

For provider referrals, health advisors contact the partners of each client (with the client's consent) to inform them of their possible HIV exposure without revealing the identity of the client. This is accomplished by visiting the contacts in person

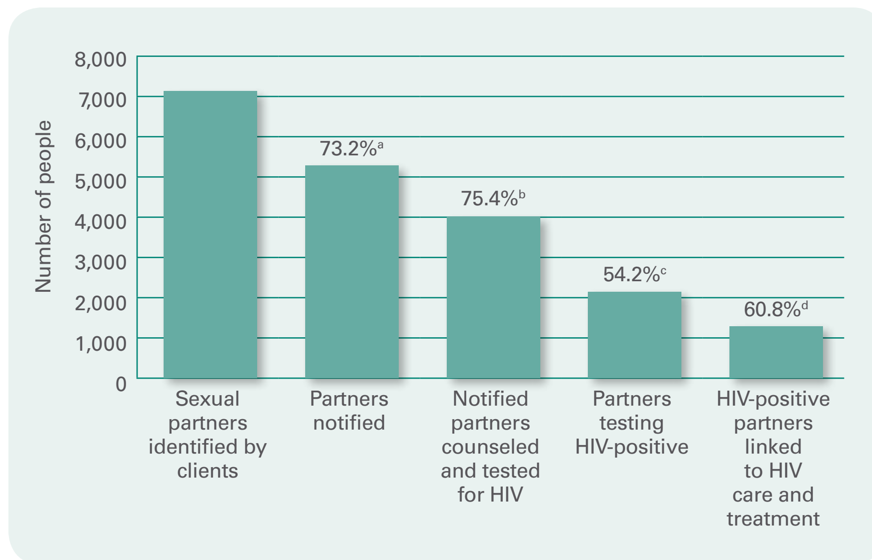

Figure 1. Extended Forum for Care partner notification results (August 2007–December 2010)

[a] Out of all partners identified.
[b] Out of all partners notified.
[c] Out of all partners counseled and tested.
[d] Out of all partners testing HIV-positive.

or communicating with them via telephone. For client referrals, the client takes on the responsibility of informing his or her sexual partners. Contract referrals are a combination of the two, whereby the health advisor agrees to notify the contact if the client is unable to do so within an agreed-upon time.

Through the provider referral approach, advisors notify partners that they may be at risk of HIV, provide pre-test counseling, and offer voluntary rapid HIV testing at a health facility or other suitable location. Both clients and their partners are educated on HIV prevention and risk reduction. Partners with positive test results are encouraged to enroll in a treatment program at any HIV/AIDS treatment center approved by the Ministry of Public Health and to join a support group. Partners with negative results are advised to repeat the test after three months (in case of a false negative result or insufficient elapsed time since last risk exposure) and are counseled on how to protect themselves from HIV infection. HIV-positive pregnant women are counseled on the importance of adhering to prophylaxis to prevent transmission of HIV to their infants.

Results

From August 2007 through December 2010, health advisors provided partner notification services to 6,642 people with newly diagnosed HIV infections; a total of 7,200 sexual partners were identified and of those, 5,271 were notified. Overall the model proved effective at reaching exposed partners and linking them with needed care, with more than 75% of those notified receiving HIV counseling and testing (see Figure 1). Data on type of notification method employed were collected for 2,991 out of 5,271 partner notifications. Among this subset, provider referral was the most frequently used method (64%), followed by patient referral (22%) and contract referral (7%). The remaining 7% were identified by the client as already knowing their HIV status and were therefore not contacted.

Two cases of domestic abuse resulting from partner notification have been reported since the inception of the program in 2007. (While these are the only cases that have been reported to date, it is important to note that domestic violence is often underreported.) In these cases, health advisors provided extensive couples counseling.

Challenges and Next Steps

Challenges have included inadequate cellular phone network coverage in certain areas; high rates of mobility, resulting in loss to follow-up of both clients and partners; and threatening behavior of notified partners toward health advisors. Additionally, the project cannot support advisors with a full-time salary for their work. As a result, advisors must supplement their incomes with other employment. The Extended Forum for Care contact tracing / partner notification program intends to address challenges by advocating for integration of contact tracing in counseling and at all testing facilities. Training more health advisors, hiring full-time health advisors,

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Support Groups in Cameroon Promote Health and Well-Being of Children and Adults Living with HIV

Esther Bonje (kunibonje@yahoo.com), Lior Miller, Delphine Fri, Vincent Ngafesson, and Joseph Wepnje

The Cameroon Baptist Convention Health Board (CBCHB) support group program was formed in 2002 with funding support from the Foundation to provide an avenue for men and women in the North-West region to engage in open discussions about HIV. Support groups are led by people living with HIV who have been selected by their peers, with the assistance of CBCHB nurse-counselors. Meetings are held at churches, clinics, and other community venues.

These groups help people living with HIV combat stigma, adhere to treatment, and adopt good nutritional habits, while also empowering participants economically and providing psychosocial counseling support. Group activities have evolved over the years to become more member-focused: Members are involved in the production of nutritious meals, fruit drinks, soaps, skin lotion, and perfume. Members also engage in income-generating activities such as food service, phone booth businesses, and livestock rearing. Businesses are situated on CBCHB properties, and materials produced are sold through hospitals, health centers, or support-group-oriented petty trade shops. The income generated is used to support a portion of the group's activities.

Today, there are 88 active support groups with 3,392 members (2,886 women and 506 men). In 2009, support groups for children were added, which offer creative activities coupled with psychosocial support, nutritional support, and school-fee assistance. There are currently 102 children enrolled in six support groups and support group leaders have reported greater sensitization to HIV/AIDS-related issues in the communities they serve.

Experienced support group members have received training from CBCHB staff on AIDS education, equipping them to promote HIV awareness in their own communities. Some members have also been trained as health advisors for CBCHB's Extended Forum for Care partner notification program (explained in greater detail on page 8). In this way, support group members have been empowered to take leadership roles in changing attitudes and beliefs about HIV and AIDS.

Support group members do not have unique patient identifier numbers that can be used by HIV care and treatment facilities to assess whether these activities have led to improved treatment uptake and retention. To address this, CBCHB is seeking additional funding for the strengthening of strategic information systems and operations research activities to assess the impact of the support groups on client health outcomes.

Cameroon Support Group Member Profiles

The following profiles feature members of the Cameroon Baptist Convention Health Board community support groups.

Mercy did not believe she could ever be HIV-positive. She understood HIV as a disease for the promiscuous. During her second pregnancy in 2002, she was diagnosed HIV-positive. Mercy said that life became more difficult for her in 2006, when her husband, also HIV-positive, passed away. Fear, discouragement, and resentment gripped her. Her sole responsibility toward her children overpowers her each day. She says, "I gave up life some time ago, but the encouragement, as I came closer to people of my [HIV-positive] status in the support group and to God, to whom I have given my life, have kept me till this time. I would like to say this to everyone reading my story: HIV is nothing to be scared of. If I can live with it, then you can too."

"My name is Agnes. I am proud to say that I was not so carried away by my diagnosis when I discovered I was HIV-positive. I easily accepted the result and started thinking of a way forward. I cannot say where I got such courage from, but that is how I found myself reacting to the situation—and this positive reaction helped me overcome stigma, which was and is still prevailing. Being positive, in thought and action, does not mean people will not look down on you. In fact, many people point fingers and throw words at me, but others see me as their hero. All my children know about my status and each is giving his/her contributions to make my life much better. We all have battles to fight in this life; mine is the fight to live with HIV. I do not know what yours may be, but no matter what the battles may be, one thing I believe is that courage is the key to win them all."

TANZANIA:

Increasing Male Involvement in PMTCT through Community-Led Sensitization

Noela Nsanzugwanko (nnsanzugwako@pedaids.org) and Tatu Mtambalike

The Foundation is supporting the government of Tanzania in improving maternal and child health (MCH) in five regions (Arusha, Kilimanjaro, Tabora, Shinyanga, and Mtwara) through services to prevent mother-to-child transmission of HIV. As of December 31, 2010, the Foundation was supporting PMTCT services at nearly 1,100 sites and care and treatment services at 165 sites. Since July of 2003, the Foundation has supported provision of PMTCT services to more than 1.5 million women, enrollment of more than 147,000 clients into HIV care and support programs, and initiation more than 74,000 individuals on ART.

Background

The guidance of the Tanzania Ministry of Health (MOH) on PMTCT encourages male partner testing in MCH clinics and more comprehensive HIV care services to women and their partners during pregnancy, labor, and delivery. While it is critical for men, the main decision makers in Tanzanian households, to actively support their female partners in receiving PMTCT services and to get tested themselves for HIV, many remain unaware of this responsibility.

Mtwara is the southernmost region of Tanzania, near the border of Mozambique, and is made up of six districts. The Foundation-supported PMTCT programs in these six districts have employed several strategies to address the issue of poor male involvement in PMTCT, including the use of invitation letters to clients' spouses, verbal invitations (in which volunteers visit clients' homes and speak directly with partners), and sensitization of members of the Village Multisectoral AIDS Committees (VMACs), which represent various social and political groups in each village.

Namatutwe VMAC

Namatutwe dispensary is located in Masasi district and serves five villages (Namatutwe, Miwale, Msikisi, Chipunda, and Mdebwede) with a combined population of 6,403 people, including 1,280 women of childbearing age. Namatutwe is one of the Foundation-supported sites employing male involvement techniques and has seen considerable success in these efforts.

The Namatutwe VMAC was established by the Council Community Development Department of the Tanzania Commission for AIDS (TACAIDS) using the TACAIDS guidelines. Committee members include the councilor or chairperson (a local resident who leads the committee), the village executive officer (or secretary), the village chairman, a local health-care worker, a teacher, an influential person (e.g., a village elder or traditional birth attendant), two youth representatives (one male and one female), two people living with HIV (one male and one female), and two religious leaders (one each from the Muslim and Christian faiths). The VMAC meets monthly to discuss matters pertaining to HIV in the village and is responsible for sending out quarterly reports to the TACAIDS ward- and district-level multisectoral committees.

In February 2010, Foundation staff, led by the community linkages program officer, worked

with the MOH, district, and Namatutwe dispensary staff to train the Namatutwe VMAC members on educating communities about HIV, as well as on how to encourage enrollment of eligible HIV-positive clients in treatment and treatment adherence. The VMAC members were also taught techniques for increasing male involvement in PMTCT clinics and ensuring that all HIV-exposed children are tested and able to access treatment. This training activity was followed by community sensitization sessions in the five villages that the dispensary serves, during which the Foundation community linkages program officer explained the Foundation's activities in the region and the importance of male involvement in PMTCT. These sessions were attended by a total of 227 villagers (116 females and 111 males).

Results

Focused involvement and active follow-up by VMAC members has resulted in higher proportions of male partners testing at Namatutwe Dispensary as compared with other sites in Masasi (see Figure 1). In the period following the sensitization sessions (held in February 2010), the proportion of HIV-positive pregnant women whose male partners came in to the clinic to be tested for HIV has ranged from 85% (April–June 2010) to 16% (July–September 2010). In contrast, the proportion of women whose partners visited other sites in Masasi to be tested ranged from 45% (October–December 2010) to 11% (January–March 2010).

Since these sensitization sessions, Namatutwe VMAC members have committed to continue sensitizing their communities on male

Bibi (grandmother) Mary Sagamila, a member of the VMAC and former traditional midwife, talks to community members about the importance of male involvement in PMTCT.

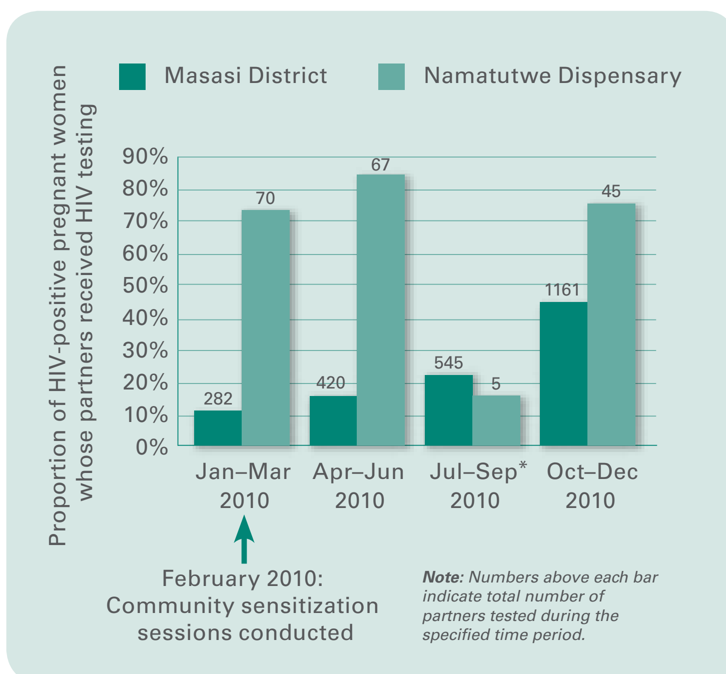

Figure 1. Male partner testing at Namatutwe Dispensary compared with other dispensaries in the Masasi district, Mtwara region, after community sensitization[1]

involvement, and also to follow up at clinics and homes to ensure that couples testing is occurring. The villagers, together with VMAC members, decided that when a pregnant mother comes to the clinic for her first prenatal visit without her partner, a VMAC member would be notified to follow up with the client's partner for testing. If the partner is identified as HIV-positive, they are referred to the nearest HIV care and treatment facility. This focused involvement and active follow-up by VMAC members has resulted in a marked increase in male partner HIV testing at Namatutwe Dispensary (see Figure 1).

Conclusion and Next Steps

VMACs have been formed by TACAIDS in the majority of villages throughout Tanzania, but most are currently inactive. Transportation is a challenge, with committee members having a hard time getting to and from neighborhoods within the village for sensitization sessions and follow-up visits. Despite these challenges, the Namatutwe VMAC has seen positive results from its work—likely due in large part to the committee members' own motivation and their extraordinary commitment to their communities.

Community structures like VMACs are promising mechanisms to help change community perceptions and behaviors relating to HIV and AIDS. The members of these committees are known and respected by community members, and thus their social guidance is generally well received. The Foundation plans to expand its approach of working with VMACs to other Foundation-supported sites in Tanzania.

References

1 GLASER database. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation. Accessed March 16, 2011.

* Reason for reported low uptake of male partner testing at Namatutwe during this period has yet to be determined.

Use of HIV-Positive Volunteers to Support Care and Treatment Adherence and Enrollment Yields Promising Results in Tanzania

Nuru Kilimba (nkilimba@pedaids.org), Tatu Mtambalike, and Mercy Nyanda.

The Foundation's community linkages program in Tanzania has recently increased the number of people living with HIV who serve as volunteers to provide HIV-positive clients with psychosocial support and treatment adherence counseling, from 1,605 in the third quarter of 2010 to 1,941 in the fourth quarter of 2010. Volunteers are stationed at a total of 165 Foundation-supported care and treatment sites.

Volunteers are selected by health facility staff and community leaders in each district. The Foundation, together with the community linkages staff and district service providers, leads a five-day training course for community volunteers on providing supportive peer counseling and health education for HIV-positive clients (including pregnant women) and their partners at health facilities. The volunteers also assist in mobilizing new clients to join support groups offering psychosocial counseling for people living with HIV and are responsible for following up through home visits and telephone calls with clients who have missed their clinic appointments. Additionally, volunteers engage in the promotion of HIV-related services in a number of community forums, such as public meetings and cultural dances.

The use of community volunteers at Foundation-supported sites has yielded promising results. From July to September 2010, 35% of 15,090 clients lost to follow-up (both on ART and pre-ART) were traced,* and 32% of the traced clients resumed care and treatment services. From October to December of 2010, 35% of 13,840 clients lost to follow-up were traced, and 42% of those traced resumed care and treatment services. The Foundation-supported Tanzania program is very proud of the work of the HIV-positive volunteers and will continue to support their ongoing efforts.

* A client is considered "traced" when a follow-up attempt has been made and one of the following occurs: client is reported as deceased, address on file is incorrect, client refuses to return to clinic, client has self-transferred to another facility, or client agrees to return to the clinic.

Zuhura Liganga lives in Tanzania's Lindi region and received lay counselor training from the Foundation. She says that the Foundation's training has increased her confidence and her commitment to serving others in her community who, like her, are living with HIV. As a volunteer working at the Foundation-supported Care and Treatment Centre of Lindi, Zuhura supports clients in accessing needed care and adhering to HIV treatment services.

Zuhura (far right) participates in the Foundation's training for volunteers living with HIV in the Lindi region of Tanzania

LESOTHO:

Partnership with Lesotho Network of AIDS Service Organizations Works to Strengthen Community–Health Facility Linkages

Marethabile Nei (mnei@pedaids.org)

Working in partnership with the Lesotho Ministry of Health, the Foundation currently supports 182 health facilities across all 10 districts of Lesotho. Since 2006, Foundation-supported facilities have provided more than 85,000 women with critical PMTCT. In addition to PMTCT, the Foundation's Lesotho program has helped enroll more than 131,000 adults and children into care and support programs. Of those ever enrolled, more than 56,000 have begun ART.

Background

The Lesotho Network of AIDS Service Organizations (LENASO) is a national body of civil society organizations implementing HIV and AIDS interventions with a strong community focus. A partnership between LENASO and the Foundation began in 2010, when the Foundation-supported Lesotho country program was awarded a five-year grant from USAID for the Strengthening Clinical Services Project. The project is being led by the Foundation in partnership with LENASO, the Baylor International Pediatric AIDS Initiative, the Apparel Lesotho Alliance to Fight AIDS (ALAFA), and mothers2mothers. The Foundation is providing LENASO with financial support as well as technical expertise on integration of HIV care and treatment services into basic health services.

LENASO is working to strengthen the network of community-based services integrating pediatric and family HIV care and treatment. Activities performed by LENASO include promoting male involvement in MCH services and partner testing, as well as supporting timely ART enrollment and treatment adherence among men. LENASO also works with mother-in-law groups to educate them about available PMTCT interventions and infant feeding choices, and helps establish support groups for people living with HIV and their families.

Supporting Community–Health Facility Linkages

In its first year, the partnership has strengthened linkages between health facilities and communities, furthering access to and use of clinical services. Community mobilization activities, such as child health days (held at community venues such as churches and schools), are providing easier access to a variety of health services, including nutritional counseling, HIV testing, and immunizations. To date, 21 child health days have been carried out, with a total of 11,559 children participating. Of the participating children, 4,186 were provided with HIV testing and counseling and 66 were found to be HIV-infected and referred to local care and treatment facilities.

The partnership sponsors community outreach events, including "Sports Against AIDS," held during sports events such as soccer games to offer mobile HIV testing and counseling as well as condom distribution. To date, 9,571 people have been offered HIV testing and counseling through the community outreach events. HIV testing campaigns and advocacy sessions with community leaders and community groups are also helping to improve uptake and retention, and strategies are being explored to improve the tracing of clients lost to follow-up and strengthen reporting systems for community-based activities. Forty-one advocacy sessions with community leaders have been organized so far and 49 health center committees have been revitalized.

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CÔTE D'IVOIRE:

Community Counselors Support Improved Follow-up for Clients with TB/HIV Coinfection

Wohi Batesti, Nathalie Krou Danho (nkroudanho@pedaids.org), Marius Lorougnon, Cathérine Sié, N'Da Atsé, Clément Adjé, and Anthony Tanoh

The Foundation's Côte d'Ivoire program began supporting HIV/AIDS care and treatment in 2004 and PMTCT services in 2005. As of December 31, 2010, the Foundation was supporting 312 PMTCT sites and 146 care and treatment sites throughout the country. Through its work in Côte d'Ivoire, the Foundation has supported provision of PMTCT services to more than 751,000 women; enrollment of more than 178,000 patients into HIV care, including more than 12,000 children under the age of 15; and enrollment of more than 84,000 individuals on ART, including more than 4,800 children under the age of 15.

Background

In 2009, the Foundation's Côte d'Ivoire program awarded grants to four local NGOs working in 44 TB centers to improve the quality of care provided to people with TB and HIV infection. Since September 2010, with financial and technical support from the Foundation, one of these NGOs, Sidalert, has been working to improve TB/HIV care services in the San Pedro Anti-Tuberculosis Center (Centre Anti-tuberculeux de San Pedro [CAT–San Pedro]). To strengthen community-health facility linkages at CAT-San Pedro, the Foundation, in collaboration with the national TB Program (PNLT), has trained a total of nine community lay counselors from Sidalert, two of whom were trained on the WHO DOTS (directly observed therapy short course) approach for TB, four on ART treatment adherence, and three on palliative care.

Activities of Community Health Workers at CAT–San Pedro

CAT–San Pedro's activities are divided into four service areas: consultation and monitoring, TB and HIV treatment services, HIV voluntary counseling and testing (VCT) and TB testing (using an on-site laboratory), and social services (e.g., increasing community awareness, post-test counseling, drug supply management, and management of patient files). The facility employs a total of five community health workers from Sidalert to work on-site under the supervision of the chief medical officer / TB coordinator for the Bas Sassandra region. Their activities include the following:

- **HIV and TB awareness sessions.** Three days a week in the CAT–San Pedro waiting room, a Sidalert community health worker hosts an information and education session on TB, HIV, and AIDS to inform clients about TB infection and treatment and to sensitize them to the importance of HIV testing, prevention, and treatment. Clients are also informed about the home visit and community outreach services provided by the on-site community health workers.
- **TB and HIV testing.** After the group education session, clients receive medical consultations and are offered TB testing services. Once TB results are analyzed, a community health worker sorts results and refers all clients who test positive for TB to VCT.

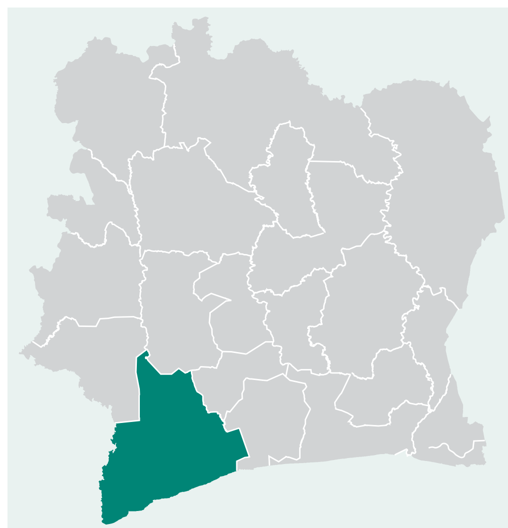

Figure 1. Bas Sassandra region of Côte d'Ivoire

- **Voluntary counseling and testing.** Two community health workers provide VCT using HIV rapid tests. All clients diagnosed with TB or TB/HIV coinfection are accompanied to their homes by a community health worker in order to support future client follow-up. The accompaniment aims to
  - determine the precise location of the client's home,
  - identify those in the client's surrounding area (family, partners, and others) who may be TB-infected but have not yet been tested, and
  - identify children under five years of age in clients' households for TB prophylaxis initiation.
- **Home-based support.** Another aim of the accompaniment is to identify a household member who can serve as a treatment "buddy" to support the client's TB treatment adherence. This person usually accompanies the client during the first follow-up visit at the CAT–San Pedro facility.

Results

By the end of 2010, Sidalert community health workers had provided TB counseling and testing to a total of 559 clients, of whom 493 (88.2%) were found to be TB-positive; 177 (35.9%) TB-positive clients received HIV testing and 84 (47.5%) were found to be coinfected with TB and HIV. During the five-month period from October 4, 2010, to February 4, 2011, Sidalert community health workers accompanied 69 clients with TB to their homes, 14 of whom were coinfected. As of February 2011, 68 clients (99%) were still on treatment for TB and/or HIV and adhering to their regimens.

Conclusion

Community outreach and engagement is instrumental in monitoring the care of patients with TB (including those with TB/HIV coinfection) and ensuring their adherence to treatment. It is important to provide adequate technical and financial support to community health workers so that they may perform follow-up and support activities. The Foundation's program in Côte d'Ivoire will continue to support community-health facility linkages, which will include further roll-out of this community approach to strengthen adherence in other large TB centers of the Bas Sassandra region as well as an evaluation of a similar strategy to expand these activities to support ART adherence.

CÔTE D'IVOIRE:

Community Counselors Strengthen PMTCT Service Uptake

Gueye Aîssetou, Cathérine Sié (csieakoua@pedaids.org), Nathalie Krou Danho, Marius Lorougnon, Gnelbin Marie Bamba, Patricia Fassinou Ekouévi, and Anthony Tanoh

Background

The Terre Rouge Maternity Center, a high-volume provider of maternal and child health (MCH) services in the Bas Sassandra region, is led by three midwives and sees more than 1,500 antenatal care (ANC) clients per year. Although PMTCT services were integrated into the center in December 2008, a monthly Foundation data analysis report from July 2009 revealed that only 51% of all pregnant women seen in ANC were receiving HIV counseling during that month. Among those tested, 10% were diagnosed as HIV-positive; only 30% of women testing positive received ARVs for treatment or prevention of vertical transmission.

Involving Community Couselors in PMTCT Service Delivery and Client Follow-Up

In October 2009, the Foundation, in collaboration with the Terre Rouge maternity management team, employed two community counselors from local NGO Elan d'Amour to strengthen PMTCT service delivery at the Terre Rouge facility. The community counselors' activities are based on three main strategies:

- **Attendance at the Terre Rouge Maternity Center:** Every morning, community counselors facilitate group education sessions and provide clients with HIV testing and pregnancy monitoring information. The health-care workers at the facility offer clients gynecological exams and HIV rapid testing. After test results are received, the community counselors initiate on-site counseling and support for HIV-positive clients. Promoting continuity of care through home-based support, HIV-positive pregnant women are referred to community-based support groups to encourage acceptance of status and provide adherence guidance, male involvement approaches, and disclosure techniques. Community counselors escort all HIV-positive women to the San Pedro Regional Hospital reference laboratory, where initial laboratory assessments (e.g., CD4 count) are performed. Community counselors then perform systematic follow-up by phone to ensure that pregnant women attend all PMTCT appointments.
- **Home visits for HIV-positive pregnant women:** During home visits, the counselors advise women on pregnancy health and management, HIV, adherence to ART, infant feeding, and infant follow-up and testing. The importance of spouse and family involvement is emphasized. The frequency of home visits depends on the needs expressed by each woman and her family.
- **Referral to support groups for people living with HIV:** All HIV-positive pregnant women are encouraged to join the support group for people living with HIV led by Elan d'Amour. During the group meeting, experiences are shared regarding pregnancy, childbirth, infant feeding, HIV testing of household members, and issues relating to disclosure.

Results

Five months after community counselors' activities at Terre Rouge began, a significant increase in uptake of PMTCT services was observed, with 100% of pregnant women offered HIV testing in ANC compared to 51% before placement of community counselors (see Figure 1).

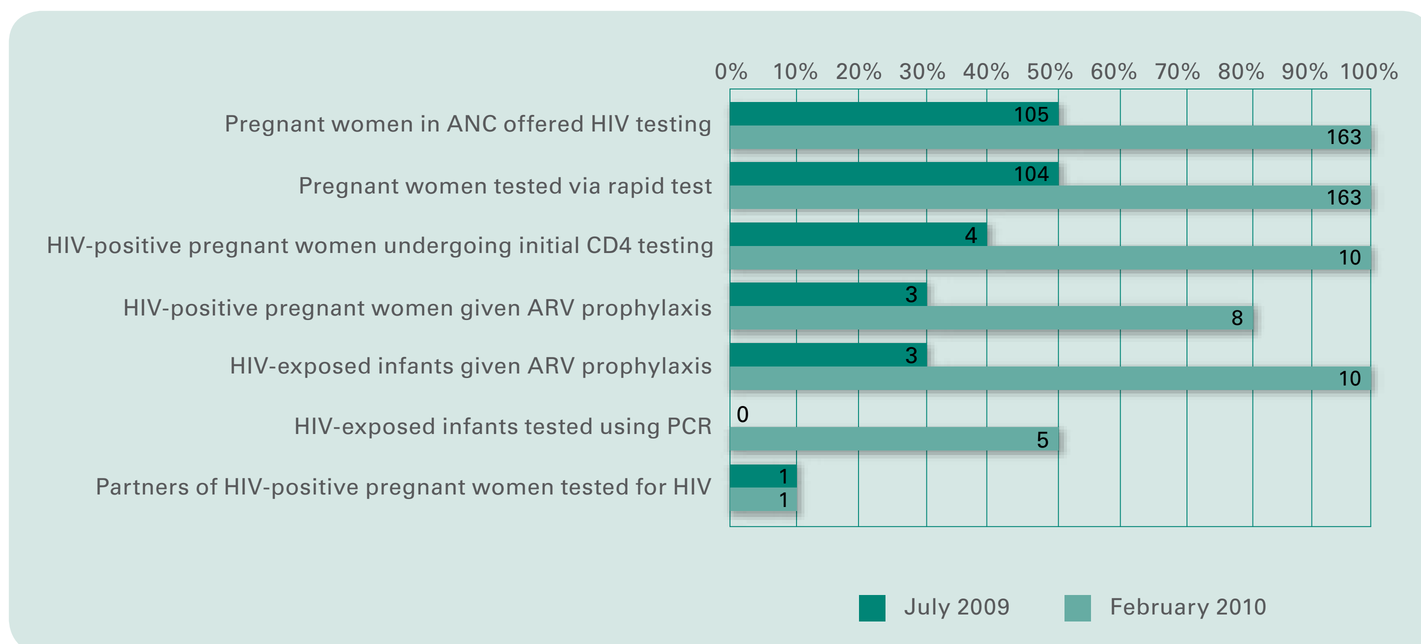

Figure 1. Uptake of key PMTCT services at Terre Rouge Maternity Center before and after community counselor intervention[1] in October 2009

Conclusion

Community counselors from Elan d'Amour have made substantial contributions to improving the quality of PMTCT care offered at the Terre Rouge Maternity Center in San Pedro. However, further improvements are needed in the areas of uptake of early testing of HIV-exposed infants and male involvement. The Foundation made recommendations to the San Pedro District Health Department and local facilities to further integrate community counselors into clinical HIV services. The Foundation also advised the Terre Rouge center to improve its referral system for better follow-up of HIV-exposed children.

As of December 2010, 80 of the 309 Foundation-supported PMTCT sites in Côte d'Ivoire have integrated community counselors into MCH services. Integration of community and medical activities will continue to be rolled out in more PMTCT sites. To address challenges with early infant diagnosis and partner testing, the Foundation has developed a strategy to identify a greater proportion of HIV-exposed children by sensitizing women, increasing the usage of child health booklets, and strengthening identification of HIV-exposed infants at all health service entry points. The Foundation has also developed a strategy to involve more partners in PMTCT by providing invitation letters for men to accompany their partners on ANC visits.

Reference

1 San Pedro District Health Department. PMTCT monthly data report. July 2009–February 2010.

SOUTH AFRICA:

Roll-out of Support Groups for People Newly Diagnosed with HIV Infection

Daphne Mpofu (dmpofu@pedaids.org), Thomas Sihlangu, and Lebowa Malaka

The Foundation has been supporting HIV prevention, care, and treatment services in South Africa since 2000. As of December 31, 2010, the Foundation was supporting the government of South Africa at 290 sites offering PMTCT services and 53 facilities offering HIV care and treatment services. Since its inception, the Foundation-supported South Africa program has provided nearly 640,000 women with PMTCT services, enrolled more than 263,000 patients into HIV care and support programs, and initiated over 169,000 individuals living with HIV on ART.

Background

The Foundation-supported South Africa program, through its community linkages initiative, is one of 20 national partners supporting the roll-out of the Basic Care Package to promote early recruitment and retention of people living with HIV into care and treatment. A key component of the Basic Care Package is an intensive six-week support group program for people newly diagnosed with HIV. Support groups meet twice a week over the six-week period; each session lasts three to four hours. The time period can be extended depending on the literacy level of the group.

Training of Support Group Facilitators

In January 2010, three Foundation program officers and the community linkages program manager attended a five-day training-of-trainers (TOT) course. The training was conducted by the Justice Resource Institute in partnership with South African Partners (SAP) and the Department of Health (DOH) and was aimed at preparing participants to train lay counselors as support group leaders. The curriculum was designed by SAP, the Justice Resource Institute, the DOH, and the U.S. Centers for Disease Control and Prevention.

In June 2010, these TOT particpants conducted the training for facilitators in Free State and Limpopo provinces. Trainees were encouraged to develop an action plan for the formation of support groups after the training.

To date, a total of 173 support group facilitators (95 men and 78 women) have been trained in Free State and 40 (36 women and 4 men) in Limpopo. The vast majority of facilitators (90% in Limpopo and 96% in Free State) are people living with HIV.

Results

Since August 2010, trained facilitators have conducted support groups for a total of 557 people (414 women and 143 men) in Limpopo and160 people (127 women and 33 men) in Free State. Facilitators and nurses at Foundation-supported facilities have reported improved treatment adherence among clients who have attended support groups.

Next Steps

The initiative in Free State now aims to ensure that every client diagnosed as HIV-positive takes part in the six-week support group program before treatment enrollment and the DOH is leading a process to introduce the program to more regions in South Africa of the country. In Limpopo, the training was also met with success. While the program has not yet been introduced in all districts, the Limpopo DOH has shown interest in rolling out the program to the entire province.

The Foundation and the National Alliance for State and Territorial AIDS Directors (NASTAD) are now working with the DOH to address challenges that arose during roll-out. These included limited space, clients' lack of reliable transportation to facilities, limited funds to provide food at support group meetings, and limited resources for group facilitator stipend payments.

ZIMBABWE:

Supporting the Continuum of Care for Children and Families Living with HIV

Tichaona Nyamundaya (tnyamundaya@pedaids.org), Etiya Chigondo, Batsirai Makunike-Chikwinya, Auxilia Muchedzi, Reuben Musarandega, and Michael Schoenke

A caretaker leads a group of children at one of 25 children's play centers.

In 2001, the Foundation-supported Zimbabwe country program began providing technical assistance to the country's program for PMTCT at the national, district, and site levels. Since that time, the Foundation, together with its implementing partners, has supported Zimbabwe's Ministry of Health and Child Welfare (MOHCW) in expanding the PMTCT program to 815 sites (as of December 2010).

Background

Ensuring that psychosocial support services for children and families living with and affected by HIV are accessible in their communities is a focus of the Foundation-supported Zimbabwe program. In December 2010, the Foundation's Zimbabwe country program completed a 15-month project entitled "Supporting the Continuum of Care for Children Living with HIV and AIDS," funded by the United Nations Children's Fund (UNICEF) and implemented through the Zimbabwe Ministry of Labor and Social Services (MLSS) under the National Action Plan (NAP) for the Orphans and Vulnerable Children Programme of Support. The aim of this project was to coordinate delivery of comprehensive, community-based psychosocial support services to orphans and vulnerable children, including children living with HIV, under of the age of five.

In partnership with other Family AIDS Initiative members (the Organization for Public Health Interventions and Development [OPHID] and the Zimbabwe AIDS Prevention Project [ZAPP]), the Foundation implemented this program in Chitungwiza city and four nearby districts: Murewa, Marondera, Mutare, and Buhera. The project supported the establishment of play centers for orphans and vulnerable children and provided training on psychosocial support, HIV follow-up, and adherence counseling to community health workers, parents, caregivers, and people living with HIV. The project also encouraged community health workers to identify and strengthen linkages and referral networks for treatment, care, and support for HIV-exposed and -infected children as well as children from vulnerable families.

Children's Play Centers

During the project period, a total of 25 play centers were established (9 on church premises, 6 at major hospitals, and 10 at local clinics). As of December 2010, the play centers had enrolled a total of 1,434 children into psychosocial support services, surpassing the target of 1,080. A total of 275 community-based resource people (25 group facilitators, 125 child caretakers, and 125 community health workers) were recruited and trained on psychosocial support, play therapy, PMTCT follow-up protocols, and group facilitation. The facilitators were provided with registers and bicycles to facilitate follow-up of children.

Play center facilitators worked closely with health professionals to coordinate HIV community awareness campaigns and to link children with HIV treatment, care, and support services. Between October 2009 and December 2010, a total of 1,462 HIV-exposed and -infected children received follow-up services and increased access to HIV care and treatment services through these centers. The project reached 47% of HIV-exposed and potentially eligible children in the targeted districts—children who were not previously receiving HIV care and treatment.

Conclusion and Next Steps

This project proved to be a promising model for linking health-care facilities with communities. The play centers served as a hub for community-based activities related to pediatric HIV and facilitated

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MOZAMBIQUE:

Creating a Community-Based Support Network to Coordinate and Link Partner Service Provision

Atanasio Mabote (amabote@pedaids.org) and Carlos Mahumane

In 2004, the Foundation initiated its activities in Mozambique in Nampula and Gaza provinces. The Foundation now works in four provinces, supporting the Ministry of Health to strengthen the implementation of PMTCT services at 209 sites across the country, as well as HIV care and treatment services at 46 sites. The Foundation's work in Mozambique has supported the provision of PMTCT services to more than 721,000 women, enrollment of more than 121,000 clients into HIV care and support programs, and initiation of over 42,000 individuals living with HIV on ART (as of December 2010).

Background

Retaining HIV-positive clients in HIV care and treatment is a challenge in Mozambique, particularly in Nampula, Gaza, and Cabo Delgado Provinces and the capital city of Maputo. According to Foundation program data from the last trimester of 2010, the percentage of HIV care and treatment clients lost to follow-up in these areas ranged from 66% in Nampula and Maputo to 85% in Cabo Delgado.[1] To address these high rates of loss to follow-up, the Foundation launched a strategy in November 2010 to create a community-based support network to better coordinate and link community-based organization (CBO) services and facilitate systematic follow-up of clients on ART.

Creation of a Support Network

The Foundation mapped all community-based service delivery partners in the four Foundation-supported provinces and drafted a memorandum for each partner detailing that organization's activities. The memorandum outlined the Foundation's roles and responsibilities for enlisting and training community volunteers. To date, two memorandums have been signed—one in Nampula province between the Foundation and the humanitarian health organization Doctors with Africa Cuamm, and the other in Gaza province between the Foundation and Save the Children. The Foundation hopes to use the memorandums with additional CBOs to facilitate improved coordination.

Quarterly meetings have been instituted in order to avoid duplication of partner efforts. These meetings are attended by partner representatives as well as district health authorities and provincial directors of medicine in each of the two implementing provinces. Traditional and religious leaders from each community are also invited to participate. Topics discussed during the meetings include challenges and solutions related to HIV service delivery, lessons learned and promising practices, and updates on organizational action plans.

Next Steps

Ensuring that all community focal people effectively carry out coordination and follow-up activities is an ongoing challenge. To address this, the Foundation is reorienting community and health-care focal persons on the use of interview tools, patient counseling, and active client tracing. The Foundation is also presently working with the Ministry of Health to increase incentives for community volunteers through stipends and the provision of bicycles (to facilitate home visits).

Resource

1 GLASER database. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation. Accessed March 11, 2011.

KENYA:

Ensuring the Sustainability of Support Groups for People Living with HIV: The Experiences of *Zingatia Maisha*

Rogers Simiyu (rsimiyu@pedaids.org)

The Foundation began an HIV/AIDS program in Kenya in 2000, which has expanded from a small, privately funded PMTCT initiative to a much larger prevention, care, and treatment program. Working with the Ministry of Health (MOH), the Foundation has become one of the nation's largest HIV/AIDS program partners, supporting 792 PMTCT sites and 150 care and treatment sites in Eastern and Western provinces (as of September 30, 2010). The Foundation's work in Kenya has helped provide PMTCT services to more than 825,000 pregnant women, provide HIV counseling and education to more than 768,000 pregnant women, enroll more than 89,000 clients into HIV care and support programs, and initiate more than 35,000 individuals on ART.

Background

Through funding from ViiV Healthcare, the Foundation partnered with the African Medical Research Foundation (AMREF) and the National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK) on the *Zingatia Maisha* ART Adherence and Support project. Launched in 2006, the project initially covered 19 ART-dispensing sites in Kenya's Eastern and Western provinces. Activities were focused on increasing knowledge of HIV care and treatment and on increasing the organizational capacity of community-based support groups for people living with HIV.

The project also worked to develop sustainable, mutually beneficial partnerships among health facilities and community-based organizations using a continuum-of-care model focused on community–health facility linkages. A Health Facility Community Linkages Committee (HCLC) of 15 members, co-chaired by community support group leaders, was initiated in 2007 to coordinate these activities. Training of support group leaders (i.e., lay counselors) takes place using a curriculum developed by project staff.

Defining a Sustainable Community Linkages Model

The *Zingatia Maisha* project defined a sustainable community linkages model as one that includes the following elements:

- **Ownership,** a strong commitment by those who will continue to implement the model after project funding has ended
- **A limited increase in service provider workload,** ensuring that implementation does not overburden health-care providers
- **Fluid integration into existing systems,** which is believed to be more effective than building a parallel system with separate staffing, reporting tools, and mechanisms
- **Building of supporting structures** to strengthen health facility and community institutions
- **A high level of financial independence,** so as to reduce dependence on external funding

Using these criteria for project success, the Foundation assessed the sustainability of *Zingatia Maisha* in April 2009 to determine the effectiveness of the project in enhancing the quality of HIV care and treatment and ART adherence. The assessment involved both qualitative and quantitative research methods, including focus group discussions with support group attendees, key informant interviews and surveys, site observation, and data extraction from ART registers and monthly reporting forms.

Key Findings

Ownership: Health-care workers at project implementing sites had taken the lead to enroll people living with HIV in adherence support activities and to identify training opportunities for volunteers. Staff attitudes at implementing sites reportedly improved over the course of implementation and people living with HIV reported satisfaction with the quality of care and health services provided.

Limited burden on health-care workers: The project has increased the number of community residents and people living with HIV volunteering at implementing health facilities. More than 500 community-based support groups have been linked to ART sites since the inception of the project and have been actively involved in tracing clients lost to follow-up and supporting ART.

Fluid integration: *Zingatia Maisha* has been strategically integrated into HIV services, although there has been an increase in the number of support groups established and one new structure: the HCLC. New project-specific reporting tools were not introduced to avoid increasing the burden on health workers.

Supporting structures: The project has succeeded in building stronger programs through an increase in the number of support groups for people living with HIV and through HCLCs. *Zingatia Maisha* project leaders helped legally register a number of support groups to receive supervision and financial support from the local government offices. A total of 255 support groups now receive funding from the National AIDS Control Council to implement community-facility linkage activities and continue to receive technical assistance from *Zingatia Maisha* project staff.

Financial sustainability: The project has implemented activities with a limited budget despite challenges, such as a lack of transportation and a lack of computers for data collection and retention. Although the project is programmatically sustainable, it is not yet fully financially sustainable.

Next Steps

With leveraged resources, the *Zingatia Maisha* project has been extended by the MOH to 56 high-volume ART sites in the Eastern, North, and Western provinces in addition to the 19 original ART sites. In order to achieve the project's goal of financial sustainability, it is hoped that district health management teams will integrate community support groups into their community outreach strategy and that monetary allowances and training to support group leaders will be provided, so that they may serve as community health workers. Going forward, the Foundation will continue to engage with the MOH to promote national adoption and scale-up of this community-facility linkage model, which has already been mentioned in Kenya's national AIDS strategic plan.

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India: Reaching Rural Women with Integrated ANC and PMTCT Services

access to health-care services. There were, however, many challenges in implementing this project, including difficulties in reaching rural villages on poor roads, lack of electricity and water, and limited space for the large number of women who came to the mobile clinic for services.

The primary lesson learned from this activity was that rural women will engage in integrated ANC and HIV/PMTCT services if these services are offered in a convenient manner within their communities. Stigma is a major obstacle to uptake of services, and thus integrating HIV prevention and treatment services with maternity care was found to be an effective approach.

Although the *Kisalaya* project is no longer active, other interventions to reach rural women with PMTCT services are currently under development. The lessons from Project *Kisalaya* will be used to inform further efforts.

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Lesotho: Partnership with Lesotho Network of AIDS Service Organizations Works to Strengthen Community–Health Facility Linkages

Next Steps

LENASO has scaled up community activities to all 10 districts it supports. The organization has gained recognition from the Ministry of Health and Social Welfare (MOHSW) as a community partner and serves on the MOHSW's national technical action committee on community engagement. The Foundation will continue to empower LENASO to position itself as a key local organization that can provide health and HIV-related services to communities. The Foundation-supported program in Lesotho will continue identifying local organizations with which this relationship model can be replicated.

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Cameroon: Using Partner Notification to Identify and Refer People Living with HIV for Care and Treatment

advocating to the government to support partner notification, and working to ensure the financial sustainability of the program have been deemed as priorities for future work.

CBCHB is currently preparing to initiate a research study funded by the Center for AIDS Research at the University of North Carolina (UNC) to assess the impact of partner notification services on partnership stability and social harm, as well as to evaluate the program's ability to link HIV-positive partners with care and to evaluate changes in risky sexual behaviors after receipt of partner notification services. Findings from this study will be incorporated into the training for health advisors to provide guidance on minimizing the risk of social harm and addressing potential domestic disputes in a swift, systematic, and appropriate manner.

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Zimbabwe: Supporting the Continuum of Care for Children and Families Living with HIV

improved access to HIV-related services for HIV-exposed and -infected children and their families. The project also improved the coordination of community health workers, allowing them to better connect with mothers and children who had been lost to follow-up for needed health services. Following its conclusion, the project's outcomes have been sustained, aided by its community-centered approach to implementation that placed strong emphasis on local ownership through the involvement of local people and leaders. The play centers have remained open with assistance from community volunteers.

Moving forward, the Foundation plans to incorporate these lessons into its overall programming and will continue to work with community partners in Zimbabwe to support the provision of care for children living with HIV. The Foundation is actively working to mobilize resources to support continuation of these activities.

Briefly Noted…

The following section contains brief reports on notable activities taking place within Foundation-supported country programs and global operations.

India: Increasing Uptake of HIV Counseling and Testing

Sowjanya Medisetti (sowjanya.saathii@gmail.com), Shubhangi Kulsange, and Randhoni Lairikyengbam (specialist in international programs for World Vision)

The Foundation and Solidarity and Action Against the HIV Infection in India (SAATHII) piloted a community outreach model to increase access to PMTCT services among pregnant women in rural settings. Conducted in collaboration with the National Rural Health Mission (NRHM) and Manipur state AIDS Control Society (MACS), the pilot took place in Imphal West District of Manipur in 2009 and has since been scaled up to the Ukhrul district. This project was funded by the Foundation and involved the integration of HIV counseling and testing services into existing NRHM mobile health camps. A total of 76 auxilary nurse-midwives from the two districts were trained to deliver HIV counseling and rapid testing along with antenatal care (ANC) services. In 2010, the program reached 1,096 pregnant women with HIV counseling and testing. Based on the results of this pilot, SAATHII advocated for the scale-up of community outreach across all districts of Manipur. In March 2011, NRHM and MACS directed all district-level officers in Manipur to replicate the model within their areas of operation.

Tanzania: Improving Client Retention in HIV Care and Treatment

Ivan Teri (iteri@pedaids.org), Doris Lutkam

In June 2010, the Foundation, together with Kibosho Mission Hospital staff, performed a baseline performance assessment that indicated poor client retention at Kibosho. The assessment, which analyzed clinical charts of 50 randomly selected care and treatment clients from October 2009 to June 2010, found that 19% of the sample population was classified as lost to follow-up (LTFU). A quality improvement (QI) team, comprised of hospital staff, examined this issue and realized that many LTFU clients were hard to trace because they had given false contact information, possibly out of fear of discrimination. It was also noted that the hospital's community liaison person was not aware of which clients had been lost to follow-up. Hospital staff subsequently worked with the community liaison person and HIV-positive volunteers to make a number of improvements in clinic procedures, systems to track LTFU clients, and in communications between clinic staff and the community liaison person, which allowed for better identification and follow-up of LTFU clients. In November 2010, a QI follow-up assessment found that there had been a marked decrease in LTFU since these activities were initiated. Among 50 randomly selected client charts reviewed, LTFU clients had decreased to 5%. Program officers realized that many clients are traceable through integration of hospital and community initiatives and that it is possible to improve patient-tracking systems and practices using a QI approach.

Uganda: Community Initiatives Support Enrollment and Retention in HIV and TB Care and Treatment

Joy Edith Angulo (jangulo@pedaids.org), Catherine Nanyunja, Edward Bitarakwate, and Lydia Murungi

The Foundation-supported Uganda program is working closely with the Uganda Ministry of Health's district health and district community development offices to support the roll-out of a variety of innovative community-level interventions as part of the Foundation-led Strengthening TB and HIV/AIDS Response in the South-West Region of Uganda

(STAR-SW) project. The project, which was initiated in May 2010, covers 13 districts in Uganda's South-West region and is focused on achieving improvements in PMTCT client follow-up, improving access to HIV- and TB-related services among mothers and children, and linking HIV-positive children and adults with psychosocial support services. To strengthen community–health facility linkages, civil society organizations (CSOs) and peer educators have been selected to work within communities, alongside village health teams, to connect community members with available health services. Partnerships with the Mulago-Mbarara Teaching Hospital's Joint AIDS Program (MJAP), the Uganda Health Marketing Group (UHMG), and the Mayaja Memorial Hospital Foundation (MMHF) will further support project activities.

Zambia: Training Pediatric HIV Counselors to Improve the Provision of Psychosocial Support to Children Living with HIV

Veronica Tembo (vtembo@pedaids.org), Sue Gibbons, Ashley Thompson, and Susan Strasser

Since 2008, the Foundation's Zambia program has trained over 100 pediatric HIV counselors at the Center for Infectious Disease Research/Zambia (CIDRZ) and Africa Directions using the MOH-approved Catholic Relief Services/African Network for Care of Children Affected by HIV/AIDS (CRS/ANECCA) two-week course on counseling HIV-positive children and adolescents. Using a training-of-trainers curriculum developed by the Foundation's Zambia team, the MOH has now trained over 200 additional pediatric HIV counselors in the country. Pediatric HIV counselors lead support group discussions and conduct home visits to children and their families. The Foundation plans to hold a Children's Support Group Forum with a number of children's support group leaders across Lusaka to enable the exchange of ideas, best practices, and mutual support. Strengthening these activities will encourage more children to live positively and receive comprehensive support from their peers, families, and communities.

Foundation Engages with World Vision to Reach More Women and Children

Adaku Ejiogu (aejiogu@pedaids.org)

Built upon a shared commitment to the elimination of pediatric HIV, the Foundation's partnership with the Christian relief and development organization, World Vision, combines the technical expertise and programmatic reach of both organizations. The partnership will focus on strengthening early infant diagnosis through testing and follow-up of children at World Vision–supported facilities, identifying children who are not responding positively to treatment through home-based outreach efforts, and helping mothers and children adhere to ART through home-based care. The partnership will also work to increase the number of PMTCT clients who deliver their infants at health facilities by providing health education through community health workers and community leaders. A global memorandum of understanding has been signed by the two organizations, and the details of partnership activities and specifications of the program models used will be further developed within each implementing country.

Q&A with…

Tatu Mtambalike and Jeanne Cathérine Sié Akoua

Tatu Matambalike is a program coordinator for community linkages in the Foundation-supported Tanzania program. *Cathérine Sié* is a community liaison officer in the Foundation-supported Côte D'Ivoire program. Tatu and Cathérine are both active members of the Foundation's community initiative core action team and were recently asked to provide their views on the importance of working with communities to improve the quality of HIV services.

Tatu Mtambalike

Cathérine Sié

When did you start working toward the elimination of pediatric HIV and AIDS, and why?

Tatu: Prior to joining the Foundation I worked with parents to help them listen to the needs and concerns of their children. I joined the Foundation in 2009 because of my interest in advocating on behalf of children and the desire to give children living with HIV the best possible care.

Cathérine: Before joining the Foundation in 2006, I worked with adults with HIV. I also worked with children who were orphaned. Many of the orphans I work with were born HIV-exposed or HIV-positive, and I felt I had to do something to help. I joined the Foundation to work for children.

Do you have a professional hero, and if so, how has he or she inspired you?

Tatu: The hero who is the most inspirational to me is a primary school teacher whom I became close with as a child. The teacher encouraged me to be positive and to remain determined through difficult times. The memory of this teacher reminds me that it is important to listen to children and provide them with psychosocial support.

Cathérine: The person I most admire is Dr. Menga. I was still a student when I met him at the national blood transfusion bank; he administered my first HIV test. He is an extraordinary person and his care is remarkably patient-focused. He pays attention to patients' concerns and will even follow up with patients in their homes when they miss an appointment. I have since developed a professional relationship with Dr. Menga, and we now consult each other for advice. This relationship has motivated me.

What are your favorite aspects of community work, and what do you most enjoy about the work you do with the Foundation?

Tatu: I most enjoy learning from communities about behavior and practices. When you are an outsider going into communities, your first step is to learn about what the people of these communities are doing and thinking. I enjoy increasing awareness of HIV treatment for families and PMTCT. I feel a great sense of accomplishment about introducing psychosocial support to children living with HIV in Tanzania, and I'm motivated to continue this work every time I hear that the Foundation is considered a pioneer in psychosocial support for children living with HIV.

Cathérine: I enjoy the element of teamwork. My favorite aspects of community work are the site visits—learning how to develop procedures and harmonize tools. It promotes community responsibility and helps us achieve our mission.

If you had five minutes with the Foundation's Global Leadership Team, what would you advocate for related to the Foundation's community work and the elimination of pediatric HIV and AIDS?

Tatu: I would advocate for increased family involvement in HIV services. The Tanzania program has worked hard to involve men, but babies are still not being brought in to PMTCT facilities for testing and treatment, and mothers are still being lost to follow-up. I think we need to tailor our approach to become more family-centered, and to do this we need to focus on the client's entire household.

Cathérine: I would make a plea for two things: increased documentation of promising practices in community approaches, and an increase in practical trainings and exchange visits to disseminate promising practices and learn from other countries' experiences.

What are the most challenging aspects of community work, and how do you think the Foundation can address these challenges?

Tatu: Realizing that change takes time. Consistent messages need to be repeated at different levels of a community to take effect. A major problem is that communities hear mixed messages from fellow community members and leaders. Stigma has been reduced, but it still exists. I feel that to address these challenges, it is important to work with local government structures and religious leaders. Religious leaders in Tanzania have been very helpful in encouraging community members to access HIV services.

Cathérine: Counseling of pregnant women from birth until the early diagnosis and monitoring of their children. Challenges often arise after the initial assessment is complete and the initial prophylaxis is given—then we do not know what happened to the child. The Foundation could address this challenge by integrating community counselors more broadly and by making regular home visits. The Foundation should also strengthen on-the-ground supervision.

If you had five minutes with the Minister of Health (or relevant minister), what would you advocate for related to community work and the elimination of pediatric HIV and AIDS at a national level?

Tatu: I would encourage more community-based activities, and I would advocate for an increase in the number of lay workers supporting clients living with HIV. Adherence counseling cannot take place only at the clinic; communities can also play a role in strengthening adherence. Income-generating activities, covering transport costs to and from clinics, and including sectors outside health care in the elimination agenda are necessary to ensure that families living with and affected by HIV receive an adequate level of support.

Cathérine: I would lobby for official and national recognition of the role of the community counselor. Community counselors often do not have offices to work from and must perform their duties in the corridors of hospitals. Sometimes doctors even refuse to work with the counselors because they have no official status.

How can we better involve communities in the Foundation's work so that they can fully contribute to the goal of elimination of pediatric HIV and be involved in our programs in a meaningful way?

Tatu: If we better involve community leaders and clarify their roles and responsibilities, we can heighten the elimination agenda. Communities need to be supportive of the elimination agenda for there to be less stigma and fear.

Cathérine: I think we should strengthen the capacity of local organizations that provide community counselors. We must continue to give on-the-ground support to communities.

What community efforts are we currently implementing that warrant more attention or should be further scaled up?

Tatu: Building the capacity of local institutions as well as psychosocial support for children both deserve more attention and need to be scaled up. We need to build the capacity of health facility staff in providing children with psychosocial support. Male involvement and a family-centered approach are also areas that need more attention.

Cathérine: We must harmonize activities and data collection. Everyone should have the same tools and procedures for monitoring women and patients. We must also continue our work with other NGOs to assess the quality of and strengthen these activities.

What is the most innovative community approach you have seen in your career related to pediatric HIV and the prevention of mother-to-child transmission?

Tatu: The involvement and encouragement of communities in decision making relating to HIV is an innovative approach. Communities need to make policies on their own, because they are capable and they should have ownership over programs. Approaches should be led by village governments and local government authorities. Male involvement strategies that we have been employing are also innovative.

Cathérine: The most innovative community approach I have seen in my career is the involvement of people with HIV as community counselors. It is easier for HIV-positive pregnant women to communicate about risks and responsibilities with counselors who are themselves HIV-positive.

Calendar of Events

International and Regional Meetings

JUN 2011

The First International HIV Social Science and Humanities Conference

June 11–13, 2011 | Durban, South Africa
Abstract Deadline: Closed

The first international conference aimed at discussing and supporting contributions of the social sciences and humanities to HIV research and action.
http://www.iaohss.org

Global Health Council Conference

June 13–17, 2011 | Washington, D.C.
Abstract Deadline: Closed

The 2011 conference theme is securing a healthier future in a changing world.
http://www.globalhealth.org/conference_2011

JUL 2011

6th International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2011)

July 17–20, 2011 | Rome, Italy
Abstract Deadline: Closed

This biennial gathering is an opportunity to examine the latest developments in HIV-related research and to explore how scientific advances can be translated quickly into effective interventions to prevent and treat HIV, particularly in low- and middle-income countries.
http://www.ias2011.org

SEP 2011

Reproductive Health 2011

September 15–17, 2011 | Las Vegas, Nevada
Abstract Deadline: Closed

Sponsored annually by the Association of Reproductive Health Professionals with content developed by leading experts in the field, including the authors of *Contraceptive Technology*.
http://www.reproductivehealth2011.org

OCT 2011

European AIDS Conference

October 12–15, 2011 | Belgrade, Serbia
Abstract Deadline: July 1, 2011

One of the goals of the European AIDS Conference is to promote an interest in clinical HIV research among young researchers and clinicians at an early stage in their career, including those from central, southeastern, and eastern Europe.
http://www.eacs-conference2011.com

OCT 2011

American Public Health Association (APHA): 139th Annual Meeting & Exposition

October 29–November 2, 2011 | Washington, D.C.
Abstract Deadline: Closed

The oldest and largest gathering of public health professionals in the world, attracting more than 13,000 national and international physicians, administrators, nurses, educators, researchers, epidemiologists, and related health
http://www.apha.org/meetings/AnnualMeeting

NOV 2011

World Congress of the World Society for Pediatric Infectious Diseases

November 16–19, 2011 | Melbourne, Australia
Abstract Deadline: June 10, 2011

Brings together experts on infectious diseases from all over the world, with much attention given to avian flu, SARS, AIDS, and other life- and world- threatening diseases.
http://www.wspid.com/announcements.asp

6th SAHARA Conference

November 28–December 2, 2011 | Port Elizabeth, South Africa
Abstract Deadline: Closed

SAHARA conferences actively seek to involve local communities and people affected by HIV in an effort to facilitate dialogue between researchers, implementers, and communities. The theme for the 6th SAHARA Conference is HIV/AIDS and human rights.
http://www.sahara.org.za

DEC 2011

International Conference on AIDS and STIs in Africa (ICASA)

December 4–8, 2011 | Addis Ababa, Ethiopia
Abstract Deadline: June 10, 2011

An opportunity for African scientists, health providers, social leaders, political leaders, and communities to come together to share experiences and updates on the response to the HIV/AIDS pandemic in the continent and around the world.
http://icasa2011addis.org

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