



ELIZABETH GLASER
PEDIATRIC AIDS FOUNDATION

Engaging People Living with HIV as Lay Counsellors in HIV Care and Treatment Services



Experiences in Kilimanjaro, Tanzania

Elizabeth Glaser Pediatric AIDS Foundation
Dar es Salaam, Tanzania
© 2010 by Elizabeth Glaser Pediatric AIDS Foundation



The specific activities described in this report were made possible through the generous support of Abbott Fund. The Elizabeth Glaser Pediatric AIDS Foundation's HIV care and treatment programme in Tanzania is supported by the U.S. Centers for Disease Control and Prevention (CDC). The contents of this report are solely the responsibility of the Elizabeth Glaser Pediatric AIDS Foundation and do not necessarily represent the official views of Abbott Fund, CDC, or other Foundation sponsors.

Acknowledgements

The Elizabeth Glaser Pediatric AIDS Foundation is grateful to the many individuals who assisted in researching and writing this document.

We would like to acknowledge the management and staff at Mawenzi Regional Hospital in Moshi and Huruma Designated District Hospital in Rombo, as well as at the health facilities in Keni, Kiboroloni, and Tarakea. Their support and sharing of knowledge and experiences enabled the team to gather valuable information.

During the period November 2008 to February 2009, Petri Blinkhoff (consultant), Atuswege Mwangomale (public health evaluation officer, Foundation-Tanzania), and Jacqueline Kalimunda (community liaison officer, Foundation-Tanzania) travelled to the districts of Moshi and Rombo to collect relevant information—through observation of activities and reports, as well as focus group discussions and in-depth interviews with stakeholders. Their findings are presented in this document.

We are particularly grateful to Abbott Fund for providing funds to make possible the innovative approach of involving people living with HIV as lay counsellors in the health services.

A heartfelt *asanteni sana* (thank you very much) goes to the numerous lay counsellors and care and treatment clinic clients who gave of their valuable time to talk with members of the team or participate in focus group discussions.

We wish to pay tribute to the late Naomi Achimpota who, in her capacity as liaison officer at Foundation-Tanzania, stood at the cradle of the lay counsellors programme.

Executive Summary

The Elizabeth Glaser Pediatric AIDS Foundation (the Foundation) is one of the leading global organisations supporting the provision of HIV prevention, care, and treatment services. The Foundation currently supports lifesaving prevention of mother-to-child transmission services at more than 4,500 sites in 17 countries, and also leads the way in provision of HIV care and treatment services, placing particular emphasis on services for children and mothers.

Although much progress has been made, a number of hurdles still need to be overcome in pursuit of expanded provision of PMTCT services. PMTCT programmes have encountered difficulties regarding the follow-up of HIV-positive mothers and their children after delivery. Thus, it is important that barriers to long-term follow-up care for women and children are addressed through a variety of strategies, especially those that foster the active involvement of the community to address these challenges.

Many opportunities to diagnose and counsel individuals at health facilities are being missed. Consequently, health facilities are losing opportunities to offer critical care and support services, as well as to provide lifesaving medications to the parents, the children, and the family as a whole. Provider-initiated HIV testing and counselling supported by the use of lay counsellors provides an opportunity to address this gap; it facilitates diagnosis and access to HIV-related services.

The effective delivery of HIV and AIDS services in Tanzania is challenged by a number of common constraints, including staffing shortages, limited rural coverage, service bottlenecks, stigma, scarcity of home-based care, and weak referral systems. Broad-based solutions to these challenges continue to require work by all stakeholders, including the Foundation.

Thanks to efforts supported by the Foundation's Tanzania country programme, people living with HIV have been trained to work as lay counsellors at health facilities and in their communities in Moshi and Rombo districts of Tanzania's Kilimanjaro Region. The 68 lay counsellors trained over the past two years play essential roles: they encourage and support HIV testing and drug adherence, complement the workforce at health facilities by taking over some nonmedical tasks, constitute an important link between health facilities and communities in the follow-up and tracing of HIV-exposed and HIV-infected children, and also help to address stigma and misconceptions associated with HIV. Moreover, the lay counsellors are empowered by the programme in terms of their own HIV awareness, personal development, and economic stability.

This document summarises the key components of the lay counsellors programme that have contributed to its success, such as careful recruitment practices and recognition of lay counsellors as valued members of health-care teams. Also highlighted are specific steps that support the use of people living with HIV as lay counsellors and parameters regarding how to monitor the impact of this work.

The lay counsellors programme in Moshi and Rombo districts has yielded promising results during its early stages of implementation. Data have been collected with a view to possible extension and replication of this programme by the Foundation and its partners. The information presented in this document is based on in-depth consultations with health-care providers, Foundation staff, lay counsellors, and clients at selected health facilities in the participating districts.

Acronyms

| | |
|--------------|--|
| AIDS | acquired immunodeficiency syndrome |
| ART | antiretroviral therapy |
| ARV | antiretroviral |
| CBO | community-based organisation |
| CTC | care and treatment clinic |
| HIV | human immunodeficiency virus |
| PITC | provider-initiated testing and counselling |
| PLHIV | people living with HIV |
| PMTCT | prevention of mother-to-child transmission |
| RCH | reproductive and child health |

Table of Contents

| | | |
|----------|---|----|
| 1 | <i>Involving PLHIV as Lay Counsellors</i> | |
| | Background | 1 |
| | Involving PLHIV in HIV Services in Kilimanjaro Region | 3 |
| <hr/> | | |
| 2 | <i>The Many Benefits of Involving PLHIV as Lay Counsellors</i> | |
| | Linking HIV Services and Communities. | 7 |
| | Making Health Facilities More User-Friendly | 8 |
| | Addressing HIV-Related Stigma and Misconceptions | 9 |
| | Empowering PLHIV | 11 |
| <hr/> | | |
| 3 | <i>Assessing Success and Confronting Challenges</i> | |
| | Assessing Success | 12 |
| | Confronting Challenges | 12 |
| <hr/> | | |
| 4 | <i>Supporting the Involvement of Lay Counsellors</i> | |
| | Essential Features of Successful Involvement of Lay Counsellors | 15 |
| | Necessary Elements of Implementation | 16 |
| | Conclusions. | 18 |

1 Involving PLHIV as Lay Counsellors

- Background
- Involving PLHIV in HIV Services in Kilimanjaro Region

Background

With some 33 million people living with HIV worldwide,¹ expanding access to antiretroviral therapy (ART) is an international health priority. Knowledge of HIV status is of crucial importance to expanding access to HIV treatment, care, and support. It also offers HIV-positive individuals an opportunity to receive information and tools to prevent HIV transmission to others. Despite this, over 60 percent of people living with HIV worldwide do not know they are HIV-positive.¹

Only 45 percent of HIV-positive women worldwide received treatment to prevent transmission of the virus to their child in 2008.¹ Without access to this set of lifesaving interventions, about one in three children born to women living with HIV will contract the virus, and, in the absence of treatment, half of infected children will die before age two.^{2,3}

About the Foundation

The Elizabeth Glaser Pediatric AIDS Foundation (the Foundation) is one of the leading global organizations supporting the provision of HIV prevention, care, and treatment services in resource-limited settings, with a particular emphasis on securing access to these vital services for children living with and affected by HIV. The Foundation currently supports prevention of mother-to-child transmission services at more than 4,500 sites in 17 countries, as

well as HIV care and treatment services for children and adults at more than 660 sites. As of September 2009, Foundation-supported programmes had provided more than 8.6 million pregnant women with PMTCT services and tested more than 7.4 million pregnant women for HIV. As national programmes in the countries it supports have grown in scale, the Foundation is now working in close partnership with local governments and other partners to better address gaps in the continuum of HIV prevention, care, and treatment for women, children, and families.

PMTCT programmes have encountered difficulties regarding the follow-up of mothers living with HIV and their HIV-exposed children after delivery. The Foundation strives to improve the identification of mothers living with HIV and their infants and to ensure their retention within the health-care system.

1. UNAIDS (Joint United Nations Programme on HIV/AIDS). AIDS epidemic update 2009. Geneva, Switzerland: UNAIDS; 2009.

2. UNAIDS. Children and AIDS: a stocktaking (Fact Sheet #1). http://data.unaids.org/pub/FactSheet/2007/20070118_stocktaking_%20fact_%20sheet_%201.pdf. Published 2005. Accessed March 9, 2010.

3. Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet*. 2004;364(9441):1236-1243.

However, many of the social and cultural constraints that interfere with the long-term follow-up of these mothers and their children cannot be directly addressed by health workers. The Foundation therefore employs a variety of strategies to address barriers to long-term follow-up care for women and children, with an emphasis on fostering the active involvement of communities to address these challenges.

Tanzania Programme Overview

Tanzania has a population of 36 million. The estimated HIV prevalence among adults is 6 percent, and is higher among women than among men (7 percent and 5 percent, respectively). It is estimated that 70,000 to 80,000 newborn infants are at risk of acquiring HIV every year, either during pregnancy, during labour and delivery, or through breastfeeding,⁴ yet in 2008 only 53 percent of women and 44 percent of men in Tanzania reported awareness that medications and other services are available to reduce the risk of mother-to-child HIV transmission.⁵ Less than 16 percent of the estimated 110,000 children living with HIV in Tanzania have received appropriate care, including ART.⁶

The Elizabeth Glaser Pediatric AIDS Foundation established a country office in Tanzania in 2004 and since then has been supporting the expansion of PMTCT services in five regions: Arusha, Kilimanjaro, Mtwara, Shinyanga, and Tabora. As a result of the partnership between the Foundation and the health services sector in Tanzania, in particular at the district level, PMTCT services have been scaled up at a rate that has exceeded expectations. At the end of 2004, the Foundation was supporting 74 PMTCT sites.

By September 2009, after implementing a district approach to scale-up,⁶ the Foundation was supporting 935 Tanzanian health facilities in offering PMTCT services. At the request of the government of Tanzania, the Foundation has more recently expanded its services to include general HIV care and treatment, including ART, for both children and adults.

At the end of 2009, the Foundation was supporting 165 sites in four regions to provide HIV care and treatment services for children and adults.

Through its critical partnerships with the U.S. government and Abbott Fund, as well as other public and private donors, the Foundation has been able to strengthen its focus on paediatric HIV infection in Tanzania and to pilot and document innovative approaches to address the numerous constraints associated with provision of HIV/AIDS-related services to infants and young children. These partnerships have also allowed for the creation of stronger linkages between Foundation-supported health facilities and the communities they serve, enabling greater access to HIV-related services.

Challenges to Service Provision

The effective delivery of HIV-related services in Tanzania is hindered by a number of common constraints, including staffing shortages, limited rural coverage, service bottlenecks, stigma, scarcity of home-based care, and weak referral systems. The implementation of broad-based solutions to overcome these challenges will continue to require work by all stakeholders, including the Foundation.

For example, even though PMTCT and HIV care and treatment services are now available in Tanzania on a wider scale, mothers with HIV and their children are often lost to follow-up after delivery. Moreover, systematic identification of HIV-exposed and infected young children is largely absent. As a result, many of the youngest children with HIV are not receiving critical care and treatment services during the first few months of life when they are most needed, putting them at risk of early death.

Many other opportunities to diagnose and counsel individuals of all ages at health facilities are being missed. This results in lost opportunities to offer critical care and support services and lifesaving medications to parents, children, and families.

Box 1. What motivates PLHIV to volunteer in the health services?

The following comments come from volunteers who joined the Foundation's programme as lay counsellors in Rombo and Moshi districts.

I went through a hard time due to this disease. But I experienced love and care from the nurses at the hospital. This motivated me to volunteer at the hospital and help other people who suffer from the same disease. I felt I somehow owed it to help others, especially because I know that if other people get the treatment that I got, they will be fine. —Lay counsellor, Keni Health Centre

I experienced prejudice in the community when it became known that I am infected with HIV. I want to share my knowledge about HIV and AIDS, and to educate the community so that I can prevent others from acquiring the disease. I don't want other people to experience what I've gone through.

—Lay counsellor, Kiboroloni Health Centre

The work at the care and treatment clinic gives me something useful to do, instead of sitting idle and worrying about my status. It gives me peace of mind. Since my wife died, I find social support in the group. —Lay counsellor, Tarakea Health Centre

Interventions like provider-initiated testing and counselling (PITC), supported by the use of lay counsellors in a variety of nonclinical roles, offer opportunities to address these gaps by facilitating diagnosis and access to HIV-related services at a variety of health service delivery points.

Involving PLHIV in HIV Services in Kilimanjaro Region

The Foundation's Tanzania country programme began supporting efforts to firmly establish PITC and routine identification of HIV-exposed children in reproductive and child health (RCH) clinics, outpatient departments, and maternity and paediatric wards in early 2007. The programme was established in response to the low rate of identification of HIV-exposed infants and children in Tanzania within the existing RCH infrastructure. A critical component of the PITC roll-out was the involvement of PLHIV as lay counsellors. The lay counsellors are uniquely positioned to serve as the vital link between the health facility and the community, an activity deemed essential to the success of the PITC intervention.

The programme is being implemented in Kilimanjaro Region (HIV prevalence 7.3 percent)⁸ beginning at Mawenzi Regional Hospital in Moshi District and Huruma Designated District Hospital in Rombo District. The Foundation and its partners have concurrently been looking to establish closer linkages between health facilities and communities in the region.

4. NBS (Tanzania National Bureau of Statistics) and ORC Macro. Tanzania HIV/AIDS and malaria indicator survey (THIS) 2003-04. Dar es Salaam, Tanzania: NBS and ORC Macro; 2004.

5. UNAIDS, 2009.

6. Tanzania Commission for AIDS (TACAIDS), Zanzibar AIDS Commission (ZAC), NBS, Office of the Chief Government Statistician (OCGS), and Macro International Inc. Tanzania HIV/AIDS and malaria indicator survey 2007-08. <http://www.tac aids.go.tz/dmdocuments/THMIS%202007-08.pdf>. Published November 2008. Accessed March 9, 2010.

7. See Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Rapid scale-up of PMTCT service provision using a district approach: the Tanzania experience. Dar es Salaam, Tanzania: EGPAF.

8. NBS and ORC Macro, 2004.

In the second half of 2008, after the expansion of the project to eight lower-level health facilities in Rombo and Moshi urban districts, 58 volunteers were engaged to be trained by the Foundation as lay counsellors. Lay counsellors are selected based on personal qualities such as demonstrated volunteerism, willingness and ability to talk about their HIV status, empathy, and membership in a PLHIV group or community-based organisation (see Box 1). The vast majority of counsellors are between the ages of 29 and 46 (youngest is 18, oldest is 61), and 72 percent are female. Lay counsellors' primary responsibilities are to make PITC services more accessible at the community level to ensure that fewer children will be lost to follow-up, and to take over some of the nonclinical tasks from overburdened staff at health facilities.

Building on Existing Initiatives and Responding to Local Needs

Many Tanzanian health-care providers have recognised the potential of HIV-positive volunteers to promote HIV testing and ART adherence in their communities and to assist with follow-up of HIV-positive mothers and HIV-exposed and infected children. Prior to the programme's initiation, some health facilities in Kilimanjaro had already begun collaborating with HIV-positive volunteers, who were assisting clinical staff by performing a variety of nonclinical tasks such as weighing clients, collecting clinic files, and sorting client cards. The Foundation initiative was therefore able to build upon these early experiences and formalise the involvement of HIV-positive volunteers in health facilities by increasing their numbers, upgrading their skills and knowledge, and supporting them with a small monthly stipend. The Foundation's programme was developed in accordance with the Tanzanian national HIV care and treatment guidelines and the existing national home-based care curriculum.

Recruitment and Training of Lay Counsellors

To recruit a pool of HIV-positive volunteers, the programme identified key CBOs operating within the catchment area of each of the eight targeted health facilities in Rombo and Moshi districts. Those CBOs linked the Foundation with PLHIV who were willing to volunteer and be trained as lay counsellors. The prospective lay counsellors participated in a five-day training course covering basic knowledge of HIV and AIDS, referral of suspected cases of HIV infection, ART, client education on treatment adherence, condom use, self-care and nutrition, service availability, and documentation and reporting. Since the volunteers were trained in the context of expanding access to PITC, much emphasis was placed on counselling skills. The training curriculum was designed by the Foundation's country programme team in collaboration with health-care providers and PLHIV groups.

At the successful completion of training, lay counsellors are invited to attend follow-up meetings once every six months. These meetings provide lay counsellors with an opportunity to share their experiences, ask questions, and obtain additional information.

Coordination and Supervision of Lay Counsellors

Care and treatment site coordinators and community liaison officers at health facilities are responsible for the day-to-day supervision of lay counsellors. In addition, the Foundation supports two coordinators who have been recruited from the ranks of the more experienced volunteers. The lay counsellors also meet quarterly with a Foundation representative to problem solve and receive support.



A lay counselor gives a health talk to clients at Huruma Hospital, Rombo District

Lay Counsellor Activities

HEALTH TALKS: Lay counsellors conduct health talks for groups of PLHIV in the waiting areas of the care and treatment clinic (CTC) on clinic days. Topics range from the importance of ART adherence to self-care, nutrition, the importance of disclosure about one's status, condom use, and the importance of joining PLHIV groups.

ONE-ON-ONE COUNSELLING: Under the supervision of a CTC nurse, lay counsellors provide one-on-one counselling to new CTC clients who have agreed to meet with a lay counsellor. Topics discussed are in accordance with those covered during the counsellor's five-day training course.

COMMUNITY LINKAGE: Lay counsellors provide referrals for individuals in the community to access HIV testing services and also to link health facility clients to social support services (nongovernmental organisations, CBOs, faith-based organisations, village leaders) as needed. In close collaboration with the liaison officers at the health facilities, the lay counsellors track clients who are lost to follow-up, and advise and encourage pregnant or newly delivered HIV-positive women to return for HIV care or antiretroviral drug (ARV) treatment or to bring their children back for HIV testing.

COMMUNITY HEALTH PROMOTION: Lay counsellors give talks at village meetings, in churches at religious meetings, and at schools. These talks are an opportunity for counsellors to give testimonies about their HIV status and to provide information about HIV testing, PMTCT, and available care and treatment services to a wide array of community members.

PLHIV GROUPS: Together with the community liaison at the health facility, lay counsellors focus on linking as many CTC clients as possible to PLHIV support groups. The lay counsellors also help PLHIV support groups to organise their meetings so that they can discuss the issues and concerns they share in common, such as HIV status disclosure, family planning, and adherence to treatment. The Foundation facilitates these meetings by providing transport refunds and refreshments to meeting participants.

Nonclinical Tasks at the Health Facility

Lay counsellors perform a range of nonclinical tasks at the health facilities, including weighing clients, file distribution, cleaning client waiting rooms, making appointments, date keeping, and escorting clients for intrafacility referrals to pharmacy, laboratory, and so forth.

Working Days and Monthly Stipend

The Foundation has agreed with the lay counsellors that they are expected to work a minimum of four to five days per month in the community and/or at health facilities. The lay counsellors receive a monthly stipend of 50,000 Tanzanian shillings (approximately US\$35) once their monthly reporting duties have been fulfilled. The stipend is provided in recognition of their efforts and to compensate their transport expenses and opportunity costs.

Monitoring and Data Collection

Lay counsellors produce monthly narrative reports of their activities that include the following indicators: number of sensitisation sessions at schools, orphanages, and churches; number of testimonies provided at village meetings and other occasions; number of home visits for follow-up; number of clients referred and/or escorted for HIV testing after counselling; and number of lost-to-follow-up clients traced and returned to the CTC after counselling.

Monitoring of lay counsellors' outputs and involvement outcomes has recently been made more effective by the introduction of so-called 'sticker referrals'. Lay counsellors use referral letters with a yellow sticker for clients who have been traced after loss to follow-up and a red sticker for clients who have been referred for HIV testing. These referral forms are collected at the health facility.

2 The Many Benefits of Involving PLHIV as Lay Counsellors

- **Linking HIV Services and Communities**
- **Making Health Facilities More User-Friendly**
- **Addressing HIV-Related Stigma and Misconceptions**
- **Empowering PLHIV**

To get a better understanding of the benefits gained from engaging lay counsellors, stakeholders were asked questions such as, ‘Why do health services work with lay counsellors?’ and ‘What difference do the lay counsellors make?’ Such questions were posed to CTC site managers, adherence nurses, liaison officers, CTC clients, lay counsellors, and Foundation staff. Furthermore, lay counsellors were asked what they gained from their involvement in the programme (i.e., ‘What is in it for you?’). The sections that follow highlight the many benefits of engaging PLHIV as lay counsellors, according to programme stakeholders. Quotes have been included where appropriate to illustrate respondents’ individual perceptions and to highlight some of the most frequently mentioned benefits, such as ‘increased accessibility’ and ‘acceptability’.

Linking HIV Services and Communities

The Foundation programme places great emphasis on creating stronger linkages between health facilities and the communities in their catchment areas. Activities undertaken during home visits include counselling on HIV testing and adherence to ART, family support, and follow-up of ART defaulters.

Lay counsellors are becoming increasingly successful at referring children for HIV testing. In the first three months of 2009, they referred 325 individuals for testing, 42 percent of whom were children.

Table 1 (see page 9) illustrates the variety of ways in which lay counsellors, through their community activities, have been actively forging this link.

During the first 12 months of the programme, lay counsellors motivated and/or referred a total of 761 people to seek HIV testing. Through active case finding, home visits, and being available and approachable in the community, the lay counsellors

Box 2. Lay counsellors on the front lines of PITC and client follow-up

The following quotes illustrate how PLHIV lay counsellors are effectively extending PITC into the community.

After prayers, the group of lay counsellors spoke to our small Christian community on HIV testing. I decided to follow one of them. I told him about the weak health of my stepson who was so sick that he couldn't even go to school. The lay counsellor advised me to take my stepson to the health facility for HIV testing, and he gave me a note with a sticker to take to the nurse-counsellor. At the health facility, it was found out that my stepson is HIV-positive. A CD4 count was done in Mawenzi Hospital. They found that his CD4 are still high and gave him Septrin. Since then he is doing well and he is able to attend school again. When he did his exams, he finished in 11th place out of 40 children.

—CTC client, Kiboroloni Health Centre

When I started to get sick, I did not know what I was suffering from. Then the lay counsellor passed my house and saw me. We talked and she advised me to take an HIV test. I went and was diagnosed with HIV. They sent me straight to the CTC. By that time I was very ill, but now, thanks to her, I am doing alright.

—Focus group discussion participant,
CTC client at Mawenzi Hospital

have brought HIV services within closer reach of members of their communities. Moreover, with attention paid to ensuring appropriate confidentiality and consent (counsellors are trained on these issues), lay counsellors often literally link clients to the health facility by personally escorting the people they have referred. This helps clients overcome their fears and get to know their way around the health facility.

It is often difficult to impossible for health centre staff, already overburdened with clinical duties, to travel to communities and follow up new mothers living with HIV who haven't returned after delivery. Follow-up is equally difficult with clients on ART who have missed appointments or stopped taking ARVs altogether. Health workers and lay counsellors alike agree that the latter are in a much better position to perform client follow-up. Because lay counsellors live in the same communities as the clients and know their backgrounds, it is relatively easy for them to approach clients and establish a rapport, and to encourage clients to return to the health facility (see Box 2). At their monthly meetings with lay counsellors, health workers provide the names and locations of people in need of follow-up. Health workers report that after sharing this task with lay counsellors, a larger number of lost-to-follow-up clients have been returning to the CTC than before the programme was initiated.

Making Health Facilities More User-Friendly

The engagement of PLHIV as lay counsellors serves to increase the number of staff at health facilities while bringing a specialised set of knowledge and skills to the team. This has helped to make HIV services more user-friendly (see Box 3 on page 10). While the programme is still being scaled up, the goal is to have at least two lay counsellors stationed at each facility, with additional counsellors stationed in the community.

Staff shortages and the added responsibilities of providing HIV services have led to congestion at health facilities, with overburdened nurses often not able to spend sufficient time on counselling and support. Health workers stated unanimously that by taking over a number of nonclinical, routine tasks at the health facility, lay counsellors have freed up more of their time for tasks requiring their special skills. Additionally, clients have noted that CTC services run more smoothly thanks to lay counsellors' efforts.

Table 1. Community Activities Reported by PLHIV Lay Counsellors (n = 48) from April 2008 to March 2009 in Moshi Municipal Council and Rombo District Council

| Activity | Occurrences Reported |
|---|----------------------|
| Visited centre for orphans/vulnerable children | 34 |
| Visited school | 114 |
| Attended community meeting (village/ward, faith-based, PLHIV) | 580 |
| Home visit | 252 |
| Referred/escorted client for HIV testing | 761 |
| Lost-to-follow-up client returned to CTC* | 42 |

* Return of clients lost to follow-up continues to increase, with a total of 144 clients followed up by lay counsellors through December 2009.

There is yet another reason why lay counsellors have increased the accessibility and user-friendliness of health services: lay counsellors and CTC clients share a lot in common. Health workers have reported that clients attach a lot of value to what lay counsellors say. For instance, as a standard component of the counselling session with a new client, lay counsellors first disclose their own HIV status and give a short personal history of how they have been living with the virus. This simple gesture helps to establish a common ground with the client and increases to his or her receptiveness to any information or guidance the lay counsellor may offer.

Health-care providers point to the increased use of lower-level health facilities as a result of lay counsellor involvement. They report that in the past, people preferred to use HIV services at distant facilities where they wouldn't risk meeting people who knew them and might guess their HIV status. People now seem to be overcoming their reluctance to use services near their homes, thanks to the presence of lay counsellors who are open about their status and put them at ease, thus reducing people's fear of stigma (see Box 4 on page 10).

Addressing HIV-Related Stigma and Misconceptions

Stigma and discrimination have been associated with HIV and AIDS from the start of the epidemic. It is difficult to precisely measure the impact that lay counsellors have had on the reduction of stigma associated with HIV. However, anecdotal evidence from interviews with health workers, clients, and lay counsellors indicates that lay counsellors are having some effect on reducing stigma. There are a variety of possible reasons for this. First, through their presence as active volunteers in the community and at health facilities, lay counsellors counteract prevailing negative stereotypes about PLHIV. They contribute positively to the community, stay healthy thanks to the availability of drugs, and survive despite being HIV-positive. Second, PLHIV explicitly address stigma and rectify misconceptions when they speak at meetings and give their testimonies. Third, lay counsellors often intervene and mediate when PLHIV in their communities become the target of stigmatisation. And lastly, some lay counsellors have formed groups where they can meet and discuss issues regarding HIV/AIDS, and through these groups have been able to access funds for income-generating activities. To date, 10 such groups have been formed in the two districts where the programme is active.

Box 3. How lay counsellors make HIV services more accessible

The following quotes illustrate stakeholder perceptions of the increased acceptability of HIV services due to the involvement of PLHIV as lay counsellors.

Clients can now leave the clinic early. Thanks to the lay counsellors, there is less waiting.

— Exit interview, CTC Huruma Hospital

If you have the medical knowledge and skills, you can explain the problem very well, but only in theory. It is different if the explanation comes from a person who provides a testimony about his or her own experience. — Health worker, Kiboroloni Health Centre

It is encouraging to meet people whose CD4 may have been as low as 10, but who now seem healthy due to HIV drugs. You then decide to accept the services, knowing that your health will improve like theirs. — Exit interview, CTC Mawenzi Hospital

When people come to the CTC for the first time, we tell them that they should not see their status as a burden. Then we open a file for them and take them to the doctor for more counselling and other services. We prepare them so that they have no fear when they go to the doctor's room.

— Lay counsellor, focus group discussion participant, Mawenzi Hospital

You know, when you are sick from a disease that you don't know, you wait for another person to tell you about the disease. PLHIV explain to us so well by saying that 'you will not die'. For that reason a person lives with hope. — CTC client, focus group participant, Mawenzi Hospital

Box 4. How lay counsellors contribute to stigma reduction

The following quotes illustrate people's perceptions of how lay counsellors contribute to the reduction of stigma and prejudice.

Since the lay counsellors started to work at the health facility, they have been telling people in the community about how HIV is transmitted and that they should not segregate us because we are also human beings. People used to look at us as if we had no rights, we were stigmatised so badly. The lay counsellors have played a great role to reduce stigma in our community.

— CTC client, focus group discussion, Huruma Hospital

I help reduce stigma, because in the community they always see me stand up and talk openly about the disease. — Lay counsellor, Tarakea Health Centre

The people in my household were segregating me. It reached a point that I would peel a piece of fruit and offer it to people around me, but no one would accept to eat it. The lay counsellor came and told them that they cannot get infected if they eat food prepared by me. Nowadays we share meals freely.

— CTC client, focus group discussion, Huruma Hospital

Box 5. How lay counsellors benefit from the programme

The following quotes are a selection of lay counsellors' answers to the question 'What do you get out of the programme?'

It has given me courage to speak in public.

— Focus group discussion, Keni Health Centre

I understand better how ARVs are working.

— Focus group discussion, Kiboroloni Health Centre

I have mobilised many people who feared to go to health facilities. Through my services I have saved people's lives.

— Focus group discussion, Huruma Hospital

The monthly incentive is helping me and my family with basic needs. I use it to buy fruit and food.

— Focus group discussion, Keni Health Centre

After the training I have become more confident and informed of my rights. I have been able to seek assistance from civil society organizations (CSOs). My children are taken to school by a CSO.

— Focus group discussion, Kiboroloni Health Centre

I was able to save some of the incentive money and bought a goat. I can sell its milk.

— In-depth interview, Tarakea Health Centre

Empowering PLHIV

Lay counsellors report that their training and engagement with the programme has brought about positive changes in their own lives as well (see Box 5). The programme has empowered them in many ways in terms of their own HIV and AIDS awareness and personal development, and economically.

HIV AND AIDS AWARENESS: Through their training and interaction with health providers, lay counsellors have gained more knowledge of HIV-related issues such as ARVs and possible side effects, HIV prevention, and the importance of ART adherence.

PERSONAL DEVELOPMENT: The programme has helped many of the lay counsellors to gain self-confidence when dealing with other people and/or organisations. Moreover, many volunteers have gained a great deal of respect from their clients and other members of the community.

ECONOMIC EMPOWERMENT: The modest stipend that lay counsellors receive from the Foundation empowers them economically by helping them to meet their basic needs. Some lay counsellors have even been able to set up small businesses with their savings.

3 Assessing Success and Confronting Challenges

- Assessing Success
- Confronting Challenges

Assessing Success

The Foundation's lay counsellor initiative in Tanzania is still at an early stage, but initial results and impressions from the work that was started in 2008 are promising. In the first year, 761 people accepted HIV testing at one of the facilities in Rombo or Moshi districts after talking with a lay counsellor in their communities. This is an important measure of the programme's success in extending the PITC approach to the community, and thus facilitating client access to much-needed HIV services.

The support and appreciation for the lay counsellors shown by health staff and clients can be taken as another measure of success. Health workers as well as clients have already suggested that the programme be expanded both in terms of increasing the number of lay counsellors and expanding their role to include new tasks. The Foundation has shared its preliminary findings with the government of Tanzania, and the two entities are working together to explore future opportunities for programme expansion and replication.

Confronting Challenges

'Kila kazi na changamoto' (Every job has its challenges), says Fatma, lay counsellor and volunteer at the CTC clinic of Mawenzi Regional Hospital.

The programme that is being piloted in Rombo and Moshi districts is no exception to this rule. Key challenges that need to be addressed throughout implementation, as well as some key lessons learned, are discussed in the following sections.

Challenges Related to Social, Economic, and Cultural Constraints

Lay counsellors will likely encounter multiple social, economic, and cultural constraints while working in their communities. In some cases, lay counsellors may have to cope with a lack of practical and moral support from their own communities, and some health workers may even try to shift the responsibility for client care almost entirely onto the lay counsellor. Lay counsellors also must often deal with clients or community members who do not understand the voluntary nature of their work and who may accuse them of benefiting financially from their work.

Lay counsellors can find themselves in a variety of difficult situations (see Box 6 on page 14), such as discussing the importance of drug adherence with a poverty-stricken client who is complaining of an empty stomach and/or the lack of funds for transport to the clinic. In other cases, clients may stop using ARVs because of religious or cultural reasons and lay counsellors will have difficulty questioning those beliefs.

If you want to understand the importance of lay counsellors at our care and treatment clinic, think of a car. Imagine what happens when you take one of the wheels away. That's how important the lay counsellors are.

— Dr. Godwin Eli Kiwelu, medical officer in charge of the CTC, Huruma Hospital

Many constraints cannot be addressed directly by the programme. However, it is important for the programme staff to stay informed about and be sensitive to the constraints that lay counsellors are facing and to provide any needed support.

Balancing Responsibilities and Incentives

In Tanzania, lay counsellors joined the programme with the understanding that they would not be paid for their work. However, people on low incomes—as is the case for most lay counsellors—have difficulty making ends meet. Many lay counsellors also have to cope with the added burden of caring for family members and looking after young orphans. The programme has therefore found it necessary to offer volunteers some modest material incentives and provide compensation for the expenses the lay counsellors incur during the course of their work.

Some lay counsellors in the programme report that their workloads have increased, leaving them even

less time for income-generating activities and family duties. Some also report that as a result of the increased workload, their expenses (transport and sometimes food for clients) have increased. These developments have prompted lay counsellors to ask the programme to increase their stipend, to assist with income-generating activities, or to provide compensation for the wear and tear of shoes, umbrellas, and other equipment used during the course of their work.

It is likely that any such programme will find it necessary to compensate lay counsellors for the increased demands on their time and resources. However, such programmes will not, in most cases, have the resources to provide counsellors with full salaries. Regardless of what compensation is provided, the programme must maintain full transparency about these issues at all times by engaging in an open dialogue with lay counsellors and reaching mutual agreement about the reasonable expectations that the parties can have of one another.

Overcoming Resistance Among Health Workers

Stigma and discrimination associated with HIV can also occur in health facilities. For instance, lay counsellors in Tanzania have encountered resistance and suspicion from health service providers, especially from those working in departments not directly involved in HIV services. Health workers may question why nonmedical people, whom they regard as 'clients', should work alongside them. In response to such issues, the Foundation has organised meetings and explained the aims of the programme to a variety of health facility staff. One of the lessons learned from these experiences is that the lay counsellors must be properly introduced in a general staff meeting to show that upper management wholeheartedly endorses their presence in the facility, to clarify their qualifications and tasks, and to request that all staff support them as colleagues.

Box 6. Challenges encountered by PLHIV lay counsellors

The following quotes represent some of the challenges that lay counsellors face in their communities.

Sometimes you are called to see a client who is terribly sick and you want to take that person to the hospital. But the hospital is far and the family cannot afford to take the client there. You then feel forced to hire a motorbike and take the sick person to the hospital at your own cost.

— Focus group discussion, Keni Health Centre

The community sees us as experts. Sometimes they knock at your door saying that 'I have sister at home who wants to see you. Please come and see her.' And that place may be a kilometre away. Or you have been invited to talk about HIV at a village meeting while at the same time a sick person is waiting for you. We don't have transport facilities. We get responsibilities which we cannot refuse but at the same time, fulfilling them becomes a problem.

— Focus group discussion, Keni Health Centre

Health Sector Policy and Sustainability of the Programme

Health sector policies do not officially recognise the position of lay counsellors in Tanzania, and the government is not directly responsible for lay counsellor programmes at the community level. Programme participants have raised this issue repeatedly in relation to issues of programme sustainability and continued funding. For instance, since health sector policies do not recognise lay counsellors, it is problematic to include a lay counsellors programme in district plans and budgets. This may endanger the long-term sustainability of the programme.

However, it may be neither feasible nor desirable for lay counsellors to receive salaries directly from the government, as that too may be unsustainable in the long term. Having a government-run programme may also diminish volunteerism and local initiatives, as volunteers would become, in effect, health workers rather than representatives of their local communities. For example, alternative government support could take the form of providing training to volunteers or assigning government-employed nurses to work as mentors in the lay counsellor programmes.

Regardless of what course is chosen, it is in the government's best interest to support such initiatives, which can help to relieve the human resource crisis in the health sector, while supporting broader initiatives to strengthen linkages between the health sector and the communities it serves.

4 Supporting the Involvement of Lay Counsellors

- **Essential Features of Successful Involvement of Lay Counsellors**
- **Necessary Elements of Implementation**
- **Conclusions**

With a view to the possible expansion and replication of the approach being piloted in Rombo and Moshi districts, medical staff and lay counsellors were asked to give their opinions concerning the dos and don'ts of engaging PLHIV as lay counsellors. They were also asked about what they considered to be essential building blocks for the implementation of such an approach. The essential features and necessary elements discussed in this chapter were distilled from their responses.

Essential Features of Successful Involvement of Lay Counsellors

1. Careful Recruitment

The success of involving lay counsellors depends greatly on careful recruitment. While educational qualifications must correspond to future tasks and the contents of the training, equally important are personal qualities such as demonstrated volunteerism, willingness and ability to talk about one's HIV status, empathy, and membership in a PLHIV group or CBO.

It is important that PLHIV are given the opportunity to offer their services voluntarily, rather than being appointed by a programme manager.

Ideally, their application should be supported by a CBO, PLHIV group, or any other organisation that is capable of determining whether a candidate is respected in his or her community and therefore likely to be accepted by community members.

2. Clear Limitation of Lay Counsellors' Tasks to Nonclinical Work

It must be clearly communicated to health facility staff, clients, and lay counsellors alike that lay counsellors are working as volunteers, and as such, their tasks are limited to nonclinical activities. Both PLHIV and medical staff must understand that medical decision making is the exclusive realm of trained medical personnel (see Box 7 on following page). This message must be continuously reinforced with all concerned.

Lay counsellors provide nonclinical services at the CTC as well as within communities. This is important, as they will have an opportunity to support clients both in and outside the clinical setting. At the clinic, lay counsellors generally interact with clients before they meet with a health-care worker.

Box 7. Working with lay counsellors

Dr. Temba, medical officer in charge at the CTC of Mawenzi Hospital, greatly values PLHIV lay counsellors. 'By being open about their HIV status,' she says, 'they encourage others to disclose their status and this will help to cut down transmission.' Dr. Temba highlights two important points:

First, she stresses the importance of empowering lay counsellors. For example, lay counsellors organise quarterly meetings at the CTC of Mawenzi Hospital and suggest what topics they would like to hear discussed. This has led to non-governmental organization representatives being invited to discuss topics such as possibilities for income generation, and on another occasion a pharmacist explained side effects of drugs.

Second, Dr. Temba emphasises that empowerment of lay counsellors should never interfere with medical activities at the facility. She warns that at times, lay counsellors can become overconfident with regard to their knowledge of medical matters and may show a tendency to advise clients on the need to change drugs due to side effects or other issues. Both PLHIV and medical staff must be aware that medical decisions are to be made only by trained medical personnel.

3. Team Spirit and Appreciation

Programme and health facility staff must demonstrate that they value the HIV-positive volunteers as colleagues and are willing to treat them as valued members of the health-care team. Their inclusion in regular staff get-togethers such as 'morning tea' is one way this can be demonstrated. Including lay counsellors in staff meetings is another way in which programme staff can show their appreciation of the lay counsellors' contributions.

4. Flexibility

There is no one-size-fits-all model for the deployment of lay counsellors. While they should not perform clinical tasks (see point 2 on previous page), flexibility must be the norm. This means that health facility staff and lay counsellors must work together to determine how best to collaborate in their specific setting in line with the needs of the health facility.

Lay counsellors will be most successful when activities are planned in accordance with their specific needs and capacities. Some volunteers have become specialised in certain tasks, for example, in helping to organise the clinic at the facility. Other volunteers have proved to be excellent counsellors and spend several hours a week counselling people before and after an HIV test, or providing other forms of psychological and social support.

Lay counsellors must be closely involved in any decisions affecting their work. In fact, some degree of autonomy is beneficial because it stimulates personal initiative and feelings of ownership.

Necessary Elements of Implementation**Participatory Training-Needs Assessment**

Once the tasks of the prospective PLHIV lay counsellors have been identified, the content of their training should be informed by a participatory assessment of lay counsellor needs. This ensures that the training is relevant to the context in which lay counsellors will perform their tasks. For example, the lay counsellors in Rombo and Moshi identified a need to increase their confidence levels to perform community mobilisation talks in churches, schools, and elsewhere and were taught techniques for effective public speaking.

Endorsement from Management and Facility-wide Engagement

It is likely that lay counsellors will at first be met by resistance and suspicion from medical staff, especially in departments that are not directly involved in HIV services. It is therefore important that the lay counsellors are properly introduced in a general staff meeting to show that their presence as team members in the facility is fully endorsed by higher management, to clarify their qualifications and tasks, and to ask for support from the medical staff.

Stipend

Lay counsellors should receive a modest stipend. It is important to compensate the lay counsellors for expenses associated with their work, such as bus fares and meals. The stipend also provides an additional incentive and recognition of their efforts. Although many of the lay counsellors in Moshi and Rombo would emphasise that they are volunteers and have agreed to do their tasks 'for free', receiving a stipend is important to them.

Introduction of Lay Counsellors to Communities

Just as it is important to properly introduce lay counsellors to staff at the health facility, they must also be introduced to community leaders. Their qualifications and tasks must be clarified, and health facility representatives should formally ask for community leaders' support. This facilitates lay counsellors' work in the community and gives them easier access to community meetings and other public events.

Certificates

It is important that lay counsellors receive a certificate at the completion of their training. A certificate serves as recognition of their qualifications and proof of their association with the health facility. Being able to show the official certificate makes it easier for lay counsellors to request time to speak at schools, churches, village committees, or other public meetings.

On-the-job Training and Mentoring

In addition to formal training, much of the lay counsellors' orientation to health facility rules, procedures, and services takes place on the job. The lay counsellors can learn a great deal by watching and accompanying another health worker. Especially during the first few weeks in their new role, the lay counsellors need close mentoring by experienced staff to teach them new skills, answer questions, resolve problems, and make them feel 'at home' in the facility.

Supportive Supervision

Much of the supportive supervision of lay counsellors is provided 'on the job' by health workers during their daily work. However, more formal supportive supervision is also needed on a regular basis, not only to help maintain high morale among lay counsellors, but also to make their work effective.

It is important to establish regular monthly meetings between lay counsellors and mentors (liaison nurses and/or CTC nurses, counsellors, and programme staff) to discuss any issues that arise in the course of lay counsellors' work and to reinforce their knowledge and skills. Lay counsellors are likely to appreciate this kind of supportive supervision and are generally keen to take advantage of opportunities to improve their capacity. Establishing regular performance checks to ensure that counsellors adhere to counselling and health education standards is useful as well.

Team Meetings and Feedback

Regular team meetings and good communication between professional staff and lay counsellors are essential. They allow for a regular exchange of ideas about how to improve tasks and increase efficiency and quality. It is particularly important for health-care workers to solicit and accept the feedback of lay counsellors on how to improve the delivery of health services to HIV-positive clients.

Monitoring Outputs and Outcomes

It is essential for the programme to monitor the outputs and impact of lay counsellor activities using tools like narrative reports, which should include standard indicators such as number of referrals for HIV testing and number of follow-up cases. Lay counsellors in the districts of Rombo and Moshi are enthusiastic about the sticker system, whereby their referrals (yellow sticker for traced clients formerly lost to follow-up, red sticker for people referred for HIV testing) can be traced. It has made the outcome of their efforts more tangible.

Confidentiality

The concept of client confidentiality is new to most lay counsellors and can sometimes be difficult to reconcile with the need for openness and disclosure that they as lay counsellors have embraced. It is therefore necessary to continuously reinforce to lay counsellors that they must respect the confidentiality of client records and files, and their clients' HIV status in particular. New clients must always be asked by one of the professional medical staff if they wish to meet the lay counsellor and must willingly accept his or her counselling and follow-up.

Preventing Burnout

It is important that volunteers are not left to fend for themselves after their initial training course. Team meetings, exchange of experiences, supportive supervision, and other means should be used together to make lay counsellors feel valued and supported. To prevent 'burnout' among the lay counsellors, medical staff must respect their limited working hours and recognise that they have other responsibilities in their communities and households that they need to attend to. Lay counsellors, just like other staff, should also be entitled to 'time off' and annual leave.

Conclusions

The training and involvement of lay counsellors in HIV services that is being piloted in Rombo and Moshi districts is proving to be a viable strategy to address critical gaps in the current Tanzanian HIV/AIDS response. Lay counsellors have been successful in increasing the accessibility and acceptability of HIV services and improving the quality of HIV and AIDS care itself. So far, their contributions have been met with widespread acceptance and enthusiasm, not just by beneficiaries but by health workers as well.

Lay counsellors have shown themselves to be capable of linking the community to the CTC and to PITC in particular. The people who have been trained as lay counsellors have been effective in helping to trace and follow up HIV-exposed and HIV-infected children, and are thus instrumental in overcoming hurdles in the provision of a comprehensive continuum of care for women with HIV, their children, and their families. The Foundation's experiences with the programme thus far have provided ample justification for the expansion and replication of this approach, especially since it could help to alleviate the current human resource crisis in the Tanzanian health system.

Finally, the engagement and training of PLHIV as lay counsellors is not just a strategy for increasing the coverage and accessibility of HIV and AIDS services. By training and supporting PLHIV to serve as lay counsellors, the programme in Rombo and Moshi districts supports local PLHIV initiatives and empowers communities with the knowledge and skills they need to cope with and ultimately overcome the challenges brought forth by the HIV epidemic.

Elizabeth Glaser Pediatric AIDS Foundation, Plots 8 & 10 off Haile Selassie Road, Oyster Bay, Dar es Salaam, Tanzania

