



Elizabeth Glaser
Pediatric AIDS
Foundation



Foreign Affairs, Trade and
Development Canada



BRIDGING RURAL SUB-SAHARAN AFRICAN COMMUNITIES AND THE GLOBAL RESPONSE TO THE HIV AND AIDS EPIDEMIC

Lessons from the Advancing Community Level Action for
Improved Maternal and Child Health and PMTCT (Project ACCLAIM)



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Introduction

Substantial advances have been made toward achieving virtual elimination of pediatric HIV and AIDS due to the efforts of numerous governmental, non-governmental, community, and multilateral organizations around the world. The primary drivers of these advances include expanded availability of services for prevention of mother-to-child transmission of HIV (PMTCT) and access to antiretroviral therapy (ART) that dramatically reduce mother-to-child transmission of HIV throughout the vertical transmission risk period (through pregnancy, labor and delivery, or through breast milk).

Unfortunately, in many resource-limited countries, advances in the use of these PMTCT services have been hampered by poor infrastructure, weak health systems, and little to no community engagement. Many barriers still exist in communities that cannot be addressed at the facility level, including a lack of education on and understanding of health issues; poor health behaviors; stigma; and harmful gender norms, attitudes, and behaviors.

There has been increasing global recognition that elimination of mother-to-child HIV transmission goals cannot be achieved and sustained using the current program framework alone, and that additional investments are needed to address community-based demand. Finding and supporting social enablers in communities hardest hit by the epidemic will create conditions for program success and sustainability.¹ In order to maximize the impact of our response to the HIV and AIDS epidemic, we must not only enhance the quality of facility-based services, but also strengthen community leadership in, ownership of, and demand for these services.

By augmenting facility-based PMTCT interventions with a bold plan for community buy-in and demand generation, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) hopes to establish a truly sustainable and effective package of interventions alongside enhanced community engagement and ownership. EGPAF proposes to use an innovative, community-based approach to overcome barriers to maternal, newborn and child health (MNCH) and HIV prevention, care and treatment in a variety of country settings. This approach, developed and implemented under the Advancing Community Level Action for Improved Maternal and Child Health and PMTCT (Project ACCLAIM), addresses gaps in health systems while linking countries closer to reaching targets set by the Global Plan for Elimination of Pediatric HIV/AIDS.² When combined with the expansion and optimization of facility-based programs, these community-focused interventions will enable countries to achieve elimination of pediatric HIV/AIDS, as well as other improvements in MNCH outcomes.

¹ Schwartlander et al., *Towards an improved investment approach for an effective response to HIV/AIDS*.

² Joint United Nations Programme for HIV and AIDS. *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive*. 2011



EGPAF's Work

EGPAF is a global leader in the fight against pediatric HIV and AIDS, and works in 14 high-prevalence countries to provide HIV prevention, care and treatment services for women, children, and families. In order to achieve our mission, EGPAF collaborates with and empowers communities to play a strong role in planning, delivering, and monitoring HIV prevention, care and treatment services. EGPAF is committed to identifying, documenting, and replicating sustainable models of community involvement and service delivery that enhance coordination and partnership between the health sector and communities in order to further the highest attainable standards of health and well-being for all. As such, EGPAF collaborates with a variety of stakeholders, including government agencies, civil society organizations, community leaders, faith-based institutions, networks of people living with and affected by HIV/AIDS, non-governmental organizations, and other entities.

EGPAF has worked within a variety of communities throughout sub-Saharan Africa and India to ensure access to PMTCT, MNCH and HIV care and treatment services. We based our evolving approach toward community involvement on the understanding that access to services which prevent mother-to-child HIV transmission should be offered in a supportive environment, as women are more likely to utilize health services that their communities and families have deemed important and necessary.

There are belief structures in certain cultures within the settings we work that can undermine PMTCT and access to care – beliefs such as choosing local traditional healers over health facility services and home-based delivery of infants over delivering at health facilities, which have the capacity to address obstetric emergencies and intervene with antiretroviral medications to reduce risk of HIV infections.

Community Sensitization Demand

EGPAF employs a variety of targeted interventions to mobilize communities, including leveraging the local media to enhance utilization of health services. In the countries we support, we conduct national level trainings for media representatives, which ensure journalists are reporting accurately on HIV and AIDS. In 2013, in Zimbabwe, EGPAF hosted a 13-part, youth-targeted radio program on HIV (risk behaviors, prevention, PMTCT, care and treatment), which resulted in widespread education of adolescents, indicated by the number of texts and call-ins from youths regarding questions around HIV acquisition, testing and treatment received by the program during and after airing of the radio segments.

Decentralization of HIV Services to Ensure Greater Access to Care

EGPAF increases service uptake and improves the quality of HIV services by bringing these services directly to local communities. For example, in India, we helped to develop a mobile antenatal clinic (ANC) that operated out of a converted bus equipped with an electrical generator, medications, and a stat laboratory. In Lesotho, EGPAF initiated Family Health Days to bring HIV prevention, care, and treatment services to remote areas, as well as to identify and appropriately manage non-communicable diseases and provide integrated primary health care services at the community level to hard-to-reach locations.

These campaigns mobilized individuals and families to access integrated health services within their own communities. Making services more accessible and integrating HIV/AIDS services within other less stigmatized health services is important to increase use of HIV testing, prevention, care and treatment services and ultimately increasing the number of infections averted and lives saved.

Involving Community Members in the Provision of HIV Care to Foster Better Community-Facility Linkages

EGPAF supports and promotes the use of community health workers, who facilitate linkages between health facilities and the wider community. Community health workers are trained to track HIV and tuberculosis clients who have been lost to follow-up and link them back into care and treatment. In recent years EGPAF has provided support to Village Health Workers, a cadre of community health workers in Zimbabwe, to ensure women enrolled in PMTCT remain on treatment. In Kenya, we worked with Mentor Mothers, HIV-positive women who disclosed their status to significant others and are willing to support and counsel peers within the clinics on a volunteer basis. These community counselors provide HIV education, counseling, and testing. We support these counselors through training, provision of equipment (bicycles, vehicles, registers, testing kits) and monetary compensation.

ACCLAIM's Beginnings



It was not until the inception of Project ACCLAIM that we were able to integrate our various community programs into one structured approach. Through ACCLAIM, EGPAF supports social mobilization and promotes health seeking behaviors; strengthens community health structures; enhances the psychosocial well-being of people living with HIV and their families; enhances health literacy and increases uptake of and retention in MNCH and HIV prevention, care and treatment services.

The ACCLAIM approach was born in response to an event that occurred in Swaziland in 2010. EGPAF was contacted by a Member of Parliament, who reported that two pregnant women in the community had been beaten and chased from their homes by their husbands who had found out about their wives' HIV-positive status, highlighting an ongoing issue around stigma within local communities. The team, tasked with developing a solution, decided the best way to mediate the problem was understand and address the beliefs and perceptions around HIV/AIDS stigma among men in the area. The team began discussions with community leaders and nearby health facility staff. Informed by these meetings and equipped with past EGPAF community engagement experiences in supported countries, EGPAF held a community event specifically targeting the men in the community.

EGPAF, with community and Ministry of Health leaders, brought the community together to engage in dialogues (particularly with men) focused on health and HIV. HIV counseling and testing and other selected health services and disease screening were provided at these discussions. Through the dialogues, it became clear that men knew almost nothing about MNCH or PMTCT (these were "women's issues"). Men also felt that their role in the family was being ignored; they felt very strongly that they were responsible for the health of their families and were looking for ways to participate in health decisions. This experience in combatting harmful social norms became EGPAF's catalyst to focus on and include local communities in the creation and discussion of their own health management.

Informed of our work with communities, the Department of Foreign Affairs, Trade and Development Canada (DFATD) invited EGPAF to submit a proposal to implement a community PMTCT project with funds from the Bill and Melinda Gates Foundation in 2012. EGPAF developed Project ACCLAIM with the goal to enhance the impact of interventions that prevent vertical transmission of HIV during pregnancy, delivery, and breastfeeding through the implementation of community-level projects.

ACCLAIM Methodology

In 2012, ACCLAIM began implementation in Swaziland, Uganda and Zimbabwe. ACCLAIM's interventions were designed using EGPAF promising practices and a literature review on what has and has not worked in community engagement in MNCH and PMTCT programming. Once the interventions were designed, operations research was pursued to understand how best to implement these interventions to a wide-scale population.

OBJECTIVES OF PROJECT ACCLAIM

1. Improve key HIV, MNCH, and gender-related health behaviors through implementation of community-based interventions that target changes in community norms and attitudes, therefore increasing the number of pregnant women accessing and completing the sequence of PMTCT services.
2. Assess the behavioral and operational outcomes of community-based interventions and determine their relative effectiveness through strategic evaluation and operations research.
3. Document and disseminate tools developed and lessons learned to facilitate expansion of community engagement activities in other settings.

ACCLAIM was designed to act on three levels of community engagement that the literature showed had a positive impact on other projects: community leadership, community dialogues on health, and supporting individual behavior change. Thus, ACCLAIM evolved into a three pronged approach and includes: 1) engaging community leaders to help communities develop action plans for health; (2) facilitating community dialogues about health and HIV through community days; and (3) supporting peer groups to engage women and men in prioritizing MNCH and PMTCT.

Formative Research and Baseline Data: Preparing for the Interventions

Once the research protocols received ethical approvals in early 2013, the team conducted formative research with community leaders, community members and health care workers in order to customize community interventions to each country's context. A knowledge, attitudes, beliefs, and practices (KAPB) survey was conducted in each of the randomized 45 community clusters across Swaziland, Uganda, and Zimbabwe. The community interventions then commenced in September 2013 in Zimbabwe, October 2013 in Swaziland and April 2014 in Uganda (due to the different times the research protocols were approved). The KAPB study measured attitudes around PMTCT and MNCH before and after implementation of the designed community interventions (results highlighted below were gathered via the KAPB).

Implementation of the Three Interventions Across Three Countries



Community Leaders: Moving from the Classroom to the Community

One intervention designed and implemented under ACCLAIM was the Community Leaders Institute (CLI). The CLI was developed to equip community leaders from various sub-sections of the population to serve as opinion leaders, empowering them with accurate information to influence attitudes, norms, and health behaviors in their communities. Leaders create opportunities for discussion, enabling target communities to collectively implement responses to low uptake of MNCH and HIV services, and to challenge harmful gender norms, attitudes, and behaviors. In all three countries, 277 community leaders were trained through the CLI (62 in Swaziland, 95 in Zimbabwe and 120 in Uganda). These leaders have hosted nearly 12,000 formal and informal meetings in their constituencies to identify challenges, gaps, and solutions to MNCH/PMTCT service use.

The community leaders, graduating from the CLI, went on to develop Community Action Plans (CAP) within each of the 45 clusters. Some CAP activities focused on addressing barriers to facility-based births and included building or improving mothers' waiting huts (to ensure women living long distances from a health facility could live near the facility at the time of her expected due date while awaiting the arrival of her child), improving safety at the facilities, and improving roads and bridges to enable easier transportation for women. Other CAP activities focused on improving male engagement, reducing stigma and discrimination, strengthening HIV-exposed infant follow up at facilities, and supporting mothers in PMTCT. Community leaders engaged with national partners (ministries of health and other health care implementing partners) and continued to advocate for community engagement in MNCH and PMTCT.

Due to differing community leadership structures in each country, activities under this intervention arm varied. In Zimbabwe trained leaders worked with councilors, village heads and the health center committees, and as a result of the multi-stakeholder training, Zimbabwe was able to develop and implement CAPs quickly, which focused on improved community dialogues around PMTCT. In Uganda trained leaders were drawn primarily from the village health workers. These community leaders worked closely with parish chiefs to mobilize people in the community and conduct their dialogues, centered on improved participation in MNCH. In Swaziland, most trained leaders were drawn from a community welfare oversight team. All trained leaders used various platforms, such as church meetings and informal meetings at cattle anti-flea/tick dip tanks, or water meetings to conduct their dialogues. The Swaziland communities identified adolescent pregnancy as a critical problem to address and developed activities to address the issue in their schools and communities.

All of these CAPs were customized by community leaders to the various areas of needs. The success of the CAP intervention in engaging and empowering the communities showcased the versatility of the approach and how the community leaders were able to accommodate differing community needs.

Accomplishments achieved in these countries attributed to the engagement of community leaders included development of mothers waiting homes in rural areas of Zimbabwe and Swaziland, clinic renovations in Swaziland and repair to roads and bridges to ensure better access to clinics in Zimbabwe.

Community Days: Bringing Hidden Issues into the Open



Community Days, the second of ACCAIIAM's designed interventions, are mobilization events, where communities come together to openly discuss MNCH, PMTCT and gender issues that comprise the key barriers to MNCH/PMTCT service uptake and retention. At these events, various health services are provided. The basic service package for ACCAIIAM Community Days consists of HIV testing and referral; diagnostic and disease management services, such as glucose and high blood pressure screening; family planning counseling; childhood growth monitoring, and TB testing. Additional services are provided depending on community needs. For example in Uganda due to great demand, community days involved provision of voluntary medical male circumcision and syphilis testing.

The countries selected community dialogue facilitators who were subsequently trained over a three day period. The training focused on facilitation skills and how to effectively conduct the discussions. Countries opted to use health care workers, health assistants, village health teams and community health workers as dialogue facilitators, as they are able to understand and respond to the technical issues that may come up during structured dialogues.

Cumulatively, nearly 68,000 community members have attended community day events and over 38,000 participated in the dialogues in all three countries. A total of 21,720 clients were tested for HIV, and HIV-positive clients were referred for further care and treatment at health facilities. Over 22,000 community members also received other health services such as family planning, ANC services, immunization, and screenings for cervical cancer, diabetes, hypertension, and TB.

PROMISING PRACTICE:

RWERERE WAKES UP TO HEALTH THROUGH COMMUNITY DAYS

Squads of program officers, health care workers, volunteers, and community organizers raise tents on the dewy grass behind the Rwerere parish church in Uganda. Within an hour, 600 local residents will be crowded onto the football pitch. By day's end, more than 1,000 villagers will have participated in a community day.

Directing the activity from the shade of the church is Sharon Ajedra. As the ACCLAIM project coordinator in Uganda, Ajedra has staged dozens of these events since the project began. She has spent a month working with the community leaders to plan this event, working with other stakeholders to pass the word. Last week an announcement ran over the radio in this rural parish in southwest Uganda that this day would be held so that all in nearby communities could engage in health care.

“The purpose of this project is to advance community-level action around health care. We know that for a long time, health efforts have not been fully directed at the community to improve welfare in these areas. So through this research we are trying to see if this is possible. We are staging these community days—coordinating with local leadership and holding dialogues, while providing access to many services at once,” Ajedra says, pointing to community members standing in queues in front of various health stations.

A doctor seated in a grove of trees is collecting dried blood spot samples from infants. This tests will help determine if the babies have been infected with HIV. Inside a concrete outbuilding, a lab technician peers into a microscope and analyzes sputum samples for tuberculosis. Men exchange nervous small talk as they stand in line outside the church, which is serving as a clinic for voluntary male circumcision, a procedure proven to reduce the spread of HIV and other sexually transmitted infections.

By mid-day, the church grounds are filled to capacity. People have been grouped by age and gender under the tents so that they can hold community dialogues about family health issues with their peers. Emmanuel Byarugaba, a district health inspector, facilitated a group of men of reproductive age, ages 18 to 50. “We talked about HIV and the prevention of mother-to-child transmission of HIV, how they can protect their wives for antenatal care,” says Byarugaba. Byarugaba says that this dialogue also presents a valuable forum for the men to express themselves—providing reasons that their family may be avoiding the health center. For example, the challenges around stigma of poverty are frequent deterrents to care. Although services are free at government health facilities, families with few resources may face transportation issues and logistics issues or may be intimidated to know their own HIV status. Through this dialogue, men are able to express their concerns and discuss ways to overcome them. Byarugaba says that he has seen an improvement in outpatient attendance since the community day dialogues have begun.

After a long day with clients, Sister Harriet Nanyange is taking a five-minute break on a white plastic chair before she heads home. A nurse-midwife at the Nyakangye Health Center III, today Nanyange immunized more than 60 children and tested their mothers for HIV. She is happy to say that all of the result came back negative. “It is a success indeed,” she proclaims. “It’s nice to see that they appreciate what we are trying to do for them—or what they are trying to do for themselves,” says Ajedra, the ACCLAIM coordinator. “Because at the end of the day, it’s actually them: we don’t make the changes; they make the changes. They do it for themselves.”

ACCLAIM MNCH Classes: What Does This Mean for Me?



ACCLAIM MNCH classes, the third of three community interventions under ACCLAIM, are a series of four, structured, peer-facilitated sessions on topics related to MNCH, gender, and PMTCT to provide information and support to pregnant women and their partners, as well as other males in the community. The classes are held in the community common spaces (meeting halls, clinics, etc.) and use a defined curriculum developed by the ACCLAIM team. Community leaders nominated peer facilitators to conduct the male and the MNCH classes. Peer facilitators were trained by EGPAF to handle adult/participatory learning methodology, specific needs and challenges of working with the specified audience, and a detailed review of the peer group process.

A total of 104 male and female peer facilitators were trained across the three countries, and conducted groups for over 2000 women and 1500 men. The classes have been extremely popular among both men and women, as reflected in the evaluations at the end of the four sessions. Many of those who have taken the classes recruited others. In Swaziland, parents requested ACCLAIM classes for their adolescent pregnant daughters. This request was made during the group sessions and during the community day dialogues. The needs of this group are generally not met with facility services alone, and the classes improved the adolescents' ability to understand and cope with their situation, and to seek health services.

PROMISING PRACTICES:

EFFECTS OF MNCH CLASSES

Mary Tusingwire is unstacking two columns of blue plastic chairs and arranging them in a circle under the shade of a jackfruit tree. From the brick church behind her can be heard the echoes of primary school children reciting their lessons.

As a peer facilitator, Mary will be conducting her own lesson today to a dozen women from Rushaka, a farming village in southwest Uganda. Mary has recruited pregnant women in the community to increase their knowledge about MNCH.

One-by-one, women—most well into their third trimester—amble down the dirt path to the circle where they chat and wait for class to begin. When a quorum has assembled, Mary addresses the women in the local dialect and launches into a discussion about postnatal care and family planning. This is the final session of four. In previous sessions, women have discussed antenatal care, nutrition, changes to a woman's body during pregnancy, and PMTCT. The course has been tailored to fill in knowledge gaps and bust common myths about reproduction and sexually transmitted infections.

Although Mary carefully follows an ACCLAIM lesson plan, this is no lecture. She punctuates her talk with questions for each woman, asking her to respond to the material and talk about her own experience.

Throughout the lesson, Mary refers to a sheaf of grain sacks printed with illustrations. One sack shows the various forms of birth control: implants, intrauterine devices, pills, tubal ligation, vasectomy, injectables, and moon beads. On the right are pictures of male and female condoms, which should be used in addition to the birth control methods to prevent sexually transmitted infections. Another sack shows pictures of food that will optimize nutrition for mother and baby during breastfeeding.

When the lesson comes to a close, Mary leads the women in a round of applause for their commitment to family health. Shortly, the women will gather for a group photo and to receive certificates of completion. But first, ACCLAIM staff sit down with individual women to discuss what they have learned through the program and complete a survey of their knowledge, attitude, belief, and practices (KAPB) relative to maternal, newborn, and child health. This data is key to determining the effectiveness of peer groups. Later, after they have had their babies and completed breastfeeding, the women will be surveyed again to see how much of an effect the course has had on their families.

Although she is now a polished facilitator, Mary has only recently been introduced to the course material. Six months ago, she was recommended for this role to community development officers. After an interview, she joined other facilitators and ACCLAIM staff on a two-week retreat to learn about family health, to get tips about leading discussions, and to practice active listening. A mother of two daughters, Mary now feels better equipped to take care of her own family. "When you go to the village to teach others, you must first be an example. I have gained more knowledge of how to handle my next pregnancy," she says.

With the data surveys completed, the peer group has now gathered by the side of the church for a photo, waiting for Mary to join them. "We are expecting 12 babies," Mary says with a satisfied smile. "And they have promised me to deliver their babies from health facilities."



Overall Results of ACCLAIM

Early results of ACCLAIM, as demonstrated by routinely-collected, facility-level data, vary across the individual countries, as do results between the various study arms. For example, Uganda was the only country that saw a considerable increase in the number of women attending clinics for the diagnosis of their HIV-exposed infant at 6-8 weeks from 20% to 34% post-implementation of the community leader intervention. There was a universal increase in the number of women attending four or more ANC visits under the community leader intervention arm from 20% at baseline to 38% at endline. However, some universal improvements have been seen, particularly in early ANC attendance in gestational age and male testing.

Notable results from the project suggest that these interventions have led to an improvement in ANC attendance at an earlier gestational age. Average gestational age at first ANC attendance decreased in Zimbabwe from 24 weeks to 20 weeks; with attendance at 12 weeks and below rising from 3% to 16%. Average gestational age at first attended ANC remained about the same in Swaziland, where historically women attend their first visit at 21 weeks. In Uganda, after a shorter ACCLAIM implementation time of less than one year, average gestational age at first ANC visit decreased from 22 to 21 weeks. The percentage of pregnant women attending ANC before 20 weeks had risen in all three countries by March 2015, with the overall percentage increasing from 45% to 51%.

Male partner testing increased under each of the three interventions, showing an increase in the percentage of male partners tested with the addition of each intervention: Community leader intervention alone: increased the percent tested from 13.7% at baseline to 17%; community day and community leader interventions combined increased testing to 16.1%; and all three interventions combined increased testing to 19.5% in all three countries.

The final analysis of the ACCLAIM results, published in the Journal of Acquired Immune Deficiency Syndrom, will provide – for the first time – an in-depth look into how community and gender norms can be changed and how this can begin to affect uptake and retention of critical facility services.

Future Directions

ACCLAIM addresses community norms and attitudes around MNCH and PMTCT services by utilizing existing community entities (leaders, health clinics) and innovative models of community-level education. A fundamental assumption of the project is that to increase uptake and retention in PMTCT, it is necessary not only to reach women but also their partners, families and communities to improve MNCH attendance and begin to de-stigmatize HIV-related services. Using a holistic approach to increase PMTCT and MNCH service uptake and adherence can strengthen efforts to reduce maternal and infant mortality.

ACCLAIM develops and implements innovative methods to overcome barriers that have typically kept women, children, and families from accessing lifesaving HIV services and aims to ensure that more women utilize MNCH and PMTCT services, allowing their children to be born healthy and HIV-free.

EGPAF SWAZILAND

MTN Office Park
Karl Grant Street
Mbabane, Swaziland

P +268 2404 8081

EGPAF UGANDA

Plot 18A, Kyadondo Road
P.O. Box 21127
Kampala, Uganda

P +256 312264380

EGPAF ZIMBABWE

107 King George Road
Avondale
Harare, Zimbabwe

P +263 (0)4 302144

WWW.PEDAIDS.ORG
