

# Promising practices in community engagement for elimination of new HIV infections among children by 2015 and keeping their mothers alive



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Promising practices in community engagement for elimination of new HIV infections among children by 2015 and keeping their mothers alive

## ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
HIV	human immunodeficiency virus
M&E	monitoring and evaluation
M2M	mothers2mothers
MDG	Millennium Development Goal
MMRPA	maternal mortality reduction programme assistant
PEPFAR	United States President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission (of HIV)
SASO	Social Awareness Service Organization
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
WOFAK	Women Fighting AIDS in Kenya
WHO	World Health Organization

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## EXECUTIVE SUMMARY

Leaders from around the world attending the 2011 High Level Meeting on AIDS committed to work towards the elimination of new HIV infections among children by 2015 and reducing AIDS-related maternal mortality. This is to be accomplished through the implementation of a new Global Plan\* for scaling up comprehensive prevention of mother-to-child transmission of HIV (PMTCT) programmes. The Global Plan calls for broader thinking and action both within and outside the formal health-care delivery system. An important feature of the plan is its emphasis on community engagement as an integral part of the scale-up strategy.

Despite the widely-recognized importance of communities, much of the PMTCT guidance focuses on antiretroviral drug prophylaxis during pregnancy and facility-based interventions. This review was commissioned by the Joint United Nations Programme on HIV/AIDS (UNAIDS) to help address the information gap around the essential and complementary role of communities. In particular, this study sought to identify and share promising practices that can strengthen programmes and facilitate efforts to stop HIV transmission to children and enable their mothers to remain healthy.

The methods used in this study included literature review and key informant interviews. “Community engagement” was defined broadly to include participation, mobilization and empowerment, while excluding activities that involve communities solely as the recipients of information or services. A “promising practice” was defined as a practice for which there is documented evidence of effectiveness in achieving intended results and some indication of replicability, scale-up or sustainability.

The promising practices identified through this research are organized below in terms of their primary intended outcome. The study describes each practice, provides documented examples, and summarizes the lessons learnt.

### **Improving the supply of PMTCT services:**

- ▶ extending the workforce through community cadres (e.g. community health workers, mentor mothers, lay counsellors, traditional birth attendants);
- ▶ strengthening linkages with community- and faith-based organizations to promote and provide PMTCT services;
- ▶ monitoring PMTCT programmes through civic participation using a rights-based approach.

### **Increasing the uptake of PMTCT services:**

- ▶ empowering communities to lead social and behaviour change communication around PMTCT;
- ▶ providing peer support through individual counsellors and in support groups;
- ▶ engaging communities to maximize their assets and address financial barriers to PMTCT.

### **Creating an enabling environment for PMTCT scale-up:**

- ▶ advocating and supporting activism for PMTCT and the right to health;
- ▶ promoting policies and strategies that support PMTCT and community engagement.

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\* Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive.

## Observations

In addition to specific learning about each of the promising practices, key observations of the study included that:

- ▶ community engagement is relevant and needed for the scale-up of comprehensive four-prong PMTCT programmes;
- ▶ engaged leadership at all levels – facility, community, district and national – is an important key to the success of community engagement;
- ▶ meaningful community engagement requires a capacity-building approach and sustained investment of financial and technical support;
- ▶ effective community engagement requires a rights-based approach that empowers individuals and communities to take greater control of their health and health care;
- ▶ meaningful involvement of networks and communities of people living with HIV will enhance PMTCT scale-up;
- ▶ local pre-intervention participative research is an essential first step in the capacity-building process and helps to ensure the relevance and sustainability of programmes;
- ▶ building on existing community structures – rather than working in parallel to them – improves programme efficiency, effectiveness and sustainability;
- ▶ monitoring, innovation and information sharing will be critical to the scale-up of promising practices in community engagement, including for the introduction of mobile and other technologies to improve programme management and implementation.

## Recommendations

Attaining the elimination of new HIV infections among children and keeping their mothers alive is possible but will not be easy. Success will require the sustained engagement and unique inputs of various communities, from small informal groups at the grass-roots level up to global coalitions. The good news, as reinforced through this review, is that implementers and experts already know and are implementing many effective community engagement strategies that are improving service uptake and achieving positive health outcomes. What remains is to share, strengthen and apply that knowledge while rapidly scaling up dedicated resources and community engagement efforts in support of PMTCT and related health programmes. The following suggestions are offered to facilitate not only achievement of the elimination of new HIV infections among children by 2015 and reduced AIDS-related maternal mortality, but also important broader benefits for women, families and communities.

### Promising practices

- ▶ Expand and support the front-line health workforce for PMTCT scale-up within national primary health-care systems.
- ▶ Increase engagement with community and faith-based organizations to support PMTCT scale-up using appropriate funding mechanisms and strategies to further develop organizational capacity.

- ▶ Bring accountability closer to the level of service provision through civic participation, community charters and other rights-based approaches.
- ▶ Promote community-driven communication on PMTCT and related health issues and address key concerns such as male involvement, early antenatal care attendance, facility delivery, and follow-up of infants exposed to HIV.
- ▶ Expand the involvement of peers (e.g. men and women living with HIV, and their partners) in PMTCT programmes.
- ▶ Empower communities to maximize their assets and identify their own solutions for PMTCT scale-up.
- ▶ Support community activism for improved and sustained political commitment to PMTCT scale-up.
- ▶ Continue to enhance policies and strategies that promote community engagement in PMTCT and other health programmes.

#### **For technical teams**

- ▶ Expand this review to identify additional relevant promising practices in HIV prevention, family planning, and care and treatment, including paediatric AIDS.
- ▶ Develop and share tools to facilitate decision-making and implementation of locally appropriate community engagement activities.
- ▶ Develop better indicators for community engagement in PMTCT.
- ▶ Conduct more evaluation and cost analysis of community engagement practices, especially in terms of associated health outcomes.

#### **For country teams**

The Global Plan encourages community engagement as an essential component of national plans for PMTCT scale-up. This review found several long-standing community engagement practices and some more recent innovations that show great promise in supporting PMTCT scale-up. In developing their national plans, country teams and their development partners are encouraged to:

- ▶ view and prioritize community engagement as an integral part of PMTCT scale-up;
- ▶ use a capacity-development approach to direct funding and technical and support to community aspects of PMTCT scale-up;
- ▶ adopt and adapt the promising practices shared in this review to suit the local context;
- ▶ examine existing community engagement activities through the participation, mobilization and empowerment lens and work to make such activities more empowering to the women, families and communities they serve.



## BACKGROUND

*Inside every mother lives a dream that her child will be born healthy. Inside every mother breathes a hope that her child will live a better life than hers. Deep in her heart are embedded fears and anxieties for her baby. And should the mother test*

*positive for HIV, her worries know no bounds (Prasanna, 2011).*

### **The Global Plan**

Today the elimination of new HIV infections in children is no longer just a dream: It is within reach. The technology and strategies exist and have been applied successfully in many industrialized countries. At the 2011 High Level Meeting on AIDS global leaders committed to work towards the elimination of new HIV infections among children and keeping their mothers alive. Specifically, global targets have been embraced for 2015 to reduce by 90% the number of new HIV infections among children and to reduce by half the number of acquired immunodeficiency syndrome (AIDS)-related maternal deaths. Released in June 2011, the Global Plan is a roadmap for scaling up comprehensive prevention of mother-to-child transmission of HIV (PMTCT) programmes and achieving these important goals (see Box 1).

#### Box 1

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##### **The Global Plan and the Millennium Development Goals (MDGs)**

Eliminating new HIV infections in children and keeping their mothers alive is integral to the achievement of:

MDG 4 – Reduce by two-thirds, between 1990 and 2015, the mortality rate of children under five

MDG 5 – 5a: Reduce by three-quarters, between 1990 and 2015, the maternal mortality ratio; and 5b: Achieve, by 2015, universal access to reproductive health

MDG 6 – 6a: Halt and begin to reverse, by 2015, the spread of HIV and AIDS; and 6b: Achieve, by 2010, universal access to treatment for HIV and AIDS for all those who need it.

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In 1994, antiretroviral drugs were first proven to be effective at reducing mother-to-child transmission of HIV. Five years later, in 1999, still without widespread availability of antiretroviral drugs, PMTCT programmes were initiated in developing countries. These initial programmes focused on voluntary HIV counselling and testing and infant feeding (Hope Humana et al., 2003). Early advice on infant feeding and HIV lacked clarity as experts struggled to balance the disadvantages of formula feeding with the risk of HIV transmission through breastfeeding. Once nevirapine became more widely available, the bulk of effort turned to providing single-dose antiretroviral prophylaxis for pregnant women in antenatal care settings along with a single infant dose for the baby within 72 hours of birth. Updated guidelines issued by the World Health Organization (WHO, 2006) recommended more efficacious prophylaxis regimens, but roll-out of these new regimens was slow and infant feeding advice continued to be articulated and implemented inadequately.

Despite these challenges, notable progress has been made. About half (48%) of all pregnant women living with HIV in lower- and middle-income countries received more efficacious antiretroviral prophylaxis or treatment in 2010 (i.e. excluding single-dose nevirapine except in emergency cases). Five countries – Botswana, Lesotho, Namibia, South Africa and Swaziland – have achieved at least 80% coverage with more efficacious antiretroviral drugs for PMTCT (WHO, UNICEF & UNAIDS, 2011). Advancement on other indicators, however, has been less encouraging. Only 45% of the mothers receiving prophylaxis were assessed for their own antiretroviral needs in 2010, and only 28% of infants exposed to HIV were tested for HIV during the first 2 months of life (WHO et al.). Leaders and stakeholders therefore recognize that rapid scale-up to achieve the global goals by 2015 will require programmes to go well beyond doing “more of the same”.

As shown in Box 2, elimination of new HIV infections among children and keeping their mothers alive will require the achievement of bold results under each of the four prongs of a comprehensive PMTCT programme (UNAIDS et al.). This includes Prong 1: Prevention of HIV among women of reproductive age within services related to reproductive health such as antenatal care, postpartum/natal care and other health and HIV service delivery points, including working with community structures.

Prong 2: Providing appropriate counselling and support, and contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births, and to optimize health outcomes for women and their children.

Prong 3: For pregnant women living with HIV, ensure HIV testing and counselling and access to the antiretroviral drugs to prevent infection being passed on to their babies during pregnancy, delivery and breastfeeding.

Prong 4: HIV care, treatment and support for women, children with HIV and their families. To succeed under each prong, full implementation of the updated WHO (2010a) guidelines will be essential. These guidelines recommend more efficacious drug regimens and earlier initiation of prophylaxis or treatment during pregnancy. By also recommending exclusive breastfeeding for 6 months and extended prophylaxis or treatment for infant–mother pairs, the 2010 guidelines provide a welcome opportunity for safer breastfeeding.

Eliminating new HIV infections in children and keeping their mothers alive will therefore require millions of women, often living in resource-poor settings, to stay engaged with the health-care system and face a range of complex and sensitive decisions over an extended period of time.

## Box 2

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### Achieving the global goals: What will it take?

#### Prong 1 – prevent new HIV infection among women of childbearing age:

- Reduce by 50% new infections among women aged 15–49 years.

#### Prong 2 – prevent unintended pregnancy among women living with HIV:

- Eliminate unmet need for family planning among women living with HIV.

#### Prong 3 – prevent vertical HIV transmission by use of ARV prophylaxis or treatment:

- Reduce mother-to-child transmission of HIV to less than 5%.
- Provide perinatal antiretroviral treatment or prophylaxis to 90% of pregnant women.
- Provide antiretroviral treatment or prophylaxis to 90% of infant–mother breastfeeding pairs.

#### Prong 4 – provide appropriate treatment, care and support to mothers living with HIV and their children and families:

- Provide antiretroviral treatment to 90% of pregnant women in need for their own health.
- 

This includes whether to accept the HIV test, whether to disclose the results to a partner, whether to inform family members and significant others, whether to ask the partner to test, whether to conceive, or whether to use contraception.

None of these questions is answered by the woman in isolation. Each decision is affected by a range of sociocultural, economic and other factors, including her partner, other family members, and the coverage and quality of the health-care system. The well-known and formidable challenges to scaling up comprehensive PMTCT programmes (Global Fund, 2010a) are summarized in Box 3 as supply- and demand-side barriers.

## Box 3

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### Commonly identified barriers to PMTCT scale-up

#### **Supply side**

- low health facility coverage resulting in limited geographical access, especially in rural areas;
- shortages of health-care workers;
- inadequate quality of care;
- weak systems of client referral, linkage and follow-up.

#### **Demand side**

- HIV-related stigma within families and communities and among health-care workers;
  - gender-based obstacles, including the influence of male partners on health-care decision-making and the fear of abandonment or abuse;
  - transport and other financial constraints;
  - unsafe community norms, practices and beliefs around pregnancy, childbirth and infant feeding, compounded by previously complex and often misunderstood guidance on infant feeding and HIV.
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To address these barriers, *the Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping Mothers Alive* was developed and is guided by a broad consultative process with key stakeholders, including governments, United Nations (UN) agencies, donors and civil society. It recommends actions to be taken at the global, regional, national and community level. New resources are being mobilized, and countries and their development partners are expected to assess gap areas and put in place national plans for achievement of these exciting goals. The Global Plan calls for broader thinking and action both within and outside the formal health-care delivery system. An important feature of the Plan is its emphasis on community engagement as an integral part of the scale-up strategy.

### ***Rationale for this study***

A mounting body of evidence over the past 10 years strongly supports the importance of engaging communities in PMTCT to better understand and address sociocultural and other barriers and to engender local ownership and sustainability while decentralizing services and scaling up coverage (Israel & Kroeger, 2003; Leonard et al., 2001; Rutenberg et al., 2003). Both the UNAIDS Investment Framework for HIV/AIDS through 2020 (Schwartlander et al., 2001) and The Global Plan promote increased community engagement as a priority. Yet, much of the PMTCT guidance and documentation to date focuses on facility-based interventions. This review was commissioned by UNAIDS to help address the information gap around the essential and complementary role of communities.

The Global Plan calls on communities to contribute to PMTCT scale-up in a variety of ways that will both improve the supply of comprehensive services and increase the uptake of those services. For example, communities are called upon to:

- ▶ serve as extension workers;
- ▶ provide services, referrals and linkages;
- ▶ help plan and monitor programmes;
- ▶ enter into charters with government authorities to strengthen accountability;
- ▶ create demand;
- ▶ address structural impediments to service uptake;
- ▶ involve male partners and families;
- ▶ reduce stigma and discrimination;
- ▶ participate in communication campaigns;
- ▶ maximize community assets.

This review aims to define these roles further by identifying and describing existing promising practices in community engagement for PMTCT scale-up. It is hoped that the findings of this review will help to inform governments, donors and implementing partners as they plan and scale up activities to eliminate new HIV infections among children by 2015 and keep their mothers alive.

### ***Methods***

The methods used for this research included literature review and interpersonal communication (e-mail, telephone and face-to-face interviews) with representatives of various stakeholder institutions.

The literature review involved extensive Internet research through keyword searches related to community engagement and PMTCT. Specific stakeholder web sites were explored, including

those of UNAIDS, the United States President's Emergency Plan for AIDS Relief (PEPFAR), WHO, the United Nations Children's Fund (UNICEF) and civil society implementing partners. Other sites that provided important leads and resources included the WHO PMTCT Monthly Intelligence Reports; AIDS Support and Technical Assistance Resources (AIDSTAR) HIV Prevention Updates; the University of California at San Francisco's Women, Children and HIV; the Joint Learning Initiative on HIV/AIDS; and the Coalition on Children Affected by AIDS. The types of literature reviewed included journal articles; published and unpublished reports, evaluations and reviews; and abstracts, posters and presentations from international conferences. In line with the epidemiology of new HIV infections, the focus was largely on sub-Saharan Africa, but case studies were identified from other regions as well.

To supplement the literature review, information was collected through e-mail exchanges and telephone and face-to-face interviews (using a semistructured questionnaire) with key informants from organizations supporting community engagement for PMTCT. Informants were identified through the literature review and by key contacts at the global, regional and national level. Participants at the August 2011 subregional consultation in Kigali on strengthening male involvement in PMTCT<sup>1</sup> were also an important resource. Information was collected from 41 individuals representing 24 organizations. Although information collected through interpersonal communication may inherently lack scientific rigour, in most cases it served to reinforce, clarify or amplify the findings from the literature. The first draft of the paper was technically reviewed by a small group of representatives of civil society, donor and implementing agencies.

Four important limitations of available data on community engagement are worth noting. First, truly grass-roots initiatives often lack the financial and technical capacity required for programme monitoring, documentation and dissemination. Second, PMTCT literature is largely focused on prong 3 (provision of antiretroviral prophylaxis). To augment findings on the other prongs, leads were sought for promising practices in community engagement for HIV prevention, family planning, AIDS care and support, and maternal, neonatal and child health. These were limited and opportunistic enquiries rather than exhaustive searches. The third limitation is the challenge of attributing causality. In most cases, community interventions have been undertaken hand in hand with facility-based activities, and it is difficult to tease out the separate impact of the community component. Fourth, the nature of community work is fluid and context-specific and therefore is often challenging to measure and interpret.

Despite these constraints, the available body of evidence provided some clear promising practices and highlighted gap areas that warrant further attention and research.

The informants are listed in Annex 1.

## *Working definitions*

Working definitions for the key concepts used in this analysis are as follows:

- ▶ **PMTCT:** As defined in the UNAIDS terminology guidelines (October 2011), PMTCT refers to a four-pronged strategy for stopping new HIV infections in children and keeping mothers alive and families healthy (see Box 2). PMTCT begins before pregnancy with primary HIV preven-

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<sup>1</sup> Subregional Consultation to Discuss Strengthening Male Involvement in the Elimination of Mother-to-child Transmission of HIV and Keeping Mothers Alive, Kigali, Rwanda, 24–26 August 2011, co-hosted by the Government of Rwanda, WHO and UNAIDS, with UNICEF and the United Nations Population Fund (UNFPA).

tion and family planning; includes prophylaxis or treatment during pregnancy; and extends beyond childbirth to include treatment, care and support for mothers and infant prophylaxis, feeding, diagnosis, care and treatment to age 18 months.<sup>2</sup>

- ▶ **Community:** Generating consensus around the definition of “community” has proven challenging across several disciplines and decades. This is in part because community is a dynamic concept that means different things in different contexts and to different people. A landmark study of 94 definitions conducted by a sociologist (Hillery, 1955) and a more recent public health analysis (MacQueen et al., 2001) provided the basis for the definition used in this review – “a group of people with diverse characteristics who are linked by common ties including shared interests, social interaction or geographical location”. This definition is deliberately inclusive to embrace the wide range of communities currently involved in PMTCT and related health programmes. Some examples include clients of PMTCT programmes; groups of women living with HIV; users of a health facility, or members of community- and faith-based organizations.
- ▶ **Community engagement:** Loosely defined, community engagement is the process of working collaboratively with and through groups of people with diverse characteristics who are linked by common ties, social interaction or geographical location (Centers for Disease Control and Prevention, 1997). This definition is intentionally generic and inclusive to cover the various community engagement approaches currently in use. The spectrum of community engagement in the health sector encompasses the three closely related concepts identified in Figure 1 (Rosato et al., 2008). As shown by the arrow in Figure 1, the literature indicates that over time programmes move towards greater community empowerment through a rights-based approach (Leonard et al., 2001; Rosato et al., 2008). Although practices reflecting all three concepts are currently in use for PMTCT scale-up, this review focuses more prominently on community mobilization and empowerment. Activities that engage communities solely as the target audience for information, behaviour change or services are excluded.

Figure 1: Spectrum of community engagement



- ▶ **Promising practice:** For the purposes of this review, a promising practice in community engagement is a practice for which there is some documented evidence in at least one setting of its effectiveness in achieving intended health-related results, usually increased PMTCT uptake or compliance. Other important factors taken into consideration are that the practice has been, or shows potential to be, replicated or implemented in a variety of settings, scaled up or sustained over time.

<sup>2</sup> Although linkages from PMTCT to programmes for children affected by AIDS are crucial, services and support for older children fall outside the scope of this review.

## Guiding assumptions

The following assumptions were made in undertaking this review:

- ▶ **Community engagement improves programmes:** Since the Alma Ata Conference in 1978, when primary health care was ratified as a key strategy and policy of WHO Member States, there has been a growing recognition and body of literature on the right of communities to participate in their health care and the added value of that participation (Rosato et al., 2008). In 2001, Leonard and colleagues presented persuasive evidence from 40 years of development projects in various sectors and concluded that projects with substantial community engagement are more likely to succeed. They convincingly extend the argument to community engagement in PMTCT programmes (Leonard et al., 2001; Rutenberg et al., 2003). This review accepts as a foundational principle that community engagement, as broadly called for in The Global Plan, will be essential to scaling up PMTCT and achieving the goals set for 2015.
- ▶ **Community and facility interventions are needed for PMTCT scale-up:** “Strong linkages between community and facility services are the foundation of an effective PMTCT programme, and fully integrating PMTCT services includes developing linkages between the two” (Israel & Kroeger, 2003). A second underlying assumption of this review is that neither community engagement nor facility interventions alone will suffice. Community engagement for PMTCT must work hand in hand with efforts to improve PMTCT services at health facilities. Demand created within communities must be linked to adequate, stigma-free, client-sensitive service delivery. Facilities must also engage with communities to address demand-side barriers and ensure provision of the full PMTCT continuum to every client. Although the focus of this review is solely on community engagement, it is understood that elimination of new infections among children and keeping their mothers alive will require harmonized scale-up of promising practices in both community engagement and facility services.
- ▶ **Integrating PMTCT services within maternal, neonatal and child health services is essential to achieve the broadest possible benefit for women, children and families:** There is general consensus among stakeholders on the importance of this integration. This review assumes that PMTCT programmes are better at providing the full continuum of care, achieving positive health outcomes, reducing stigma and strengthening health-care systems when they are well integrated as part of the maternal, neonatal and child health platform.
- ▶ **There is no one-size-fits-all approach for community engagement:** The nature of communities and health-care systems varies widely. Differences in available resources, health-care infrastructure, health worker cadres, leadership systems and sociocultural factors all affect health-care service delivery and uptake. Availability and use of antenatal care and facility delivery, gender norms, beliefs and practices around pregnancy, childbirth, family planning and nutrition are a few of the important variables to consider in PMTCT scale-up. A review of promising practices in community engagement therefore cannot be prescriptive. It is assumed that no single community engagement strategy or set of practices will work equally well in all contexts. Selection and adaptation based on a detailed understanding of the local environment is required.



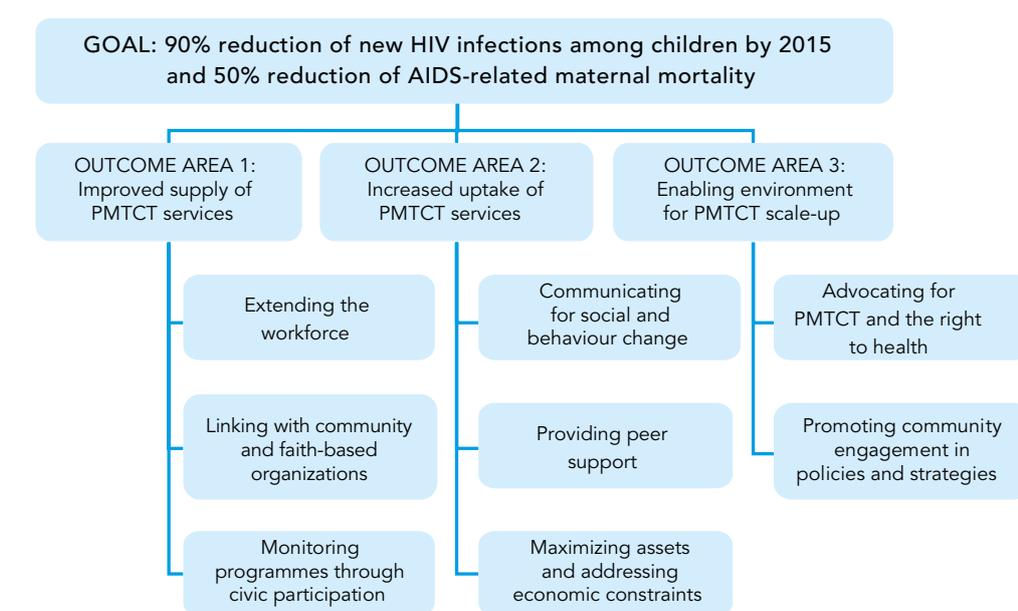
## PROMISING PRACTICES IN COMMUNITY ENGAGEMENT FOR PMTCT SCALE-UP

### Introduction

The promising practices identified for community engagement in PMTCT scale-up are organized in Figure 2 according to their primary intended outcome – improved supply of comprehensive PMTCT services, increased uptake of PMTCT services, and an enabling environment for PMTCT. Although Figure 2 simplifies the reality by masking the dynamics and overlap between the three outcome areas,<sup>3</sup> it is offered as a conceptual framework for stakeholders as they plan and respond to identified barriers and gaps in their PMTCT programmes.

In the section that follows, promising practices are described for each outcome area, along with a few examples and a brief summary of lessons learnt. The evidence and examples presented are not exhaustive but are offered to illustrate the practice in operation and some of the results achieved to date. Gaps in the evidence are discussed more fully in the Observations and Recommendations sections later in this document.

Figure 2: Community engagement practices by intended outcome



### Outcome area 1: Improving the supply of comprehensive PMTCT services

Some of the key supply-side barriers addressed through community engagement include shortages of health workers and limited geographical coverage; inadequate quality of service; and weak systems of referral, linkage and follow-up. The promising practices highlighted in this area include engaging community members as extension workers; linking with community and faith-based organizations; and monitoring programmes through civic participation.

<sup>3</sup> For example, peer counsellors often contribute to all three outcomes. They can extend the supply of essential services (e.g. adherence counselling), increase the uptake of services (e.g. through follow-up), and help to create an enabling environment by modelling positive living.

## Communities extending the workforce

For decades and across various sectors, community members have been engaged in social development efforts either as volunteers or with remuneration from government or civil society. The benefits of this long-standing practice are well-documented and include extending the workforce cost-effectively; bringing services closer to people in need; and benefiting from the intimate knowledge these workers have of their communities. Reflecting the importance of front-line health workers<sup>4</sup> for achieving the Millennium Development Goals (MDGs), the Global Community Health Worker Task Force has issued a report providing broad cost guidance, a deployment strategy and operational design considerations for subsystems to support 1 million government-salaried community health workers globally by 2015 (Earth Institute, 2011).

The [community health workers] are very important to us for follow-up of clients. They are so useful because they link the community to the health centre and the community people are comfortable with them and not afraid to ask them questions. Many [community health workers] even bring the women here for services. They are our voice in the community (Deputy District Public Health Nurse, Langata Health Center, Nairobi, Kenya; Colton, 2005).

### Box 4

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#### Mentor mothers

The Global Plan cites the engagement of mentor mothers as an important strategy for PMTCT scale-up. Mentor mothers are defined as mothers living with HIV who are trained and employed as part of a medical team to support, educate and empower pregnant women and new mothers about their health and the health of their babies, and to extend capacity to provide education and support and address the complex psychosocial issues many women face in the community and in health services. This practice is used in many countries.

The foremost example of mentor mothers at work was developed by the Mothers2Mothers (M2M) project. In this model, mentor mothers are salaried and brought into a well-developed structure that includes training, supervision and career development, providing encouragement and access to the labour market. The M2M model has been replicated and expanded and in May 2011 was operating at 714 sites in 9 countries. This project has recorded improvements in client retention through postpartum CD4 testing, antiretroviral drug uptake, treatment initiation, disclosure and infant testing. For example, in Kenya rates of antiretroviral drug uptake among women who interacted with mentor mothers four or more times were found to be 97%, compared with 62% among women with no interaction (Besser, 2006).

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WHO's analysis of HIV-related health sector tasks indicates there is great potential for front-line health workers to play a critical role in PMTCT scale-up. WHO lists 313 essential tasks for the continuum of HIV prevention, care and treatment; it recommends that 115 of these tasks, or more than a third of all required tasks, can be performed by front-line health workers (WHO, 2008). Various types of front-line health worker (e.g. mentor mothers (see Box 4), adherence counsellors, community health workers) have been trained and supported to take on PMTCT-related tasks across many programmes and countries. In line with the greater involvement of people living

<sup>4</sup> "Front-line health workers" is a recent term adopted to include the full range of the community health workforce, including paid and volunteer cadres (Earth Institute, 2011).

with HIV, some of these cadres are PMTCT clients or peers. The following are a few examples of documented results achieved in PMTCT scale-up by working with various cadres of front-line health workers:

- ▶ At a high-volume, thinly staffed maternity centre in Côte d'Ivoire, more than 1500 antenatal clients per year are seen by only 3 midwives. In December 2009, two community counsellors were recruited from a local community organization to strengthen PMTCT service delivery. The community counsellors conduct education and counselling at the centre, make home visits, and encourage all PMTCT clients to join a local support group. During the month before employment of the counsellors, only 51% of pregnant women seen in antenatal care received HIV counselling. Five months after the counsellors began work, 100% of pregnant women are offered and accept HIV testing in antenatal care; 100% of women who test positive accept initial CD4 testing; and the proportion of women and exposed infants given prophylaxis has risen from 30% in both cases to 80% and 100%, respectively. By December 2010, 80 PMTCT sites in Côte d'Ivoire had integrated community counsellors for PMTCT into maternal and child health services, and this number continues to rise (Elizabeth Glaser Pediatric AIDS Foundation, 2011).
- ▶ As part of a large project to extend the involvement of people living with HIV in Uganda's national HIV response, network support agents were recruited from groups for people living with HIV. They were trained and based in health facilities for 2–3 days each week, with the rest of their time spent working in communities. The network support agents support all HIV-related services, including PMTCT. Uptake of PMTCT services increased from 1264 women annually at the start of the project in 2006 to 15 892 women in 2009. Although the funded programme and monthly stipends ended in July 2009 (Kim et al, 2009). Network support agents were still working in 2011 to support community-facility referrals and linkages. The sustainability of this effort is credited to the network support agents' sense of empowerment and ownership in addressing real problems within their own communities.
- ▶ Traditional birth attendants have been trained to support PMTCT in some programmes. In 2002, the Cameroon Baptist Convention Health Board in Cameroon trained its long-standing cadre of traditional birth attendants to provide PMTCT services. Between July 2002 and June 2005, 30 trained traditional birth attendants reached over 2000 women with HIV counselling and testing. They attained prophylaxis coverage rates of more than 85% for mothers living with HIV and their babies. All of the babies who received prophylaxis were tested for HIV after 15 months, and treatment was initiated for the two babies with a positive result. Some of the challenges experienced within this programme included maintaining adequate supplies for the traditional birth attendants and regular supervision (Wanyu et al., 2007).
- ▶ A programme in the mountainous areas of rural Lesotho has realized improvements at each point in the PMTCT continuum of care through a combined effort of training traditional birth attendants and other community members as maternal mortality reduction programme assistants (MMRPAs); supporting waiting houses adjacent to health facilities for women approaching their due date; providing performance-based monetary incentives to MMRPAs; and distributing in-kind incentives to antenatal care clients. The MMRPAs are responsible for identifying and counselling women in their own villages about the importance of comprehensive antenatal care and delivery at the health centre. Starting in 2009 as a pilot in one health facility, this programme has expanded to cover eight facilities in 2011 and a target population

of roughly 235 000 people. There have been dramatic increases in attendance, including a tripling of the number of women enrolled at the pilot site between 2009 and 2010. Women make a greater number of antenatal care visits during each pregnancy, and facility deliveries have dramatically increased. Key factors identified for the success of the MMRPA programme include community involvement in their selection, affiliating each MMRPA with a health facility, and providing monthly facility-based refresher training (Partners in Health personal communication, November 2011).<sup>5</sup>

- ▶ Loss to follow-up of infants exposed to HIV after delivery is a particular challenge for PMTCT programmes. These children often do not access early infant diagnosis, cotrimoxazole and early initiation of treatment, thereby reducing their chances of survival. With rates of loss to follow-up greater than 50%, this is a major challenge for PMTCT and early infant diagnosis programmes in Malawi. In response, a pilot programme was undertaken in 2009 to train 16 community health workers as case managers for 1027 antenatal care clients living with HIV. The community health workers made monthly home visits until verification of the infant's final HIV status. Over a period of one year, 95% of the women not already on antiretroviral treatment received CD4 test results, and 75% of the women eligible for treatment were initiated on antiretroviral treatment. Of the 746 live births, 99% of mothers and 98% of infants received antiretroviral prophylaxis, 77% of the babies were tested for HIV, and all were started on cotrimoxazole. Of the 26 babies who tested positive, 92% were successfully enrolled in an antiretroviral treatment clinic. The study concluded that case management by community health workers is an effective strategy for reducing loss to follow-up and ensuring the full continuum of PMTCT (Kim et al., 2011).
- ▶ Front-line health workers can be especially helpful in supporting behaviours that extend over a period of time and those that encounter community resistance. In a non-randomized intervention cohort study to improve rates of exclusive breastfeeding in the high-prevalence area of Kwa Zulu-Natal, South Africa, lay counsellors visited HIV-positive and HIV-negative women four times during the first two weeks postpartum and then every 2 weeks for 6 months. Over 1200 mother–infant pairs were followed from October 2011 to April 2005. Counselling visits were strongly associated with adherence to exclusive breastfeeding at 4 months. The women who received the scheduled visits were more than twice as likely to be exclusively breastfeeding compared with the women who did not receive scheduled visits. The authors recommend that further research is needed to identify how this approach could be scaled up and the most cost-effective level of intensity of exclusive breastfeeding counselling (Bland et al., 2008).

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5 See <http://www.pih.org>.

## Box 5

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### Front-line health workers: Some lessons learnt

- With limited staffing and geographical coverage of health facilities in most resource-poor and high HIV prevalence countries, expanding the availability and use of front-line health workers will be essential to PMTCT scale-up and will support the Global Community Health Worker Task Force recommendations for the achievement of MDGs 4, 5 and 6.
  - To ensure sustainable, good-quality services, front-line health workers should be anchored within national primary health-care systems that promote task sharing and quality service standards.
  - Remuneration and functional systems for training and supervision are essential to the long-term engagement and success of front-line health workers.
  - Front-line health workers need to be linked closely to health facilities with effective two-way communication for referrals and linkage.
  - Front-line health workers operate most effectively when communities have a say in their recruitment and are informed and engaged in the improvement of their own health.
  - Integration of PMTCT within the broader job descriptions of existing front-line health worker cadres is an effective means for providing more holistic services. Adding responsibilities to existing portfolios can be overwhelming, however, and can result in overextension and burnout. Another option is to have specialized front-line health workers who focus specifically on PMTCT and maternal, neonatal and child health without aggravating stigma or neglecting other health concerns in the community.
  - Few examples were found of efforts to integrate the traditional health sector into the PMTCT network of care. Given the importance of this sector in many countries with high HIV prevalence, traditional birth attendants, traditional healers and others are likely to be an important but currently underused resource for PMTCT scale-up.
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### Linking with community- and faith-based organizations

Organized community responses by community and faith-based organizations were at the forefront of the HIV response and over the years have grown to become a highly prevalent and crucial source of support for millions of families affected by HIV. Community and faith-based organizations responding to HIV are probably most visible globally for their work with children affected by HIV;<sup>6</sup> however, community organizations engage in all aspects of the HIV response, including those related to the four prongs of PMTCT, such as HIV prevention, nutrition and infant feeding, psychosocial and spiritual support, follow-up and referrals, addressing gender-based violence, harmful gender norms and implementing income-generating activities. Although less frequent in the literature, the examples highlighted below hint at the potential of the engagement of community and faith-based organizations for PMTCT scale-up:

- ▶ Women Fighting AIDS in Kenya (WOFAK) is a community-based organization started in 1994 by a group of local women, many who had tested positive for HIV and were facing challenges coping with the diagnosis. WOFAK is a member of the much larger National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK), which supports PMTCT scale-up both at the policy level and through community programmes.

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6 For example, the Joint Learning Initiative on Children and AIDS and the Coalition for Children Affected by AIDS.

Today 15 000 women and 5000 children receive direct care and support at seven WOFAK centres.<sup>7</sup> Services include prevention education for groups most at risk, counselling and support groups, clinical care, nutritional care and feeding programmes, and income-generating activities for caregivers. WOFAK Mamas' Clubs also provide education and access to micro-credit loans through community outreach to individuals and groups (personal communication GNP+, February 2012). WOFAK promotes male involvement in PMTCT through counselling and home visits. These interventions are reducing loss to follow up and increasing counselling for discordant couples. At one WOFAK centre, about 50% of male partners attended antenatal care in 2009, compared with none in 2007.<sup>8</sup>

- ▶ Community organizations are noted for reaching marginalized and vulnerable populations with HIV-related services and support, including PMTCT. For example, Social Awareness Service Organization (SASO), a community organization that operates in Manipur, India, is integrating PMTCT into its ongoing efforts to support women who use drugs and their families. A baseline study indicated that these women experience high rates of homelessness, unmet need for contraceptives, symptoms of sexually transmitted infections and physical violence, have poor health-seeking behaviour, and have a low level of knowledge about PMTCT. SASO has designed and is implementing activities to support these women around each of the four prongs of PMTCT, including condom promotion and advocacy against violence; family planning counselling and referral; accompanied referrals for HIV counselling and testing and antiretroviral drugs; and linkage to social welfare programmes and benefits, including nutrition support and transport fees (International HIV/AIDS Alliance, personal correspondence, July 2011).
- ▶ Faith-based health institutions provide a significant portion of health-care services in many countries. With dedicated resources and commitment to serving in remote areas, these facilities often provide models for comprehensive, integrated facility and community-based health-care programmes. One example comes from the Mingende Rural Hospital in Papua New Guinea. Starting in 2003, this mission hospital rolled out PMTCT within the context of strengthened maternal, neonatal and child health services. Since 2009, all 25 babies exposed to HIV have tested negative. The community component of this programme is considered an important part of its success. The programme engages community members to conduct “foot patrols” and outreach communication activities. It involves men and women living with HIV as peers and has a hospital board comprised of 13 male community leaders representing the 13 different ethnic groups living in the area. These leaders conduct outreach education and have established an agreement that public facilities, including hospitals, will never be affected during conflict (Prasanna, 2011).
- ▶ Faith leaders and faith-based organizations are recognized as having tremendous potential for influencing opinions and beliefs and inspiring action. This includes reducing HIV-related stigma within their congregations and communities. Channels of Hope, a strategy of World Vision International, currently operates in 59 countries to mobilize faith and other community leaders to respond positively to important local challenges, including HIV and AIDS. Channels of Hope provides an 8- to 10-day training course for facilitators, who in turn conducted 205 workshops within their communities. The curriculum combines

7 [http://www.wofak.or.ke/about\\_wofak.htm](http://www.wofak.or.ke/about_wofak.htm).

8 [http://www.FHI.org/en/Country\\_Profiles/Kenya/res\\_male\\_involve\\_PMTCT.htm](http://www.FHI.org/en/Country_Profiles/Kenya/res_male_involve_PMTCT.htm).

technical information with scripture to engender compassion and inspire action. Out of these workshops, congregations and communities develop action plans on HIV, gender, maternal, neonatal and child health services, and other key local concerns. A recent evaluation of Channels of Hope activities in Uganda and Zambia surveyed respondents and generated a stigma score. Statistically significant reductions in stigma were documented among children, adults and representatives of nongovernmental and faith-based organizations between the pre-intervention and final evaluation surveys (World Vision International, personal correspondence, November 2011).

## Box 6

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### Community and faith-based organizations: Some lessons learnt

- Community and faith-based organizations provide tremendous support to the global HIV response. PMTCT can be integrated effectively into the ongoing work of many community and faith-based organizations, including both facility- and community-based services.
- A wide range of community-based services and support is already provided by community and faith-based organizations and can complement facility-based PMTCT services and create a more holistic response for women, children and their families.
- Community and faith-based organizations can support implementation of most of the promising practices described in this review, including engaging front-line health workers and peers, conducting community-led communication activities, monitoring programmes, maximizing community assets and advocacy.
- Community engagement works best if it builds on existing community responses and structures. A preliminary step for PMTCT programmes in developing a community engagement strategy is to become familiar with the community and faith-based organizations serving their population. This can be accomplished through a participative enquiry and mapping exercise of local organizations and the services they provide. Working with groups and networks of people living with HIV is of particular importance.
- Community and faith-based organization activities should be linked to health facilities with an agreement that spells out how each group operates and how the groups interact with and support one another.
- Establishing linkages with community organizations that support older children affected by HIV is extremely important to ensure continued support for children exposed to HIV as they grow out of the PMTCT continuum.

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### Monitoring PMTCT programmes through civic participation

Poor quality of services is a widely acknowledged and challenging constraint to PMTCT and other health services. Many supply-side strategies, such as clinical mentoring, supervision and the promotion of service standards, are being implemented to improve quality. In most resource-poor countries, however, the governmental institutions assigned to monitor and supervise public services are weak and have limited incentives for performance. There is increasing interest and experience with the potential role of communities as complementary monitors for health and other public services. The Global Plan suggests community charters as a means for providing communities with greater ownership of and accountability for the PMTCT programmes that serve them. A randomized field experiment on increasing community-based monitoring conducted in Uganda provides significant insight on this promising practice (Bjorkman & Svensson, 2007) (see Box 7).

## Box 7

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### Power to the people: Civic engagement in monitoring health services

This large-scale randomized field experiment looked at the possibility of strengthening health-sector performance through increased accountability at the level of the client population. The experiment took place in 50 communities across nine districts of Uganda. The intervention communities were informed on their rights, provided with baseline information on health services and community health status in the form of "report cards", and encouraged to develop a remedial action plan. This process was accomplished through a series of meetings facilitated by local community organizations with community members, with health facility staff, and then with both groups together. The end result of these dialogues was a jointly owned action plan to address the identified concerns within the existing resource envelope.

One year into the experiment, the researchers found a significant difference between the intervention and control communities. Waiting times and absenteeism at the intervention health centres were reduced significantly, while the cleanliness of these health centres had improved notably. Average service use was 16% higher in the intervention communities. Of particular relevance to PMTCT, antenatal visits, facility deliveries and family planning visits had all increased in the intervention communities. Visits to traditional healers and the extent of self-treatment had declined. In terms of health outcomes, there were significant gains in infant weight-for-age scores and a notable 33% reduction in deaths among children under 5 years of age in the intervention communities. At a roughly estimated US\$ 300 per child death averted, this intervention was found to be fairly cost-effective and scalable, since it reached approximately 55 000 households.

A key feature of this experiment was the level of participation. Communities were engaged through surveys in completing the report cards and actively took part in identifying solutions and planning for and monitoring their implementation (Bjorkman & Svensson, 2007).

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Some countries, such as Rwanda and India, are shifting accountability for public services to lower levels on a national scale. In Rwanda, multisectoral performance contracts (including for health) are signed between the head of state and each mayor in the country, who in turn signs a performance contract with each local authority. Performance is assessed twice a year against the targets set in these contracts, and districts are ranked publicly. Although not directly involved in monitoring activities, community-level constituents are keenly aware of their standing and pressure their elected leaders for good results (Mugwaneza, 2011).

In India, community-based monitoring as part of the National Rural Health Mission is in the early piloting stage in a small sample of primary health centres and communities in nine states. Lessons learnt have been taken from other projects currently under way in the country and include the importance of establishing a monitoring committee and the strong engagement of community organizations, health sector personnel and the community (Garg & Laskar, 2010).

## Box 8

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### Community-based monitoring: Some lessons learnt

- Community-based monitoring is a rights-based approach that can improve the quantity and quality of health services, including PMTCT services, leading to improved health outcomes.
  - Effective community-based monitoring demands participative approaches that engage the community early and in all phases of the process.
  - Broad involvement of the community, including all key stakeholders, promotes better appreciation of community demands and leads to implementation of agreed reforms.
  - In order to monitor services, communities need access to timely information on indicators related to the delivery and use of health care in, and the health status of, the community. They must also be aware of the standards expected for different services in order to assess performance.
  - Local community organizations can be effectively engaged to facilitate community-based monitoring.
  - Consensus building among health personnel, government authorities and the community around their respective roles and indicators of progress is critical to the success of community-based monitoring. This includes consensus and commitment at the facility, community, district and national level.
  - More research and evaluation is needed on user-friendly tools to enhance accountability and on the sustainability of community-based monitoring efforts and results.
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### *Outcome area 2: Increasing the uptake of PMTCT services*

Key demand-side factors that inhibit PMTCT uptake include inadequate knowledge and misconceptions about HIV and PMTCT; gender inequities and other harmful gender norms; HIV-related stigma; and financial constraints, including transport. PMTCT programmes are engaging with communities in a variety of ways to address these barriers through social and behaviour change communication, through peer support, and by maximizing local assets and identifying creative solutions to resource constraints.

### Community-led social and behaviour change communication

The focus of this section is on the promising practice of engaging communities in the planning and implementation of social and behaviour change communication activities aimed at transforming attitudes to improve PMTCT uptake and promote behaviours that reduce the risk of HIV transmission and promote family health. A few examples – both those specific to PMTCT and those that address HIV more broadly – are highlighted below, including a large-scale effort from Ethiopia described in Box 9.

## Box 9

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### Empowerment through community conversations in Ethiopia

Community conversations are a core component of Ethiopia's national HIV response and aim to empower people at the grass-roots level to engage in open discussions about HIV and to take innovative steps to reverse the spread of the epidemic. Local facilitators are trained to help the community explore the factors fuelling the spread of HIV and to develop plans to address locally identified drivers and needs. By August 2010, nearly 25 000 facilitators had been trained and nearly 16 000 conversations had been conducted across all regions of the country. One output is that more than 13 600 communities have prepared a local action plan. Anecdotal reports indicate that HIV testing has increased, and practices such as "wife-sharing" have been identified as harmful and against religious teachings (FHAPCO, 2010; UNDP, 2004). Harder to measure is the sense of ownership and empowerment that communities are gaining as a result of these conversations and related behaviour change. In 2008, the National Alliance of State and Territorial AIDS Directors evaluated the community conversation process in three states and found that performance was stronger where salaried health extension workers, rather than trained volunteers, conducted the conversations (Slater et al., 2009). The Ethiopian Federal Government is supporting a national evaluation of community conversations in 2011–2012, which will shed further light on the outcomes and impact of this activity.

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## Box 10

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### Prong 2: Reducing unintended pregnancy – one man's impact

Ahmed Nuriye, a 38-year-old Ethiopian man, was included in an effort to train 250 community volunteers to provide family planning information to women and men in communities throughout the Amhara region. The training focused on tools to facilitate participative community dialogues about the benefits of and barriers to family planning.

After training Ahmed held dialogues in which he "let the community have the floor ... they are learning from each other about long-acting and permanent methods ... misconceptions are decreasing and uptake is increasing."

Service statistics from the nearby health centre confirm that caseloads for long-acting and permanent methods were three times higher in June 2010 than in the previous 6 months (EngenderHealth, 2011).

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- ▶ Men Taking Action was a communication strategy undertaken in Zambia to promote male involvement in PMTCT.<sup>9</sup> Male community leaders took part in formative research to identify the specific male attitudes and practices that negatively impact women accessing HIV counselling and testing and PMTCT. Based on the findings, a targeted community education strategy was developed and implemented. Messages were delivered through faith-based health institutions and trained traditional and cultural leaders. After each session, men were encouraged to test for HIV in an opt-out manner. In the first 5 months, 65% of the 2261 men reached by the programme tested for HIV, compared with a baseline rate of 11%. There was a fourfold increase for same-day pregnant couples counselling and testing. Antenatal clinic clients' acceptance of HIV counselling and testing rose from 60% to 95%, and acceptance rates for antiretroviral prophylaxis or treatment rose from 40% to 70% among women who tested positive. Qualitatively, participants reported a dramatic paradigm shift among

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<sup>9</sup> The important and well-documented benefits of male involvement in PMTCT and recommended approaches and practices are the focus of a review commissioned by UNAIDS (Ramirez-Ferrero, 2011).

community leaders on human rights in the context of HIV. Men in the community began taking leadership in encouraging women to attend for antenatal care and lobbying faith-based health institutions to increase the frequency of antenatal care services. Implementers credited the success of the programme to the full engagement and leadership of culturally revered community leaders (Sinkala et al, 2008).

- ▶ Participatory communication is a particularly important tool for stigma reduction. By tackling harmful attitudes and norms “from within”, programmes can inspire uniquely strong and relevant responses. For example, a participatory process undertaken with a rural community in the Eastern Cape of South Africa led to the adoption of a community declaration on HIV. This declaration distinctively reflects the voice of the community it intends to influence and in so doing increases relevance and engenders ownership (Parker & Birdsall, 2005):
  - ▶ **We resolve to discuss [HIV] in community gatherings.**
  - ▶ **We agree to disclose our HIV status with the knowledge that we will have support from our community.**
  - ▶ **We encourage all and their families to disclose HIV status.**
  - ▶ **We pledge to support, and never to gossip about or humiliate in any way, those who are known to have HIV/AIDS.**
  - ▶ **We pledge to draw [people living with HIV] close and to encourage them to live positively.**
  - ▶ **The community will deal severely with anyone seen to discriminate against [people living with HIV].**
  - ▶ **We will preach and pray about AIDS at church, in schools and in concerts.**
  - ▶ **We have started holding inter-faith AIDS prayer services and will continue doing this.**
  - ▶ **We commit to use AIDS symbols in our workplaces as a visual sign of our commitment.**
  - ▶ **We commit ourselves to maintaining and building on this initiative.**

## Box 11

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### Community-led communication: Some lessons learnt

- Community-led communication is a powerful tool for transforming attitudes and reducing stigma, engendering local leadership, and increasing service uptake.
- Participative formative research is essential to ensure that messages are relevant and tailored to the local context.
- Engaging men, especially cultural and traditional leaders, in communication efforts to improve male involvement and uptake of services can be highly effective.
- Community members and groups need training and ongoing support to master participative communication techniques and to facilitate community dialogues that lead to change.
- Communication agents may require some form of compensation or incentive to sustain their activities.
- Health facilities must be prepared to respond adequately to demand generated through communication campaigns and activities.
- The outcomes of community-based social and behaviour change communication activities are complex to measure; better indicators and tools are needed.

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## Providing peer support

The engagement of people living with HIV to support other people living with HIV in the community is practised widely within the global HIV response and within PMTCT programmes. Peer support may be provided by an individual or as part of a group. Both practices aim to support women and their families in a variety of ways throughout the PMTCT process.

### Individual peer support

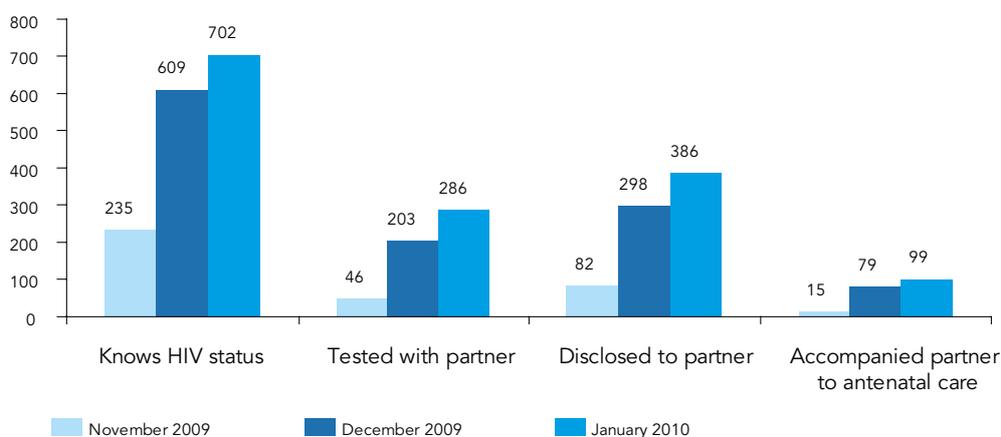
Individual peers, such as the mentor mothers and network support agents described above, are serving in many programmes as front-line health workers. Peers have the unique ability to act as role models for positive living for PMTCT clients and their families and to provide experience-based counselling and support. Peers have been credited with helping to reduce stigma in various settings. A few examples are described here:

- ▶ A key objective of the M2M programme described above is to support disclosure and fight stigma by empowering women to live positively. Disclosure rates are consistently higher among women with the support of a mentor mother. For example, in Zambia 84% of women in the programme have disclosed their status; in Kenya the rate is also 84%, compared with only 53% among women without peer interaction. Nurses working in clinics with mentor mothers report that positive role modelling also benefits health workers: “Even if the mentor mothers are helping the clients, they are also helping the health workers who are positive because when they see others coming out in the open about their status, they also come out in the open ... In the past we used to bury many of our nurses who had stigma because of the way we health providers talk, but now if they see others living positively they are also able to appreciate it.”<sup>10</sup>
- ▶ In an evaluation of the project Expanding the Role of Networks of People living with HIV/AIDS in Uganda, network support agents were found to be one of the most successful components. These peer extension workers were credited with having mobilized people living with HIV to use existing services, including clinic-based and supportive services provided by community organizations. A health unit in-charge from the project said: “The [network support agents] have managed to convince the communities that HIV is real and the people believe them in a way they never believed the health workers. They have helped bridge the gap between the health care system and the community: People are more comfortable coming to the clinics since they know they will be finding their peers at the facility” (Kim et al., 2009).
- ▶ In recognition of the important role of male partners in health care, financial and family decision-making, a small but increasing number of PMTCT programmes recruit and support peer males. Like their female counterparts, these men are often graduates of the PMTCT programme. They interact with the partners of current PMTCT clients while modelling positive living and parental responsibility. In Botswana, an international nongovernmental organization partnered with a local faith-based organization to launch a 5-year peer education programme. Peer males were recruited to provide one-to-one counselling and group discussions in clinics and community settings. Job descriptions, performance standards, standard operating procedures and topic guides were developed. Monthly supervision was provided by a skilled counsellor from the district. According to self-reported data (see Figure 3), four key indicators, including couples testing and disclosure, showed marked improvement within 3 months of engagement of peer males. The peer males reported several lessons learnt, including the need to allow time to develop rapport and trust, to find settings that are conducive to

<sup>10</sup> Quoted from <http://www.m2m.org>.

serious conversations, and to target partners of PMTCT clients more precisely. Peer males from the programme also integrate with the Men's Sector Committees, a national initiative aimed at improving male involvement in HIV and AIDS. Through this mechanism, they are expanding their target audience for communication around PMTCT (AED, 2011).

Figure 3: Peer males as champions of change in Botswana



### Support groups

All support groups provide an opportunity for people living with HIV to interact with and support one another, but they differ across programmes and communities in many ways. Some support groups are clinic-based and led by a health worker to focus on sharing information and adherence, while other support groups are community-based and focus on positive living, income-generation or other activities. Although support groups are very common within communities and health programmes, evaluation data are limited. A few examples with documented results are listed here:

- ▶ One project in Ethiopia promoted mothers' support groups based at a health centre and had scaled up to 84 sites by June 2008. The project documented that 90% of mothers and babies enrolled in support groups received antiretroviral prophylaxis; this compared very favourably with the national rate of 53%. Babies of women in support groups were far more likely to receive recommended antiretroviral drugs and prophylaxis for opportunistic infections and to engage in exclusive breastfeeding. In exit interviews, mothers graduating from support groups expressed a high level of appreciation for the psychosocial support provided (McLaughlin et al., 2009). An evaluation of the programme also found that mothers' support groups reduced stigma in the community and from health workers and self-stigma. The mothers' support groups were found to reach the "poorest of the poor", and some had initiated income-generation activities in response to the members' needs. The following factors were found to be critical to the successful scale-up of mothers' support groups in Ethiopia: sufficiently high levels of use of antenatal care and PMTCT services and of HIV prevalence; women living with HIV willing to serve as mentor mothers to the groups; and access to antiretroviral treatment. As the groups were based at health centres, this limited participation for women who had to

travel long distances. Implementers concluded that the timing and location of mothers' support groups need careful consideration (Hope & Bodasing, 2009).

- ▶ A more recent development in PMTCT programmes is the expansion of support groups to focus on other family members influential in PMTCT decision-making – for example, male partner support groups and mother-in-law support groups in Lesotho, and family support groups in several countries. As described below, there is some evidence that these efforts can also have a favourable impact on PMTCT service uptake and compliance. A programme review in the United Republic of Tanzania looked at 16 family support groups with 359 members, 14% of whom were male partners. Programme implementers found that the support group members tended to make more than one antenatal care visit and were more often linked to care and treatment centres. Disclosure rates (60%) and rates of family planning and use of condoms (75% among postnatal clients) were also found to be encouraging. Through support group linkages, members also received food, transport and legal support (Sequeira D'Mello et al., 2009). A qualitative assessment of a family support group initiative in Uganda that focused primarily on couples found that the male members provided more support for their pregnant wives; communication between partners improved; couples engaged in better birth planning and adherence to antiretroviral prophylaxis; and guidance on infant feeding increased (Muwa et al., 2007).
- ▶ Some community-based and PMTCT-initiated support groups have a broader mandate or have evolved to take on a wider range of issues and activities. Many have engaged in income-generating activities to sustain themselves and extend their HIV-related activities in the community. Some programmes have found support groups to be an excellent resource for identifying lay counsellors and other extension workers. In Mozambique, a new and highly effective community organization emerged out of a PMTCT support group (UNICEF Mozambique, personal correspondence, September 2011). A mothers' support group based at a health centre, initiated in 2008, evolved into a national registered association and in 2011 expanded its reach from one to six health facilities. Currently made up of 29 mothers and 3 male partners, this support group conducts awareness campaigns and tracks down clients who miss their appointments. In 2011, the group has achieved an impressive return rate of 64% for infants exposed to HIV at risk of defaulting from care. The support group members are volunteers, but they receive a small incentive for returning clients to care. The association structures complemented by small income-generating activities will help to ensure the sustainability of this group after project support ends.

## Box 12

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### Peer support: Some lessons learnt

- Peer support provided by individuals or in groups is a widely used practice that provides PMTCT clients with role models for positive living and experience-based counselling and support.
- Peer counsellors and support groups have been associated with improved PMTCT service uptake and adherence and reduced stigma, including self-stigma and positive living.

#### *Individual peer support*

- All of the lessons cited for front-line health workers also apply for peers, including ensuring adequate remuneration, training and supervision.
- Engaging peers in PMTCT programmes supports the greater involvement of people living with HIV by empowering them, most of whom are women, to care for themselves and their families; to mobilize and be respected by their communities; to have a public voice; and to understand and advocate for the rights of people living with PLHIV and the rights of patients.
- Engaging male peers shows promise as an effective strategy to encourage male involvement and transform negative gender norms.
- When engaging peer counsellors at health facilities, it is important to address any potential HIV-related stigma from health-care workers and to formally introduce and incorporate peer counsellors as an integral part of the health-care team.

#### *Support groups*

- There are many different support group models, which vary in terms of their location and how they are initiated (facility- or community-based), their leadership (nurses, peers or lay counsellors), their primary purpose (e.g. to promote adherence, to generate income, to provide psychosocial support, to contribute to the HIV response), their length of membership (through delivery or breastfeeding or more long term) and other characteristics. Programmes can benefit from working with existing support groups to incorporate PMTCT and by supporting the establishment of new groups using locally appropriate models.
- Much of the information shared within PMTCT-focused support groups (e.g. nutrition counselling, birth planning, well-baby and parenting information, family planning, reproductive health) is relevant for all women, regardless of their HIV status. To achieve broader health benefits and reduce the possibility of stigmatizing their members, some programmes use mixed support groups, including all pregnant women regardless of their HIV status.
- Other life demands (e.g. childcare, income generation) can challenge the recruitment and retention of support group members. Support groups that expand their discussions and activities beyond transfer of medical information seem to fare better in this regard, especially if the support group agenda is driven by the members' concerns and issues.

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### Maximizing community assets and addressing economic constraints

The Global Plan suggests that communities can facilitate scale-up by maximizing local assets in support of PMTCT programmes. Examples of communities generating resources and innovative solutions to improve programmes and reduce economic barriers are found within in the literature (see Box 13). The examples below come from PMTCT programmes, and also from HIV and maternal, neonatal and child health services more broadly:

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### Community advisory boards in India strengthen PMTCT programmes

As many as 65,000 women living with HIV in India give birth each year. Approximately 60% deliver in health facilities, with half occurring in the private sector. In 2009, PMTCT services were almost exclusively provided in the public sector. As part of a larger effort to promote PMTCT in the private sector, community advisory boards were established for two model private-sector facilities. Each community advisory board has 22 members, including lawyers, physicians, members of networks of people living with HIV, representatives of community organizations and partner hospitals, social workers, members of at-risk groups (including men who have sex with men, and sex workers), homemakers and district medical officers. The two community advisory boards are empowered to provide guidance and monitor PMTCT activities at their respective facilities, to ensure that all activities are ethically correct and culturally sensitive, to leverage resources from different stakeholders, and to plan for sustainability. The community advisory boards meet quarterly and have been supported with training, exchange visits and technical assistance.

Over 2 years, the supported centres provided counselling and services to more than 7500 women. The community advisory boards supported the engagement of local nongovernmental organizations to provide follow-up on PMTCT clients; as a result, the centres achieved a rate of follow-up of 90%. The community advisory boards also developed a resource-mobilization plan and leveraged resources for nutritional supplements, infant HIV test kits and infrastructure. They also played a crucial role in negotiation with the private partner hospital to reduce rates for caesarean delivery by more than half (Bhanot et al., 2009; Kapoor et al., 2009,).

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- ▶ An intervention trial was conducted in rural Nepal to organize women in the community to reduce neonatal mortality. Although the intervention did not specifically target PMTCT, the objectives, strategies and outcomes are highly relevant to the elimination of new HIV infections in children and keeping their mothers alive. The first step was to equip local women as programme facilitators by training them in participatory communication techniques. Once trained, these facilitators conducted initial discussions with women's groups about local childbirth practices and weaknesses in antenatal care, delivery and newborn care. Monthly meetings were held for the next year as the women's groups planned, implemented and assessed their own strategies to reduce neonatal mortality. Common tactics included community-generated funds for maternal and infant care; stretcher schemes; production and distribution of clean delivery kits; home visits to newly pregnant mothers; and raising awareness using a locally made film to create a forum for discussion. Indicator outcomes demonstrated that women in the intervention areas were more likely to have antenatal care, to deliver in facilities and to have had safer childbirth practices. At the end of the project, neonatal mortality had dropped by 30%. Although maternal mortality was not targeted specifically, it was significantly lower in the intervention areas (Manandhar et al., 2004; USAID & Access, 2009).
  - ▶ In Uganda, a quasi-experimental study was undertaken to look at the use of motorcyclists and transport vouchers. The local motorcyclists organized themselves to accept vouchers in exchange for transport to antenatal care, deliveries and postnatal care. During the intervention, they became actively involved in ensuring that women obtain the care they needed. Facility deliveries jumped from fewer than 200 per month to more than 500 per month, and antenatal care visits increased. In addition, the transport providers, their families and the community benefited economically. Challenges included setting affordable prices

and traffic safety (Ekirapa-Kiracho et al., 2011).

- ▶ In South Sudan, local rickshaws are used as low-cost community ambulances. When not in use for health-care services, they are used to provide a taxi service as an income-generating activity (International HIV/AIDS Alliance, personal communication, July 2011).
- ▶ Expanding from one to four states in northern Nigeria, the transport unions partnered with the health sector and communities to provide the use of their vehicles free of charge to transport any pregnant woman to a health-care facility. Drivers were trained to manage pregnant women en route to facilities and communities were sensitized. One partner documented that 850 women were transferred in 3 states during the first 12 months of implementation. Further evaluation of this effort is currently under way (Silva, 2011).

### ***Outcome area 3: Creating an enabling environment for PMTCT scale-up***

In this section, an enabling environment for PMTCT scale-up is considered from two perspectives. First, communities engage in advocacy and activism to improve policies and actions around PMTCT and maternal, neonatal and child health. Second, governments and their development partners promote policies and frameworks that encourage community engagement in PMTCT.

#### **Communities advocating for their right to health**

From speaking up against stigma and being the voice of at-risk but marginalized populations, to fighting for reduced prices of antiretroviral drugs and challenging the status quo in service delivery, community activists have played a key role since the inception of the HIV response. Three highly visible and relevant examples of advocacy by community coalitions are described in Box 14.

#### **Box 14**

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#### **Advocacy and activism for PMTCT, maternal, neonatal and child health, and the right to health**

##### ***Advocacy and activism led to the national roll-out of PMTCT in South Africa***

The Treatment Action Campaign (TAC) is a long-standing world-renowned coalition of activists that uses a human rights-based framework combining social mobilization and legal action to improve access to antiretroviral drugs and treatment for HIV and AIDS. TAC's first major campaign, between December 1998 and December 2001, combined human rights education, HIV treatment literacy, public marches and demonstration with a constitutional court case to pressure the government to roll out antiretroviral drugs for PMTCT at a national scale. TAC worked at the community level through branches in more than 100 poor villages and townships to empower citizens with information on their right to health. Lessons learnt from this successful campaign include that treatment literacy training and human rights education are the backbone of efforts to empower communities, especially those that are marginalized; that people who are directly in need of health care, in this case people living with HIV, will mobilize around tangible needs; and that litigation alone can result in "pieces of paper with a latent untapped potential", but litigation combined with organized social mobilization is more likely to lead to changes being implemented and tangible improvements in peoples' lives (Heywood, 2009).

### ***Four4Women raises national and global awareness of PMTCT prongs 1, 2 and 4***

Four4Women is an ongoing global and national campaign sponsored by the International Treatment Preparedness Coalition (ITPC), a global network of people living with HIV advocates.<sup>11</sup> Research conducted with small grants from ITPC in six countries led to a 2009 report entitled *Failing women, failing children: HIV, vertical transmission and women's health*. This report was a harsh indictment of the narrow focus of PMTCT programmes on single-dose nevirapine and their neglect of fundamental issues around women's health. The aim of Four4Women is to share evidence, materials and experiences for advocacy on the comprehensive four-pronged approach to PMTCT. Eleven countries have now received small grants for research and advocacy. Achievements from the first year include building a coalition of women's and HIV organizations for the campaign in Argentina; persuading the Moldovan Government to provide social support for children living with HIV in the national strategic plan; and successfully using media to inform people about PMTCT, a subject previously ignored by journalists, in Morocco. The coalition is now soliciting input from civil society organizations around the world, especially networks of women living with HIV, on the development and implementation of the Global Plan.

### ***National partnership platforms in eastern and southern Africa promote maternal, neonatal and child health***

The national partnership platforms effort is a large-scale capacity-building approach to create space for effective dialogue between civil society, governments and other stakeholders and strengthen coordination, ownership and accountability of the HIV response. Operating across several countries, national partnership platforms in eastern and southern Africa include more than 55 civil society and community networks in 2010, which in turn represent hundreds of community and faith-based organizations. Membership of national partnership platforms is inclusive and diverse, with representation of groups often overlooked but with a key stake in the HIV response. Members include women, young people living with HIV, academics, people with disabilities, sex workers, and lesbian, gay, bisexual and transvestite people.

In Uganda, Zambia, Kenya and South Sudan, the national partnership platforms model is being applied to maternal, neonatal and child health. The aims of this effort are to influence national policy to focus on reducing maternal mortality; to strengthen community-level referral; to develop a model for integrated HIV and maternal, neonatal and child health; and to fully engage communities in the links between HIV and maternal mortality. The most highly visible activities related to this effort are taking place in Uganda. One of the supported local organizations along with two families has taken the Ugandan Government to court for two preventable maternal deaths that occurred in public-sector facilities. When court action was



Activists protest maternal deaths in Uganda

delayed, hundreds of advocates took to the streets in protest. The trial is ongoing and the outcome therefore unknown, but the case has brought high-level attention to the issues of women's health and health as a basic human right (International HIV/AIDS Alliance July 2011):

*In this unprecedented case in East Africa, Civil Society Organisations and families of two women who died in childbirth are suing the Uganda Government for non provision of essential services for pregnant women and their newborns which breaches its fundamental obligation to uphold the Constitution and violates the right to health and the right to life (Nakkazi, 2011).*

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<sup>11</sup> See <http://www.four4women.org>.

## Box 15

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### Communities as advocates and activists: Some lessons learnt

- Community advocates and activists have played a major role in the HIV response and can strengthen PMTCT and maternal, neonatal and child health programmes.
  - Human rights education and information sharing on PMTCT, maternal, neonatal and child health and local health issues are the backbone of efforts to empower communities as advocates and activists.
  - Ongoing financial and technical investment is required to build advocacy skills and to coordinate social mobilization and organized activism.
  - Populations considered to be most at risk of acquiring and highly vulnerable to HIV are often disenfranchised, without a voice in public policy. These include poor rural women, children, people who inject drugs, and sex workers. Building capacity in advocacy among these groups strengthens their voice in shaping the policies and programmes that affect them.
  - Sustained advocacy and activism around PMTCT, HIV and maternal, neonatal and child health is likely to be required at the national and local level to build a sufficiently enabling environment for the elimination of new HIV infections in children by 2015 and keeping their mothers alive.
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### Promoting policies and strategies that support PMTCT and community engagement

Strong leadership is widely recognized as a key ingredient of success in responding to the HIV epidemic. Eliminating new HIV infections in children by 2015 and keeping their mothers alive will require committed leadership evidenced in supportive policies and strategies for community engagement in PMTCT scale-up.

Most major donors and international partners are now promoting community engagement for PMTCT in their technical and funding guidance. As noted previously, The Global Plan and the UNAIDS Investment Framework highlight community engagement as an important element of scale-up. The WHO Strategic Vision 2010–2015 emphasizes the need to “promote community participation to support and deliver PMTCT services” (WHO, 2010b). PEPFAR (2011) guidance asserts that “community involvement is necessary for PMTCT implementation and scale up”. The Global Fund to Fight AIDS, Malaria and Tuberculosis (2010b) has gone a step further to introduce a community systems strengthening framework that encourages countries to adopt a systematic approach to community engagement in their funding proposals.

It is encouraging to note the priority given to community engagement in PMTCT scale-up at the global level; however, leadership and commitment at the national and local level will ultimately determine the success of PMTCT scale-up. Botswana (Box 16) and other countries are examples of highly committed national governments and their PMTCT successes are presented below.

## Box 16

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### Political commitment and community mobilization in Botswana

In the face of a severe generalized epidemic, Botswana scaled up PMTCT and reduced mother-to-child transmission of HIV to less than 4% by 2009, a rate comparable to that of industrialized countries. In the same year, 93% of pregnant women received counseling and testing for HIV and more than 95% of those in need received antiretroviral prophylaxis. Underpinning this success is tremendous political commitment to addressing HIV head on and to the implementation of an intense community mobilization effort.

Total Community Mobilization was a national effort that ran from 2001 to 2005 and set the groundwork for full community engagement in the national HIV response. During the exercise, trained field officers assisted nearly 500 000 people in communities throughout the country to develop individual action plans for taking control of HIV and AIDS. An estimated 300 000 (60%) of the people reached reported having complied with their plans and changed their lifestyle (Humana People to People, 2010).

Today, the Government of Botswana's Department of HIV/AIDS Prevention and Care cites community mobilization as one of three main strategies for the national PMTCT programme. Communities are encouraged to take the lead in promoting the importance of HIV testing and PMTCT enrolment. Communities are also encouraged to prevent health problems related to PMTCT through their own efforts. As cited by the Government of Botswana, the main lesson learnt is that "political commitment is necessary". Other lessons include that all stakeholders, especially nongovernmental organizations, must collaborate; and that community ownership is enhanced through community capacity development (Department of HIV/AIDS Prevention and Care, 2009).

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Rwanda is a success story in PMTCT scale-up. Mother-to-child transmission rates were reduced to less than 3% by 2010. Improving male involvement, a national Rwandan Government priority, is identified as key to this success. Cited as an MDG good practice, Rwanda's Going for Gold male involvement effort is grounded in high-level political advocacy and intensive community mobilization, with local authorities, community health workers and "male champion" peer educators. Programme accountability has also been decentralized through performance-based contracts with local authorities that include indicators on PMTCT and male involvement. As a result, male partner testing has increased rapidly, from 16% in 2002–2003 to 84% in 2009–2010. This progress hints at widespread transformation of deep-seated gender norms and practices.

Implementing agencies, including international nongovernmental organizations, are also increasing their support of community engagement and developing frameworks, strategies and programmes to promote and coordinate various community engagement efforts. World Vision International, a faith-based organization with child-focused HIV programmes operating around the world, is currently developing a strategic framework that offers a conceptual model to illustrate the role of communities in promoting all four prongs of PMTCT. The model is being integrated into World Vision's maternal, neonatal and child health programming (World Vision, 2011).

On the ground, several implementing agencies support programmes that engage local community and faith-based organizations to link better with health facilities on PMTCT and HIV. For example, Pact International uses an organizational development approach to build the capacity of local community and faith-based organizations to provide HIV services and support, including PMTCT.<sup>12</sup> The International Center for AIDS Care and Treatment Programs (ICAP) in Nigeria works to strengthen PMTCT service delivery through a hub-and-spoke model that includes care

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12 See <http://www.pactworld.org>.

and treatment “hubs” linked to primary health-care facilities and community organizations as the “spokes” (Oyeledun et al., 2007). The Elizabeth Glaser Pediatric AIDS Foundation in Lesotho works in partnership with the Lesotho Network of AIDS Service Organizations, a national coordinating body for community and faith-based organizations, to promote PMTCT and other HIV activities throughout the country (Tiam et al., 2011). In both Nigeria and Lesotho, the work with community and faith-based organizations aims to provide seamless two-way referrals between facilities and communities and more holistic care for women and their families.

#### Box 17

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#### Leadership, policies and strategies to promote PMTCT and community engagement: Some lessons learnt

- ▶ High-level political leadership is an essential ingredient for successful community engagement and PMTCT scale-up. More effort is needed to generate sufficient political commitment in all countries working on the Global Plan.
  - ▶ The importance of community engagement for PMTCT scale-up is increasingly reflected in global funding and technical guidance. Continued work is needed to develop and assess conceptual models, frameworks and tools for effectively engaging communities in PMTCT scale-up.
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### *Community engagement and information management*

Information management around community engagement, including client-level documentation, reporting, monitoring and evaluation, is challenged by low literacy levels, dispersed populations, lack of infrastructure, confidentiality issues and the fluidity of community level activities. This section briefly discusses these issues and presents a few promising practices.

#### Client-level documentation

Front-line health workers who conduct outreach activities must keep track of their clients. These clients may be dispersed across wide areas that are far from the nearest health facility. Incorporating PMTCT information into mother and infant registers and hand-held cards is a common approach for client follow-up. Using this information for timely client follow-up and transfer to health facilities, however, is an ongoing challenge. To address these issues, several programmes have innovated with the use of mobile technology for patient follow-up, referrals and outreach supervision. Two examples are described here:

- ▶ A mobile patient-tracing programme for PMTCT was introduced through the Millennium Villages Project in the Sauri Cluster of Kenya and then replicated in Ghana. The system sends messages to community health workers to remind them of clinic visits for pregnant women and their babies up to 18 months of age, including early infant diagnosis and follow-up for babies who test positive for HIV. The system has significantly reduced the community health workers’ paper documentation requirements, saving them time each month for direct patient care activities. All pregnant women are included in the system, regardless of their HIV status, which is kept confidential throughout the process.<sup>13</sup> Anecdotal information indicates that antenatal care visits have increased since the introduction of this system. An effort to assess the first-year results of this initiative more formally is now under way in Kenya.

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13 See <http://www.childcount.org>.

- ▶ In a much dispersed area of Malawi where community health workers and clients have to travel long distances to health facilities, a solar-powered mobile phone system was introduced to coordinate and supervise outreach services. In 6 months, it is estimated that the programme saved the hospital staff 1200 hours of follow-up time and over US\$ 3000 in motorbike fuel. During this time, 1400 patient updates were processed via text messaging, saving front-line health workers 900 hours of travel time. With 75 community health workers, the programme cost US\$ 20 per community health worker to launch and can be sustained for less than US\$ 7 per community health worker per year (Nesbit & Smith, 2009).

## Monitoring and evaluation

Measuring community engagement and related health outcomes is complex. Commonly used, simple-to-measure indicators are inadequate to reflect the quality and dynamics of community engagement. For example, an indicator such as the number of community dialogues held reveals nothing about the nature and effect of those dialogues, and setting targets is a challenge. Would increasing the number of dialogues held lead to better outcomes? More relevant and informative indicators for community engagement are needed urgently.

For evaluation purposes, controlled studies that compare sites and clients with and without various community engagement practices are ideal, but they are often expensive and impractical. Moreover, community and faith-based organizations often have very limited capacity and resources to dedicate to reporting and monitoring and evaluation (M&E). As described in the example below, community and faith-based organizations can benefit from their engagement in efforts to improve M&E.

The Firelight Foundation, an international faith-based organization, worked with 43 community and faith-based organizations in Lesotho, Malawi and Zambia to improve their M&E practices. The approach was to train M&E facilitators to demystify M&E, while building the capacity of the local organizations through an experiential process. Community and faith-based organization participants developed their own data-collection tools and considered ways in which to apply this knowledge. Implementers report that this process led to improvements in confidence, programme management reporting and access to funding (Firelight Foundation, 2010).

### Box 18

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#### Information management: Some lessons learnt

- Innovations with mobile technology are showing promise in streamlining supervision and improving client-level data at the community level, including appointment tracking, follow-up and referrals for mother–infant pairs.
  - There is an urgent need for better indicators to measure and monitor the outcomes of efforts in community engagement.
  - Community engagement practices and outcomes can be enhanced by building the capacity of community and faith-based organizations in documentation, reporting and M&E.
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## OBSERVATIONS

In researching the promising practices in community engagement for PMTCT scale-up, several cross-cutting observations were made:

- ▶ **Community engagement is relevant and needed in all four prongs of PMTCT:** The need for community engagement in PMTCT scale-up was a guiding assumption of this review and was revalidated in the strength of the promising practices identified and results achieved. Community engagement should be viewed by all stakeholders as an integral feature of any comprehensive PMTCT programme.
- ▶ **Meaningful community engagement requires a capacity-building approach:** Community engagement is not a one-off event, but rather is a rights-based process that ultimately leads to greater empowerment. Governments, donors and other development partners should plan for sustained financial and technical investment in community engagement as part of their national plan towards the elimination of new HIV infections in children by 2015 and keeping their mothers alive.
- ▶ **Engaged leadership at all levels is an important key for success:** Whether at the clinic, community, district, national or global level, an engaged leadership will help to ensure the success of any PMTCT programme. Encouraging national-level leadership and the expression of this leadership in policies, strategies, frameworks and tools for greater community engagement will be vital to the way forward.
- ▶ **Community engagement requires sustained investment of financial and technical support:** The community engagement practices described in this report can be relatively inexpensive compared with externally driven interventions. Yet, the community aspects of programmes are often underresourced or overfunded to the point of discouraging local initiative. In planning national scale-up efforts, country teams should include locally appropriate budget levels and technical support for planned community engagement. As recommended in a study supported by UNICEF and World Vision, funding mechanisms and reporting requirements should be simplified for more efficient and effective management by community and faith-based organizations (Amoaten, 2011).
- ▶ **Effective community engagement requires a rights-based approach that empowers individuals and communities to take greater control of their health and health care:** Empowerment is both the end goal and the means for getting there. All community engagement strategies can be implemented in ways that are more or less empowering for the individuals and groups that they target. Programme implementation is more empowering when it actively involves beneficiaries right from the planning stage; when it adopts a participative management style; when it builds knowledge and skills; and when it transfers progressively increasing responsibility, control and accountability to its beneficiaries. Referring back to the conceptual model presented in Figure 1, governments, donors and implementing partners should strive to move from participation and mobilization to more empowering community engagement practices.

- ▶ **Meaningful involvement of networks of people living with HIV and communities will enhance PMTCT scale-up:** In most of the promising practices reviewed, people living with HIV – especially women – were actively engaged. Greater empowerment of women and men who are most affected by the HIV epidemic is an important priority for the success of PMTCT scale-up.
- ▶ **Pre-intervention participative research is an essential first step in the capacity-building process:** Effective community engagement demands an intimate knowledge of the local situation. Low-cost formative research – in the form of service mapping, surveys, focus group discussions, exit interviews or other methods – is necessary to ensure that interventions make sense in the local context. Engaging the target communities in the planning, conduct, analysis and dissemination of this research enriches the outcome and engenders local ownership of the programme.
- ▶ **Building on existing community structures improves programme efficiency and effectiveness:** Pre-intervention research helps to identify existing local resources, including ongoing community groups, networks and programmes. Building on these efforts, rather than setting up new or parallel structures, helps to ensure the community's acceptance of the interventions, reduces start up time, and enhances the potential for sustainability.
- ▶ **Exchange visits between community programmes can facilitate programme implementation:** From local community groups to national programme managers, exchange visits can provide an important means of sharing information and motivating for change. Programmes can encourage such visits as part of the scale-up process.
- ▶ **Monitoring, innovation and information sharing will be critical to the scale-up of promising practices in community engagement:** As countries work towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, programme M&E, information exchange and innovation will expedite progress. Front-line health workers, peer support and advocacy are not new strategies; however, learning continues and there is always room to improve. Further development of emerging strategies such as community-based monitoring and the use of mobile technology depends on effective monitoring and feedback to programme managers and supporters. It would be of great value to establish a dedicated Internet-based data bank and international forum for information exchange on community engagement experiences and promising practices in the scale-up of PMTCT.



## RECOMMENDATIONS

Attaining the elimination of new HIV infections among children and keeping their mothers alive is possible but will not be easy. Success will require the sustained engagement and unique inputs of various communities, from small informal groups at the grass-roots level to global coalitions. The good news, as reinforced through this review, is that implementers and experts already know and are implementing many effective community engagement strategies that are improving service uptake and achieving positive health outcomes. What remains is to share, strengthen and apply that knowledge while rapidly scaling up dedicated resources and community engagement programmes in support of PMTCT, HIV and maternal, neonatal and child health. The following suggestions are offered to facilitate not only achievement of the elimination of new HIV infections among children by 2015 and reduced maternal mortality, but also important broader benefits for women, families and communities.

### *Promising practices*

- ▶ **Expand and support the front-line health workforce for PMTCT scale-up:** Based on an extensive review of the evidence, the Global Community Health Worker Task Force has advised that expansion of the front-line health workforce will be essential for the attainment of health-related MDGs. The Task Force put forward a strong recommendation in 2011 to expand this workforce within national primary health-care systems to 1 million by 2015. Given the documented benefits of an extended front-line health workforce for PMTCT and maternal, neonatal and child health, this review strongly supports increasing the engagement of front-line health workers, including peers, as lay service providers in PMTCT scale-up. Front-line health workers should be selected with input from the community, remunerated in line with local standards, and trained and supervised as an integral part of the health-care team.
- ▶ **Increase engagement with community and faith-based organizations to support PMTCT scale-up:** Community and faith-based organizations are a highly prevalent resource and have been on the front line of the global HIV response since its inception. With a predominant focus on facility-based antiretroviral prophylaxis, most PMTCT programmes have yet to fully embrace this important source of support. Where community organizations have been engaged, they are supplementing public-sector PMTCT services; staffing the front-line health workforce; challenging gender, stigma and cultural norms that hinder PMTCT uptake; and providing psychosocial, material and other support to families affected by HIV. It is therefore recommended that (1) PMTCT implementers identify and collaborate with local community and faith-based organizations; (2) donors channel an increased share of financial and technical PMTCT resources to community and faith-based organizations on a sustained basis; and (3) governments promote the engagement and capacity development of community and faith-based organizations through their policies, guidelines and actions.
- ▶ **Bring accountability closer to the level of service provision:** Emerging evidence indicates that community-based monitoring can increase the uptake and quality of health services, ultimately improving health outcomes. National and local PMTCT programmes are encouraged to explore and pursue frameworks and mechanisms for community-based monitoring using a rights-based approach. Community charters, as recommended in the Global Plan, can be developed through a collaborative process engaging communities, health workers and local authorities to outline and monitor their respective commitments towards eliminating new HIV infections in children by 2015 and keeping their mothers alive.

- ▶ **Promote community-driven communication on PMTCT, sexual and reproductive health, and maternal, neonatal and child health:** The issues surrounding PMTCT, HIV, sexual and reproductive health, and maternal, neonatal and child health – including gender relations – are rooted deeply in culture and community. Communities are best positioned to identify, challenge and transform harmful practices and norms. Engaging communities in the design and delivery of social and behaviour change communication messages and approaches helps to ensure their relevance, resonance and impact. Governments, implementers and donors should invest in programmes that empower communities, including those that are especially vulnerable and hard to reach, through capacity development to lead communication efforts for PMTCT scale-up.
- ▶ **Engage people living with HIV to provide peer support in PMTCT programmes:** Peer support, in the form of individual counsellors such as mentor mothers or as provided through support groups, is a key element of many PMTCT programmes. Qualitative evidence suggests that peer support can improve self-esteem, encourage positive living and reduce stigma, including self-stigma. A few studies have found that peer support also improves PMTCT service uptake and compliance. In line with the greater involvement of people living with HIV, it is recommended that all PMTCT programmes engage peers in locally relevant and sensitive ways to facilitate scale-up. As is true for other front-line cadres, peers need to be supported practically through remuneration and with training and supervision. Peer programmes must also establish systems to monitor and reduce HIV-related stigma, including from other health-care workers.
- ▶ **Empower communities to maximize their assets and identify their own solutions for PMTCT scale-up:** Important assets for health exist in all communities. Programmes can benefit by supporting community members and groups to identify programme barriers, mobilize existing resources, and create their own local solutions. Factors in the success of this approach include providing communities with the relevant information, opportunity for constructive dialogue, and adequate seed resources and technical support to mount and sustain their responses.
- ▶ **Support community activism for improved and sustained political commitment to maternal, neonatal and child health and HIV, including PMTCT:** Community advocates and activists have had a role in shaping and advancing the HIV response since its inception. They have been an outspoken and effective voice for disenfranchised groups hit hard by the epidemic. Activism also played a role in inspiring the global commitment to eliminate new HIV infections in children by 2015 and keep their mothers alive. Even greater activism will be required to sustain the momentum and overcome various policy, resource and sociocultural constraints, especially at the national and local level. Investment in developing local advocacy skills and sustaining strategic activism may prove pivotal in global success.
- ▶ **Governments and their development partners should continue to enhance policies and strategies that promote community engagement in PMTCT and other health programmes:** Stakeholders at all levels are recognizing the importance of community engagement for PMTCT scale-up. More work is needed, however, to promote supportive policies and develop evidence-based frameworks, strategies and guidelines to improve the efficiency and effectiveness of community engagement efforts.

## *The evidence base*

- ▶ **Expand on this review to provide more guidance on community engagement in the scale-up of all four prongs of a comprehensive PMTCT programme:** This review covered a wide breadth of activities and strategies in community engagement for PMTCT scale-up. As a result, the depth of analysis on each practice – in terms of the context, process, results and lessons learnt – was limited. Also, promising practices around antiretroviral prophylaxis dominated in this review because of the historical focus of PMTCT programmes on prong three. More in-depth studies of the individual practices and more systematic reviews of relevant promising practices in primary HIV prevention, family planning, paediatric AIDS care and treatment, and maternal, neonatal and child health (including infant feeding) are recommended to generate additional insight and guidance for PMTCT scale-up.
- ▶ **Develop and share tools to facilitate decision-making and implementation of locally appropriate community engagement activities:** There is an urgent need for concrete tools to assist country teams in planning, implementing and evaluating their community engagement strategies and activities.
- ▶ **Develop better indicators for community engagement in PMTCT:** As discussed earlier, there is a pressing need for better indicators to describe and measure the process and results of the various community engagement practices.
- ▶ **Conduct more evaluation of community engagement practices, especially in terms of health outcomes:** Most of the evidence on community engagement in PMTCT scale-up can be classified as grey literature. Very few controlled studies or even programme evaluations have been done. Rapid and effective evaluation and operations research is needed to help identify and describe the characteristics of community engagement strategies that lead to improved health outcomes.
- ▶ **Cost analysis:** Very little information was found on the costs associated with community engagement. Guidance for donors and implementers would be strengthened greatly by more cost analysis, especially studies that compare the cost-effectiveness of different approaches to community engagement.

## *For country teams*

*The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive* encourages community engagement as an essential component of PMTCT scale-up. This review found several long-standing community engagement practices and some more recent innovations that show great promise in supporting PMTCT scale-up. In developing their national plans, country teams and their development partners are encouraged to:

- ▶ view and prioritize community engagement as an integral part of PMTCT scale-up;
- ▶ use a capacity development approach to direct increasing and sustained funding, and technical and organizational support to community aspects of PMTCT scale-up;
- ▶ adopt and adapt the promising practices shared in this review to suit the local context;
- ▶ examine existing community engagement activities through the participation, mobilization and empowerment lens and work to make them more empowering to the women, families and communities that they serve.

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