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# Second Road to Washington Meeting Advocacy and Best Practice Report

2-3 December 2011

Addis Regency Hotel, Addis Ababa,  
Ethiopia

## Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
CABA	Children Affected by AIDS
CBCHB	Cameroon Baptist Convention Health Board
CBO	Community Based Organisation
ECD	Early Childhood Development
HEID	HIV Early Infant Diagnosis
HIV	Human Immunodeficiency Virus
HRH	Human Resource for Health
HTC	Home Based Testing and Counselling
IEC	Information, Education, Communication
LENASO	Lesotho Network of AIDS Services Organizations
OVC	Orphans and Vulnerable Children
NGO	Non-Governmental Organisation
NSAs	Network Support Agents
NVP	Nevirapine
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PNC	Post Natal Care
PPTCT	Prevention of Parent to Child Transmission
RIATT	Regional Inter-Agency Task Team
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing

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## 1. INTRODUCTION

The Coalition for Children Affected by AIDS believes that children need to be made a higher priority in the international response to HIV and AIDS. The Coalition brings funders and technical experts together to advocate for the best policy, research, and programs for children because children are a vulnerable population that has too often been overlooked.

The Coalition for Children Affected by AIDS hosted the Road To Washington meeting series to bring researchers, policy makers, and practitioners together to explore how family-centred services, community support, and social protection can bolster and enhance the efforts to end mother-to-child transmission of HIV.

In industrialized countries, perinatal treatment for mothers and babies has nearly eliminated mother-to-child transmission of HIV. In resource-poor settings, however, hundreds of thousands of babies are still born with HIV every year because their mothers lack access to these life-saving services. The Coalition for Children is working in partnership with the global development community to address this outrageous disparity.

CCABA's three meetings on the *Road to Washington* are intended to assemble and explore what is currently being done to bring health and community systems together and identify what more can be done through partnerships with community groups, to minimize HIV transmission and improve the health and wellbeing of children affected by HIV and AIDS, their mothers and families by 2015. Meeting 1 took place in Geneva in May 2011, with the goal of understanding the concepts and issues involved, what is currently being done to reduce vertical transmission, identify the gaps between the community and health sectors and outline how family and community strengthening and social protection can help achieve the global PMTCT targets.

The *Road to Washington* will culminate in a symposium and/or satellite at the International AIDS Conference in Washington in July 2012, as well as being the principal focus of the CCABA pre-conference symposium. As with the 2009-2010 Road to Vienna series of meetings, which resulted in the publication of two special issues of journals (*AIDS Care* and the *Journal of the International AIDS Society*)<sup>1</sup>, the intention is to launch a special journal issue in Washington, together with an integrated document. In addition, CCABA will use all opportunities over the next year and a half to increase shared understanding of the opportunities and challenges to expand family and community participation in the campaign to end vertical transmission, to improve the health and wellbeing of children and families affected by HIV and AIDS and to insure that social protection measures, such as social transfers, are implemented in a way that encourages uptake and continuity in PMTCT services.

The second meeting, the subject of this report, was planned to specific issues for implementation and research. The third meeting, to be held in London in February

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<sup>1</sup> Please go to [http://www.ccaba.org/resources\\_children.html](http://www.ccaba.org/resources_children.html) to find the links to both of these Open Access journals

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2012, will plan for action based on the findings of the first two meetings, and on other initiatives being undertaken by partners.

This two day meeting in Addis involved a diverse group of stakeholders from Community Based Organisations (CBOs), national government departments, national and international NGOs, donors and multilateral agencies, private funders and academics convened by The Coalition in partnership with the Global Fund, UNAIDS, RIATT, and UNICEF took place from 2-3 December 2011 in Addis Ababa, Ethiopia.

During the meeting, time was dedicated to discussing frameworks developed to support the articulation of the community response in area of Preventing Mother to Child Transmission (PMTCT). In addition time was dedicated to the sharing of best practices from community-based projects to identify key components of community engagement to end vertical transmission.

This document, bringing to the fore as it does key messages and best practices as shared by practitioners working in communities, is intended to support advocacy around the critical importance of community engagement and to provide practical guidance for those both implementing PMTCT services and supporting those programmes.

## **2. PMTCT AND THE COMMUNITY ENGAGEMENT IMPERATIVE**

The prevention of mother-to-child transmission of HIV has been a priority area in the global response to HIV since 1998 with the success of short-term and single dose clinical drug trials<sup>2</sup>. Over the last decade increasing attention has been directed towards other effective responses particularly within high burden resource-constrained contexts. The global commitment to PMTCT is the most significant to children and families since the start of the epidemic<sup>3</sup>. Given The Coalition's focus on children, this commitment is ripe with possibilities.

### **So what are the goals of PMTCT programmes?**

Globally there is great momentum around ending vertical transmission with a number of international frameworks and plans setting out targets to achieve this. The Political Declaration on HIV/AIDS agreed at the High Level Meeting in June 2011 committed to: "working towards the elimination of mother-to-child transmission of HIV by 2015 and substantially reducing AIDS-related maternal deaths."<sup>4</sup> The UNAIDS target for the PMTCT agenda is the elimination of mother to child transmission by 2015 and to substantially reduce AIDS-related maternal deaths<sup>5</sup>.

#### **KEY MESSAGE:**

**The significant global commitment to PMTCT is alive with possibilities for The Coalition and others committed to the wellbeing of children and families.**

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<sup>2</sup> WHO Strategic Vision

<sup>3</sup> As stressed by Professor Linda Richter in an opening presentation during The Coalition's meeting

<sup>4</sup> UN (2011), Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS, A/RES/65/277, 10 June 2011

<sup>5</sup> UNAIDS (2012) Global AIDS response progress reporting 2012

The overall targets of the Global Plan<sup>6</sup> towards the elimination of new infections among children by 2015 and keeping their mothers alive are:

- A reduction in the number of new infections among children by 90%; and
- A reduction in the number of maternal AIDS related deaths by 50%.

From the perspective of community-based organisations, what defines a successful PMTCT programmes is amongst others:

- The prevention of unplanned and unwanted pregnancies in HIV+ women;
- The number of pregnant women who test negative and remain negative antenatal and postpartum;
- Identifying HIV+ pregnant women;
- The number of HIV pregnant women initiated on ARV prophylaxis and ART;
- The number of HIV-exposed infants who test negative at 6 weeks; and
- The number of HIV-exposed infants who are alive and test negative at 18 months.

### **What's required to achieve these goals?**

The Global Plan directs attention to the 4 prongs of PMTCT<sup>7</sup> a package of interventions which must be implemented simultaneously to achieve these goals.

**Prong 1:** Primary 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 to women living with HIV to enable them make an informed decision about their future reproductive life, with special attention to preventing unintended pregnancies.

**Prong 3:** For pregnant women living with HIV, ensure HIV testing and access to the antiretroviral drugs that will help mothers' own health and prevent infection being passed on to their babies during pregnancy, delivery and breastfeeding.

**Prong 4:** Better integration of HIV care, treatment and support for women found to be positive and their families.

#### **KEY MESSAGE:**

The 4 prong strategy provides a vision of integrated family-centred care across the lifecycle. Reaching the goal of reducing the number of children newly infected with HIV by 90% requires concerted action on all four prongs.

In essence the 4 pronged strategy presents a vision of integrated, family-centred prevention, treatment and care across the lifecycle. All four prongs are required to

<sup>6</sup> UNAIDS (2011) Global Plan towards the elimination of new infections among children by 2015 and keeping their mothers alive

<sup>7</sup> WHO (2007) *Guidance on Global Scale-Up of the Prevention of Mother-to-Child Transmission of HIV: Towards Universal Access for Women, Infants and Young Children and Eliminating HIV and AIDS among Children*

reach the aspirational PMTCT targets which have been set. It is impossible to achieve the four prongs without the involvement of the community.

An effective and comprehensive response involves various elements all working together to achieve health outcomes.



**Fig 1. HIV Treatment Cascade**

Numerous advances have been achieved across this cascade. We know more and we are doing better. So much has been achieved and yet much remains to be done.

### **PMTCT in Africa: What gets in the way of an effective response?**

Significant progress has been made in high resource countries to eliminate the existence of paediatric AIDS; however, a very different situation exists in Africa.

The number of new infections among children that took place in three hours in sub-Saharan Africa in 2010 (120) was greater than the total new infections of children in western and central Europe (<100) for the entire year. By 2010, only 48% of pregnant women with HIV were receiving antiretrovirals for PMTCT<sup>8</sup>. Significant disparities also exist between rich and poor women in terms of access to integrated PMTCT services. In fact access to such services can be viewed as a “barometer of inequality”.

Implementation challenges exist:

- Too many:
  - women are not reached
  - women and children are not followed up and treated
  - male partners and children are not tested
  - families are without support
  - opportunities for testing and treatment of women and children and follow-up of families are missed.

#### **KEY MESSAGE:**

Reducing transmission requires high levels of participation every step of the way. In Africa implementation challenges are undermining access to the required cascade of services.

The critical pathway of interventions for PMTCT is often referred to as a cascade which ensures that all services from counselling, testing, initiation of ARVs, early infant testing and ART are delivered in full to all clients and their infants. However within many

<sup>8</sup> WHO,UNAIDS, UNICEF (2011) Global HIV/AIDS response: epidemic update and health sector progress towards universal access: progress report 2011.

contexts there is huge attrition along this pathway that it has become more akin to a funnel with only a fraction of the number of individuals initiated into PMTCT programmes receiving the full set of interventions.

Reducing transmission requires high levels of participation every step of the way; a cascade of services rather than a funnel is imperative.

### **The role of communities**

While guidance on community engagement specific to PMTCT has been limited, efforts have been made to address the situation. The UNAIDS' Global Plan for example specifies roles for civil society and communities and their accountability actions.

According to the Global Plan, some of these roles include:

- Develop and implement community charters and accountability structures and hold government and others accountable;
- Participate in design and implementation including monitoring and accountability;
- Ensure the participation of all stakeholders;
- Ensure that all community resources and assets are engaged;
- Provide leadership, innovation and assets;
- Unify global, regional, national civil society and activists groups in their advocacy.

Other roles that have also been identified include:

- Challenging inequity and assisting with redress;
- Advocating for comprehensive, equitable quality services;
- Demanding the testing and expansion of promising practices;
- Improving community knowledge and norms;
- Helping marginalised groups access services;
- Providing support to women and children to enable them to:
  - access services
  - adhere to prevention and treatment
  - return for follow up
- Protecting marginalised groups from victimization;
- Offering companionship;
- Providing accompaniment;
- Helping with disclosure;
- Supporting retention in treatment;
- Contributing to family planning;
- Promoting child health and development.

## The significance of community engagement including the OVC community in PMTCT

Community Based Organisations (including those providing care and support to OVC) have a range of strengths and potential opportunities to advancing the PMTCT agenda.

- They are a massive “workforce” committed to the wellbeing of children
- Many are trained and organised
- They have the trust and endorsement of communities
- As extensive networks with deep penetration in communities they have contacts and reach into the community
- They tend to offer support from the perspective of community needs rather than narrow programming goals; this tends to make their response more holistic
- They visit homes initiating uptake of services and following up on clients
- They are family-centred and work holistically and with families on behalf of children identifying individuals for referrals
- They are networked

### KEY MESSAGES:

- Communities have a central role to play in the attainment of set targets.
- Community-based organisations have some important qualities and characteristics that should be leveraged in PMTCT.
- The role of the OVC community has not yet been recognised. It has been sidelined, siloed, silent and cut off from various elements of the HIV treatment cascade.

### 3. ORGANISING FRAMEWORKS

There are several frameworks that can be useful for considering the promising or best practices that are emerging from community organisations involved in supporting national PMTCT programmes.

These frameworks can:

- clarify what is meant by community engagement;
- help to situate the various community responses that are required and on offer;
- map the extent of services being supported by community groups;
- highlight gaps in the response; and
- assist CBOs to contextualise their interventions (i.e. by identifying the levels at which constraints or barriers exist).

#### A Spectrum of Community Engagement

Communities can help governments to achieve the aspirational targets. What is meant by community engagement can be explained by considering different degrees of involvement as depicted below:

Fig 2. Spectrum of Community Engagement in draft UNAIDS paper

# Spectrum of Community Engagement

PARTICIPATION	MOBILISATION	EMPOWERMENT
Male involvement Support groups Family-centred care Campaigns	Community Cadres Peer Support Linking with CBOs	Leadership Monitoring Advocacy

- **Participation** involves communities as passive or active recipients of health services, including demand creation and awareness about entitlements to services.
- **Mobilisation** engages communities in health programmes through direction or facilitation by health professionals.
- **Empowerment** engenders community ownership, leadership and accountability for health and health care. Communities are engaged through a capacity building process to plan, implement and/or evaluate activities on a sustained basis to improve their health.

## UNAIDS Community Engagement by Intended Outcome

Community engagement practices can also be categorised according to intended outcomes as does UNAIDS in Figure 3.<sup>9</sup>

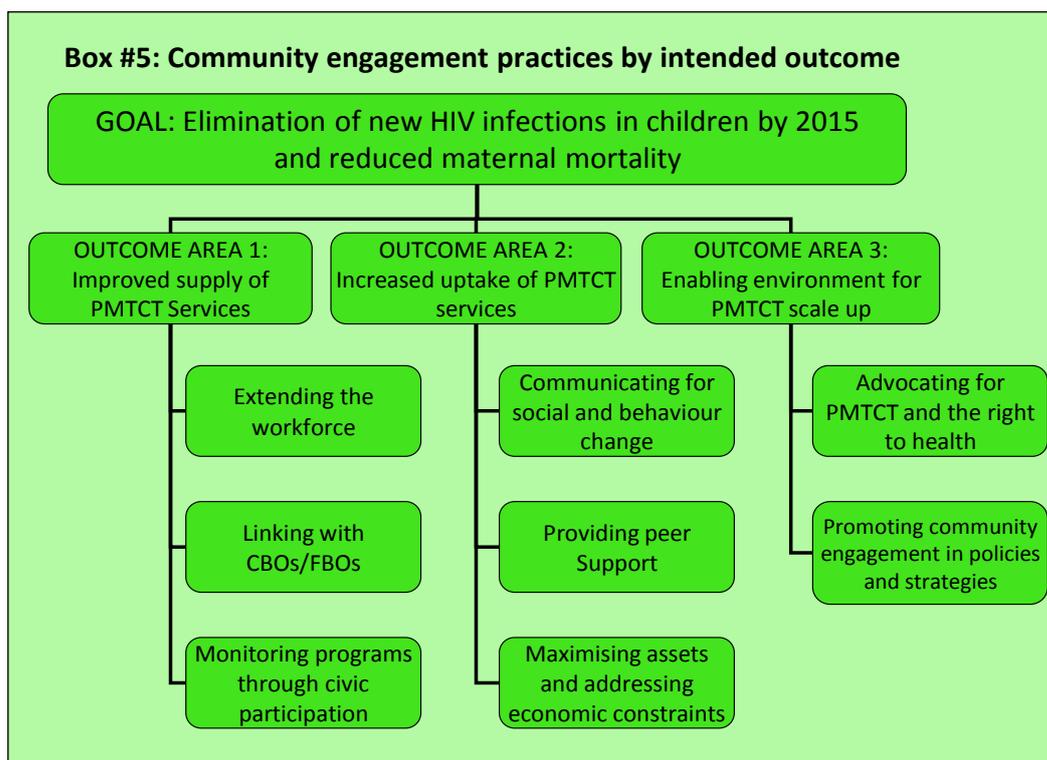


Fig. 3 Community Engagement Practices by Intended Outcomes

## The social ecological model:

<sup>9</sup> Draft UNAIDS research on promising practice on community engagement for PMTCT  
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Finally the socio-ecological framework outlined in Figure 4 is useful to:

- Conceptually organise community responses according to the various levels which a comprehensive response would need to target;
- Broadly identify gaps in the response;
- Ensure that programmers consider the enabling and constraining factors that might exist in a local community at the various levels.

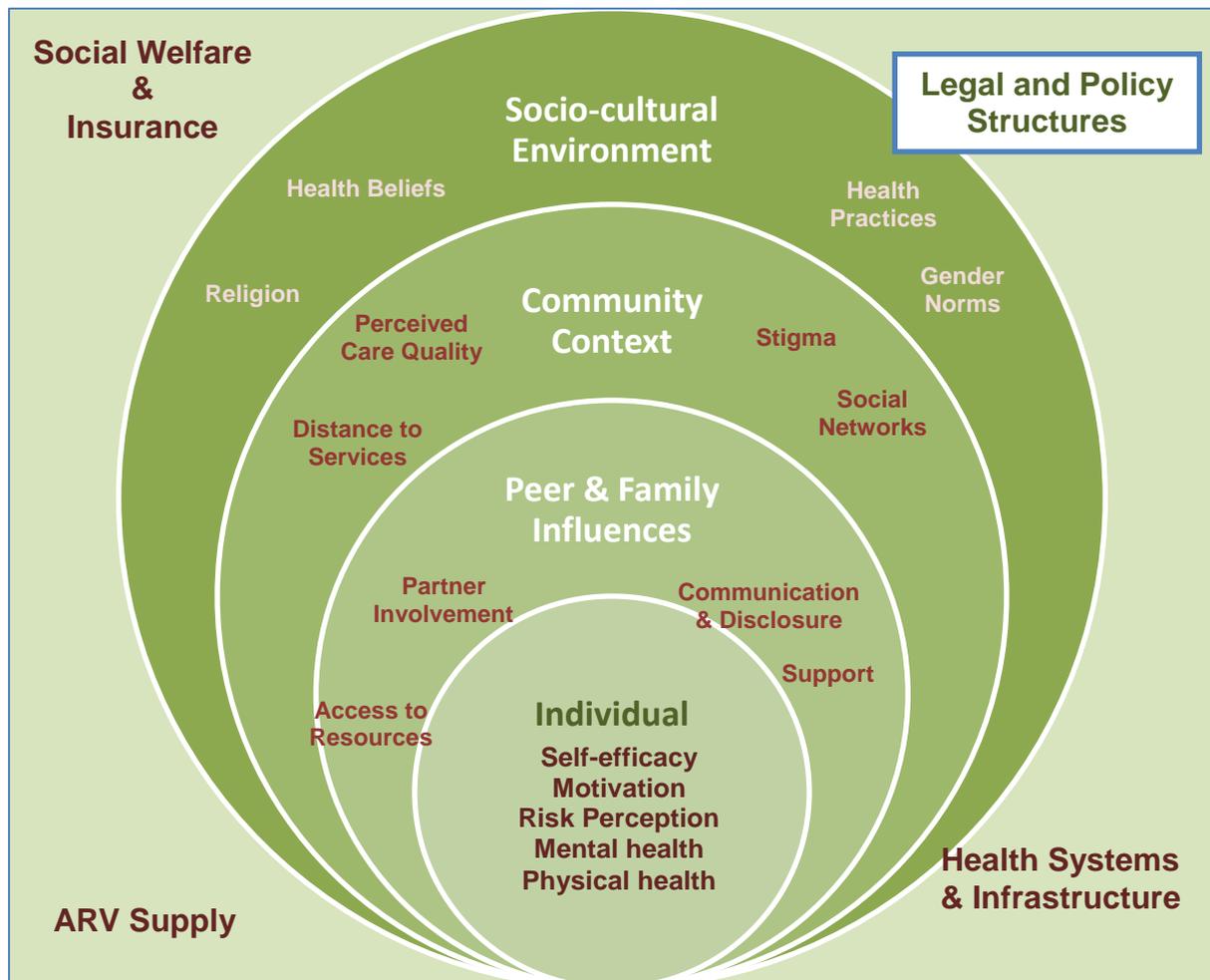


Fig 4. Applying the Social Ecological model to community based approaches<sup>10</sup>

An additional lens for assessing the contribution of Community Based Organisations is to assess them according to a set of organisational criteria such as:

- Skills and Capacity;
- Resources;
- Reach;
- Coordination;
- Integration with existing health structures;

<sup>10</sup> Busza, J. (2011) "Community based approaches: A review of intervention models and evidence of their effectiveness for preventing maternal-to-child transmission of HIV" Second Road to Washington Meeting Presentation  
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- Spectrum of services;
- Partnerships;
- Involvement;
- Accountability.

#### **4. BEST PRACTICES AND PRACTICAL GUIDANCE**

In this section of the document the best practices offered by community based organisations is summarised. These best practices are organised according to some general principles for PMTCT, and then according to outcome areas. In addition practical guidance is offered on the topics including Social Protection, the 4<sup>th</sup> Prong, Male Involvement, and social barriers, structural barriers and norms.

##### **4.1. General/Cross-Cutting Principles**

A set of guidelines or principles for community based PMTCT programmes emerged during The Coalition's second Road to Washington meeting.

These include:

1. The contextualisation of approaches
  - a. Working with people as contextualised beings (in relationships, in families, and in communities)- see Figure 4
  - b. Seeking to address the barriers to PMTCT that emerge in each context)
  - c. Using social and cultural events to promote PMTCT uptake
2. Having broad programme goals that reflect community needs and extend beyond the confines of health outcomes
3. Holistic and developmental care models
4. Comprehensive approaches
5. Family-based approaches
6. Building links between communities and health facilities, between line departments and NGOS, and between community groups

##### **Case Study: BWAFFANO COMMUNITY HOME BASED CARE, ZAMBIA**

A case study that powerfully illustrates almost all of these principles is provided by BWAFFANO Community Home Based Care in Zambia.

**Family-Based:** Operating primarily at the level of families, the organisation strives to meet the HIV, MNCH and social support needs of mothers and children.

**A linked up, comprehensive approach:** Client identification is a significant part of the intervention and HIV + mothers are identified through HTC (Home-Based Testing and Counselling), Prevention of Parent To Child Transmission and Home Based Care. Enrolment into the HBC programme facilitates follow-up. The follow up of baby/mother Second Road to Washington Meeting 2-3 December, Addis Ababa Advocacy and Best Practice Document

pairs takes place at both community and health facility level through Maternal and Child Health as well as Home Based Care.

**Holistic and Developmental:** This follow up includes clinical care, post-natal PPTCT, follow up care, immunization and growth monitoring. Mothers receive nutrition counselling and food supplements, especially for weaning of babies. PPTCT mothers are provided with income generation skills training. The focus of attention does not end as the babies mature. Children are enrolled into the Early Child Development (ECD) Programme between the ages of 4 and 6 years; the programme currently has a total of 150 children. Children are then entered into primary school at the age of 7 and the organisation has supported 650 children to enter primary school and 2000 have been sent to upper primary and secondary school. The organisation continues to support OVC in government schools. The children access nutrition support in the form of two meals a day. They also access health promotion and curative services, psychosocial support, and occasional shelter.

**Building links:** Community partnerships such as with the Habitat Zambia partnership widens the range of support provided. Older OVC are provided with skills training to facilitate their transition into gainful employment or Income Generating Activities. While the programme focuses on mothers and children, men are not overlooked and participate actively in the Home-Based Care Programme.

The organisation has seen the benefits of an integrated and comprehensive service. These include:

- Reduction in the mortality rate of the cohort;
- Low HIV rates among children born of HIV+ mothers;
- Very low treatment defaulter rates;
- High retention in care and support programmes because of the one-stop shop approach (which means they do not have to be referred elsewhere);
- Improved adherence to treatment by mothers and children due to paediatric ART support groups and follow ups by trained community volunteers;
- Improved access to basic child services including education;
- Stigma and discrimination tackled early in the paediatric support groups.

### **Case Study: MAMA+, Russia**

Another exemplary example is the Russian HealthRight Programme MAMA+.

**Comprehensive and Family-Based:** The programme offers a comprehensive model of assistance to HIV-affected families. The model includes several components including early identification, outreach and home visits, MAMA+ Day-care Centre and a MAMA+ shelter. Those on the programme are offered psychosocial counselling; training on HIV and parenting skills; client training; vocational counselling; substitution therapy; access to welfare support and peer support groups for women, partners, grandparents; day-care for children; and residential services for homeless women and victims of domestic abuse. Services are provided by a professional team of lawyers, psychologists, social workers, medical personnel, educators and peer counsellors.

## **Case Study: Millennium Villages Project, Tanzania**

**Building Links:** With the aim of increasing uptake, accessibility and quality of comprehensive PMTCT services, the project strategically forged a strong collaboration with central and local government, other government systems, and NGOs. This forum served a number of purposes: resource mobilisation; accessing human resources for health capacity building; strengthening referral and feedback systems; sharing best practices; joint supportive supervision; and enabling the integration of innovative strategies and advocacy for community support and scaling up of sustainable interventions. These strategic partnerships achieved some notable results: improved health facility infrastructure; improved Human Resource capacity; improved supply chain management; timely operationalization of new PMTCT information; increase in number care and support treatment clinics, significant increase in enrolment of new HIV clients, male 100% increase in male involvement over a year, doubling of Family Planning uptake and improved PMTCT programme retention.

## 4.2. Improving Supply of PMTCT Services

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	CASE STUDIES AND OTHER REFERENCES OF VALUE
IMPROVED SUPPLY OF PMTCT SERVICES			
1. Extending the Workforce a. Reaching out)	<p>Engage and empower communities as frontline health workers (Community Health Workers, Network Support Agents, mentor mothers, adherence counsellors, traditional birth attendants, linkage nurses or peer educators)to:</p> <ul style="list-style-type: none"> <li>• Strengthen links between communities and health facilities</li> <li>• Offer companionship and support</li> <li>• Access and serve remote communities</li> <li>• To identify barriers uptake of PMTCT (and often through being role models themselves as PLHIV play a part in addressing these)</li> <li>• Increase uptake of prophylaxis, CD4 testing and enrolment in care, Community sensitization and service across the spectrum of care</li> </ul>	<ul style="list-style-type: none"> <li>• Extremely important to build on resources that already exist in communities</li> <li>• Formalised links improve facility “friendliness and support”, improve relationships but no evidence that they address barriers</li> <li>• Extended workforce should preferably be anchored within a primary health care system that supports task sharing</li> <li>• Remuneration is necessary (and it might be preferable to rename volunteers to “community health workers” or something which does not suggest unpaid labour</li> <li>• It is important not to lose sight of the inspirational individuals who serve their communities despite their own economic plight</li> <li>• Training offered should be functional</li> <li>• Works best where communities have a say in the process</li> <li>• May need specialised frontline workers (e.g. PMTCT and</li> </ul>	<ul style="list-style-type: none"> <li>• BWAFFANO Community Home Based Care, Zambia</li> <li>• Nyimbwa Multipurpose Self-Help Group, Uganda</li> <li>• LEPR, India</li> <li>• Cameroon Baptist Convention Health Board</li> <li>• Millennium Villages Project, Tanzania</li> <li>• Kenya Network of Women with AIDS – KENWA; Southern Sudan Network of women with AIDS</li> </ul>

		<p>MNCH)</p> <ul style="list-style-type: none"> <li>Traditional Birth Attendants appear to be under-utilised</li> </ul>	
<b>TOPIC</b>	<b>BEST PRACTICES</b>	<b>LESSONS LEARNED/GUIDANCE OFFERED</b>	<b>CASE STUDIES AND OTHER REFERENCES OF VALUE</b>
<b>IMPROVED SUPPLY OF PMTCT SERVICES</b>			
1. Extending the Workforce b. Referring Back	<ul style="list-style-type: none"> <li>Expand role of frontline health workers to include PMTCT referrals</li> <li>Empowerment of PLHIV in role of CHWs or NSAs to conduct follow up of women in communities and ensure referral back to clinics</li> <li>Use linkage nurses and peer educators for follow up after VCT</li> </ul>		<ul style="list-style-type: none"> <li>BWAFANO Community Home Based Care, Zambia</li> <li>Nyimbwa Multipurpose Self-Help Group, Uganda</li> <li>Cameroon Baptist Convention Health Board</li> <li>Millennium Villages Project</li> </ul>
2. Linkages, Networking and Partnerships	<ul style="list-style-type: none"> <li>Public-private partnerships to maximise resources</li> </ul>		BWAFWANO
	<ul style="list-style-type: none"> <li>Link clients to other CBOS and NGOS to broaden service offering and facilitate referrals</li> <li>Link with government and other organisations to leverage different capacity</li> </ul>		<ul style="list-style-type: none"> <li>LEPRA, India</li> <li>BWAFANO Community Home Based Care, Zambia</li> <li>TAC, South Africa</li> <li>Millennium Villages Project, Tanzania</li> </ul>
	<ul style="list-style-type: none"> <li>Forge links with other community structures such as women's forums to offer support to those in ante- and post-natal care services.</li> </ul>		LEPRA, India

3. One-stop shop approach to service provision	<ul style="list-style-type: none"> <li>• Use of multidisciplinary teams that address range of family issues (mother and child services)</li> <li>• Integrated services across HIV, TB and Malaria</li> </ul>		MAMA+, Russia CARE, Cameroon
<b>TOPIC</b>	<b>BEST PRACTICES</b>	<b>LESSONS LEARNED/GUIDANCE OFFERED</b>	<b>CASE STUDIES AND OTHER REFERENCES OF VALUE</b>
<b>IMPROVED SUPPLY OF PMTCT SERVICES</b>			
Promoting organisational performance/service	<ul style="list-style-type: none"> <li>• Establishment of organisationally incentivised performance measures for health centres and CBOS</li> </ul>	<ul style="list-style-type: none"> <li>• Incentives might include extension of training/capacity building partnership offered to health facility</li> </ul>	CARE, Cameroon.
	<ul style="list-style-type: none"> <li>• Adoption of a case management approach with specific steps and documentation throughout the case from first contact to needs assessment, case management plan, implementation and review</li> </ul>	<ul style="list-style-type: none"> <li>• Ideally supported by a multidisciplinary team approach</li> </ul>	MAMA+, Russia
	<ul style="list-style-type: none"> <li>• Documentation and endorsement of best practice models by government</li> </ul>		MAMA+, Russia
Addressing social barriers (provider/service related)	<ul style="list-style-type: none"> <li>• Strategies or approaches that overcome socio-economic barriers to accessing services: Mobile clinics; Outreach, Home Based Services`</li> <li>• Involve Community Health Committees</li> <li>• Introduce Performance-based incentives e.g. access to training (link to levels of customer satisfaction)</li> <li>• Staff supervision and training to overcome prejudicial attitudes</li> <li>• Integration and comprehensive</li> </ul>	<ul style="list-style-type: none"> <li>• Community based and home testing increases: <ul style="list-style-type: none"> <li>○ opportunity to test;</li> <li>○ introduces perception of risk;</li> <li>○ engages family as a unit</li> <li>○ HIV case finding but does not increase diagnosis of HIV+ pregnant women, who attend stand-alone clinics</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Etafeni Day Care Centre Trust</li> <li>• CARE, Cameroon</li> <li>• Millennium Villages Project, Tanzania</li> <li>• Joanna Busza Meeting Presentation</li> </ul>

	<p>one-stop services (e.g. mobile services VCT, care &amp; treatment, HPV vac., TB, cervical cancer screen)</p> <ul style="list-style-type: none"> <li>• Strengthening existing services at an institutional level (including the provision of the necessary equipment – health systems strengthening)</li> <li>• Involve community in M&amp;E of services</li> </ul>		
<b>TOPIC</b>	<b>BEST PRACTICES</b>	<b>LESSONS LEARNED/GUIDANCE OFFERED</b>	<b>CASE STUDIES AND OTHER REFERENCES OF VALUE</b>
IMPROVED SUPPLY OF PMTCT SERVICES			
4 <sup>th</sup> Prong Programming (Better integration of HIV care, treatment and support for women found to be positive and their families)	<ul style="list-style-type: none"> <li>• Integrated, comprehensive services</li> <li>• Holistic life-cycle care model for mother and child (including ECD)</li> <li>• Adoption of a non-medical model</li> </ul>		<ul style="list-style-type: none"> <li>• Etafeni Day Care Centre Trust, South Africa</li> <li>• BWAFFANO, Zambia</li> </ul>
	<ul style="list-style-type: none"> <li>• Community based approach</li> <li>• Family-based approach</li> </ul>		<ul style="list-style-type: none"> <li>• Etafeni Day Care Centre Trust, South Africa</li> <li>• BWAFFANO, Zambia</li> </ul>
	<ul style="list-style-type: none"> <li>• Creating a welcoming and enabling environment for expectant mothers)</li> </ul>		<ul style="list-style-type: none"> <li>• Etafeni Day Care Centre Trust, South Africa</li> </ul>
	<ul style="list-style-type: none"> <li>• Use of innovative communication technology/infrastructure for information dissemination to support mothers</li> </ul>		SMS Masi Project South Africa

	<ul style="list-style-type: none"> <li>Routine testing at six weeks and beyond</li> </ul>		Nigel Rollins paper " <i>HIV Surveillance of mother-to-child transmission prevention programmes at immunization clinics: the case for universal screening AIDS 2007, 21:1341-1347</i>
	<ul style="list-style-type: none"> <li>Keeping contact with mothers and babies, following up and referring back to services</li> </ul>		The Teresa Group
	<ul style="list-style-type: none"> <li>Advocacy/voice for parenting and HIV</li> </ul>		TAC, South Africa
		<ul style="list-style-type: none"> <li>Mobilise additional support and resources beyond testing Prong 4 is often forgotten especially in cases where success is seen as reduction in transmission rather than on healthy babies and mothers 4<sup>th</sup> prong should address children that have been exposed to HIV and not just those who have been infected</li> </ul>	Zimbabwean article on level of untested children/living with HIV that is undiagnosed (Linda Richter)
		<ul style="list-style-type: none"> <li>Home based testing is successful and includes children but is not sufficient.</li> </ul>	<ul style="list-style-type: none"> <li>Kenya and Uganda</li> </ul>
		<ul style="list-style-type: none"> <li>CBOs have a role to play in increasing an understanding of the barriers to testing so that they can be addressed. Commonly found support clubs for mothers and babies should include HIV element</li> </ul>	<ul style="list-style-type: none"> <li>Best Practice Guide from Women and Children First, Bangladesh provides model that could be adapted to support this integration.</li> </ul>

		<ul style="list-style-type: none"> <li>• More examples of support groups for parents and children within PLHIV networks are needed</li> </ul>	
		<ul style="list-style-type: none"> <li>• Community organisations should create demand for treatment but in its absence create demand for other services for children exposed and infected (e.g. Cotrimoxazole, palliative care)</li> </ul>	<ul style="list-style-type: none"> <li>• India national advocacy campaign to increase access and demand for co-trimoxazole for HIV exposed infants: LEPR</li> </ul>
		<ul style="list-style-type: none"> <li>• CBOs can play an important role in addressing confusion around breastfeeding and to contextualise the breastfeeding guidance</li> <li>• Consider breastfeeding support beyond the recommendations and address barriers to optimal feeding (e.g. financial costs, pressure from relatives, disclosure expectations, fear of infection, guilt).</li> </ul>	<ul style="list-style-type: none"> <li>• Etafeni Day Care Centre Trust, South Africa</li> </ul>
		<ul style="list-style-type: none"> <li>• Parental depression, anxiety and stress are a reality for parents affected by HIV that can impact on the care-giving environment. Address mental health issues.</li> </ul>	
		<ul style="list-style-type: none"> <li>• Facilitate awareness of the importance of ECD in the early years and address barriers to communication and good</li> </ul>	

		parenting through companionship - frontline workers	
		<ul style="list-style-type: none"> <li>• Link demand created for ECD services to care and support services for CABA.</li> <li>• Link children in ECD programmes post PMTCT interventions to traditional care and support programmes.</li> </ul>	

## **Case Study: Etafeni Day Care Centre Trust**

**Family and Community-Based:** Etafeni's interventions are located at the family and community levels. The Trust works to offer holistic sustainable community-based care for AIDS-affected and vulnerable children and their caregivers. It is through a multi-purpose day care centre in the community that the Trust aims to take into account the needs of vulnerable children, those who care for them and the needs of the community who will, of necessity, be their safety net.

**Warm and Enabling Environment:** Etafeni relies on its staff and its physical structures to support the gradual growth of trust, creativity and enjoyment of self and others. Emphasis is placed on ensuring that women with a positive diagnosis that enter the Centre experience a warm, welcoming and enabling environment.

**Holistic, life-cycle approach:** The programme works with pregnant mothers through the ANC and PNC processes. This entails aiming to address the needs of the person from birth through the different stages. Working from an attachment model which is cognisant of the disrupted childhoods and traumatic loss of the AIDS-affected child,

**Comprehensive:** One-on-one counselling, the companionship of other healthy HIV + women, be supported through PMTCT to have a healthy baby and receive support when the baby is tested, but also education and skills training for economic empowerment. In addition there is nutritional and health care support, and a breastfeeding programme. Mothers are helped to become positive parents. Children are supported through an ECD programme, and an Afterschool Care programme.

**Non-medical:** In an effort to normalise HIV and also get services to the community use is made of mobile VCT and TB screening outside of a clinic or institutional environment. The programme strives instead to address the social, emotional, psychological and economic issues that confront the people who access the Etafeni programme.

## **Case Study: CARE Cameroon**

**Comprehensive and Family and Community Based:** CARE, through its Garoua Urban Health Project, seeks to contribute to the improvement of maternal and child health. To this end it focuses on a range of services oriented towards malaria prevention and treatment, HIV & AIDS including PMTCT, family planning and sexual and reproductive health. Its primary target groups are pregnant and other women of childbearing age and their sexual partners. The project includes a number of partners including the health districts, women's, men's and youth groups, a regional CBO with the role of coordination being a shared function between two of the organisations.

The project has focused on community and health systems strengthening which has included capacity building for both CBOs and the health system both organisationally and technically. The health systems that were included were those located in closest proximity to the target population. In addition to the training and capacity building ICT equipment was provided, as was equipment to ensure safe deliveries and improve lab capacity.

**Integrated:** The programme uses an integrated approach which is HIV-sensitive not HIV-specific. As a result of the fact that the services offered by trained community health care workers included not only HIV & AIDS focused services but also malaria, SRH and family planning and home-based care, stigma was averted and access to households was facilitated.

**Contextualised:** Given the contextual constraints, particularly that men in the area prevented their wives from accessing PMTCT services, men's groups were used in a great deal of advocacy and sensitization of men about the importance of women accessing health services. Given that some men were reluctant for their wives to travel to the clinic the programme initiated a mobile clinic involving the health centre and CHWs to bring services closer to the community. These mobile clinics were responsible for more than 40% of the uptake of the services offered.

**Civic Engagement in Monitoring Services and the Promotion of Accountability and Service:** The innovative approach of performance-based assistance saw continued programme support only being offered to those CBOs or health centres that had high levels of client satisfaction. Additional support beyond the initial capacity building was also conditional on satisfactory achievement of a set of objectives.

### 4.3. Increased Uptake of PMTCT Services

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	REFERENCES OF VALUE
<b>INCREASED UPTAKE OF PMTCT SERVICES</b>			
1. Social and behaviour change communication programmes and approaches	<ul style="list-style-type: none"> <li>Utilisation of community-led participatory approaches from the ground- up that engage communities (drama, community conversations, community problem-solving processes)</li> </ul>	<ul style="list-style-type: none"> <li>Community-led Social and Behaviour Change Communication (SBCC) programmes can be effective in increasing participation and retention</li> <li>Formative research is however important to assess this</li> <li>Communication agents may need compensation</li> <li>Health facilities should be prepared to meet the demand created</li> </ul>	<ul style="list-style-type: none"> <li>Kenya Network of Women with AIDS –KENWA; Southern Sudan Network of women with AIDS</li> <li>ANOPA+, Ethiopia</li> <li>Men Taking Action, Zambia</li> </ul>
	<ul style="list-style-type: none"> <li>Utilisation of community role models (CHWs, Cluster Change Champions village health committees, religious and local community leaders, other influential people &amp; PLHIV expert clients) to promote services</li> </ul>		<ul style="list-style-type: none"> <li>Millennium Villages Project, Tanzania</li> </ul>
	<ul style="list-style-type: none"> <li>Empowerment of key stakeholder groups and community members including PLHIV to become active agents of change and the promoters of behaviour change</li> </ul>		<ul style="list-style-type: none"> <li>LEPRA, India</li> <li>CMMB, Zambia</li> <li>Bwafana Community HBC</li> <li>Nyimbwa Multipurpose Self-Help Group, Uganda</li> </ul>

	<ul style="list-style-type: none"> <li>• Positive messaging by role models &amp; through social and cultural events which show positive outcomes and rupture misperceptions</li> </ul>		LEPRA, India
2. Peer Support	<ul style="list-style-type: none"> <li>• Mentor mothers</li> <li>• Companionship</li> <li>• Follow up and tracking of defaulters</li> <li>• Role-modelling by PLHIV and service providers (e.g. doctors helping other doctors overcome their fear of offering C-sections to HIV + women).</li> <li>• Peer counselling</li> </ul>	<ul style="list-style-type: none"> <li>• Important to provide sufficient training and on-going supervision</li> <li>• Assuming the role of mentor can be empowering in terms of: <ul style="list-style-type: none"> <li>○ Having a title (mentor)</li> <li>○ Working and earning money</li> <li>○ Being seen as a leader in their community</li> <li>○ Being able to be supported through their own process of disclosure</li> </ul> </li> <li>• Evidence suggests that peer counselling results in: <ul style="list-style-type: none"> <li>○ some improvement in psychosocial health of HIV+ women</li> <li>○ No difference in Nevirapine uptake</li> <li>○ Improvement in initiation, duration and exclusivity of breastfeeding</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Project Masihambisane, South Africa</li> <li>• LEPRA, India</li> <li>• Nymibwa Multipurpose self-Help Group, Uganda</li> <li>• Joanna Busza Meeting Presentation</li> </ul>
3. Maximising Community Assets and addressing community constraints	<ul style="list-style-type: none"> <li>• Utilisation of community transport for adherence defaulters and contact tracers</li> </ul>	When offering training for economic empowerment it is of critical importance to ensure the skills offered are matched with market opportunities so that training/IGA actually result in economic empowerment	<ul style="list-style-type: none"> <li>• BWFANO Community Home Based Care, Zambia</li> </ul>

4. Addressing economic barriers and increasing motivation	<p>Integration of economic empowerment into programming:</p> <ul style="list-style-type: none"> <li>• Promoting IGA to provide resources to access services</li> <li>• Training for IGA</li> <li>• Management of funds/microfinance through support groups</li> <li>• Skills development for employment</li> </ul>	One of the significant barriers to PMTCT uptake is economic. While IGAs can be effective it is critical to ensure that there is a market for the goods that are being produced so that the activities actually assist with economic empowerment	<ul style="list-style-type: none"> <li>• Nyimbwa Multipurpose Self-Help Group, Uganda</li> <li>• BWAFAANO Community Home Based Care, Zambia</li> <li>• Etafeni Day Care Centre</li> </ul>
	<ul style="list-style-type: none"> <li>• Utilise range of strategies to address economic constraints: <ul style="list-style-type: none"> <li>○ Reduce cost of service delivery</li> <li>○ Brokering of nutritional support</li> <li>○ Issuing of transport vouchers</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>• Joanna Busza Meeting Presentation</li> </ul>
	<ul style="list-style-type: none"> <li>• Use of incentives in the form of kits: <ul style="list-style-type: none"> <li>○ Baby Kits</li> <li>○ Mama Kits</li> <li>○ Clothing packs</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>• LEpra, India</li> </ul>
	<ul style="list-style-type: none"> <li>• Employing a companionship approach to build the trust of community members and facilitate communication and sensitization regarding HIV, testing, PMTCT and so forth.</li> <li>• Placement of NSAs in the clinic to impact positively on stigma and discrimination</li> </ul>	<ul style="list-style-type: none"> <li>• Reaching isolated and unreached communities</li> </ul>	<ul style="list-style-type: none"> <li>• Nyimbwa Multipurpose Self-Help Group, Uganda</li> </ul>

5. Structural Barriers to Service	Comprehensive Home Based Care which assists with accessing available welfare support		LEPRA, India
	Mobile services		CARE, Cameroon
6. Male Involvement	Engage men directly through HBC and invite them to attend ANC	<ul style="list-style-type: none"> <li>• Male involvement remains poorly defined</li> <li>• Nevirapine uptake is higher among women whose partners have been tested</li> <li>• Men are more likely to become actively involved if engaged directly rather than via their wives/partners</li> <li>• There is a tendency for men to be treated as resistant and as passive participants rather than active agents of change</li> <li>• When seeking to involve men in services it is imperative to consider pragmatic factors which serve as barriers (e.g. work schedules during the rainy season) and socio-cultural factors.</li> <li>• Leaders can feel threatened or undermined when they are not involved in community engagement processes</li> <li>• Sufficient time needs to be allocated to training to allow the numerous questions people have to be adequately addressed</li> </ul>	<ul style="list-style-type: none"> <li>• Joanna Busza Meeting Presentation</li> <li>• BWAFFANO Community Home Based Care, Zambia</li> </ul>
	<ul style="list-style-type: none"> <li>• Invite men to participate in PMTCT directly rather than through their partners</li> <li>• Target men through PMTCT interventions to become part of the solution to paediatric HIV</li> </ul>		<p>Catholic Medical Mission Board, Zambia</p> <p>Cameroon Baptist Convention Health Board</p>
	<ul style="list-style-type: none"> <li>• Intervene at a community level by empowering traditional leaders to become champions of PMTCT and engage other men and also as a way to start to address social and gender norms</li> </ul>		<p>Catholic Medical Mission Board, Zambia</p>
	<ul style="list-style-type: none"> <li>• Utilise men's groups in advocacy and community sensitisation</li> </ul>		<ul style="list-style-type: none"> <li>• CARE, Cameroon</li> <li>• TAC, South</li> </ul>

			Africa
	<ul style="list-style-type: none"> <li>• Use traditional birth attendants across a range of functions including the promotion of male involvement in PMTCT</li> </ul>		Millennium Villages Project, Tanzania
	<ul style="list-style-type: none"> <li>• Contact tracing and partner notification (counselling and testing)</li> </ul>	<ul style="list-style-type: none"> <li>• Improves male involvement in PMTCT especially care</li> <li>• Feasible in Africa, typically well-received</li> <li>• Those newly diagnosed with HIV need a substantial amount of counselling.</li> <li>• Should be integrated into PMTCT</li> <li>• Monitor and separate Partner Notification and PMTCT to show effect</li> <li>• Incorporate operational research including any possible effect of partner notification on partner violence</li> <li>• Health advisors should be counsellors who are then offered effective training to conduct partner notifications and provided with regular supervision</li> <li>• On-the-spot VCT promotes uptake</li> <li>• Contact tracing is still largely an untapped opportunity for PMTCT</li> </ul>	<ul style="list-style-type: none"> <li>• Cameroon Baptist Convention Health Board</li> <li>• Kenya Network of Women with AIDS –KENWA; Southern Sudan Network of women with AIDS</li> <li>• TAC, South Africa</li> </ul>
	<ul style="list-style-type: none"> <li>• Put policies in place that can support male accountability</li> </ul>		Global practice in this area vary from mandatory male involvement in India, to accountability frameworks at the district level in Rwanda, to no formal policy but

			community level engagement with the issues as is the case in Zambia.
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## **Case Study – Catholic Medical Mission Board, Zambia**

**Male Involvement through empowerment of leaders as PMTCT champions:** In rural areas of Zambia, health systems cannot function effectively without the buy-in, support and uptake of key gatekeepers, particularly the traditional community leaders. By engaging the traditional leaders as champions of PMTCT in the Men Taking Action (MTA) Programme strong links are established between the community and the health facility. This creates a more robust rural health system for increasing the uptake of HIV care and prevention services including PMTCT and HCT as well as other programmes that potentially have an impact on HIV such as alcohol and substance abuse, gender based violence, child abuse, and economic vulnerability. The MTA Programme identified that traditional leaders can feel very threatened and become resistant if they are left out of community based programming and hence it is important to ensure that they become allies rather than opponents to PMTCT. The empowerment of traditional leaders is achieved through training and discussions.

**Male Involvement through direct engagement with men:** The Men Taking Action programme is also interested in targeting men to be meaningfully part of the solution for the vertical elimination of paediatric HIV through PMTCT interventions. Partner involvement in health programmes has numerous positive outcomes. For men in rural areas, traditional cultural norms and gender roles can act as a constraint or barrier to male involvement. The MTA aggressively targets men to support their spouses to enrol in PMTCT early, get tested for HIV together, and enrol in HIV care services including PMTCT and ART if they test positive. One of the mechanisms for targeting men is through the traditional leaders who have been trained and therefore empowered to encourage men to become part of the solution for vertical transmission of paediatric HIV. The involvement of men has seen an increase not only in PMTCT but also institutional deliveries.

**Strategic Partnerships and Networks to ensure synergy and share best practice:** In order to ensure synergy in the mobilisation of communities for PMTCT and also to share best practices and influence policy and practice, the organisation networks with the Ministry of Health and other CBOs working with PMTCT.

## **Case Study – Cameroon Baptist Convention Health Board**

**Contact Tracing and Partner Notification to increase male involvement:** Community-based faith based organisation Cameroon Baptist Convention Health Board (CBCHB) runs 5 large hospitals, 25 integrated health centres and approximately 50 primary health care centres in six of the ten regions in Cameroon. The organisation has been running PMTCT for the past eleven years. One of the major challenges it has encountered has been male involvement. This led to the Men as Partners Programme and to contact tracing and partner notification. With respect to the contract tracing and partner notification staff (typically counsellors and PLHIV) are trained as Health Second Road to Washington Meeting 2-3 December, Addis Ababa Advocacy and Best Practice Document

Advisors. Women who test positive (the index person) are linked to a health advisor on the day of diagnosis. Women give their consent to participate after being counselled and receiving information about the programme. The index person provides details about her sexual contacts in the past 1 to 3 years and how they might be contacted or they select to notify the partners themselves. Notification is by contacting the contact the helping him/her to know that they have been exposed to HIV without revealing the source of the information. Cell phones are used to establish contact and take appointments. VCT is conducted on the spot. Those who test positive then become identified as an index person, are linked to counselling and treatment and followed up to get enrolled in care.

From August 2007 to December 2010 6,642 index persons were identified for whom 5,271 contacts were traced and notified, 75.4% of whom were tested (54.2% testing positive). 60.8% of those tested positive were enrolled in care.

Contact tracing and partner notification helps to break the transmission chain, improves disclosure, improves male involvement in PMTCT and helps people to know their status and seek treatment early.

Factors that have been identified to help the process include: the effective training of Health Advisors, counsellors being selected as Health Advisors, regular supervision and coordination meetings, on the spot VCT which promotes uptake, use of data to identify gaps and improve services. Those factors which hinder the process have included: limited funds for service expansion and sustainability, erroneous address details and regular changes of address which have a negative effect on follow-up, stigma and discrimination and a few cases of violence towards the health advisor.

### **Case Study - Nyimbwa Multipurpose Self-Help Group, Uganda**

**Empowerment of PLHIV and other community members to become active agents of change:** This initiative is situated at the peer and community levels. The network is composed of people openly living with HIV who are selected from the community. These Network Support Agents (NSAs) are offered training in a range of topics including: adherence, nutrition, PMTCT, disclosure and counselling. They then spend two days at the clinic and three in the community. As an example of the use of community as an extended workforce, the NSAs are used to link the community to the health services and other government bodies and strengthen referral systems to the clinics and follow up back in the communities. Their ability to be open about their HIV + status has positive benefits in terms of addressing stigma and discrimination not only in the community but in hospitals as well.

The NSA's reach remote communities on foot or by bicycle sharing the message that all is lost with a diagnosis of HIV or TB and sensitising the community to the fact that treatment is available. They have earned the acceptance of clinic staff in recognition of

the ability of the NSAs to engage with the community. They have also earned the trust of the community and serve as role models for them in terms of living openly with HIV. This trust has facilitated the sharing of information and dissemination of key messages about PMTCT, testing, MNCH and TB services.

Evidence points to the successful reach and impact of the services of the NSAs in this project. Over a three year period from 2006-2009 1300 NSAs operated in 40 districts and in one district the number of people accessing PMTCT services increased from 1,264 to 15,892 between 2008 and 2009 as a result of the referrals of the NSAs.

Working closely with the community has made the NSAs keenly aware of the barriers constraining the uptake of PMTCT services and in the case of Uganda this tends to be: women fearing going to the hospitals due to stigma, men stopping their wives from going to the health facilities and lack of financial resources for transport, medical cards, services, food for adherence or to buy the Mama Kits. The NSAs have used their PLHIV support groups to promote IGA activities and the management of funds and microfinance.

The commitment of the NSAs is notable especially given that funding ended in 2009 and yet they have continued to offer the same services to the women in their community.

### **Case Study, Masihambisane, South Africa**

**Mentor Mothers for Peer Support:** Community Sisters in charge of health care workers provide a list of names of HIV positive women who are actively involved in the clinic in community work/volunteering. Women are selected to become mentors mothers on the basis of an interview and certain criteria including literacy, ability to speak the local languages, passionate about community empowerment and ability to disclose their status in public.

Six weeks of didactic and experiential training with active practice which is video-taped, is then supported by on-going observation, supervision and debriefing with a psychologist. Thereafter the mentors are ready to “walk together” with other women.

The mentors meet with women undergoing testing, disclose their status and offer support. They also run group sessions and one-on-one sessions with the women usually after the women have tested. Finally the mentors are also involved in giving informational talks at the clinic to all pregnant women.

While the work of the mentor is not easy and even traumatising at times requiring regular support, supervision and debriefing, disclosure is typically experienced as therapeutic. The mentors also draw esteem and pride from the work they do and being seen as leaders in their communities typically preferring to themselves be called the more professional sounding “mentor” rather than “mentor mother”

#### 4.4. Creating and Enabling Environment

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	CASE STUDIES/REFERENCES OF VALUE
CREATING AN ENABLING ENVIRONMENT			
1. Advocacy	<ul style="list-style-type: none"> <li>Advocacy programmes with government service providers to sensitise them to the issues faced by the community and on quality of service</li> </ul>	Advocate for male friendly local clinic services to increase male involvement.	LEPRA, India
	<ul style="list-style-type: none"> <li>Advocacy with government to maintain the community component of successful interventions (making use of legal means)</li> </ul>		LEPRA, India
	<ul style="list-style-type: none"> <li>Advocacy through networking with government to share good community practices to influence policy or government strategies</li> </ul>		Catholic Medical Mission Board, Zambia
2. Stigma and Discrimination	<ul style="list-style-type: none"> <li>Intervene early to address stigma through paediatric support groups</li> </ul>	<ul style="list-style-type: none"> <li>Still a substantial barrier to uptake of services</li> <li>Exists in community and in health facilities.</li> <li>Can be underpinned by fear of transmission which if removed in the health institutional setting (e.g. amongst doctors afraid to perform C-sections on HIV + women) can greatly enhance institutional services and uptake of services</li> <li>Using positive messaging and sharing the achievable positive outcomes can break down prejudice and misperceptions</li> </ul>	BWAFANO Community Home Based Care, Zambia
	<ul style="list-style-type: none"> <li>Use PLHIV as role-models of living openly with HIV and empower them to assume change agent roles in the community</li> <li>Meaningful involvement and empowerment of PLHIV as educators to promote PMTCT, testing, MNCH and other services (e.g. TB).</li> </ul>		<ul style="list-style-type: none"> <li>LEPRA, India</li> <li>Kenya Network of Women with AIDS –KENWA; Southern Sudan Network of women with AIDS</li> <li>Nyimbwa Multipurpose Self-Help Group, Uganda</li> </ul>

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	CASE STUDIES/REFERENCES OF VALUE
CREATING AN ENABLING ENVIRONMENT			
	<ul style="list-style-type: none"> <li>Use cultural and social events to challenge stigma and change practice</li> <li>Use of peer support groups and community mobilisation to fight stigma and discrimination</li> <li>Offer integrated HIV-sensitive rather than HIV-specific programmes to remove any potential stigma, increase access to households and provide a more holistic intervention</li> </ul>	<ul style="list-style-type: none"> <li>Use of PLHIV as educators in community can have dual benefit of reducing stigma and empowering mothers diagnosed with HIV to embrace positive living</li> </ul>	<p>LEPRA, India</p> <ul style="list-style-type: none"> <li>LEPRA, India</li> <li>CBCHB, Cameroon</li> <li>TAC, South Africa</li> </ul> <p>Care, Cameroon</p>
3. Ownership by Community	<ul style="list-style-type: none"> <li>Promote community ownership of interventions</li> <li>Engage and empower community leaders to play a leadership role in driving the PMTCT agenda</li> <li>Empower community members to become key change enablers through leadership promotion and skills development</li> <li>Utilisation of community led participatory processes</li> </ul>		<p><i>Modelling the Impact of Stigma on HIV and AIDS Programmes: Preliminary Projections for Mother-to-Child Transmission.</i> ICRW/LSHTM</p> <ul style="list-style-type: none"> <li>Catholic Medical Mission Board, Zambia</li> </ul>
4. Social Barriers	<ul style="list-style-type: none"> <li>In order to address problematic cultural norms that contribute to gender based violence or intolerance of diversity through: <ul style="list-style-type: none"> <li>Use participatory community processes such as community dialogues,</li> <li>group therapy/support groups</li> </ul> </li> </ul>		<ul style="list-style-type: none"> <li>LEPRA, India</li> <li>Catholic Medical Mission Board, Zambia</li> <li>Millennium Villages Project,</li> </ul>

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	CASE STUDIES/REFERENCES OF VALUE
CREATING AN ENABLING ENVIRONMENT	<ul style="list-style-type: none"> <li>○ opinion leaders</li> <li>○ campaigns that target men</li> <li>○ disclosure support</li> <li>○ couple counselling</li> <li>● Promote collective responsibility through multisectoral involvement</li> </ul>		<p>Tanzania</p> <ul style="list-style-type: none"> <li>● TAC, South Africa</li> </ul>
5. Monitoring programmes through civic engagement	<ul style="list-style-type: none"> <li>● Civic engagement in monitoring health services workers</li> </ul>	<ul style="list-style-type: none"> <li>● In order to monitor services, communities need capacity building and timely information on monitoring indicators</li> <li>● Consensus building around roles and responsibilities required</li> </ul> <p>User-friendly tools needed to enhance accountability and strengthen sustainability</p>	Bjorkman (Uganda)
	<ul style="list-style-type: none"> <li>● Performance based contracts and community pressure on leaders to deliver</li> </ul>		Rwanda; Care Cameroon
	<ul style="list-style-type: none"> <li>● Sensitisation of service providers by community of the community needs and requirements in terms of quality programming</li> </ul>		LEPRA, India
6. Social Protection	<ul style="list-style-type: none"> <li>● Provision of economic support to women and families through: <ul style="list-style-type: none"> <li>○ Cash transfers</li> <li>○ Treatment subsidies</li> <li>○ Transport vouchers</li> <li>○ Free MNCH services</li> </ul> </li> <li>● Social wage (no fee schools, no fee water public works)</li> <li>● Case workers linking families with social protection to increase access to health services</li> <li>● Promoting inclusion of marginalised groups</li> </ul>	<ul style="list-style-type: none"> <li>● Consideration could be given to seeking to address living costs in the form of out-of-pocket counter finance</li> <li>● Social protection should be HIV sensitive not HIV specific (care needs to be taken to not inadvertently incentivise the wrong behaviour)</li> <li>● Demand needs to be created and realised</li> </ul>	<ul style="list-style-type: none"> <li>● Linda Richter Meeting presentation</li> <li>● LEPRA</li> <li>● Isibindi South Africa</li> </ul>

TOPIC	BEST PRACTICES	LESSONS LEARNED/GUIDANCE OFFERED	CASE STUDIES/REFERENCES OF VALUE
CREATING AN ENABLING ENVIRONMENT			
7. Establishing a more conducive operating environment (Resource Mobilisation, Sustainability and impact)	<ul style="list-style-type: none"> <li>• Increase the voice of the community so that there is a single focus (this can sometimes be facilitated by convening communities.</li> <li>• Promote shared accountability as called for in the Global Plan</li> <li>• Implement PMTCT at public health care rather than at secondary health institutions for cost-efficiency</li>   <li>• The establishment of deliberate strategic collaborations with a wide range of like-minded institutions (government, NGOs) to facilitate the operating environment for organisations working in the area of PMTCT, access to quality services and increased uptake at the district level</li> </ul>	<ul style="list-style-type: none"> <li>• Even with a single focus, a challenge can be created by lack of capacity and a mechanism for distributing grants or providing technical assistance</li> <li>• The community model needs to be costed<sup>11</sup></li>   <li>• Use partner meetings as a forum to address coordination</li> <li>• Can bring benefits to the organisations through sharing of practices and resources, facilitate a more powerful voice for advocacy, open up new possibilities for community health workers, strengthen the health system infrastructure, enhance service provision and quality and uptake of service.</li> </ul>	<ul style="list-style-type: none"> <li>• Zambia Global Fund</li> <li>• Lesotho – LENASO</li> <li>• Examples from Tanzania.</li> <li>• TAC, South Africa</li>   <li>• Millennium Villages Project, Tanzania</li> <li>• LEPR, India</li> <li>• BWAFA, Zambia</li> </ul>

<sup>11</sup> See discussion under Issues Requiring Additional Attention section of this document  
Second Road to Washington Meeting 2-3 December, Addis Ababa Advocacy and Best Practice Document

## Case Study: LEPRA, India

LEPRA's PPTCT Plus Project is an outreach project focusing on antenatal and postnatal care that was established to bridge the gap between clinic services and the community. The reach of the project is evident, operating as it does in 8 districts, 5000 villages, 9 hospitals and 27 PPTCT centres.

**Comprehensive:** 220 community members, including PLHIV, were engaged as community health workers to roll out the programme. The programme offers a comprehensive package of services including home visits, one-on-one counselling, group interaction, family support, disclosure support, partner and infant testing, and follows up.

**Empowering community members/PLHIV to be active agents of change:** 80 of the community members were successfully empowered through training to serve as positive speakers who could share their views at national and international forums. They were also provided with opportunities/training for improving their social and economic status.

**Use of cultural and social events to change perceptions and address stigma:** In order to achieve its objective to increase institutional deliveries of HIV + women, the programme made use of cultural and social events to promote the legitimacy and rights of women living with HIV to pregnancy, safe deliveries and healthy babies. The use of blessings also served to build rapport with women in the community so that women were more willing to share personal information which women were typically reticent about sharing with clinic staff such as family history and addresses which enabled follow up after the delivery. These follow up resulted in success with child immunisations, breastfeeding, Nevirapine administration and further institutional deliveries.

**Use of role-models and positive messaging to reduce stigma in institutional settings:** Given the extreme resistance of doctors to support HIV + women in their antenatal care and delivery as a result of the doctor's fears of transmission in carrying out caesareans, the *Bold Doctors Club* was established which involved doctors who had safely carried out the c-sections speaking with other doctors and allaying their fears. *Well Baby Shows* also aimed to challenge perceptions about HIV positive women and their babies. They show that HIV+ women can have healthy babies. The shows are supported by the Bold Doctors Club and hospital staff members that also contribute the prizes which are given to babies. Hospital staff was also involved in birthday celebrations of the children living with HIV. Marriage anniversary celebrations of HIV + couples were also used to break negative perceptions.

Significant impact is reported by LEPRA as a result of these interventions. The Bold Doctors initiative saw 500 doctors and 225 para-medical staff being trained and institutional deliveries increasing from 48% to 93% over a five year period. Through events such as the Well Baby Shows women and babies are followed up post NVP administrations and a reduction in HIV transmission to babies from 24% to 3% has been achieved.

**Links:** LEpra has established extensive networks and partnerships with District care and support centres, VCT centres, STD/STI clinics, women's groups, local NGOs and CBOs amongst others to increase the services offered to clients.

**Advocacy:** In order to facilitate an understanding of issues faced by service users in the community and sensitise the government service providers to the importance of maintaining quality services, advocacy programmes were run on HIV services, facilities conducting institutional deliveries and ensuring NVP administration, ART initiation and the community role in advocacy in the mitigation of issues. In addition the organisation has advocated for the importance of the community dimension to their particular programme. This was sparked by the fact that the government had handed programme management and funding to a private organisation that as a result of their lack of experience in working with communities and PLHIV communities in particular reduced staffing and the community components. The organisation filed a case with the courts charging the company with negligence in management which undid the previous gains made by the community programme.

### **Case Study – Treatment Action Campaign (TAC), South Africa**

Working in the rural setting TAC have learned that it is much cheaper to tackle PMTCT through the primary health care system than the secondary health institutions and to do so also serves to benefit clients throughout their lives. The TAC approach is also an integrated/linked up approach. It relies on awareness and mobilisation, education, HCT referrals, and contact tracing and follow up. Mobilisation and awareness is achieved through community door-to-door campaigns conducted by TAC branch members and media prints and newsletters calling for equal rights to treatment and dealing with issues such as pregnancy. In addition to the education that is achieved through the media and door-to-door campaigns, education is also achieved through the work conducted with patient during sessions at health sites by prevention and treatment literacy practitioners, workshops and in-service training of clinic staff. Contact tracing is done with assistance from registers and treatment collection dates, and measuring levels of adherence through pill counts ensures that the PCR confirmatory test is conducted at 6 weeks and 18 months. Partnerships with government and other NGOs assist with several services: IEC provision for mass communication, access to health care sites that are conducive for pregnant women, HIV counselling and testing and ART initiation assisting with the overloaded health care workers, patient tracing and assistance with transportation of contact and defaulters tracers. Despite the merits of the design of the programme, challenges are noted including: low attendance of men at couples PMTCT counselling, issues with follow up, disclosure, and the attendance at the confirmatory PCR testing to name just some. TAC offers guidance to overcome some of these issues: such as strengthening stakeholder coordination of NGOs within districts through partners' meetings, creating awareness of the benefits of PMTCT early on in the pregnancy, utilising men sector meetings consisting of organisations that work with men in health and social care, to engage traditional leaders and other prominent members within the community to promote PMTCT participation, and advocating for male friendly services in local clinics inclusive of ANC.

## Case Study – Millennium Villages Project, Tanzania

**Strategic collaborations to improve access to quality services, uptake of services and a more conducive operating environment for organisations:** With the aim of increasing uptake, accessibility and quality of comprehensive PMTCT services, the organisation strategically forged links with a number of other stakeholders including central and local government, NGOs and established a strong collaboration. This collaboration took the form of a forum with a host of objectives including:

- Resource mobilisation;
- Accessing human resource for health capacity strengthening;
- Setting facilitating by-laws in communities;
- Ensuring staff wellbeing;
- Strengthening the referral system;
- Feedback provision;
- Sharing best practices;
- Accessing joint supportive supervision;
- Enabling integration of innovative strategies and scale up of sustainable interventions;
- Advocacy for community support.

The **partnership with government** achieved a number of valuable outcomes including:

- Improved health facility infrastructure
- Improved Health Resources for Health (HRH) capacity
- Improved supply chain management system
- Timely operationalization of new PMTCT information
- Increased HIV Early Infant Diagnosis (HEID) sites, PMTCT sites, care and treatment clinics for PLHIV
- Significantly increased enrolment of new HIV clients
- Registered scaling up of TBAs and integration discussions for CHWs programme into national health systems.

## 5. ISSUES REQUIRING ADDITIONAL ANALYSIS

While various promising approaches should be tested, expanded and replicated, various issues pertaining to community engagement require further attention.

- **Definitions:** The meaning of community and community engagement needs clarification.
- **Funding and Costing:**
  - Securing sustained funding for community engagement
  - Protection of budgets for community engagement including the coordination of activities
  - How best to bring communities to the funding table
  - The development of relatively simple frameworks that can outline the multiple outcomes of PMTCT which can be included in costing frameworks
  - Establishing costing markers for community capacity building and the community workforce model
- **Coordination and Integration:**
  - Facilitating a single community voice and strengthening coordination of organisations at a district level
  - Who manages coordination, whose mandate is it and whose budget?
  - Who funds the district level coordination? Donors fund specific organisations not the coordination between organisations.
  - How best to push the merits of integration and ensure the capacity to respond to this integration without quality of service being compromised or already taxed systems becoming overloaded.
- **Coordination of CBOs** to prevent duplication of services
- **Compensation** for “peer workers” (volunteers should be paid)
- Exploring possibilities of covering out-of-pocket costs with counter finance within social protection
- Increasing effectiveness of addressing the major barrier of **stigma and discrimination**
- **Evaluations:** More process evaluations required to understand how initiatives work
- **Accountability:**
  - Demand for services has not only to be created but realised over and over again to address expectation
  - The establishment of effective partnerships with government
  - Identifying the success stories of successful partnerships with government
  - Ensuring there is shared accountability to respond to the demand which is created through community engagement
- **Health systems and community system strengthening:**
  - Through the empowerment of health care practitioners to promote participation and ownership of PMTCT programmes
  - Improving task delegation given the shortfall in human capital
  - Building community capacity for service provision

- Not losing the **inspiration of single individuals, recognising where it is model and where it is the work of individual**

## 6. CONCLUDING COMMENTS

The evidence offered by community organisations in support of their proposed best practices highlights the progress that has been made in the last four years in terms of clarifying what needs to be achieved.

Certain principles for PMTCT programming can be extracted from the best practices and lessons that were offered by community organisations.

These include:

- Integration (of a spectrum of care response, at a district level, and with the urban health programme)
- Involvement (of target groups within the community)
- Ownership (by the community and its leadership structures)
- Defining accountability to ensure that supply matches the demand that is created.
- Contextualising responses
- Moving beyond the medical model to aim to achieve broader outcomes than simply health outcomes.

Some of the most pressing stumbling blocks remain stigma and poor coordination of local organisations. The latter is something which ideally needs to be budgeted for as one aspect of community engagement. A long term commitment is required to sustain community motivation. Community action is not homogenous and consideration should be given to different kinds of funding that might be required for different community stakeholders.

In recognition of the importance of economics and costing, the Interagency Task Team on PMTCT has created a working group.