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HIV & AIDS

Establishing mother support groups: Best practices to reduce HIV vertical transmission

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INTRODUCTION

There is an urgent need to improve access for HIV-positive pregnant women to services that can dramatically reduce the transmission of HIV to their babies. Globally, approximately 48 per cent of women in resource-poor settings have access to prevention of mother-to-child transmission (PMTCT) services.[1] There is growing recognition of the need to create greater awareness amongst HIV-positive women and others about the value of PMTCT in order to create demand for services at the community level and to support adherence and follow-up after delivery. In recent years, community-based mother support groups have played a key role in creating this awareness and building confidence among HIV-positive women to have access to these services. Mother support groups provide safe environments in which women can learn how to help themselves in making difficult decisions.

An effective package of PMTCT services should cover the following key areas:

- Prevention of HIV infection in women of child-bearing age
- Prevention of unwanted pregnancy in women living with HIV
- Access to anti-retroviral treatment (ART) before, during and after delivery to reduce transmission to the infant
- Ongoing prevention of transmission after delivery including early testing and referral, preventive treatment and safe infant feeding.

Key reasons for poor access to services include the lack of trained staff, stockouts in health facilities, as well as distance and expense associated with using health facilities. Barriers to PMTCT services are not only economic, but also cultural, including:

- Low level of knowledge of prevention of vertical transmission (PVT)[2]
- Stigma associated with HIV status and/or fear of disclosure
- Traditional child-rearing practices encourage breastfeeding, making it difficult to change if HIV status known
- Entrenched gender norms reduce female decision-making power around actions to reduce PVT, including sexual or reproductive choices.

Greater awareness amongst HIV-positive women and others about the value of PMTCT services is needed in order to create demand at the community level, as well as to support adherence and follow-up after delivery. In recent years, community-based mother support groups have played a key role in creating this awareness and building confidence amongst HIV-positive women to have access to these services. There is evidence that mother support groups provide a safe environment in which women are able to learn more to help them make informed decisions.

[1] WHO, UNAIDS and UNICEF, 2011, *Progress report 2011: Global HIV/AIDS response. Epidemic update and health sector progress towards universal access. Geneva.*

[2] There is a growing movement to replace the term PMTCT with a more neutral phrase, i.e. Prevention of Parent to Child Transmission (PPTCT) or Prevention of Vertical Transmission (PVT), thereby reducing the sole focus being on the mother. This report uses PVT when referring to technical interventions and PMTCT when describing programmes.

PURPOSE OF REVIEW

World Vision is scaling-up its programming and advocacy on maternal and child heath, with a focus on primary health care with families and communities. This report highlights key lessons learned around emerging good practice when establishing mother support groups, thereby increasing access to PMTCT programmes and thus strengthening maternal, newborn, and child health (MNCH) in general, as well as within World Vision's health and HIV programming.[3]

The report focuses primarily on sub-Saharan Africa as there is limited available information for other contexts. Although a community-based approach to PMTCT is most effective where there are large numbers of HIV-positive women, there is value in exploring opportunities for implementation in low-prevalence contexts as well as in more urban hot spot areas of Asia and Latin America.

BACKGROUND

The transmission of HIV from mother to child remains a significant challenge, despite the availability of simple and affordable technical solutions (Figure 1). As of 2010, an estimated:[4]

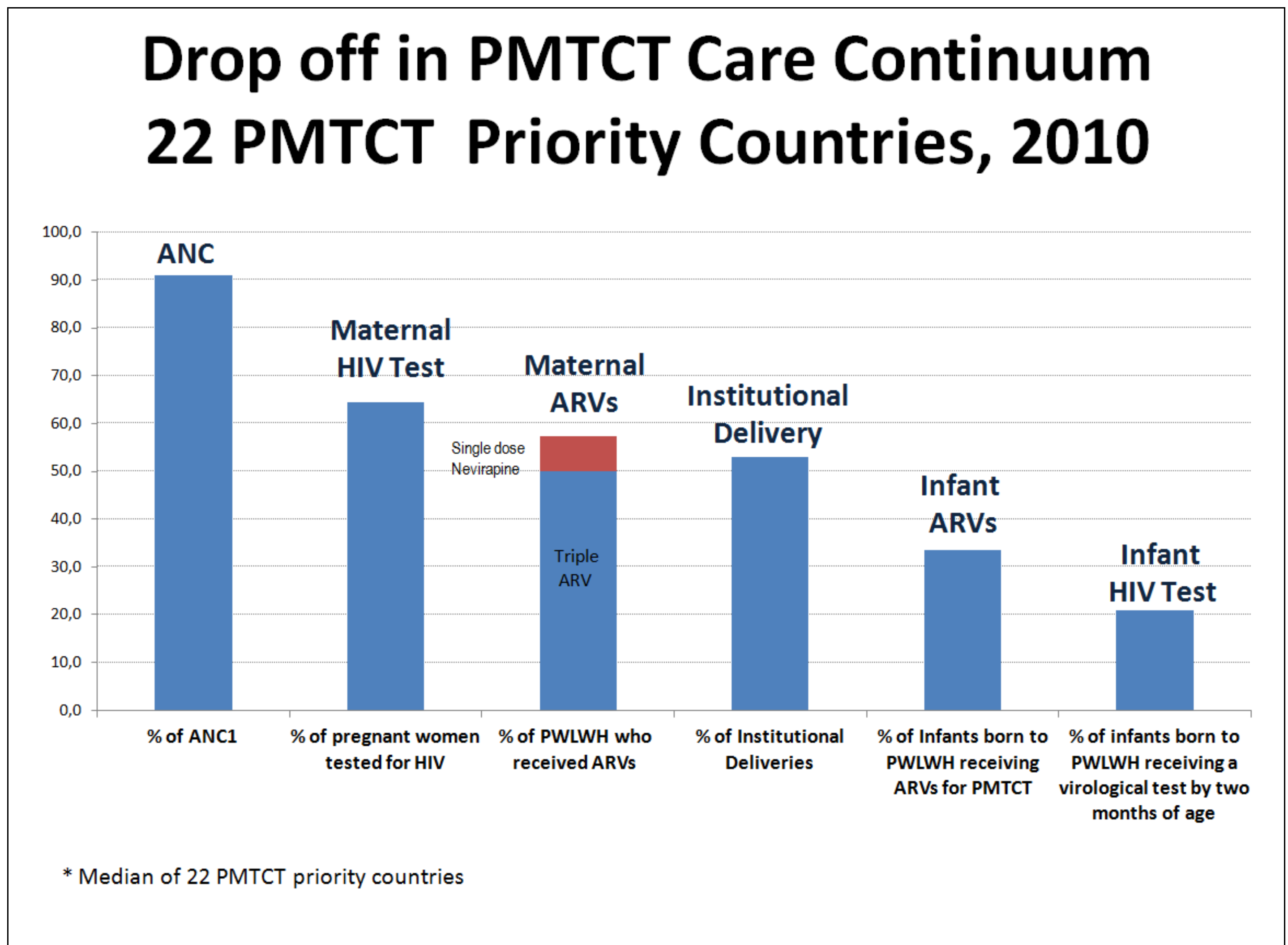
- 3.4 million children under 15 years of age are living with HIV
- 1,068 babies are born every day with HIV or get HIV from breastfeeding
- 90% of infections are the result of transmission during pregnancy, labour and delivery, or breastfeeding
- 48% of women living with HIV in low/middle-income countries receive antiretroviral drugs (ARVs)
- 42% of exposed children receive medication to reduce transmission.[5]

Without interventions, there is a 30–45 per cent chance an 18–24-month-old baby born to an HIV-infected mother will become infected.[6] Until recently, two doses of nevirapine were administered, one to the mother during labour and one to the baby soon after birth. New and improved multiple drug regimens require more complex assessment procedures and greater reliance on follow-up requirements. While data are incomplete, a high share of women still receives single-dose treatment of nevirapine, thereby placing them at risk of developing drug-resistance.[7] Further complicating matters, the drop-out rate along the treatment chain is very high and due to a variety of factors, including:

- Poor access to health facilities
- Shortage of trained health personnel
- Lack of testing kits
- Stockouts
- Lack of support when HIV status is known
- Stigma as a barrier to access
- Limited post-delivery support
- Inability to pursue safe infant-feeding practices

[3] This review was undertaken by Sian Long in 2010 *Review of best practices for establishing mother support groups to reduce HIV vertical transmission*, and included a literature review as well as interviews with key informants.
[4] WHO, UNAIDS and UNICEF, 2011, *Progress report 2011: Global HIV/AIDS response. Epidemic update and health sector progress towards universal access. Geneva.*
[5] For further information on revised recommendations, see WHO, 2009, *Rapid advice: use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants*
[6] WHO, 2007, *HIV Transmission through Breastfeeding: A review of available evidence*
[7] For further information on revised regimens, see WHO, 2009, *Rapid advice: use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants*

Figure 1: **Drop off in PMTCT continuum of care in 22 Priority Countries**
Source: Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access, 2011



COMMUNITY-BASED GROUPS: IMPROVING PMTCT RESPONSE

Working with and within the community is an essential part of an effective PMTCT response. The only way to address stigma effectively is through a change in attitude at all levels within the community, including addressing fear and ignorance about HIV, supporting those who are HIV-positive to live openly and positively, and working with key stakeholders to understand and accept HIV as a part of life and the community. Community engagement must therefore address both cultural and social practices influencing childbirth and rearing practices, as well as economic barriers to the prevention of vertical transmission.

Why set up a mother support group?

The most common reason to establish a support group has been low take-up in services through facility-based PMTCT programmes leading to a need for greater community mobilisation. All organisations running support groups cited the following motivation for the initial establishment:

- Enhanced uptake of clinic-based PMTCT services by addressing women's information and increasing peer support for disclosure and addressing stigma
- Support for HIV-positive women going through pregnancy and childbirth through information and peer support

- Improved referral into post-delivery HIV-related care.

The groups that were started independently of clinic provision mentioned additional objectives:
- Women's empowerment through increased access to information and, for many women, skills building and entry into the job market
- Access to economic support through income-generation activities run by autonomous support groups
- Building an evidence base to advocate for resources and policies for women's peer support groups.

How do they work?

Support groups are always run in collaboration with PMTCT services, although the extent to which the health facility or the government service is involved varies. In many cases groups are initiated by health staff from local PMTCT programmes. In other cases non-governmental organisations (NGOs) initiate group formation and carry out the necessary training. There are some exceptions, such as the Mama's Club in Uganda which is exclusively run by women living with HIV and partners with The AIDS Support Organisation in Uganda (TASO).

Although some ministries of health are supporting or endorsing guidelines developed by different NGOs, information varies widely and does not provide any minimum standards for running the groups. The establishment of national minimum standards for community support groups appears to be a gap that may limit the engagement and provision of appropriate resources to national and district health facilities. Once groups are formed, the next step is to identify and train peer educators, who are almost exclusively HIV-positive women who have been through the process (see case study).

CASE STUDY: MOTHERS2MOTHERS

Mothers2mothers (m2m) trains and employs mothers living with HIV to provide education and support to women just like themselves. These Mentor Mothers work alongside doctors and nurses to serve the needs of pregnant women and new mothers living with HIV, helping to fill the gaps in critically understaffed health systems. The m2m model offers a sustainable, scalable and cost-effective solution to the challenge of providing PMTCT services in resource-limited settings. This approach recruits, trains, and employs mothers living with HIV who have personally received PMTCT care. Mentor mothers are selected according to the following criteria:

- Willingness to be a mentor and disclose HIV status with peers
- First-hand experience with PMTCT services
- Ability to read and write to a reasonable level.

Mentor mothers are salaried and based in a health facility where they are required to commit to at least three full days per week of mentoring and supporting HIV-positive mothers. The m2m mentor programme is well-structured and recruits mentor mothers usually for 13-month terms. Mentor mothers are then encouraged to 'retire', but active steps are taken to find them jobs in the community or health care system. The reason for rotating mentor mothers is in order to educate and empower as many women living with HIV as possible. For more information on m2m in different countries, visit: http://www.m2m.org/

Group objectives

In large part, the purpose of most groups appears to be on the clinical aspects of transmission focusing on the reduction of transmission during delivery and immediately after, and during breastfeeding. All groups reviewed recognise that the best way to achieve this is to also address issues of stigma, provide psychosocial support, and advocate for women's empowerment.

RUNNING COMMUNITY-BASED GROUPS

Meeting location and frequency

Most commonly, groups have women who are pregnant and women who have delivered their babies. The majority of community groups meet in clinics; this arrangement draws women into the formal health care system who may otherwise not seek out such services. One exception was a group meeting in a local community setting in order to interact with women where they live their daily lives. Meetings generally occur once or twice per month, and most informants stressed the importance of providing some form of refreshment for women. Many groups use the meetings as an opportunity to not only provide nutritional advice to women but also give pregnant and lactating women a nutritious, locally-produced additional meal.

Group facilitation

This review found the most successful facilitators are peer educators able to adapt and introduce new issues on a case-by-case basis, instead of using ready-made manuals. The average length of facilitator training is five days and regular monthly updates are essential due to rapidly evolving information. The use of stipends varied enormously across programmes, even within the same country. A priority for all is on making the information understandable to women. Group meetings generally included discussions around the following topics:

- The PMTCT process/ART for mothers
- Infant feeding options and nutrition
- HIV testing for the infant
- ART for infants that test positive
- HIV-related child health
- Psychosocial support
- Reproductive health.

Duration of participation

Most informants reported that women tend to visit regularly immediately after delivery and just before delivery. A general rule of thumb seems to be that women are 'weaned off clinic-based groups when their children reach 18 months'.[8]

GROUP MEMBERSHIP

Barriers to group attendance may be socio-cultural, economic, geographic or demographic. Reaching women in rural areas, for example, was particularly challenging. Outreach support and follow up varies significantly. Initially most groups seemed to be women only, although there has been a substantial focus on male involvement in PMTCT in general, including in support groups. Male involvement in community groups, however, must be done strategically in order to preserve women's sense of freedom to discuss complex issues within these groups and ability to seek out services with confidence. There is also a movement to have 'family support groups', rather than male- or female-only groups. There is a clear need

[8] Interview, Winfreda Chandisarewa, ZAPP, Zimbabwe

to get men more involved at the community level in processes of childbirth and infant-feeding choices, by promoting their participation in general antenatal classes, focusing on couple testing and providing fathers of HIV-exposed infants with information and space for themselves.

Although child participation in the PMTCT process is still largely absent, some are experimenting with children's support groups, although these tend to be orphan and vulnerable children support groups rather than specifically for children who are themselves HIV-positive or have an HIV-positive mother. Zimbabwe AIDS Prevention Programme (ZAPP) holds a group for children whose mothers have gone through the programme, and they meet twice a week for recreational and psychosocial support activities.[9] Similarly, the ZAPP experience indicates that using the PMTCT activity as an entry point to broader childcare is potentially a powerful intervention.

Reaching other important influencers in the community

Reaching other members of the community who influence women is also an important part of prevention. To this end, groups are trying to reach out to traditional birth attendants and other older women, especially mothers-in-law, who can have a profound impact on safe delivery practices and infant feeding.

Linkages with health services

In general, support groups seem to have good links with adult as well as paediatric HIV treatment. However, very few linkages were found between community groups and bodies such as child support groups, and spiritual or faith-based support mechanisms. This is a glaring gap. Likewise, there are limited examples of how referrals are made from the support groups to other social welfare services, and there were no examples of linkages with more explicit child development and health interventions in the form of partnerships, i.e. links with community-based early childhood development (ECD) services.

LESSONS LEARNED: KEY GAPS AND CHALLENGES

Community-based support groups are an essential element of effective PMTCT from the perspective of the HIV-positive woman. Although documented evidence is limited, where available, community-based support groups help to reduce HIV transmission to infants, as well as provide improved psychosocial outcomes for the mother. Some key elements to success include:

- Involvement of people living with HIV
- Ensuring community groups are safe havens for women where they're free to discuss problems
- Involvement of men in the PMTCT where gender-sensitive and contextually appropriate
- Focus on infant and young-child feeding
- Complemented by other community interventions
- Supporting community change with change within the health sector, especially on male involvement and attitudes to safe infant feeding
- A district-wide approach, which is more likely to have positive outcomes – a key focus area for World Vision.

Support groups alone will not address community norms that facilitate vertical HIV transmission. Economic barriers remain a challenge to effective reduction in vertical transmission, especially from breastfeeding. The lack of integration of community support groups into national to district guidance on PMTCT is a key challenge. While it seems fairly evident that investing in community support groups that increase PMTCT uptake should be a necessary component of PMTCT programmes, there does not seem

[9] Interview, Winfreda Chandisarewa, ZAPP, Zimbabwe

to be sufficient information to robustly advocate for when such groups should be established, how they should be structured, and what level of financing is needed. With improved monitoring from some of the NGOs working across more than one country, it may soon be possible to draw some lessons learned about level of investment required.

Programming: options for engagement

As an organisation with child well-being at the core of its mission and that works primarily through a community development approach, World Vision is well placed to engage in community-based support groups for PMTCT. In particular, World Vision could focus on the following areas of engagement:

- HIV and maternal and child health and nutrition
- Community engagement and links to local service providers
- Community Care Coalitions – a useful entry point for raising awareness about PMTCT
- Livelihoods expertise
- Faith-based approaches.

In particular, World Vision could engage through its Channels of Hope[10] programme, as well as link advocacy to programming at the local level, particularly using the approach outlined in the Citizen Voice and Action model[11].

Community-PMTCT is most relevant to World Vision's maternal, newborn and child health (MNCH) programmes in high HIV-prevalence countries and particularly to:

- Nutrition interventions for HIV-positive pregnant women
- Malaria prevention to PMTCT support groups
- Birth spacing programming and support
- Ensuring PMTCT services are accessible at all health facilities as soon as possible.

Of the 11 priority interventions for children in World Vision's health and nutrition strategy, appropriate breastfeeding and complementary feeding, as well as essential newborn care, are of particular relevance.

WORLD VISION: GLOBAL PROGRAMMING

Action on PMTCT should be a core part of all World Vision MNCH activities as it is an affordable and relatively straightforward intervention at the health facility level, and many of the community priorities, such as safe infant and young-child feeding, are an important part of any comprehensive MNCH strategy. All programmes working with people living with HIV should be able to provide high quality information on PMTCT, and ensure that all adults of child-bearing age who are HIV-positive have access to PMTCT services.

It is unlikely that community-based support groups specifically for PMTCT would be feasible or a priority for most countries with lower HIV prevalence. Experience has shown there has to be a sufficiently large number of women that qualify for the programme to make it relevant.

[10] Channels of Hope (CoH) is World Vision's programme for mobilising community leaders—especially faith leaders-- to respond to core issues affecting their communities, such as HIV and AIDS, maternal and child health, and gender equity and gender-based violence issues, and child protection. It is particularly effective in transforming attitudes about HIV & AIDS and for tackling stigma and discrimination.

[11] Citizen Voice and Action (CVA) is World Vision's approach to social accountability. CVA informs community members about their entitlements to services and their role as citizens. Using this information community members engage in discussion with service providers about the quality and coverage of the services provided. An action plan is produced that commits community members, service providers and other key stakeholders to working to address identified bottlenecks.

The first priority in high-prevalence areas or 'hot spots' is to ensure there is some form of systematised – *recognised and resourced* – support for community groups that link HIV-positive women and their families in the community to both PMTCT and to other HIV-treatment services. The next step should then be to address PMTCT through the following potential entry points:

- Community Care Coalitions (CCCs)
- Channels of Hope (CoH)
- Livelihoods support
- Timed and targeted counselling (ttC).

KEY ADVOCACY MESSAGES

- Comprehensive PMTCT services should be included when advocating for a global scale up to maternal, newborn and child health.
- National PMTCT guidance should include community-based components of PMTCT and include national minimum standards for community support groups.
- Information on prevention of vertical transmission, including infant and young-child feeding, must be presented in accessible forms to all women, literate and non-literate; health workers must have access to the latest information and be supported to share this information with others.
- Faith leaders and faith communities can provide a supportive environment for HIV-positive mothers, their partners and children to be able to reduce the risks of vertical transmission.
- National PMTCT policies and plans should support family involvement, primarily supporting the leadership of women living with HIV along with their families.

KEY RESEARCH QUESTIONS

Much remains to be learned about the added value of community-based mothers' support groups to reduce vertical HIV transmission and about how this is best undertaken. Some key research questions that need to be answered include:

- What are the costs and cost-effectiveness of community-based support groups?
- What is the best way to support safe infant feeding for HIV-positive mothers?
- Is a combination of group versus individual counselling support possible in lower-prevalence and deep rural areas?
- What approaches and mechanisms help ensure that marginalised groups of women have full access to PMTCT services?
- Are there additional 'enabling environment' factors to enhance support group outcomes? What is the best way to link support groups to economic and other parenting and maternal health support?

CONCLUSIONS

Overall, World Vision is in a very strong position to significantly increase PMTCT uptake and success where it already has HIV-related or MNCH activities and can make a successful community-health facility linkage. The engagement of faith communities, linked to other forms of community mobilisation, can do much to address stigma. Involvement of children is another 'added value' element that World Vision can bring, as is linking women's groups to non-health services such as livelihoods interventions and access to other social protection.