

# Communities taking action for women, mothers and children

**Communities are taking action to support women, mothers, their children and families to stay healthy and strong.**

*The Global Plan towards the Elimination of New Infections among Children by 2015 and Keeping their Mothers Alive* prioritizes community engagement. Without community, the Global Plan will struggle to reach its targets to reduce by 90% the number of new HIV infections among children and reduce by half the number of AIDS-related maternal deaths by 2015.

Now is the time to promote and support community action for women, mothers and children. This paper highlights good, replicable practices in community engagement. It is for:

- **Communities** looking for ideas on how to structure their work and how to advocate to policy makers to support and scale up community-led programs;
- **Governments and supporters** seeking to work with communities to develop effective responses to end vertical HIV transmission and keep mothers alive.



## WHY DO COMMUNITIES ENGAGE IN THIS WORK?

Most of the current efforts to reduce vertical transmission focus on accessing services through the formal health care system, particularly the HIV testing of pregnant women and provision of antiretroviral (ARV) prophylaxis. However, there are many gaps in the service delivery and in the uptake of services. These include:

- shortages of health workers and limited geographical coverage;
- discrimination by health care workers;
- poor quality of services, and weak referral systems and follow-up;
- inadequate information and misconceptions about how HIV is transmitted to babies;
- men preventing their partners from accessing services;

- financial difficulties of women living with HIV, including transport costs;
- women not knowing their rights and not being supported to claim their rights.

This is where community engagement can make a **big** difference.

Expanding access to services requires programs to go well beyond doing “more of the same”. The formal health care system alone is not dynamic enough to meet the needs of women and their families.

It is only by working with communities in the response that we can identify and address the real challenges to providing quality services that work for women, mothers and children.

Engaging communities in the design, development and delivery of programs ensures relevance, impact, ownership and sustainability and contributes to a reduction of HIV-related discrimination throughout the health sector.



## WHAT IS COMMUNITY ENGAGEMENT?

Communities are groups of people linked by common ties. Within the HIV response these communities include:

- networks of people living with HIV,
- community leaders, service users,
- faith-based organizations,
- advocacy groups.

Community engagement is a process of the community working collaboratively with Global Plan partners (governments, donors, medical service providers, legislators) to empower women to access health care through a rights-based approach.

## WHY WORK WITH COMMUNITY?

Community-based organizations, especially networks of women and mothers living with HIV, have many strengths that can be leveraged to advance rapid expansion of services for women, mothers and children and reduce HIV transmission and promote health and survival.

- We have the trust and endorsement of our communities.
- We have invaluable lived experiences.
- We are a massive “workforce”.
- We deeply care about the wellbeing of our children and families.
- We are trained, organized and highly skilled.
- We have extensive networks that reach into the community and beyond.
- We offer support from the perspective of community needs, making our response more holistic.
- We can build strong linkages with health facilities, ensuring women in the community have the direct peer support they need and are comfortable and feel confident to use services.

## HOW CAN OUR COMMUNITIES ENGAGE IN THIS WORK TO ACHIEVE RAPID SCALE UP?

Communities can play a vital role in reducing vertical transmission and keeping women and mothers alive. We can:

### 1. Improve the supply and quality of services by:

- serving as extension workers and expanding and supporting front-line health care workers
- creating links between community- and faith-based organizations and facility-based services
- monitoring and holding governments accountable to provide services that suit the needs of women and men.

### 2. Increase the uptake of services, including ARV adherence and facility delivery and follow-up by:

- participating in campaigns for behavior change and reduction of discrimination
- providing peer support
- maximizing the use of community assets and resources

### 3. Create an enabling environment by:

- advocating for scale-up and the right to sexual and reproductive health
- promoting community engagement in policies and strategies



# 1 IMPROVE THE SUPPLY AND QUALITY OF SERVICES



Community engagement complements work done by health facilities by engaging community members as extension workers, and linking community-based and faith-based organizations. Engaging communities in monitoring and evaluation of services can increase quality and uptake. A collaborative process between communities, health workers and local authorities benefits programs by increasing ownership and accountability of programs, and this ultimately improves health outcomes.



## MENTOR MOTHERS, SOUTH AFRICA AND BEYOND



**Engagement of women living with HIV as mentor mothers is an important strategy for scale-up of quality services to reduce vertical HIV transmission and keep mothers healthy. Mothers living with HIV are trained and employed as part of a medical team to support, educate and empower pregnant women and new mothers about their health and the health of their babies.**

In Masihambisane, South Africa, women living with HIV are recruited as “Mentor Mothers”. Selection criteria includes being passionate about community empowerment. Six weeks training is supported by on-going supervision and debriefing with a psychologist. The mentors then meet with women undergoing testing, disclose their status, and offer support. They give information talks at the clinic and run groups and one-on-one sessions with pregnant women after they have tested.

Another example of mentor mothers is “Mothers2Mothers” (M2M) project which operates at 714 sites in nine countries. In M2M, mentor mothers are salaried and brought into a well-developed structure that includes training, supervision and career development. The project has recorded increased postpartum CD4 testing, ARV uptake, treatment initiation, HIV disclosure, and infant testing. In Kenya rates of ARV uptake among women who interacted with mentor mothers at least four times was 97%, compared with 62% among women with no interaction.

## WOMEN-LED RESPONSE, KENYA



**Women Fighting AIDS Kenya (WOFAK) is a community-based organization that supports scale up of programs to reduce vertical HIV transmission both at the policy level and through community programs.** Today 15,000 women and 5,000 children receive care and support at seven centres. Services include prevention education, support groups, clinical care, nutritional care and feeding programs. WOFAK Mamas’ Clubs provide micro-credit loans through community outreach to individuals and groups. WOFAK promotes male involvement through counselling and home visits. These interventions led to an increase in counselling for discordant couples and reduced loss to follow up. At one centre, 50% of male partners attended antenatal care in 2009, compared to none in 2007. This program is an example of sustainability as it continues to grow and be led by women living with HIV after other NGOs have left.

## COMMUNITY ENGAGEMENT IN MONITORING SERVICES, UGANDA



**In Uganda, 50 communities over nine districts were informed of their rights, given baseline information on health services and issued with “report cards”. The communities were encouraged to identify solutions, develop remedial action plans, and implement and monitor them.** The process was accomplished through meetings with community members, with health facility staff, and then with both groups together. The end result was a jointly-owned action plan to address identified concerns within existing resources. After one year, as well as an increase in antenatal visits, facility deliveries and family planning visits, there were significant gains in infant weight-for-age and a 33% reduction in deaths among children under five years. At an estimated US\$300 per child death averted, this intervention is cost-effective and scalable, since it reached approximately 55,000 households.

## 2 INCREASE UPTAKE OF SERVICES



Community-led communication is a powerful tool for building local leadership and transforming attitudes. Involvement of people living with HIV results in significant reduction of discrimination in the health sector and improves service uptake. Peers have the unique ability to act as role models and provide experience-based counselling, including treatment adherence counselling.



Promising practices described here include faith-based organizations involving men to lead behaviour change, empowering people living with HIV and other community members to become active agents of change, and making the best use of the assets and resources that communities have.

### INVOLVING MEN IN ANTENATAL CARE, ZAMBIA



The Catholic Medical Mission Board in Zambia developed a communication strategy, “Men Taking Action” (MTA), to promote male involvement in reducing paediatric HIV. MTA identified that traditional leaders can feel threatened and become resistant if they are left out of community-based programming so they engaged these leaders as allies and champions of prevention of vertical transmission. MTA identified male attitudes and practices that negatively impact on women’s access to services and then developed a community education strategy that aggressively targeted men to support their spouses, get tested for HIV together, and enrol in HIV care services if they test positive. Men began taking a lead in encouraging women to attend antenatal care. In the first five months, 65% of the 2,261 men reached by the program tested for HIV, compared with a baseline rate of 11%. There was a fourfold increase in same-day counselling and testing of pregnant couples. Antenatal clinic clients’ acceptance of HIV counselling and testing rose from 60% to 95%, and acceptance rates for ARV prophylaxis or treatment rose from 40% to 70% among women who tested positive. Success of the program was due to the full engagement of respected community leaders.





## COMMUNITY OUTREACH, INDIA



**LEPRA is a community-based organization in India that operates in 5,000 villages and has managed to reduce parent-to-child transmission of HIV and improve antenatal and postnatal care.**

**Community members, including people living with HIV, are engaged as community health workers to bridge the gap between clinical services and the community.** The program offers a comprehensive package of services including home visits, one-on-one counselling, group interaction, family support, HIV disclosure support, and partner and infant testing. The program uses cultural events to promote the legitimacy and rights of women living with HIV to pregnancy and safe deliveries. *Well Baby Shows* challenge perceptions and show that women with HIV can have healthy babies. Significant impact is reported as a result of the program. Women have become more willing to share personal information which they were typically reticent to share with clinic staff, and this enables follow up after delivery. Institutional deliveries increased from 48% to 93% over five years, and HIV transmission to babies reduced from 24% to 3%.



## PEER EXTENSION WORKERS, UGANDA



**In the Nyimbwa Multipurpose Self-Help Group in Uganda, people openly living with HIV are selected as Network Support Agents (NSAs) and trained in ARV adherence, nutrition, pregnancy and HIV, disclosure, and counselling.**

They then spend two days a week at the clinic and three in the community. NSAs bridge the gap between the health care system and the community by strengthening referral systems and follow up. They mobilize people to use existing clinic-based services and support services. NSAs' ability to be open about their HIV status has positive benefits in addressing stigma and discrimination in the community and in hospitals. The NSAs reach remote communities on foot or by bicycle, sharing the message that all is not lost with a diagnosis of HIV, and sensitizing the community to the fact that treatment is available. These peer extension workers serve as role models and have earned the respect of clinic staff and the community. A health worker from the project said: *"People believe them in a way they never believed the health workers. They have helped. People are more comfortable coming to the clinics since they know they will find their peers at the facility"*. From 2006 to 2009, 1,300 NSAs operated in 40 districts. In one district, between 2008 and 2009, the number of people accessing services to reduce vertical transmission increased from 1,264 to 15,892 as a result of NSA referrals.

# 3 CREATE AN ENABLING ENVIRONMENT FOR SCALE-UP



Communities can effectively advocate to improve policies and programs that support maternal, neonatal and child health, and get results. Women living with HIV play an essential role in sensitizing maternal health care workers about their sexual and reproductive rights. Sustained advocacy and activism is required to build a sufficiently enabling environment for the rapid scale up of the Global Plan.



## COMMUNITY MOBILIZATION, SOUTH AFRICA



**The Treatment Action Campaign (TAC) in South Africa combined human rights education, HIV treatment literacy, and public demonstrations, with a constitutional court case to pressure the Government to roll out ARVs for prevention of vertical HIV transmission, and these combined actions led to tangible improvements.** In rural settings, TAC learnt that it is much cheaper to tackle reduction of paediatric HIV through the primary health care system than secondary health institutions and that this approach benefits clients throughout their lives. TAC conducts in-service training of health clinic staff and education of clinic clients via “Prevention and Treatment Literacy Practitioners”. They do contact tracing, adherence measuring, and ensuring infants’ PCR confirmatory tests are conducted at six weeks and 18 months. Mobilization and awareness about equal rights to treatment and to freely choose pregnancy is achieved through media as well as community door-to-door campaigns conducted by TAC members.

## LEGAL CHALLENGE TO RIGHT TO HEALTH, UGANDA



**In an unprecedented case concerning preventable maternal deaths in public-sector facilities in Uganda, civil society organizations and the families of two women who died in childbirth are suing the Government** for non-provision of essential services to pregnant women and their newborns, claiming this is a breach of the Government’s fundamental obligation to uphold the Constitution and a violation of the right to health and the right to life. When court action was delayed, hundreds of advocates took to the streets in protest.

## GOING FOR GOLD, RWANDA



**In Rwanda vertical HIV transmission rates had reduced to less than 3% by 2010. Improving male involvement was identified as key to this success.** Rwanda’s effort is grounded in political advocacy and intensive community mobilization with local authorities, community health workers and “male champion” peer educators. Program accountability was decentralized through performance-based contracts with local authorities. Male partner testing increased rapidly from 16% in 2002–3 to 84% in 2009–10, indicating widespread transformation of deep-seated gender norms and practices.



## HOW CAN COMMUNITIES BE SUPPORTED?

Effective community engagement needs a sustained capacity-building process to enable community members to participate in program design, implementation and monitoring. This in turn requires financial and technical support and investment.

Meaningful involvement of networks of people living with HIV is a key element of many successful HIV programs and will enhance scale-up. People living with HIV are experts and are already implementing diverse, effective, community-engagement strategies that are improving services.

## INVESTING IN SUSTAINABILITY

Training and ongoing supervision are critical for effective community engagement. Investment in developing local advocacy skills and sustaining strategic activism, particularly among women and mothers living with HIV, who are the people most committed to having healthy, HIV-free babies, may prove pivotal in global success to reduce vertical HIV transmission and reduce maternal AIDS-related deaths.

Community engagement can be relatively inexpensive compared with externally-driven interventions but it still requires support. Financial and technical investment is needed not only to build skills but also to coordinate and implement programs. Community workers operate optimally when communities have a say in their recruitment. These workers and their organizations also need some form of compensation to sustain their activities.

Many effective community engagement strategies are improving service uptake and achieving positive health outcomes. We know what is needed and it cannot be done without us. What remains is to share, strengthen and apply that knowledge and rapidly scale up community engagement programs that will reduce HIV in children and keep their mothers alive.

## ADDITIONAL RESOURCES

- GNP+, ICW, ITPC, 2011. Briefing Paper. *What is the 'Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive'?* *What does it mean for people living with HIV?* Available at: [http://www.gnplus.net/images/stories/SRHR/2011\\_PVT\\_GP\\_briefing\\_paper.pdf](http://www.gnplus.net/images/stories/SRHR/2011_PVT_GP_briefing_paper.pdf)
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- CCABA, Global Fund, RIATT, UNICEF, UNAIDS, 2011. *Second Road to Washington Meeting Advocacy and Best Practice Report, Addis Ababa, 2–3 December 2011.* Available at: [http://ccaba.org/resources\\_addisababa.html](http://ccaba.org/resources_addisababa.html)
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For any questions or comments, please contact [globalplan@unaids.org](mailto:globalplan@unaids.org), and your enquiry will be directed to the appropriate person for follow-up.

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