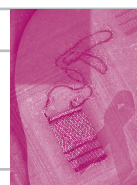


Mothers 2 Mothers



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South Africa has the highest number of AIDS orphans (1.2 million) and the highest number of women (3.1 million) and children below the age of 15 (240 000) living with HIV in the world. One of the most critical elements in the fight against the HIV/AIDS epidemic is prevention of mother-to-child transmission (PMTCT) of the virus – both during and after pregnancy. In resource-rich nations with access to antiretroviral therapy (ART) and replacement feeding, transmission has been reduced to 1 - 2%, and paediatric AIDS has been virtually eliminated. In resource-poor countries this is not the case, and transmission rates may be as high as 40% if mothers do not know their HIV status, do not receive prophylactic antiretroviral therapy during pregnancy and do not adhere to exclusive infant feeding methods.

For effective PMTCT intervention, a pregnant woman must be informed, choose to undergo testing for HIV and adhere to drug regimens. Optimally she will educate herself and her family about the protocols for caring for herself and her new baby. Most women in South Africa only discover that they are HIV positive when they become pregnant. Often a pregnant woman faces these challenges on her own, afraid to disclose her HIV status to partner, friends or family. Health care workers at state facilities in South Africa are dealing with high patient volumes and have barely enough time to manage their traditional clinical responsibilities, let alone provide the complementary social and emotional support necessary for comprehensive and effective HIV/AIDS care. Without such measures to ensure that mother and baby access ongoing wellness care and, when indicated, clinics providing ART, the benefits of PMTCT care are diminished and opportunities are lost to maintain the health and survival of mother and child.

An innovative and powerful HIV/AIDS prevention and treatment support project, Mothers 2 Mothers (M2M), uses education and empowerment as tools to prevent mother-to-child transmission of HIV, combat stigma within families and communities, support a mother's adherence to medical treatment, reduce the likelihood of AIDS orphans and support the transition to ART. Located in clinics that offer medical treatment to HIV-positive women, M2M provides the essential social services that complement the medical services provided by the public health system; providing a secure, warm environment where women can feel safe to share their

feelings and fears – about the health of their children; disclosure to their partners, friends and family; and the helplessness engendered by being alone, pregnant and infected with the AIDS virus. A simple idea, M2M has developed a unique model at the community level that is both cost-effective and easily replicable and adaptable to any culture.

In collaboration and close consultation with medical and local non-governmental organisation (NGO) partners, M2M has customised its services to meet the needs of populations and clinics in widely varying areas. Its services are offered in clinics, delivery suites, postpartum wards and patients' homes and communities. M2M services can link women to antenatal and postnatal services, infant HIV prophylaxis, testing and related services, ART sites, home-based care, treatment for opportunistic infections and care for orphans and vulnerable children. Most importantly, M2M is able to link mothers to local networks that provide ongoing social support, making referrals to community-based and faith-based organisations that offer clinical, psychological and economic support and services.

Background

M2M was founded in 2001 by US-trained obstetrician and gynaecologist Dr Mitchell Besser. After extensive experience during the 1990s in PMTCT services in the USA, Dr Besser joined the University of Cape Town's Department of Obstetrics and Gynaecology in 1999. During his involvement in establishing antenatal care programmes and co-ordinating services for HIV-infected pregnant women, new mothers and infants in the Western Cape Province, Dr Besser became familiar with the design, implementation and shortcomings of provincial and national PMTCT programmes. His recognition of some of the key gaps in antenatal and PMTCT care, and the special social, education and economic needs of HIV-positive pregnant women and mothers, inspired the M2M programme.

HIV-positive women in PMTCT care face a set of specific challenges that may inhibit successful prevention of HIV infection in their infants.

- **Reluctance to undergo HIV testing related to stigma.** Despite testing being offered at most antenatal care sites, there is still considerable reluctance among women to undergo testing.

- **Inability to effectively deliver PMTCT-related antiretroviral therapy to pregnant women with HIV.** While medications such as zidovudine (AZT) and nevirapine (NVP) are readily available and affordable, clinic staff often lack time to ensure their effective delivery to mothers and to provide the educational and psychosocial component of support necessary for adherence.
- **Non-exclusive infant feeding causing postpartum transmission of the virus to the baby.** Exclusive formula feeding and breastfeeding have both been associated with reduced rates of HIV transmission. However, mixed feeding is the norm in South Africa. Mothers who are able to disclose their HIV status and receive support from partner, family members and friends are more likely to adhere to an exclusive method of infant feeding and are thus less likely to expose their babies to higher risks of HIV transmission.
- **Mothers and babies failing to access health and life-sustaining medical/HIV care after delivery.** For most women PMTCT programmes are the entry point into HIV/AIDS care. PMTCT interventions during antenatal care and delivery are dedicated to reducing vertical transmission. Yet after delivery, when these efforts need to be redoubled, mothers do not routinely bring infants back for HIV testing or access HIV care for themselves. With the state rollout of ARV therapy in South Africa, it is vital to ensure a smooth transition from PMTCT programmes to HIV/AIDS care for women and children after pregnancy.
- **Lack of understanding about and support for women living with HIV/AIDS.** A positive HIV test is often seen as a death sentence without hope or options. With education and understanding comes a greater acceptance among mothers of measures to reduce vertical transmission and promote health. With social support women are more likely to disclose their HIV status to partners, family and friends. Decisions and actions that contribute to safer sex practices, proper nutrition and adherence to medical therapies are all encouraged with education and support.

The Mothers 2 Mothers programme

M2M's key objectives are to:

- Reduce the number of babies infected with HIV during or after delivery
- Promote the health of pregnant women and new mothers and increase their opportunities to access and effectively use health and life-sustaining ART
- Support disclosure and fight stigma

- Empower HIV-positive pregnant women and new mothers to engage partners, families and communities, increasing awareness about HIV and services available to people living with HIV/AIDS (PLWHA)
- Strengthen health care services by training health care workers in care, education, counselling and treatment related to PMTCT.

M2M has developed an effective, innovative model to achieve its objectives, employing mothers living with HIV as peer educators and care providers, and calling them 'Mentor Mothers'. Mothers, as primary caregivers, comprise an affected community's greatest renewable resource. The strength and success of M2M lies in its utilisation of this previously untapped resource: HIV-positive mothers who are uniquely qualified to address the special needs of other pregnant women and new mothers. Mothers living with HIV, serving as peer mentors and educators, can ensure continued access to medical care for pregnant women and postpartum mothers, as well as adherence to ART and infant feeding practices that will decrease the incidence of vertical transmission of the disease. Through peer-peer mentoring and support groups, mothers living with HIV help to empower other HIV-positive women to take control of their social, economic and sexual lives. As positive role models and professional, integrated members of the PMTCT health care team, Mentor Mothers play a powerful role in destigmatising HIV.

M2M works in partnership with provincial health departments in public health facilities to provide support services as part of a continuum of medical care that starts with a pregnant woman accessing antenatal care and continues through pregnancy, delivery and postpartum care. Although a woman begins this psychosocial care alone in a health facility after being diagnosed with HIV, the services rapidly extend to her partner, family, home and community. M2M activities complement the efforts of – and fill the gaps in – a clinical model reliant on doctors, nurses, and lay counsellors already overburdened fulfilling their clinical responsibilities. M2M aims to make a significant contribution to developing sustainable, patient-responsive structures in the public health facilities within which it works.

Mentor Mothers are the key care providers. Drawn from the pool of women living with HIV who have attended PMTCT programmes in the health care facility, Mentor Mothers engage women individually and in groups, sharing material from a formal curriculum developed by and distributed to all service sites by M2M. Site Coordinators, HIV-positive mothers trained in HIV, ART and PMTCT care and programme management, oversee the day-to-day activities at each M2M service site, and are responsible for collecting data for monitoring and evaluation. M2M Programme Managers are responsible for service at all sites in a district and are the primary managers of site establishment.

M2M's curriculum for patient care contributes to increased testing and improved adherence to interventions during and after pregnancy in order to sustain the health of the mother and reduce the risk of the baby acquiring HIV. In addition, M2M strives to build the capacity of health care staff, including doctors, nurses and lay counsellors, through involvement in M2M training activities.

M2M programmes are offered as part of the antenatal care package in hospitals, community health centres and clinics providing PMTCT services. M2M offers services with a primary objective of increasing the number of women learning about HIV in pregnancy, receiving counselling related to HIV testing during pregnancy and accepting HIV testing as part of antenatal care. M2M introduces HIV and voluntary counselling and testing (VCT) to all women attending antenatal care for their first 'booking' visit during group and individual education sessions. In some PMTCT clinics, M2M staff will provide the morning health talk, conduct pre-test group and individual pre- and post-test counselling, and make referrals to ongoing support groups.

The real impact of M2M begins when mothers who test positive for HIV or decline HIV testing are referred by lay counsellors and nurses to M2M support systems. M2M site staff engage with these patients, educating and supporting those who are positive and discussing the merits of HIV testing for those who may initially have declined to test. Mothers who test positive are included in individual and group education and support activities designed to increase their knowledge, understanding and acceptance of their HIV status.

The M2M programme is designed to be a critical entry point to care for women dealing with a life-transforming experience. During individual and group support, education topics include life-sustaining ARV therapy for people with advanced HIV infections or AIDS, safer sex practices, disclosure of HIV status to partner and family, and individualised consideration of how best to feed the newborn baby. In addition, Mentor Mothers help women to understand how to take the ARV medicines administered during pregnancy for PMTCT, an education component that doctors and nurses are often too pressed for time to undertake.

Pregnant women who test positive for HIV are also seen by Mentor Mothers during and after delivery, and women in labour can also receive this support. After delivery Mentor Mothers ensure that babies receive NVP before discharge; educate mothers about self-care and infant care, including guidance on feeding choices; encourage mothers to return for follow-up visits at the baby clinic and M2M support groups; and assist nursing staff with discharge teaching and planning.

During postpartum ward education mothers are encouraged to return with their infants for follow-up care at M2M groups, ideally until the baby can undergo HIV testing. Mentor Mothers emphasise the importance

of adherence to the selected infant feeding method, practising safer sex, and accessing medical services for both mother and baby. Women who are eligible for ARVs will be referred to clinics for treatment and will be monitored during postpartum M2M groups to ensure their attendance for these services. Mothers on ARV therapy will be supported to promote adherence. Mothers will be encouraged to return to the clinic with the baby for HIV testing. Mentor Mothers also visit women at home to provide additional support where necessary, often with issues around disclosure.

M2M was designed specifically to speak to the postpartum woman's questions and needs with regard to feeding, accessing wellness and ARV services, and adjusting to life in the community as a woman and mother living with HIV. M2M fully acknowledges the physically and emotionally charged nature of the postpartum period, with its challenges no less than, and probably greater than, those faced in pregnancy.

Through their co-location in PMTCT programmes, M2M services reach HIV-positive pregnant women and mothers and extend beyond to their families – promoting the health of unborn babies, and engaging older children and partners in prevention and treatment for HIV/AIDS and other illnesses. By providing consistent education and mentoring, M2M develops relationships of trust with entire families. Partners of women living with HIV are encouraged to test for HIV, be faithful and adhere to safer sex methods. Mentor Mothers, themselves living with HIV, bring with them credibility and sensitivity often missing in traditional clinical settings.

Community outreach

M2M also extends its services into the community as part of a comprehensive service model to address the needs of pregnant women and mothers living with HIV. M2M's community programme provides community outreach, visiting women in their homes, encouraging adherence to infant feeding choices, safe sex, family planning, healthy lifestyles, adherence to ARV therapy and attendance at medical appointments. M2M mentors also link up with existing community-based organisations promoting awareness about HIV and contributing to the de-stigmatisation of HIV. With the roll-out of ARV programmes across South Africa, M2M programmes can play an important role in ensuring that mothers who are eligible access treatment services and that those on ARVs continue to take them properly after delivery. In rural areas where women cannot travel to the nearest health care facility for ANC visits and/or delivery, Mentor Mothers travel (either on their own or with mobile clinics) to provide education and mentoring in farming communities.

In two of M2M's Cape Town's sites, postpartum support groups were used as a platform for a skills development and income generation programme, Mothers' Creations. The rationale for Mothers' Creations is the reality



that many mothers living with HIV are the primary providers for their families and therefore need to generate income to ensure their survival. Since November 2002, Mothers' Creations has paid participating mothers more than R3 million for the products made in their groups.

History of Mothers 2 Mothers

In October 2001, the first M2M pilot site was launched at the Maternity Centre at Groote Schuur Hospital in Cape Town, South Africa. As the demand for its services grew, M2M scaled up its services in the country rapidly, expanding from 11 to 60 sites in just 18 months. At present, M2M offers services in over 74 sites in four provinces in South Africa – Western Cape, KwaZulu-Natal, Eastern Cape and Mpumalanga – providing care for more than 17 000 women each month at an overall cost per mother of around \$30 (Fig. 1).

M2M meets needs in urban, peri-urban and rural settings, providing care in both high population density, high HIV seroprevalence areas such as Khayelitsha, Cape Town, and low population density, high HIV seroprevalence areas such as the Western Cape's Garden Route. In busy sites like Khayelitsha's Site B clinic, three to four Mentor Mothers and a Site Co-ordinator attend the clinic each day providing care to women attending antenatal care, women in postpartum wards and women returning with their babies for post-delivery support (Fig. 2). In quieter clinics along the Garden Route, where fewer women receive care and women do not deliver in primary health centres, M2M may only provide service one or two days each week and one Mentor Mother may provide care in multiple clinics (Fig. 3).

In the coming years, grants from the United States Government's Presidential Emergency Plan for AIDS Relief (PEPFAR) will extend services in South Africa to an additional 60 sites in KwaZulu-

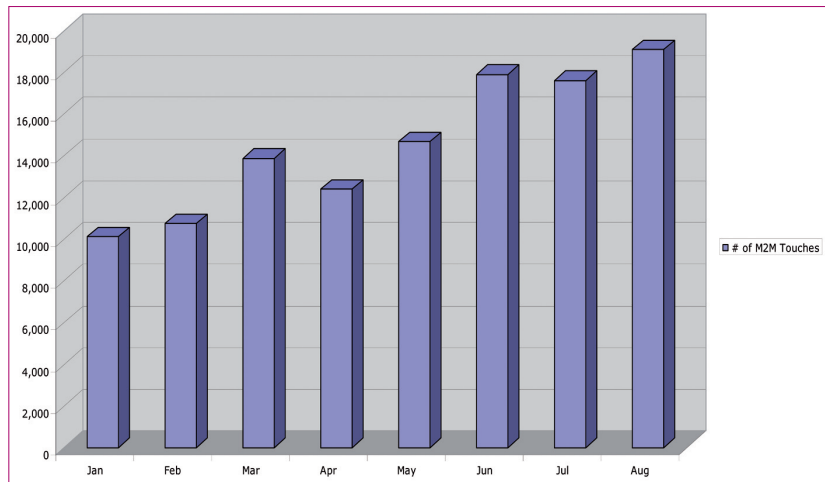


Fig. 1. M2M-SA client touches by month, 2006.

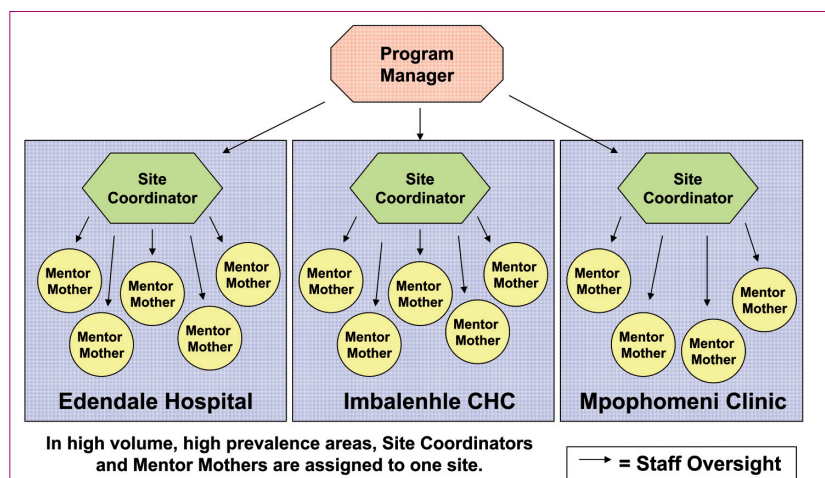


Fig. 2. Site management plan: high volume, high prevalence (as practised in Pietermaritzburg, KwaZulu-Natal).

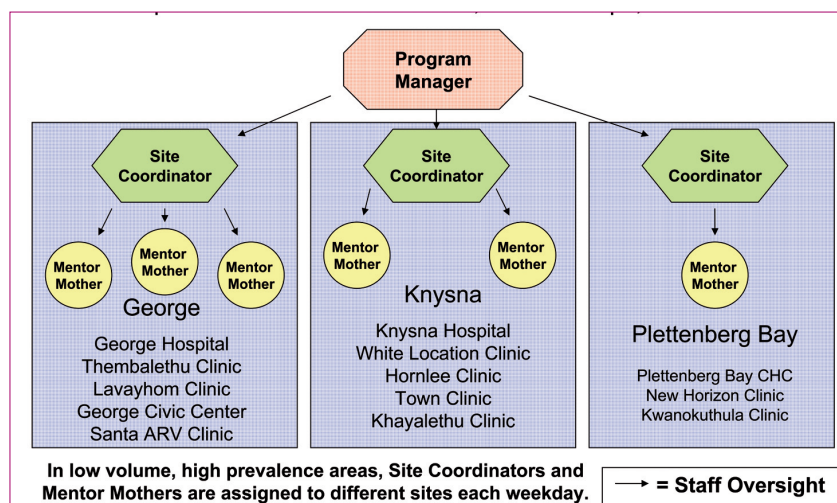


Fig. 3. Site management plan: low volume, high prevalence (as practised on the Garden Route, Eastern Cape).

Natal and 5 sites in the Western Cape. Funding from Atlantic Philanthropies will support 15 new sites in KwaZulu Natal; and funding from the Mpumalanga Department of Health will contribute to doubling

services from seven existing sites to a total of 14 sites.

At each M2M site, the positive response from the beneficiaries and health care staff has confirmed

the powerful role that support services and education can play in the delivery of HIV-related medical services. A formal evaluation of M2M services, sponsored by the Population Council's Horizon Programme, is underway at three sites in Pietermaritzburg, KZN. Findings from this evaluation will be available in 2007. Data obtained from two M2M programmes in the Eastern Cape Province support its impact on the number of women electing to undergo PMTCT-linked HIV testing; increasing from 100 - 150 per month before either programme opened, to 200 in September (after the first programme opened in August), to 250 - 300 per month after the second programme had opened in January 2006 (Fig. 4).

Since 2005, M2M programmes have been in operation in Ethiopia, in partnership with IntraHealth, and in Botswana, in partnership with Pathfinder International and the Botswana Christian AIDS Intervention Program (BOCAIP). In the coming year M2M will extend its services in Africa to low population density, lower HIV seroprevalence areas such as rural Kenya, in partnership with the Catholic Medical Missions Board, and to other parts of East Africa in affiliation with UNICEF. In these communities, women attend antenatal care less frequently, are more likely to deliver at home and need PMTCT services brought to their door. M2M will station a Mentor Mother in a community-based health station from which she can engage mothers who deliver at home (Fig. 5). Proposals under consideration would contribute to 150 programmes in Rwanda, Kenya and Zambia. Discussions with the Clinton HIV/AIDS Initiative will carry M2M into Lesotho in 2007.

M2M is incorporated as a non-profit organisation in South Africa, England and the USA. The National Office, based in Cape Town, is responsible for centralised functions including curriculum development for training site and facility staff and M2M participants; financial management; human resources; programme

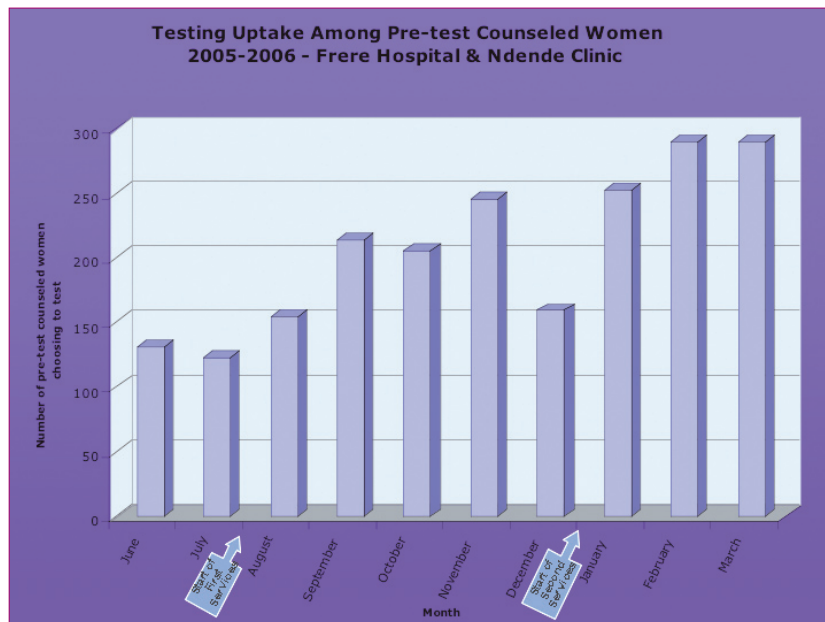


Fig. 4. Testing uptake among pre-test counselled women, 2005 - 2006, Frere Hospital and Ndende Clinic (East London, E Cape).

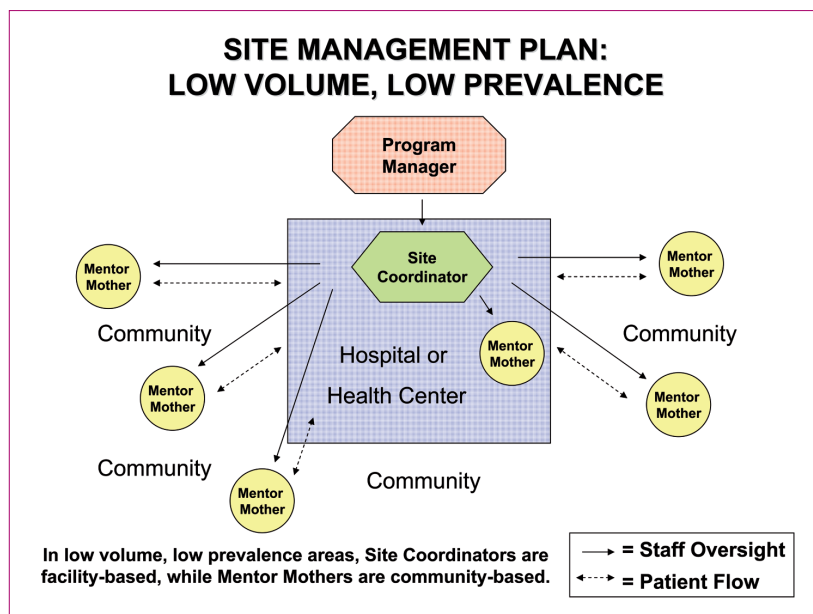


Fig. 5. Site management plan: low volume, low prevalence.

monitoring and evaluation; technical assistance; new site development; Mothers' Creations management; and advocacy. A second office in Los Angeles, California, focuses on fundraising, partnership development, programme planning and public relations.

In addition to the support M2M receives from PEPFAR, the United States Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC), in South Africa the programme has benefited

from substantial funding support from a wide range of stakeholders, including the Community Chest of the Western Cape, City of Cape Town, Doctors without Borders (Médecins sans Frontières), the Ackerman Foundation, Pick 'n Pay, Nederberg Wines, First National Bank, Woolworths and the Mpumalanga Department of Health.

Conclusion

Over the past 5 years, M2M has developed and refined a replicable, scalable, sustainable, integrated

cost-effective model of peer-based psychosocial support, based within clinical settings, to support the delivery and effectiveness of PMTCT services and to address the specific challenges facing pregnant women and mothers living with HIV.

M2M is, at its core, a project to foster female empowerment and develop local capacity and resources in the struggle against HIV/AIDS. Through their involvement in M2M, Mentor Mothers take 'ownership' of the programme, and through their work and example they empower other HIV-positive women to make informed choices and adopt positive attitudes as they take control of their social, economic and sexual lives. M2M staff act as role models and leaders among their peers and in their families and communities, and contribute to de-stigmatising HIV and promoting disclosure. The sense of community and support engendered by M2M groups encourages mothers to return to the clinic for antenatal, postnatal, and paediatric care. Similarly, by engaging PLWHA, M2M mobilises entire communities towards awareness and de-stigmatisation, stimulating broad-reaching change.

We see this epidemic in terms of populations affected. We count faceless millions who get infected and die. We measure prevention and treatment programmes

by numbers of HIV cases averted and people receiving ART. We see our programme's growth in the size of budgets and the numbers of programme sites – but in the end, its impact can be heard most clearly in the stories of the women who have been touched by M2M as patients and caregivers.

'Only after I had conquered all my fears, doubts, uncertainties and ignorance towards my condition ... was I able to dream again ... My involvement with M2M gave me the opportunity to bring this positive message closer to home ... M2M expanded my knowledge about HIV/AIDS. It empowered me to empower the other positive women with whom I work on a daily basis. Last but not least, it really gives me a sense of belonging where there is a common goal.' (Patty Thomas Brooks, M2M Site Co-ordinator at TC Newman Community Health Centre in Paarl, Western Cape.)

'If I feel telling someone my status can help, I don't hesitate. If you think being HIV-positive is going to send you to the grave tomorrow, just look at me.' (Boniswa, 28 years old, M2M participant.)

For more information on Mothers 2 Mothers, please contact Robin Smalley at robin@m2m.org or visit the website: www.m2m.org

