

Interim Findings on the National PMTCT Pilot Sites



**HEALTH
SYSTEMS
TRUST**



DEPARTMENT OF HEALTH
South Africa

**Summary of
Lessons and
Recommendations**

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Introducing this booklet

HIV/AIDS is affecting everyone in South Africa. There are many organisations and individuals working hard to fight the spread of the virus. In 2000 the South African government introduced a programme offering prevention of mother-to-child transmission (PMTCT) services at 18 pilot sites. The programme is an important part of the country's response to the epidemic.

This booklet provides some basic facts about the effects of the

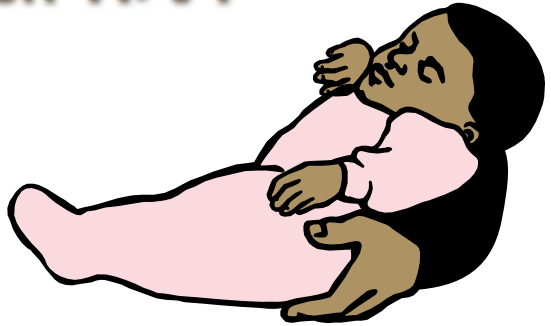
medicine, Nevirapine, and formula feeding in a PMTCT programme. It then goes on to summarise the interim findings of an evaluation of the pilot sites. In the evaluation the process of setting up the sites and the progress being made in delivering services at each site was examined.

In particular, the evaluation aimed at assessing how successfully the following were being provided:

- > Voluntary HIV testing to pregnant women.
- > The Nevirapine drug to HIV positive pregnant women.
- > Appropriate counselling and support for safe infant feeding practices.
- > Follow-up care for mothers and their babies after delivery.

It is important to note that the quality and effectiveness of any PMTCT programme rests on the efficiency of the public health system as a whole and not just on the dedicated management of the PMTCT programme itself. The evaluation therefore makes recommendations regarding the improvement of the health system as well as the PMTCT programme.

How do babies get infected with HIV?



There are three main stages when a baby can become infected with HIV:

- > **While the mother is pregnant**
- > **At the time of birth**
- > **When the mother is breastfeeding**

How do Nevirapine and formula feeding help prevent infection?

Various research studies have shown that Nevirapine is a safe drug that helps to prevent the transmission of HIV from a pregnant mother to her child. Studies have also shown that HIV can be passed over to a baby if it is breastfed. If a baby is exclusively formula fed (fed only on formula milk and nothing else) this stage of infection can be prevented. Formula feeding, however, has its own difficulties and complications and these are discussed further on in this booklet.

Here are some statistics of the rates of infection of a sample of 100 pregnant HIV positive women. The rates are approximate. They are not based on the evaluation of the South African pilot sites, but on various research studies.

Rates of Infection

In a sample of 100 HIV positive pregnant women who receive no PMTCT treatment:

- 23 babies will be born HIV positive.
- During 12 months of breast feeding, a further 8 will become infected.
- There will be a total of 31 infected babies.

In the same sample, where Nevirapine is administered, but mothers continue to breastfeed their babies:

- 13 babies will be born HIV positive.
- During 12 months of breast feeding, a further 9 will become infected.
- There will be a total of 22 infected babies.

In the same sample, where Nevirapine is administered and babies are given exclusive formula feeding:

- 13 babies will be born HIV positive.
- There will be no further infections.
- There will be a total of 13 infected babies.

The steps involved in preventing mother to child transmission

A PMTCT programme involves more than simply handing out Nevirapine and milk formula. The following are essential steps that must be provided for pregnant women and their babies, in any PMTCT programme:

- ✓ **Informing all pregnant women about HIV/AIDS and the benefits of HIV testing in pregnancy, so that they can decide if they want to be tested.**
- ✓ **Testing those women who wish to be tested.**
- ✓ **Reporting the results of the test to each woman, individually, and counselling those who are HIV positive.**
- ✓ **Ensuring that HIV positive pregnant women are given a tablet of Nevirapine to take home with them, which must be taken when they go into labour.**
- ✓ **Giving Nevirapine to the babies of HIV positive women between 24 and 72 hours after birth.**
- ✓ **Counselling HIV positive mothers about safe feeding practices and ensuring that those who choose not to breast feed are given milk formula.**

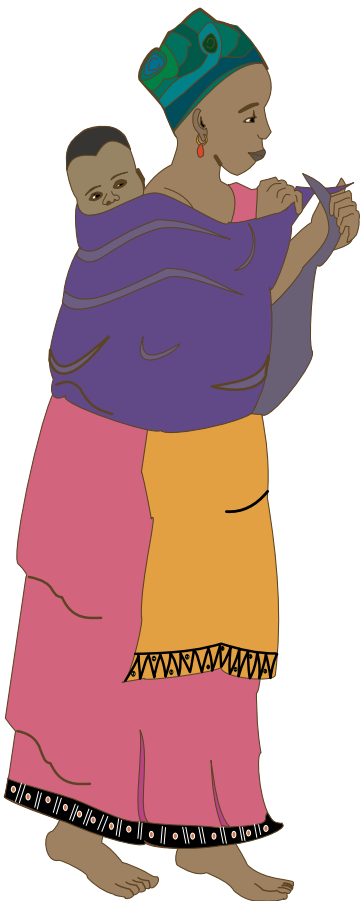
Providing these services would involve the country's health system in new organisation, co-ordination, management, and training. But they will result in the protection of numbers of babies from becoming infected with HIV.

Setting up the PMTCT pilot sites

The national HIV/AIDS Directorate set up 18 sites where a PMTCT programme could be piloted and where the lessons learnt from these pilot sites could be transferred to a wider programme. There are two sites in each province. Each site consists of at least one hospital and a number of other health facilities such as community health centres, Midwife obstetric units or clinics. In all, 193 health facilities are part of the programme.

Setting up the sites involved:

- **Developing guidelines for the treatment and care of patients and the financing of this.**
- **Selecting and preparing the 18 sites and training personnel as well as lay counsellors.**
- **Obtaining medicines, HIV testing kits and formula milk powder and working out how to store and distribute these.**
- **Creating new provincial posts to support the implementation of the programme.**
- **Developing an information and monitoring system.**



Start-up difficulties

Setting up the sites was a complex process and some sites only began implementing the programme in the second half of 2001. Some of the difficulties experienced were linked to the fact that the health system is still undergoing transformation. On-going structural changes, inefficiency and bureaucracy were some of the factors preventing the rapid implementation of the new programme. In many sites there were staff shortages and poor health facilities, as well as low morale and motivation amongst staff and denial and stigma within communities. The difficulty of working with nine different provincial Departments of Health was another factor.



Statistical information from pilot sites

An average of just over 6000 HIV pregnant women made use of PMTCT services at the pilot sites each month. This is approximately 9% of all pregnant women country wide who visit health facilities each month.

As PMTCT services are also being provided at other sites as well, which are not part of the pilot programme, the total number of pregnant women with access to testing, counselling and Nevirapine, is likely to be between 12% and 15%.

Other statistical information emerging from these sites:

- Of all the pregnant women visiting the sites, only 51% agreed to an HIV test. This percentage varies considerably amongst provinces. Western Cape and KwaZulu-Natal have the highest rates of women making use of the services and Mpumalanga and Limpopo the lowest rates.
- Of the women who agreed to testing, 30% were HIV positive.
- The correct administration of Nevirapine to both mother and child was only given to just under one third of pregnant HIV positive women.

Findings and recommendations from the PMTCT sites

The experiences in implementing the PMTCT programme have differed widely. Some provinces and sites are doing well, but others are struggling. Some of these difficulties are due to problems in the health care system in general and to unequal provision of infrastructure between provinces and sites. However, the evaluation of the PMTCT pilot sites, has provided important information on which to build a wider programme.

Organisation and Management

Good management and a well functioning provincial Department of Health as well as sound management at the district and sub-district levels, is a key factor to the success and sustainability of a PMTCT programme.

A number of organisational factors are involved. New staff have to be recruited and trained, space has to be created for counselling and an effective system must be set up to make sure that referrals take place correctly, that medicine, testing kits and formula are supplied and that the community is mobilised around the programme. All this requires effective and efficient management.

The following findings arise from the evaluation:

The Involvement of Provincial Governments

The most successful sites are where provincial government is involved at the highest level and where Directors of Primary Health Care, of HIV and of Maternal, Child and Women's Health play active leadership roles.

Some of the steps that successful provincial management has taken, include:

- The appointment of a dedicated 'driver' of the provincial programme, with the authority to make and implement decisions.
- The involvement of senior managers across department units, to ensure that the workload is shared and the programme operates at a horizontal level.
- The creation of a Chief Community Liaison Officer for the province.
- The co-ordination of a pool of PMTCT experts that sites in the province can draw on.

Preparation of sites

Sites that are well prepared before the services are implemented are most successful. This includes the planning of space and privacy, staff training and recruitment and training of lay counsellors.

Sites that are made up of a network of health facilities, including clinics are better suited for successful delivery of PMTCT services than a single isolated facility.

Budgets and funding

The grant from national government was held up and did not reach the provinces until September 2001. Provincial funds were used initially in order to move ahead with developing the pilot sites. When the national grant did come through, money was not available for infrastructure and provincial budgets had to be used for this.

Recommendations

- The highest level of provincial government needs to be involved in PMTCT services.
- There should be a more pro-active approach in some provinces towards the development of NGOs and other support groups such as People Living With AIDS. It will also be necessary to improve the capacity of the various Departments of Health to work with these groups effectively.
- In most provinces and sites there is a need to strengthen data capture, data management and programme evaluation skills.
- There is a need to strengthen financial management and develop on-site plans and budgets. This should include budgets for the creation of adequate space for HIV counselling and testing in the current sites and at other sites.
- The public health care sector should urgently speed up its structural re-organisation and establish functional sub-district health systems with decentralised management structures. Plans to upgrade physical infrastructure of Primary Health Care facilities and district hospitals across the country need to be speeded up.

Staff

The PMTCT programme has meant an increase in the workload and responsibilities for staff. In some provinces lay counsellors have been employed to help carry the load of counselling, but the workload of professional staff has increased, in spite of this. The HIV test, which takes an average of 30 minutes per client, must be done by professionals. Despite the presence of lay counsellors professional staff still have to do some counselling and teaching.

Some of the findings are:

- In a few sites there has been no additional staff and there are concerns that this increase in workload may lead to poor quality of care in other areas and to stress and burn-out.
- The recruitment and training of lay HIV counsellors to work with professional staff has been a very positive aspect of the PMTCT programme. However, some provinces are still not employing them and many of the 18 sites do not have enough.
- Provinces differ widely in the way that they recruit, train, manage and pay lay counsellors. Some provinces have chosen to contract NGOs to be responsible for all of this. Payment varies from nothing to R2 800 per month. Another problem in some provinces is that PMTCT counsellors are not paid the same as other community health workers, such as home based carers or DOTS supervisors of TB patients. All these inequalities are causing problems that ultimately affect the rate of women taking up the PMTCT services.

Recommendations

- ❑ The workload problem should be overcome by establishing minimum staffing levels for midwives, nurses, doctors and lay HIV workers. These should be based on workload and need. The national and provincial Departments of Health, particularly the Human Resource Directorates, must then be responsible for developing and implementing a plan to reach these staffing levels.
- ❑ Minimum staffing levels for PMTCT counselling should be based on the following:
 - Counselling before and after testing – an average of 60 minutes per client.
 - Two follow up sessions of counselling and support for HIV positive pregnant women – an average of 30 minutes per visit.
 - A maximum of 8 clients seen per day per counsellor.
- ❑ The management, training and remuneration of counsellors lacks co-ordination and consistency and needs to be addressed. There should be a move towards having a community of lay workers at sub-district level who could support both the HIV and TB programmes.
- ❑ The distribution of staff and staff rotation policies all point to a need to improve human resource management at all levels of the health system.
- ❑ Frontline staff need support and supervision. Peer support groups need to be organised to help prevent burn-out as well as de-briefing sessions with trained psychologists or social workers.
- ❑ The possibility of using a saliva test for HIV, which could be administered by lay counsellors, should be explored. This could relieve some of the workload on professional staff.

Training

Training is critical for the success of a PMTCT programme. Extensive training has taken place in the current pilot programme but not all staff have been covered. Organising training would therefore be a major challenge if the programme is expanded further.

Some of the findings include:

- The quality of counselling is strongly influenced by the quality of the training that counsellors receive. The way that provinces train counsellors varies. Many rely heavily on NGOs and university departments. Some have worked with nurse training institutions to develop undergraduate curricula that cover PMTCT. AIDS training and information centres have also been brought in to help provide training.

The evaluation of this training indicates that it is sometimes not culturally appropriate, it provides too much theory and not enough practice and does not adequately deal with the attitudes and prejudices of the trainees themselves.

- Many provinces have a high staff turnover which makes training a key challenge.
- There is insufficient on-site training and not enough focus on skills development and problem solving.
- Doctors play an important role in clinical leadership, quality control and training. Sites where doctors take a visible and proactive part in the PMTCT programme show positive benefits, whereas sites with little interest or support from doctors experience problems.



Recommendations

- ❑ A pool of experts and trainers with the commitment and time to provide training is needed in each province, especially if the PMTCT programme is to be expanded. These experts should be deployed to develop capacity in district hospitals and rural areas.
- ❑ HIV counselling and PMTCT must be taught thoroughly and effectively at all undergraduate health sciences training institutions. In addition, this needs to be balanced with more on-site, in-service training with a focus on skills development, local problem solving and changing attitudes towards HIV. There also needs to be more training on infant feeding and child health.
- ❑ The national office can provide additional assistance in such cases, by facilitating training support from non-governmental agencies and academic institutions.

HIV Counselling and Testing

The number of women taking up the PMTCT services offered at the pilot sites, depends to a large extent on the space available for counselling, on the quality and availability of good counselling and testing and also on the attitude within the community towards HIV/AIDS.

Below are some of the findings in relation to this.

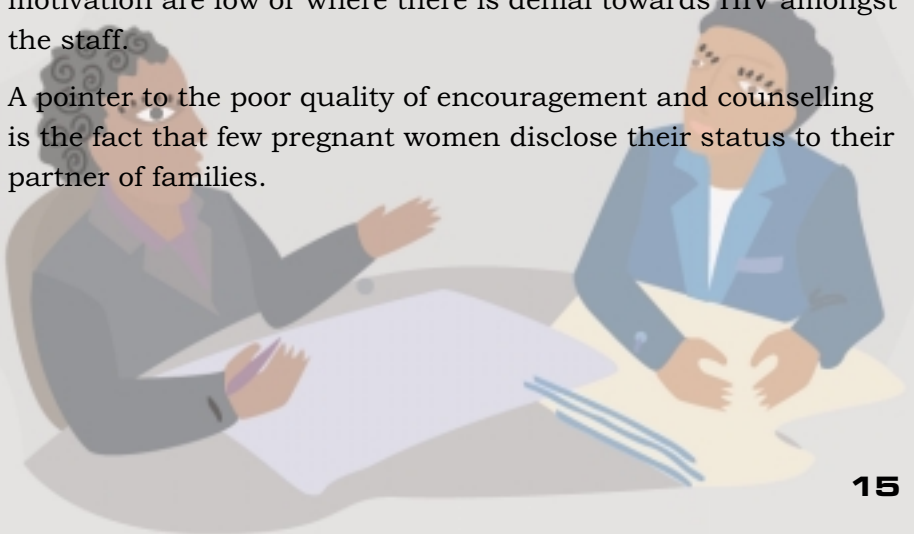
Space and privacy requirements

Counselling and testing require privacy and additional space. An evaluation of the 18 sites showed wide differences in facilities. Where testing and counselling take place in inappropriate places, this has a negative effect on the number of people making use of the services. However, where rooms for HIV counselling and testing are obviously marked off from other rooms, this can also act as a deterrent as people do not want to be seen going into one of these rooms.

The quality of encouragement and counselling

The PMTCT programme requires a pro-active approach whereby all pregnant women are actively encouraged to gain from the benefits of HIV testing.

- Quality is a serious problem in facilities where morale and motivation are low or where there is denial towards HIV amongst the staff.
- A pointer to the poor quality of encouragement and counselling is the fact that few pregnant women disclose their status to their partner or families.



Community attitudes

Community attitudes towards those living with AIDS can make a major difference to the number of pregnant women willing to be tested and counselled. Some provinces and sites have organised campaigns to help overcome stigma, denial, prejudice and ignorance.

Recommendations

- ❑ Many of the recommendations under 'Training' will impact on the quality of counselling.
- ❑ The term 'counselling' has come to be associated with gaining the consent for an HIV test. However, other important aspects of counselling need to be emphasised. These include the empowerment of women by providing them with information about HIV/AIDS, childbirth, child care and nutrition; advice and information about social security; support and advice about disclosing their HIV status and about how to live with the knowledge of being HIV positive.
- ❑ The PMTCT programme does not put sufficient emphasis on the possibility of providing 'couple HIV testing' as well as community-targeted interventions to address stigma, ignorance and prejudice. These components of the programme should be strengthened.



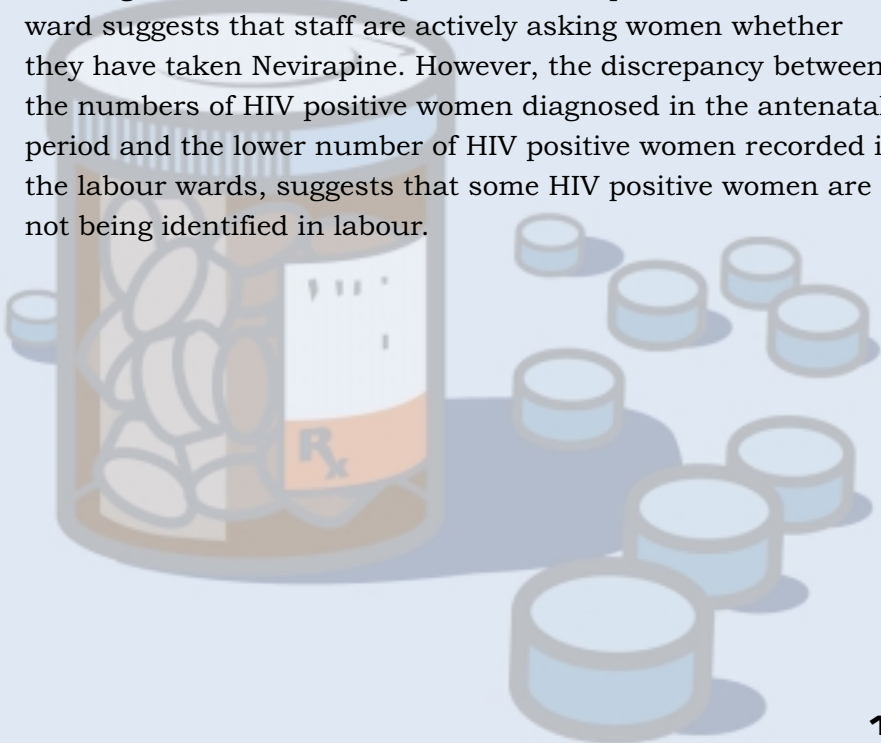
The administration of Nevirapine to mothers

HIV positive women who are over 28 weeks pregnant, and who have indicated that they wish to take up PMTCT services, should be given a tablet of Nevirapine to take when they go into labour. The earlier they take the tablet during active labour the better. If a woman takes the tablet without going into active labour, she should be given another tablet when she is in labour.

All this means that midwives and doctors working in a labour ward have to find out whether HIV positive women have taken a tablet and if not, to make sure that they are given one.

Some of the findings regarding this are:

- A high number of women require Nevirapine in the labour ward. This suggests that they either lost the tablet they were given or that they did not take it correctly when they went into labour.
- This high number of Nevirapine tablets dispensed in the labour ward suggests that staff are actively asking women whether they have taken Nevirapine. However, the discrepancy between the numbers of HIV positive women diagnosed in the antenatal period and the lower number of HIV positive women recorded in the labour wards, suggests that some HIV positive women are not being identified in labour.



Recommendations

Research is required to find out more information about the following:

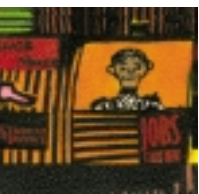


- Is Nevirapine, that has been dispensed to pregnant mothers, taken correctly?
- Are midwives and doctors pro-active in finding out if women in labour are HIV positive and have taken a Nevirapine tablet when they went into labour?
- Are labour wards able to provide adequate patient confidentiality regarding HIV status?

Obstetric practices

Obstetric practices refer to the medical and surgical practices that must happen at childbirth. A number of these are important for the correct and safe care of HIV positive women in labour. They help to reduce the possibility of transmission of the HIV virus to the child. The correct implementation of these practices will depend on staffing levels, expertise, experience and the capacity of doctors and midwives at the site. There has not yet been an in-depth review of these practices but the shortage of staff and the low quality of care in some facilities, indicate that these standard surgical practices may be inadequate.

Labour wards at some sites are currently treating all pregnant women as though they were HIV positive. At other sites there is an understanding that obstetric practices are different for women known to be HIV positive. There is therefore a lack of clarity around the guidelines for the care of HIV positive women in labour.



Recommendation

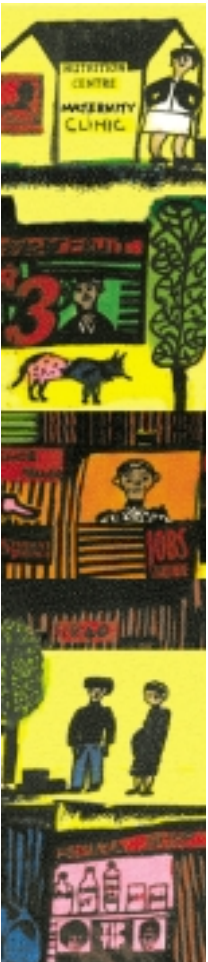
- The lack of clarity about the clinical and obstetric management of HIV positive women in labour needs to be addressed.

The administration of Nevirapine to newly born children

Babies of all HIV positive mothers should receive a dose of Nevirapine between 24 and 72 hours after delivery. If a mother took a Nevirapine tablet less than two hours before delivery, the baby should have two doses. Good continuity of care between the labour ward and the wards where the babies are cared for after birth is therefore very important.

Recommendation

- The guidelines on the timing of the Nevirapine given to babies after delivery needs to be reviewed as many women do not stay at the health facility for 24 hours after giving birth.



Formula Feeding

As the figures at the beginning of this booklet demonstrated, a breastfed baby can become infected with HIV. This is why the government is providing six months of free formula to all HIV positive mothers who wish to avoid breastfeeding. However formula feeding has a number of harmful effects.

The following are some of the findings related to formula feeding:

- Formula fed babies face an increased risk of dying from other diseases in the first six months of their lives.
- If formula is prepared in unhygienic conditions, there is a strong risk that it can cause diarrhoea and consequently malnutrition. It is estimated that breastfeeding would reduce current childhood deaths from diarrhoea by 66%.
- While providing free formula does reduce the cost for HIV positive women who do not wish to breastfeed, they must still collect water, sterilise feeding implements and carry the cost of fuel.
- Many of the HIV positive women who have been given free formula for six months would normally have breast fed their baby for at least a year. When the formula stops after six months and there is no breast milk, there is a danger of malnutrition unless the mother is able to afford her own supply of formula and other food.
- It is likely that the promotion of formula feeding for HIV positive women will have a negative effect on efforts to promote breastfeeding in HIV negative women.
- In some sites free formula is only available at the delivery facility and not at local clinics. This makes it costly and expensive for mothers to obtain the formula.

Nurses are advised to try to assess the circumstances of each HIV positive pregnant woman during antenatal counselling. If the risks of

formula feeding outweigh the risks of HIV transmission through breastfeeding, then the woman should be advised to exclusively breastfeed her child. However, nurses and counsellors are struggling to weigh up the risks of one type of feeding against the other.

Recommendations

- ❑ The current policy to provide free formula needs to be reconsidered as there is a danger that it may do more harm than good in some communities. A national commission of experts should be set up as a matter of urgency, to discuss infant feeding in relation to HIV and mother-to-child transmission. Some public health specialists recommend that the Department of Health should no longer make formula freely available. Instead all women should be thoroughly informed about the risks and benefits of different feeding options. Exclusive formula feeding should only be encouraged for mothers who are able to afford the formula themselves.

Other specialists recommend that the government should continue to provide free formula, but should target this at communities and households that would be able to exclusively formula feed only.

- ❑ If free formula is to continue then it must be made easily accessible. It is wrong to give out an initial supply and then make it expensive and difficult for mothers to travel to a health facility to get further supplies.
- ❑ Serious consideration should be given to the administration of a post-natal short course antiretroviral treatment to mother or their babies as a strategy for making breastfeeding safe.
- ❑ This issue of free formula requires a much broader response from the government and civil society to address the unacceptable levels of child poverty and preventable child deaths. Issues such as household food security, access to social welfare grants, care systems for orphans and clean water in all households need to be addressed as a matter of urgency.



Follow-up Care

There is a policy guideline that babies of HIV positive mothers receive follow-up visits weekly during the first month of life, monthly after that until they are 12 months old and then every three months until they are two years old. In addition, if the mother decides to take up the option to provide exclusive formula feeding, then she must be counselled about how this should be done and the formula must be provided.

Providing this on-going care is an enormous task. Some of the findings show that:

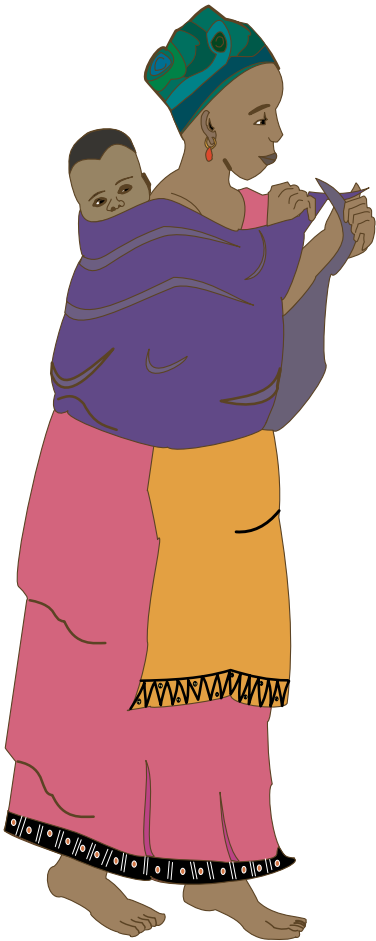
- Long distances and the cost of transport to health facilities make follow-up visits difficult.
- Long waiting times and queues discourage visits.
- Poor patient records and patient mobility make it difficult to maintain continuity of care.

Recommendation

- The policy and guidelines on the follow-up care of children born to women with HIV, needs to be reviewed. Current guidelines are largely unrealistic. Sites should develop their own targets for follow-up care that are more feasible.



Conclusion



There are no good reasons why the expansion of PMTCT services should not begin in all provinces by the middle of 2002. A number of important lessons have been learnt from the PMTCT pilot sites and these can now be put to use.

Expansion should be carefully planned and the provinces most in need of training and infrastructure should be targeted for additional support. Some provinces will be able to expand at a faster rate than others, but the weaknesses identified in the evaluation are not sufficient to prevent all provinces from taking the programme forward.

The PMTCT programme has the potential, not only to protect thousands of babies from becoming infected with the HIV virus, but also to help strengthen the health system as a whole, raise the general standard of maternal and child health care and break through the denial and stigma of HIV within communities.

PMTCT Pilot Sites

Gauteng	Natalspruit – Natalspruit Hospital and J. Dumane CHC Kalafong – Kalafong Hospital and Pretoria West MOU
Western Cape	Guguletu – Guguletu MOU and 8 clinics in Nyanga district Paarl – Paarl Hospital, T C Newman CHC and 17 clinics
Limpopo	Mankweng – Mankweng Hospital and 19 clinics Siloam – Siloam Hospital and 6 clinics
Mpumalanga	Shongwe – Shongwe Hospital and 9 clinics Evander – Evander Hospital, Lebohang CHC and Embalenthle clinic
Free State	Virginia – Virginia Hospital and 8 clinics Frankfort – Frankfort Hospital and 8 clinics
KwaZulu-Natal	Durban – King Edward VIII Hospital and Kwamashu Polyclinic, Prince Mysheni Hospital and feeder clinics in section D and K, Umlazi Pietermaritzburg – Grey's Hospital, Northdale Hospital and Sabantu and Northdale clinics, Edendale Hospital and Imbalenhle and Taylors Halt clinics, Church of Scotland Hospital
Eastern Cape	East London Complex – Frere Hospital and 29 clinics, Cecilia Makiwane Hospital and 19 clinics Umzimkulu Sub-district – Rietvlei Hospital and 12 clinics
Northern Cape	Galashewe – Galashewe Day Hospital, Kimberley Hospital, Masakhane clinic and Roodepan clinic De Aar – De Aar Day Hospital, Motana clinic, Amalia clinic, Nomzwakazi clinic and one CHC
North West	Thlabane – Rustenberg Hospital, Thlabane Health centre and 4 clinics Lehurutshe – Lehurutshe District Hospital and 21 clinics



LIMPOPO

GAUTENG

MPUMALANGA

SWAZI
LAND

NORTH WEST

FREE STATE

KWAZULU-NATAL

NORTHERN CAPE

LESOTHO

EASTERN CAPE

WESTERN CAPE

