7

CONCLUSIONS AND RECOMMENDATIONS

7.1 ADDRESSING THE ISSUES OF SYSTEMS AND INFRASTRUCTURE

PMTCT implementation varies between provinces and from site to site considerably. Some provinces and sites are doing well, whilst others are struggling.

Those sites that are struggling to provide good PMTCT services tend to be those that operate within a context of poor health care delivery in general and a poorly functioning health care system. At the core of the differences between sites and provinces are the large inequities in health care infrastructure within the country.

The differential level of capacity between some of the urban sites (with academic/ tertiary support, good physical infrastructure and adequate staffing levels) and some of the rural sites (where several clinics lack electricity, working telephones, space and adequate staffing levels and where hospitals may lack, amongst other things, sufficient doctors) is large. The moral and political imperative of preventing mother-to-child HIV transmission offers South Africa an opportunity to redress the unacceptable inequities within the health care system with more vigour and urgency.

Many of the difficulties and constraints identified in the pilot sites are systemic in nature, and relate to the functionality of the health care system as a whole (as opposed to the functionality of the PMTCT programme specifically). In order to improve the quality and sustainability of PMTCT services, and to ensure that any expansion of PMTCT services runs smoothly, these systemic issues must be addressed.

Because of the significant differences in functionality and health care infrastructure between provinces, recommendations and actions to improve the current PMTCT services, as well as an expansion of the programme, should be developed on a province by province basis.

It is useful to consider the issue of systems and health care infrastructure in terms of three dimensions:

- Human infrastructure
- Physical infrastructure
- Management infrastructure.

Human infrastructure

The presence and availability of adequate human infrastructure is the most important ingredient of a successful PMTCT programme. The term 'human infrastructure' incorporates staffing levels, staffing mix and staff competencies and motivation.

Staffing levels

Services that run with inadequate staff don't run well. In all facilities, the PMTCT programme has entailed an increase in workload and clinical responsibilities. In a few sites, this additional workload has not been compensated for by any additional staff, and has resulted in stress and possibly, a deterioration in the overall quality of care provided. In most sites the PMTCT programme has been accompanied by the recruitment of lay counsellors, although some sites still do not have enough lay counsellors. Nurse and medical staffing levels have been mostly unchanged.

In order to sustain the current PMTCT programme, as well as expand it to new sites, minimum staffing levels for midwives, nurses, doctors and lay HIV workers need to be established for clinics and hospitals, based on workload and need. The national and provincial Departments of Health, particularly their Human Resource Directorates, must then be tasked with developing and implementing a plan to reach these staffing levels.

Minimum staffing levels for PMTCT counselling should be based on the following norms: Initial pre- and post-test counselling - average of 60 minutes per client; follow-up counselling and support - an average of 30 minutes per visit on two separate occasions for HIV positive women; a maximum of 8 clients seen per day per counsellor.

Staff mix

Lay counsellors are a critical element of the PMTCT programme (as well as of other programmes within the broader national HIV strategy). The recruitment and training of lay HIV counsellors to work in close collaboration with professional staff has been a very positive feature of the PMTCT programme.

The lack of co-ordination and consistency in the management, training and remuneration of different kinds of lay workers needs to be addressed. One recommendation is to move towards the concept of generic 'lay community HIV workers' who would form a pool of human resources at the sub-district level to support the full range of HIV/TB sub-programmes in a more integrated manner.

Although the quality of service provided by lay counsellors has not been formally evaluated, it is clear that they provide a critical service. However, it is important to note that a comprehensive PMTCT programme requires a mix of clinic nurses, midwives, obstetric and paediatric ward staff and doctors playing complimentary roles. In some sites, the involvement and support of doctors who should be providing important

clinical leadership within the PMTCT programme, needs to be improved. In addition, the post-partum care and support of mothers with HIV and their children requires better links between PMTCT services with welfare and nutrition staff.

Staff competencies, morale and motivation

Training and human capacity development is critical for the development of adequate staff competencies, morale and motivation. Unfortunately, many staff do not have a strong foundation of knowledge and skills in HIV and PHC. Extensive and fairly lengthy training interventions have therefore been required, and arranging this has required a big effort. In many sites, despite major training efforts, not all relevant staff have been covered. The sheer volume of training required in the pilot sites points to a major challenge should provinces expand the programme to new sites.

A number of lessons have been learnt about training. In terms of content, there is a need to balance the focus on HIV counselling and testing with more training on infant feeding and child health. Off-site, formal classroom-based training needs to be complimented with more on-site, in-service training with a focus on skills development, local problem solving and on changing attitudes towards HIV.

Without regular support and supervision of frontline staff, the positive impact of training is not sustained. Support and supervison, as well as organising peer support groups, is required to help prevent staff burn-out. Providing effective and appropriate support and supervision to frontline staff is a highly skilled job that should also be part of a human resource development plan.

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. The availability of skilled clinicians capable of providing good care to HIV positive mothers is limited, especially in the rural areas. Clinicians in academic/tertiary institutions with HIV expertise should be deployed to develop capacity in district hospitals and rural areas through outreach programmes.

Finally, a strategy to ensure that HIV counselling, PMTCT and infant feeding is taught thoroughly and effectively in all undergraduate nurse and medical training institutions must be developed and implemented immediately.

Management infrastructure

Good management and a functional provincial DoH is a key factor determining the success, efficiency, effectiveness and sustainability of the PMTCT programme. Provincial leadership has been shown to make a big difference. Where senior managers have taken an active interest in the PMTCT programme, faster and more effective implementation has usually followed.

Senior managers are important for integrating the programme horizontally across the department and creating an enabling bureaucratic environment for programmatic staff. In some provinces and sites, tension between personalities and conflict about roles and responsibilities amongst managers has impeded progress with implementation. On the other hand, provinces with effective multi-departmental steering committees were able to establish support systems that helped make the sites work.

Strong technical capacity and the presence of experienced clinicians with a commitment to HIV within the provincial PMTCT management structures is also an important component of provincial capacity.

At the site level, effective sub-district leadership and management as well as the presence of a PMTCT driver is important. The support and involvement of local medical staff, the sub-district HIV, MCH and Health Information System(HIS) managers and hospital matrons are equally important. The lack of integration between hospitals and clinics, or between local authority and provincial facilities, undermines the programme. All this requires effective and integrated management at the sub-district level.

NGOs are important potential role-players in the recruitment, training, remuneration, support and supervision of lay counsellors. The importance and benefit of local PWA support groups has also been noted in several facilities. A more pro-active development of NGOs and PWA support groups in those sites that currently lack them is recommended. However, it will be necessary to improve the capacity within the DoH to work with NGOs efficiently, effectively and in the spirit of partnership.

Effective management is dependent on the availability of accurate and relevant data and information. Although the quality of data is improving, in most provinces and sites, there is a need to strengthen data capture, data management and programme evaluation skills.

Unco-ordinated training, the maldistribution of staff and inappropriate staff rotation policies point to the need for improved human resource management at all levels of the health system.

The fact that many provinces did not develop site-specific plans and budgets, as well as the lack of reporting to Pretoria on the national grant, suggests a need to strengthen financial management.

Finally, the slow progress with the establishment of functional health sub-districts with decentralised management structures capable of integrating PHC delivery is a weakness that will also constrain any expansion of the PMTCT programme. This requires the public health care sector to urgently speed up its structural re-organisation, and the establishment of a functional 'sub-district health system'.

Physical infrastructure

The importance of physical infrastructure has been reflected in two ways. First of all, the inadequate amount of physical space and privacy has hampered the ability of many facilities to provide adequate counselling and HIV testing services. Many provinces have therefore spent substantial amounts of money to renovate facilities or establish new spaces.

In addition, the lack of physical infrastructure has been felt in terms of access to facilities. In many of the rural sites, the difficulties and expense of simply getting to health facilities that provide antenatal, delivery and postnatal care remain major barriers to adequate coverage of the programme as well as to adequate continuity of care.

Provinces need to plan and budget for the creation of adequate space for HIV counselling and testing services in other sites.

7.2 Improving the quality of PMTCT services

Counselling and testing

The uptake of HIV testing is a rate-limiting step within the PMTCT programme. The recruitment of lay counsellors to assist with HIV counselling and testing has therefore received a great deal of attention. The term 'counselling' has consequently become strongly associated with the gaining of consent for an HIV test. However, other dimensions of counselling need to be strengthened. These include the empowerment of women with clear and accessible information about HIV/AIDS, childbirth, child care and infant nutrition; advice and information about social security entitlements and sources of community support; ongoing emotional and psychological support to women who now have to live with the knowledge of being HIV positive; and advice to women about disclosure.

Efforts and capacity to provide 'couple HIV testing' as well as community-targeted interventions to address stigma, ignorance and prejudice in the community, also need to be strengthened as adjuncts to the services targeting pregnant women. In this way the PMTCT programme can become a potent adult HIV prevention programme.

Finally, on a practical note, the option of using rapid saliva tests as an alternative to rapid blood spot tests should be explored as this could relieve some of the workload on professional staff.

Care during labour

In terms of clinical policy, there are no reasons to question the clinical efficacy of NVP and the international consensus that the drug is safe and sound. The main recommendation related to NVP is to implement some operational research to determine whether:

- NVP is dispensed and actually self-administered correctly
- midwives and doctors pro-actively ask women about their HIV status and self-administration of NVP during labour (so as to avoid 'missed opportunities')
- labour wards are able to provide adequate patient confidentiality and privacy regarding HIV status.

In addition, clearer policies and guidelines on the clinical management of HIV positive women in labour and the appropriateness of applying revised obstetric guidelines universally are required. The potential impact of revised obstetric practices resulting in higher caesarian sections should also be monitored.

A rapid audit of obstetric care and the continuity of care between the labour ward and the postnatal care of babies is being conducted in a sample of labour wards, and will provide a clearer picture of these issues soon.

Finally, the clinical guidelines on the timing of the paediatric dose of NVP after delivery needs to be reviewed given that many women leave the health facility within 24 hours of delivery.

Post-partum care

The policy and guidelines on the post-partum care of children born of women with HIV needs to be looked at again as current guidelines are largely unrealistic. Sites should rather develop their own targets for follow-up care that are realistic and feasible.

Patient held records are essential for adequate continuity of care. At the present moment, the need to protect patient confidentiality about HIV status is given greater weight than the need to promote continuity of care and encourage a greater openness about HIV status within the health care setting.

Several public health specialists have been questioning the appropriateness of prescribing prophylactic co-trimoxazole. Unless there are sound public health grounds for doing so, the DoH may want to re-consider this policy. Using co-trimoxazole as an incentive for attending follow-up care is inappropriate.

7.3 Using the PMTCT programme as an engine for improving the quality of health care

As described earlier, the PMTCT programme incorporates a unique collection of services and activities that when put together, has the potential to act as an engine or catalyst for the improvement of primary health care services in general.

Apart from demanding an improvement of the infrastructure of the health care system, as described above, the PMTCT programme can help catalyse the improvement of clinical aspects of the health care system. By acting as an entry point for improving the quality of:

- obstetric services
- HIV counselling and post-test care and support
- clinical care for patient with HIV/AIDS
- child health care and nutrition.

Linking the PMTCT programme to these other areas of patient care is important not just to maximise the full potential of the programme, but also to help avoid the possible 'neglect' of other essential maternal and child health services. Failing to conceptualise the PMTCT programme in this broader and catalytic role could represent a tremendous missed opportunity for the country.

While it would be tempting to adopt a rapid and vertical approach to the immediate coverage of PMTCT services across the country, a slower but ultimately more effective and more sustainable approach could realise the potential for the PMTCT programme to revitalise the entire health care system, invigorate the broader HIV/AIDS programme and raise the general standard of maternal and child health services.This would not only benefit the broader population, but is of particular importance for the postnatal care and well-being of the mother-child clients of the PMTCT programme who will be receiving this care from the general PHC services. However, the case for expanding the PMTCT programme in a holistic and systems-building manner should not be interpreted or used as an argument for inaction and delay in expanding the state's

capacity to prevent mother-to-child transmission.

7.4 Infant feeding

With all the publicity surrounding government's position on antiretrovirals, the more important and serious issue of its policy on infant feeding and providing free formula has been neglected. Infant feeding is probably *the* major policy issue for the government.

The current policy to provide free formula needs to be reconsidered. There is a real danger that it may do more harm than good in many communities. While the long-term aim is to make it possible for all HIV positive women to provide safe and affordable *exclusive* formula feeding, under the current social, economic, environmental and cultural circumstances, the policy may contribute to higher rates of mortality and morbidity due to other diseases, as well as higher rates of mixed feeding.

A national commission of experts should be urgently set up to discuss infant feeding in the context of HIV and mother-to-child transmission. There is a very delicate balance between avoiding HIV tranmission through breastfeeding with avoiding the harmful effects of promoting free formula.

Some public health specialists would recommend that the DoH no longer make formula freely available, but continue to thoroughly inform all women about the risks and benefits of different feeding options, and encourage exclusive formula feeding only for those mothers who are able to afford the formula themselves. Such a policy should also be complimented with a strategy to enable women to provide *exclusive* breastfeeding (as opposed to the norm of mixed feeding with breastmilk). Other public health specialists would recommend that government continue to provide free formula, but to target this to communities and households that would be able to exclusively formula feed safely.

An option that should receive serious attention is the postnatal administration of antiretroviral medication to mothers and/or babies as a deliberate strategy for making breastfeeding a safe option.

If formula is going to continue to be made available for free, it is then obligatory that it is made easily accessible. While it may be unwise to provide a full six months worth of free fomula to a mother on discharge, it would be wrong to provide an initial supply of formula and then make it expensive and difficult to receive continued supplies.

Finally, the imperative to save babies from HIV should also provoke a much broader and urgent response from the government and civil society to address the unacceptable levels of child poverty and mortality due to preventable causes. The commission should therefore adopt a broader perspective that incorporates the country's response to household food security, poverty alleviation, access to social welfare grants, care systems for orphans and the provision of clean water to all households.

7.5 Expanding the PMTCT programme

The initial focus on two learning sites per province has given national and provincial management the opportunity to learn from their experiences, as well as improve the PMTCT guidelines. There have been many lessons learnt, as well as the development of training and IEC materials and tools to support programme management.

With this in mind, there are now no good reasons for delaying the gradual and phased expansion of PMTCT services.

Given the differences in capacity and infrastructure, it would be reasonable for provinces to expand the provision of PMTCT services at different speeds. What is important is for the expansion to be properly planned, implemented strategically and systematically, and that it takes into account the many lessons that have been learned.

For provinces that are currently struggling with implementation in their two learning sites, a plan for expansion should include and begin with a strengthening of provincial management and support structures and the continued improvement of services in the learning sites. These provinces should be targeted by the national DoH for support and capacity development.

Plans for expansion must also address the many systemic and infrastructural constraints that have been identified in order to avoid a multiplication of poor and/or non-sustainable service delivery, as well as to reduce the levels of health care inequity. The lack of optimal health systems infrastructure is therefore *not* a reason for delaying the expansion of PMTCT services, but should rather inform the strategic expansion of PMTCT services. Without paying some attention to the systems and infrastructure issues, the expansion of PMTCT services may not be cost effective or sustainable. In addition, leaving the poor state of health care infrastructure unattended to in many parts of the country will result in the existing inequities in health care being widened even further by an expansion of PMTCT services.

A more appropriate budgeting formula will be required to ensure that sites and provinces that are historically under-resourced receive a more equitable share of funding and support should there be an expansion of the programme. The 'gap' between existing resources and a minimum standard of health care infrastructure (especially in terms of human resources) should be measured in every sub-district across the country to ensure that this is addressed in the fullness of time.

With coherent and committed political and senior management leadership at the national and provincial levels, it should be possible for all provinces to begin implementing PMTCT services in some new sites by the middle of 2002.

The variation in health care infrastructure, geography, population density, HIV prevalence and socio-economic status necessitates a more context-based approach to planning and implementation. Local conditions and problems require local solutions. The formation of an effective 'sub-district health system' offers the best organisational framework for the delivery of PMTCT services and of PHC in general.

In order for provinces to gradually expand the provision of PMTCT services, as individual sites 'mature', provincial management should hand over the day-to-day

management of PMTCT services and their ongoing development to district and sub-district management structures. With the provincial office increasingly playing a supportive and monitoring role, sub-district and district health management teams should implement continuous quality improvement cycles based on routine monitoring and local operational research. Implementation in this regard can be considered as an ongoing process of continual improvement.

The PMTCT programme demonstrates the need to integrate community-based, clinic, CHC and hospital care as part of a seamless continuum of care. Any expansion of the PMTCT programme should therefore be based on a sub-district model. Targeting individual facilities, as opposed to sub-district areas, for any expansion of PMTCT services should ideally be resisted. Planning the expansion of the PMTCT programme on the basis of 'health sub-districts' will also offer a better framework for addressing the many systemic issues at the same time.

A phased and systematic expansion of comprehensive PMTCT services should be combined with the *immediate* provision of NVP to pregnant women already known to be HIV positive. However, in doing so, it would be important to avoid reinforcing the current portrayal of the PMTCT programme as being only about the administration of NVP.

Finally, there is still a need to continue to learn from the 18 learning sites, and these sites should continue to host in-depth research.