Strengthening PMTCT through communication: A review of the literature

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Abstract

A literature review on social mobilization and communication in support of prevention of mother to child transmission (PMTCT) of HIV. Prepared as part of a research project in support of the South African ‘Operational Plan for Accelerating PMTCT Services’ with the support of UNICEF. The preparation of this literature review was supported by funding and technical assistance from UNICEF, South Africa.

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1 Grantholder: UNICEF-CADRE PMTCT Literature review
<table>
<thead>
<tr>
<th>Acronyms</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACADA</td>
<td>Assessment, Communication, Analysis, Design, Action</td>
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<tr>
<td>AFASS</td>
<td>Acceptability, Feasibility, Affordability, Safety, Sustainability</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ANC</td>
<td>Antenatal Care</td>
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<td>ARVs</td>
<td>Antiretrovirals</td>
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<td>AZT</td>
<td>Zidovudine</td>
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<td>BCC</td>
<td>Behaviour change communication</td>
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<td>CAPRISA</td>
<td>Center for AIDS Programmeme of Research in South Africa</td>
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<td>CADRE</td>
<td>Centre for AIDS Development Research and Evaluation</td>
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<tr>
<td>CBO</td>
<td>Community Based Organization</td>
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<td>CHW</td>
<td>Community Health Worker</td>
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<td>FBO</td>
<td>Faith Based Organization</td>
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<td>FHI</td>
<td>Family Health Institute</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>ICP</td>
<td>Interpersonal communication</td>
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<td>IEC</td>
<td>Information education communication</td>
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<td>HSRC</td>
<td>Human Sciences Research Council</td>
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<td>JHHESA</td>
<td>Johns Hopkins Health and Education in South Africa</td>
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<tr>
<td>m2m</td>
<td>Mother to mother</td>
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<td>m2m2b</td>
<td>Mothers to mothers to be</td>
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<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
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<td>MRC</td>
<td>Medical Research Council</td>
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<td>MTCT</td>
<td>Mother to Child Transmission</td>
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<td>NGO</td>
<td>Non Governmental Organization</td>
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<td>OBs</td>
<td>Obstetrics</td>
</tr>
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<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<td>PIC</td>
<td>Programmeme Implementation Committee</td>
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<td>PLWHA</td>
<td>Person Living with HIV/AIDS</td>
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<td>PMTCT</td>
<td>Prevent/Prevention (of) Mother to Child Transmission</td>
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<td>PPTCT</td>
<td>Prevention of Parent to Child Transmission</td>
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<td>SADC</td>
<td>Southern African Development Community</td>
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<td>SANAC</td>
<td>South African National AIDS Council</td>
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<td>STD</td>
<td>Sexually Transmitted Disease</td>
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<td>TBA</td>
<td>Traditional Birth Attendant</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UKZN</td>
<td>University of KwaZulu Natal</td>
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<td>UNAIDS</td>
<td>United Nations Programmeme on HIV/AIDS</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>WHO</td>
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1. Executive Summary

Prevention of new HIV infections remains a significant public health challenge for South Africa. The high HIV infection and mortality rate of under five-year-olds due to MTCT of HIV together with the continuing need pregnant HIV-positive women have for ARVs and PMTCT, underscore the urgency for renewed efforts to offer quality PMTCT services in South Africa.

This report begins with a background historical contextualization of PMTCT in South Africa, providing a brief overview of the political and operational factors that shaped policy and intervention around HIV/AIDS generally, and that led to the delay in the implementation of the national PMTCT programme more specifically. This background accentuates the imperative for coherent policy and implementation of a sustained PMTCT programme with a strong communication strategy.

The first half of the report considers communication strategies in the HIV/AIDS context and the key barriers to PMTCT. The multifaceted nature of the factors that together sustain the HIV/AIDS epidemic in South Africa need to be taken into account in the communication strategy that is adopted. The various limitations of top-down models of persuasion highlight the need for a contextually located and participatory communication approach, emphasizing dialogue and collective action and aiming for social as well as individual outcomes.

The report gives an overview of the different communication theories and approaches that have been used in the PMTCT context in sub-Saharan Africa (behaviour change communication, information education communication and interpersonal communication, community oriented behaviour change approach, targeted education messages and communication, communication for development and the ACADA process).

The ‘communication for social and behavioural change model’ is drawn on and used to structure the presentation of findings of the literature review. This ‘social ecology’ model describes four levels of address in social and behavioural communication change: societal; community; interpersonal; and behavioural. These categories are used to structure the findings in each of the following areas: barriers to PMTCT implementation; key participants to be addressed; key messages; and best practices in planning and implementing successful HIV/AIDS communication campaigns.

The factors inhibiting the up-take of PMTCT services are listed and described. These factors include:

- Health care infrastructure, shortage of staff, poor referral links and a lack of communication within the health care system. A consequence of these barriers is a lack of integration of PMTCT and family planning services.
- Poor quality of counselling and health care worker’s poor attitudes and interactions with clients.
- Gender related issues, particularly the role of the male partner in reproductive issues and his involvement in PMTCT services.
- Poverty and structural barriers.
- Cultural factors around appropriate behaviours linked to PMTCT, and stigma, including the perception of poor social support and discriminatory perceptions of PMTCT practices.
- Lack of awareness and knowledge in the general population and pregnant women or mothers, particularly information and services around PMTCT.
- The reproductive needs of youth are not adequately addressed.
- Psychological barriers such as denial, fear of death and HIV testing and disclosure.

The second half of the report highlights the key participants to be reached through communication strategies and the key PMTCT themes. The following target stakeholders are discussed:

- Health care workers in rural and urban sites.
- Relevant government departments and policy makers.
- Community organizations and influential community members.
- HIV-positive and HIV-negative men and women in rural and urban areas and the families of HIV-positive women.

Emerging from the literature were key PMTCT message
themes to be incorporated into PMTCT communication strategies. The importance of consistency and accuracy of key message themes was stressed as well as the fact that all messages needed to reach all key participants. Message themes included:

- The importance of non-judgmental and non-discriminatory attitudes and actions towards PLWHAs.
- The sexual and reproductive rights of HIV-positive women and of gender equity and women’s rights more generally.
- Family planning options for HIV-positive women and their partners and the youth.
- The importance of male support and engagement.
- Key components for prevention at an individual level and accurate facts about HIV/AIDS, MTCT and PMTCT.
- Stressing the various testing approaches for pregnant mothers.
- The importance of knowing your status and stressing skills on disclosure.
- The importance of a family-centered health model and on-going support for mothers.
- The importance of on-going training of health care workers.
- Various cultural, traditional and religious beliefs around reproduction, childbirth and childrearing.
- The importance of integrated ANC, PMTCT and family planning services.
- Clear, consistent and current information on feeding practices for PMTCT.
- Up-to-date information on programmes’ implementation and policies.
- Constraints to uptake of PMTCT services (socioeconomic and infrastructure).
- The importance of partnering with relevant NGOs, FBOs and CBOs.

The concluding section of the report focuses on strengthening PMTCT through interpersonal and community communication strategies, including media communication strategies and addressing stigma reduction and gender equality. In addition it describes how PMTCT could be strengthened through strengthening health systems and integrating services. The review ends with recommendations for future research.

2. Review methodology

The literature search for this review included a search for qualitative and quantitative peer reviewed journal articles, full research reports, summary reports, policy documents, guideline documents and chapters in books. Key words were used to initiate the search for relevant literature, which in turn was used to identify further relevant literature and organizational websites where relevant documents were searched for. A number of academic search hosts, including Ebscohost, Swetswise and Academic Search Complete (through the UKZN library link) were used to locate peer reviewed academic articles. Organizational websites such as CAPRISA, HSRC, Panos, the Perinatal Research Unity, the Health Systems Trust and The Reproductive Health Research Unit were searched for relevant literature. Direct contact was also made with CAPRISA, who linked the reviewers to the Women’s Health and HIV Unit at UKZN Medical School.

Literature from a variety of developing countries has been included in this review. While South Africa is engaging in relevant and important research, the country’s political and operational history around PMTCT appears to have resulted in a lag in research. For example, of the 161 documents that were accessed in preparation for this review only 59 documents reported directly on PMTCT research or policy within South Africa specifically. Further, 46 of the 58 South African focused documents commented on PMTCT communication in particular. These documents touched on a variety of communication issues including PMTCT communication strategies, counselling, a rights based approach to counselling, family communication, mass media communication, knowledge levels, quality of referrals, disclosure to partners and the communication of policy to appropriate stakeholders. A significant body of literature emerged from other developing countries including, inter alia, Zambia, Zimbabwe, India, Tanzania, Nigeria, Malawi, Botswana and
Lesotho. This research offers valuable insights and possible directions for future PMTCT research in the South African context. This literature has, therefore, been included in the literature review.

In total this review has included 132 documents of which 74 are journal articles, 24 are research reports, 32 are relevant documents (for example, government documents and guidelines), and 2 are chapters from books.

3. Introduction and background to PMTCT in South Africa.

3.1 HIV/AIDS and MTCT in Southern-Africa and South Africa

Sub-Saharan Africa, with more than two-thirds of the World’s total number of HIV-infected people, remains the region most affected by the HIV/AIDS pandemic. Women continue to be disproportionately affected in this region, representing 61% of people living with HIV. Southern-Africa accounts for almost a third of all new HIV infections and AIDS-related deaths globally, while South Africa is considered to be the country with the largest number of people living with HIV in the world. It is estimated that 5.5 million of South Africa’s people are living with HIV. In this country, among 15-24 year olds, females account for 90% of all new infections, confirming the gendered nature of the South African epidemic. The trends in HIV prevalence in South Africa over the last 5 years show that while there is a gradual decline in HIV prevalence amongst participants in the younger age groups (15-19 and 20-24 years) there has been increasing growth in the prevalence in the older age groups (30-34 and 35-39 years) suggesting that they have been relatively neglected or not reached by prevention programmes. Prevention of new HIV infections remains a major public health challenge for South Africa.

It has been estimated that in 108 low and middle-income countries, around 1.5 million women living with HIV gave birth in 2006. In South Africa it is estimated that in 2007, 707 948 pregnant women were tested for HIV and 290 000 pregnant women living with HIV needed ARVs to MTCT. It was further estimated that close on 200 000 children (0-4 years) in South Africa were infected with HIV in 2007. Based on mortality data from 2005 it has been further estimated that each year at least 75 000 children die before their fifth birthday in South Africa. While there are a number of health challenges that contribute to these deaths, it is argued that HIV/AIDS accounts for a large proportion and that the most common route of HIV infection for children under the age of 5 years is through mother to child transmission (MTCT).

MTCT of HIV can occur during pregnancy, labour, delivery, and breastfeeding, especially mixed feeding. It is estimated that well over 90% of new HIV infections amongst infants as well as young children occur through MTCT. Without any interventions, between 20% and 45% of infants may become infected with HIV through MTCT, with an estimated risk of 5-10% during pregnancy, 10-20% during labour and delivery and 5-20% through breastfeeding.

It is, however, estimated that the overall risk of transmission can be reduced to less than 2% if a package of evidence-based interventions are made available and used by HIV-positive pregnant women and mothers. The package of interventions is based on the United Nations four-pillar strategy for PMTCT. The first three of these strategies are prevention focused, while the fourth focuses on ongoing care and treatment for HIV-positive mothers and HIV-exposed infants and children. The four-pillar approach highlights the protracted nature of PMTCT and highlights the need for commitment to a long-term, comprehensive and integrated response. The four-pillars are:

- Primary prevention of HIV infections of individuals of a child-bearing age.
- Prevention of unintended pregnancies among HIV-positive and HIV-negative females of a child-bearing age.

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1 (UNAIDS & WHO, 2008)
2 (UNAIDS & WHO, 2008)
3 (Department of Health (S.A.), 2008a)
4 (UNICEF, 2009)
5 (WHO, UNAIDS & UNICEF, 2008)
6 (Velaphi, 2008)
7 (Department of Health (S.A.), 2008b)
8 (WHO & UNICEF, 2007)
9 (WHO & UNICEF, 2007)
10 (WHO & UNICEF, 2007)
• Prevention of MTCT of HIV.
• Provision of appropriate treatment, care and support for women living with HIV to children and families.

The package of evidence-based services available also highlights the protracted and complex nature of PMTCT and the importance of a comprehensive and integrated response. The following are examples of evidence-based services recommended:

- Health education.
- Provider-initiated HIV testing and counselling.
- Promotion and provision of male and female condoms.
- Couples and partner counselling.
- Screening for HIV and gender-based violence.
- Obstetric care.
- Nutritional support and provision of supplements.
- Infant feeding counselling and support.
- Family planning.
- Birth preparedness.
- Provision of ARV prophylaxis.
- ARV treatment and adherence.
- Psychological support.
- Tetanus vaccinations, STD screening and treatment and TB screening and treatment.

The success of PMTCT programmes, therefore, rests on expanding access to services and ensuring that these services are used frequently. The success, however, also rests on providing adequate information to the general population and relevant service providers and on providing adequate and ongoing support to HIV-positive mothers once they have given birth. The potential for PMTCT to reduce the risk of HIV transmission to less than 2% underscores the importance of a communication strategy that reaches all relevant stakeholders.

3.2 PMTCT in South Africa: Operational and political history

In 1994 a study reported that mono-therapy with AZT dramatically reduced the risk of MTCT. Due to the cost of AZT at the time and the South African government’s resistance to its use, it took time before a national PMTCT programme would be implemented in South Africa and before dual therapy (AZT and Nevirapine) would be used to prevent MTCT. In 2001 TAC, Save Our Babies and the Children’s Rights Centre took the government to court, which subsequently found in their favour and ordered the government to develop a comprehensive national programme to prevent MTCT.

Due to these operational and political factors the PMTCT programme (conceptualized in 2001) was implemented in pilot sites in 2001, but only nationally in 2002. It has been estimated that 35 000 babies were born with HIV because a feasible and timely ARV programme was not implemented in South Africa. This underscores the imperative for coherent policy and implementation of a sustained PMTCT programme with a strong communication strategy capable of mobilizing uptake, broad based community support, retention and quality interpersonal communication amongst health workers and with their clients.

Currently the national PMTCT programme is available in 3 000 primary health care facilities across the country. The programme offers a package of services that together contribute to the reduction of MTCT. Despite this, only 60% of pregnant women who tested positive received Nevirapine during the 2005/06 financial years. It is further estimated that 290 000 pregnant HIV-positive women in South Africa are in need of ARVs to PMTCT. In 2002 the estimated HIV prevalence among children aged 2-14 years was 5.6%, which dropped to 3.3% in 2005. Despite this decrease, findings from 2005 confirm that South African children have a high HIV prevalence. The HIV preva-

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11 (WHO & UNICEF, 2007)
12 (WHO & UNICEF, 2007)
13 (Coovadia, 2009)
14 (Department of Health (S.A), 2008b)
15 (Chigwedere, Seage, Gruskin, Lee, & Essex, 2008)
16 (Department of Health (S.A), 2008b)
17 (Department of Health (S.A), 2008b)
18 (WHO, UNAIDS, & UNICEF, 2008)
lence amongst 2-4 year olds is 4.9% for males and 5.3 for females and the prevalence amongst 5-9 year olds is 4.2% for males and 4.8% for females.\(^\text{19}\)

South Africa continues to have one of the highest under-five mortality rates.\(^\text{20}\) In 2007 it was estimated that the under-five mortality rate in South Africa was 59 deaths per 1000 live births. Out of eighty-four countries described as less developed, South Africa has the fourteenth highest under-five mortality rate.\(^\text{21}\) While there is evidence to show that PMTCT programmemes are acceptable, feasible and cost-effective, they have not been implemented widely in low- and middle-income countries.\(^\text{22}\) There is an urgent need for renewed efforts to offer quality PMTCT services in the South African context and to ensure that these services are offered routinely and that uptake rates increase.

Ongoing research in Khayelitsha (South Africa) reported that the vertical transmission of MTCT in 2007 was 3.5% and that the testing acceptance rate was nearly 100%. These findings provide evidence that PMTCT programmemes in resource constrained settings can reach all mothers who need the services and can bring about a reduction in MTCT.\(^\text{23}\)

4. Relevant HIV/AIDS policies in South Africa

4.1 HIV and AIDS and STI Strategic Plan for South Africa (2007-2011)

The strategic plan identifies prevention and treatment as two of its priority areas. It further recognises the importance of preventing MTCT and making provision for the special treatment needs of pregnant women and children.\(^\text{24}\)

4.2 Policy and guidelines for the implementation of PMTCT (2008)

In line with international standards, the South African national PMTCT policy recognises the need for a comprehensive, four-pronged response to reduce MTCT of HIV:\(^\text{25}\)

- Primary prevention of HIV especially among women of childbearing age.
- Prevention of unintended pregnancies among HIV-positive women.
- Prevention of HIV transmission from a HIV-positive woman to her infant.
- Provision of appropriate treatment, care and support to women with HIV, their children and families.

The following package of services is available for the prevention of MTCT:

- Routine offer of VCT to pregnant women.
- Infant feeding counselling and support.
- Safe OB practices.
- Single-dose nevirapine to mother and infant.
- Provision of formula feed to those who chose to use replacement feed and for whom it is affordable, feasible and sustainable.

The policy further prioritizes effective implementation through:\(^\text{26}\)

- Supportive leadership.
- The right to information.
- Effective communication.
- Effective partnerships.
- Creating a supportive environment for PMTCT.
- Tackling inequality and poverty.
- Strengthening and integrating service delivery.

To realize the principle of effective communication and the right to information, the national PMTCT programmemes aims to develop a comprehensive integrated communication strategy. The strategy involves the use of mass media

\(^{19}\) (Shisana, Rehele, Simbayi, Zuma, Connolly, Jooste 2005)
\(^{20}\) (Coovadia, 2009)
\(^{21}\) (Save the Children, 2009)
\(^{22}\) (WHO, 2006)
\(^{23}\) (Booth, 2008)
\(^{24}\) (Department of Health (S.A), 2007)
\(^{25}\) (Department of Health (S.A), 2008b)
\(^{26}\) (Department of Health (S.A), 2008b)
campaigns and effective comprehensive communication methods to disseminate information about PMTCT to key target groups including service users and providers, the public at large, and community leaders. The programme also aims to strengthen community-based outreach through household and door-to-door activities to increase awareness of PMTCT services.

4.3 Department of Health Strategic plan 2009/10 - 2011/12

The strategic plan outlines a number of priorities to strengthen the national PMTCT programme. Communication is recognised as important to promote policy and buy-in, in support of government programmes. The strategic plan describes intentions to conduct 13 Ministerial Izimbizos with different communities where members will be able to interact directly with the Minister of Health. The plan further expresses a commitment to strengthening partnerships with all stakeholders, including grassroots structures. For example 27 000 community HIV/AIDS caregivers will receive stipends by the end of 2009/10. In this way the department aims to revive constructive grassroots level participation in health service delivery.

The plan also aims to accelerate the implementation of the HIV and AIDS strategic plan and to strengthen the implementation of the national PMTCT programme. In line with Millennium Development Goal (MDG) four the Department of Health will:

- Ensure an increase in the number of HIV-exposed infants who receive dual-therapy to PMTCT.
- Ensure that the proportion of pregnant women who are tested for HIV increases.
- Ensure an increase in the number of pregnant women who are placed on dual-therapy.
- Ensure an increase in the number of eligible pregnant women who are placed on HAART.

4.4 SANAC Programme Implementation Committee (PIC) meeting

In February 2009, during a SANAC PIC, Dr Nonhlanhla Dlamini announced the PMTCT accelerated roll-out plan for South Africa. SANAC endorses the Department of Health’s strategic plan to strengthen the implementation of the national PMTCT programme. The PMTCT accelerated roll-out plan will include developing a comprehensive monitoring system and community mobilization programme. Existing community health care workers (CHW) will be used to help monitor clients enrolled in PMTCT programmes. The programme will take place both within clinics and within the broader community. Training will commence in Zululand and will then be extended nationally. During the PIC meeting Mark Heywood, the deputy chairperson, commented that the accelerated roll-out plan provides an opportunity for the Department of Health, SANAC and civil society to work together around social mobilization. He went on to request that a communication campaign be integrated into the accelerated roll out plan.

5. Communication in the context of HIV/AIDS

5.1 Communication theories and approaches in the context of HIV/AIDS

The HIV/AIDS epidemic is driven by a complex set of factors in South Africa including social, cultural, historical, political, economic and gendered factors. HIV/AIDS also touches on sensitive issues such as people’s sexuality and identity. It challenges notions of morality and questions our accepted understandings of gender, disease and death. The complexity of this disease renders communication ap-
proaches that are based on the assumption of a rational in-
dividual who makes choices in a social vacuum both redund-
ant and ineffective. 32 33 34

Models of transmission and persuasion tend to dominate
the design of strategic communication in the field of health.
Communication, from this perspective, involves delivering
a predetermined message to a particular group of individu-
als in an attempt to persuade them to behave in a desired
way. Such an approach is one-sided, top-down; persuasion
oriented and tends to view communities as homogenous
objects of change.35 This is also critiqued for promoting a
paternalistic view of development. For example, such ap-
proaches implicitly assume that the knowledge of the orga-
nization/agency/government developing the message is al-
ways right, while those receiving the message are assumed
to be ignorant.36

What is needed in the context of HIV/AIDS is an ap-
proach to communication that takes seriously the social
context in which people negotiate their lives and recognises
the need for long-term and sustained efforts that engage lo-
cal communities in the development of contextually relevant
and appropriate responses. Such an approach promotes col-
clective discussion and debate in addition to individual re-
fection and self-awareness, and simultaneously attempts to
address the social, cultural, economic and political factors
in an attempt to create health enabling contexts.37 38 39 40 An
integrated and comprehensive approach to communication
emphasizes, firstly, a process of dialogue and collective ac-
tion and, secondly, aims for social outcomes alongside indi-
vidual outcomes.41

Four theories and/or approaches have challenged per-
suasive and top-down approaches to communication:42

- **Dependency theory**: Argues that the problems of many
underdeveloped countries are political rather than the
outcome of a lack of knowledge or information and rec-
ognises the need to bring about structural change rather
than targeting the individual.

- **Participatory theories and approaches**: Challenge the pa-
ternalistic approach of dominant communication strate-
gies, arguing for the active ownership and participation
of community members and the use of interpersonal
communication (small media) in contexts where mass
media and technology can be experienced as alienating
and foreign.

- **Media advocacy**: Rather than aiming to directly influence
audiences, aims at creating public debate around public
health issues. It focuses on social themes and argues that
social conditions, rather than the behaviour of individu-
als, should be the focus of interventions. The focus of
media advocacy is therefore socio-political change and
inequity.

- **Social mobilization**: Recognises the importance of mo-
bilizing social actors to be involved in increasing aware-
ness of a particular programme and assisting in the
delivery of services. The focus is on mutual benefits of
partners and the decentralization of structures. Social
mobilization involves an appeal for community partici-
pation rather than appealing to individuals to assist.

The following points of convergence between the different
communication theories and approaches, including the tra-
ditional dominant approaches, suggest the need for a com-
 munications strategy that integrates valuable aspects of the
different theories and approaches:43

- **The need for political will**

- A ‘tool-kit’ conception of communication techniques,
which are chosen based on their appropriateness in
certain contexts under certain conditions. For example,
conventional approaches are appropriate as a short-
term strategy when large numbers of people have to be
reached quickly.

- Integration of ‘top-down’ and ‘bottom-up’ approaches.
This involves government commitment and community
mobilization.

- Integration of multimedia and interpersonal commu-
nication.

32 (Vincent, 2006)
33 (Melkote, Muppide, & Goswami, 2000)
34 (Airhihenbuwa, Makinwa & Obregon, 2000)
35 (Figueroa, Kincaid, Rani & Lewis, 2002)
36 (Scalway, 2001)
37 (Vincent, 2006)
38 (Scalway, 2000)
39 (Melkote, Muppide, & Goswami, 2000)
40 (Airhihenbuwa, Makinwa & Obregon, 2000)
41 (Figueroa et al., 2002)
42 (Waisbord, 2001)
43 (Waisbord, 2001)
Personal and environmental approaches should be integrated.

5.2 Communication for social change: An integrated approach

The communication for social change approach has been recognised as one of the approaches that has integrated various aspects of different theories and approaches into an effective communication strategy. Such a strategy is based on the following principles and approaches:

- Community ownership to improve sustainability of social change.
- Empowering, horizontal communication that gives voice to members of the community.
- Community members are seen as agents of their own change rather than objects of change.
- Emphasis is on debate and the negotiation of issues that are meaningful to the community.

Change extends beyond individual behaviour to social norms, policies, culture and other contextual factors that undermine a health-enabling environment.

5.3 JHU’s Social Ecology Model

JHU uses a Strategic communication approach, which combines different mediums and modes – for instance mass media, community messaging, interpersonal communication, and advocacy - to bring about behavioural and social change. A Strategic approach recognises that in order to influence change, communication needs to operate at multiple levels - societal, community, social network and individual. To this end JHU adopts a conceptual framework based on the Social Ecology Model, illustrated below:

As noted in the 2008-2009 strategic plan for the JHU Programme in South Africa (p.14):

“Change at one level may be facilitated or obstructed by another level. For example, a woman may choose to make use of prevention of mother to child transmission services such as formula feeding. However, this may be impacted upon if her partner is aware and supportive of her status and thereby enables the use of formula feed, or where formula feeding may be culturally regarded as not being appropriate this may also impede usage. The ability to access PMTCT services will further be influenced by the societal policy and legislative levels where the availability or lack of PMTCT services or the cost of accessing these resources can impede usage as a result of poverty that places this beyond the realm of those most in need.”

6. Communication theories and approaches in use in PMTCT programmes

A number of different communication theories and approaches have been used in the context of PMTCT across sub-Saharan Africa:

6.1 Communication for development and ACADA process

UNICEF, (based on pilot programmes in Botswana and Rwanda), encourages the use of the communication for development approach, which involves developing PMTCT communication strategies around advocacy, social mobilization and programme communication. Multi-sectoral teams use the ACADA (assessment, communication analysis, design and action) process to develop integrated PMTCT communication strategies for advocacy, social mobilization and programme communication.

6.1.1 Communication for development in the South African context

In 2002 the Government of South Africa in collaboration with the Centers for Disease Control (CDC) tested the communication for development approach, based on the ACA-
DA planning process, and concluded that this was the best alternative for South Africa. The approach is collaborative and ensured community participation in the development of context specific strategies in each province. Training was provided to multi-sectoral teams.

The PMTCT communication strategy aimed to:

- Increase access to condoms in non-traditional sites.
- Decrease stigma in communities to increase support and care.
- Increase access to VCT in non-traditional sites.
- Increase exclusive feeding through family counselling aimed at establishing new community norms.
- Encourage up-take of ANC services.
- Mobilize stakeholders like traditional healers to increase support for PMTCT and VCT services through community dialogue.

In developing this review attempts to locate follow-up documentation of this programme or evaluations of its outcomes, proved unsuccessful. This highlights the importance of ongoing monitoring and evaluation during the development of future PMTCT communication strategies. This will ensure that lessons learned are documented and can feedback into and contribute towards the development of appropriate communication strategies. It would, for example, be useful to know what the outcomes of the 2003 collaboration between the government and CDC were and what lessons were learned during the process.

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### Social Ecology Model & Communication for Social and Behavioural Change

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**Social Networks**

- Partner and family relationships (communication, trust, understanding, agreement and power, peer influence, gender equity, bounded normative influence)

**Community**

- Leadership; level of participation, information equity; access to resources; shared ownership; collective efficacy; social capital; value for continual improvement

**Societal**

- National leadership; per capita income; income inequality; health policy and infrastructure; mass media; religious and cultural values; gender norms

**Physical Environment and Infrastructure**

- Burden of disease; climate and seasonability; transportation and communication networks; access to healthcare facilities, access to water, sanitation and household technologies; etc

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48 (The Communication Initiative Network, 2003)
6.2 Behaviour change communication

PEPFAR has been actively involved in designing and implementing behaviour change communication (BCC) PMTCT strategies in countries including South Africa. BCC strategies using information, education and communication (IEC) aim at promoting comprehensive prevention messages and delivering these messages to specific audiences with the aim of changing health-related behaviour.

6.3 Information education communication (IEC)

A number of programmemes make use of locally developed IEC materials to raise awareness in the wider community about PMTCT and available services.

6.4 Community oriented approach to behaviour change

Community oriented behaviour recognises that behaviour change occurs in a context of social change. Information is placed within communities to facilitate dialogue, debate and collective action. Within the context of PMTCT it recognises the importance of creating widespread awareness about the range of behaviours that are necessary for PMTCT. For example, the necessary obstetric practices should not only be communicated to professional health practitioners, but also to traditional birth attendants, families and the wider community.

6.5 Targeted education messages and communication

Evaluative research shows the importance of targeted education messages. Areas of misconception about HIV/AIDS and PMTCT need to be identified so that local health authorities can design and target appropriate messages to fill in knowledge gaps.

6.6 Interpersonal communication (ICP)

Some PMTCT programmemes argue for investment in ICP, where IEC materials are used to support interpersonal communication rather than as the main method of communication.

6.7 Communication for social change

A number of PMTCT programmemes make use of communication for social change. Some programmemes argue for targeted education messages to be combined with communication for social change techniques. Such an approach acknowledges the importance of filling in knowledge gaps, but also addressing the social, cultural and economic contexts that impact on behaviours like feeding practices and sexuality. Communication for social change recognises the need for community ownership; the importance of horizontal communication rather than top-down vertical message transmission and the importance of seeing people as agents of change rather than objects of change. It values dialogue and debate over and above persuasion and aims to support behaviour change by addressing social norms, cultural practices and policies that constrain health enabling practices.

7. Barriers to PMTCT

Evidence suggests that while many women may enroll in a PMTCT programmem a number of factors result in a high drop-out rate. Coverage of key HIV interventions for women with children drops at the time of childbirth through to postnatal care. Statistical data of health care coverage in

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49 (PEPFAR, 2004)
50 (PEPFAR, 2005)
51 (Shetty et al. 2008)
52 (Perez et al. 2004)
53 (IMAU & CDC Uganda, 2003)
54 (Moore, 2003)
55 (Orne-Glieman et al., 2006)
56 (UNICEF, 2002)
57 (Orne-Glieman et al., 2006)
58 (Scalway, 2002)
South Africa shows that while 94% of women attend ANC at least once, only 73% attend four or more times and only 27% attend ANC by the time their infant is 20 weeks old. This shows a cascade of diminishing service use and highlights that there are many missed opportunities for PMTCT, especially through follow-up services. This coverage gap is influenced by the availability of appropriately skilled health care workers (quality gap). Further, hidden in the national averages are clear disparities between the rich and poor, public and private health care sectors, and between rural and urban settings (equity gap). For example skilled attendance during birth is a third lower among the poorest families when compared to richer families.59

The following barriers have been identified as inhibiting the up-take of PMTCT services and loss to follow-up in a number of African countries.

### 7.1 Societal barriers

#### 7.1.1 Health care infrastructure and shortage of staff

- A shortage of appropriately trained and skilled health workers impacts on general service delivery.60 61 62 63 Research at a clinic in the rural Eastern Cape in South Africa, for example, reports that after PMTCT was integrated into the clinic no additional staff was allocated to the clinic. As a result the clinic is staffed by nurses and nurse assistants who report that they do not have the capacity to provide quality services.64

- A lack of trained lay counselors has been found to inhibit the number of people who receive services like VCT.65 66 67 68 South African research, for example, indicates that the North West and Eastern Cape provinces are still struggling to integrate lay counselors into their VCT programme. It is not surprising, therefore, that these two provinces report low percentages of testing in the ANC setting (North West 14% and Eastern Cape 34%).69

In comparison; Gauteng, KwaZulu Natal and the Western Cape, who prioritize the utilization of lay counselors, have the smallest drop off between the first ANC visit and women accepting to be tested for HIV.70

- Research in South Africa indicates that health care workers who offer family planning services have seldom been trained in HIV/AIDS care, which in turn points to lack of an integrated approach to health care provision. This research also indicates a high turnover of staff, which means that expertise around family planning is not always sustainable.71

- Poor working conditions of health care workers leads to a low retention of staff in resource poor contexts.72 In South Africa a high turn over of staff may be due to poor incentives, infrastructure and remuneration.73

- Inadequate spaces for confidential counselling and private disclosure and a low number of sites in widely dispersed populations have been found to inhibit the uptake of PMTCT services.74 75 76 Research in South Africa has found that a lack of privacy in delivery rooms may prevent a woman from disclosing her status when asked by a health care worker.77 An early evaluation of the PMTCT programme in South Africa found that in some provinces there is insufficient space dedicated to counselling. In some counselling sites, rooms often serve dual purposes. A storeroom, for example, will be used as a counselling room, with frequent disruptions to the counselling process.78

- Although PMTCT programmes might be integrated into antenatal services, the different services may be

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59 (Department of Health (S.A) et al., 2008)
60 (Department of Health (S.A) et al., 2008)
61 (WHO, 2007)
62 (Tearfund, 2008)
63 (Burke, 2002)
64 (Skinner et al., 2003)
65 (WHO & UNICEF, 2007)
66 (Perez et al., 2004)
67 (WHO, 2007)
68 (DoHerty et al., 2005)
69 (DoHerty, Besser, Donohoue, Kamoga, Stoops & Williamson, 2005)
70 (Perez et al., 2004)
71 (UNAIDS et al., 2005)
72 (Manzi et al., 2005)
73 (UNAIDS et al., 2005)
74 (Skinner et al., 2003)
75 (WHO & UNICEF, 2007)
76 (WHO & UNICEF, 2007)
77 (DoHerty et al., 2005)
78 (DoHerty et al., 2003)
housed in different buildings, which make HIV-positive women attending certain services vulnerable to stigmatization.79

7.1.2 Poor health care worker attitudes and interactions with clients

- Clients who are fearful of health care workers are not likely to return for follow-up sessions. In a study in Cote d’Ivoire women reported being afraid of the staff. For example, an HIV-positive mother who had decided to keep her baby was afraid of being chased away by the doctors if she returned to the clinic. Another woman described how on a follow-up visit she could not find the right staff member and was too afraid to ask anyone in case she got reprimanded in front of the other pregnant women. This woman never returned for further follow-up sessions.80

- Research suggests that the South African health care system is characterized by highly coercive relationships between programme providers and service users, particularly between nurses and their clients. Findings from research found that HIV-positive women who chose to have a child ran the risk of being judged by the health care worker.81 Two-thirds of the research participants from an informal settlement in the Western Cape (South Africa) reported that the health care worker had advised them to formula feed. These women had not received information about the different feeding options. Other studies have found that health workers influenced 80% of the women’s feeding choices. This suggests biased and subjective counselling, leaning in the direction of formula feeding.82 It also suggests that interpersonal communication in medical setting is an important site for communication interventions given this powerful influence. This is discussed further under the heading, strengthening PMTCT through interpersonal communication.

- Nurses are primarily schooled in a medical discourse where value is attached to compliance to evidence-based medical interventions, rather than individual rights. For example research in Pietermaritzburg (South Africa) showed that women who, for whatever reason, choose not to breastfeed in contexts where exclusive breastfeeding is promoted run the risk of being discriminated against and judged by nurses providing information and advice.83 Some counselors in research conducted in Durban (South Africa) were found to be judgmental and coercive when counselling mothers around breastfeeding.84 Staff members have been found to take over decision making for women. For example, staff force women to test their infants and coerce women into medically preferred decisions. Paternalistic and punitive approaches have also been reported, for example, some women have been denied ARV treatment for not remembering the names of certain medications while being prepared for treatment.858687

- Support group leaders use their position of power and an advisory bio-medical approach (again, with preferred outcomes) to discourage HIV-positive women who want a child from doing so. In these cases options are not discussed with the women leaving them ill informed. Research in Kenya found that the health care workers gave directive counselling for HIV-positive women that discouraged women from having children.88

- Research in a resource poor setting in the Eastern Cape (South Africa) found that clients fear a lack of confidentiality amongst counselors.89

- In Faith Based Organizations (FBO) limited extensive family planning counselling might not be offered due to religious perspectives on sexuality.90

7.1.3 Poor quality of counselling and information

- The uptake of testing and PMTCT services is low in sites

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79 (Thorsen, Sunby, & Martinson, 2008)
80 (Painter, Diaby, Matia, Lin, Sibailly, Kouassi, et al., 2004)
81 (London, Orner, & Myer, 2008)
82 (Petrie, Schmidt, Koonhof, & Marias, 2007)
83 (Seidel, 2000)
84 (de Paoli, Mkhwanazi, Richter, & Rollins, 2008)
85 (Kgabe, 2008)
86 (Sorgie & Crankshaw, 2008)
87 (Stevens, 2008)
88 (Baek et al., 2005)
89 (Peltzer, Msolola, Shisana, Nqueko, & Mngqundanis, 2007)
90 (Rutenberg & Baek, 2004)
Where counselling is of a poor quality. 91 94

- Poor counselling often results in the transmission of incomplete knowledge, which can impede on the effectiveness of PMTCT programmes.93 94 Research in South Africa, for example, found that while the communication skills of counselors were good the mother’s knowledge remained low post-counselling. Observations of counselling sessions found that in only 32% of the sessions were inaccurate beliefs corrected by counselors. It was further found that the counselors did not adequately assess which feeding practice was most appropriate for the client they were counselling. Only 12 out of 34 clients were told about the risks of MTCT and only 3 of these clients were asked whether they had access to clean water. Only 13 of the 34 clients were asked if they had a partner and if they knew their partner’s status. While the counselor explained the advantages of disclosure, only 7 of the clients were encouraged to make a decision during the session. The advice given to mothers about their different feeding options was patchy and they were often left to make decisions on their own. On the whole, only 9% of the mothers were asked if they knew the meaning of exclusive breastfeeding and not one was asked if they thought it was a feasible option. Only 7 out of 15 HIV-positive mothers who chose to formula feed were given instructions on where to collect further supplies of formula, 5 of these mothers were given the opportunity to reconsider the feeding option and only 5 were asked if they had previously prepared formula and then provided with instructions. The counselors did not discuss with the mother how they would explain the decision to not breastfeed to their partner or family.95

- Another study in the Eastern Cape (South Africa) found that while knowledge about MTCT was relatively high, knowledge about PMTCT was low. There was very little knowledge around exclusive breastfeeding and formula feeding.96 Similar findings emerged from research conducted in Botswana, Kenya, Malawi and Uganda. Here it was found that 70% of health workers were unable to correctly transmit risks of breastfeeding after training. Infant feeding options were only mentioned in 48% of the counselling sessions and discussed in detail in only 5.5% of these sessions of which 54.3% were rated as poor by the observer.97

- In another study that explored the effect of a PMTCT programme on infant feeding in South Africa, none of the healthcare workers could correctly estimate the risk of spreading HIV through breast-feeding and many reported feeling confused about what they should tell mothers.98

- It is suggested that the avoidance of infant feeding in PMTCT counselling might reflect the counselor’s own confusion about infant feeding practices.99 It is suggested that some mothers might experience being told that they can breastfeed, but for only 6 months as contradictory and confusing.100 Low levels of general MTCT knowledge and breastfeeding in particular have also been found in rural India, rural Zimbabwe and Nigeria.101 102 103 Further research in Botswana confirmed significant gaps in the information given by counselors about PMTCT.104

- The uncertainty around breastfeeding has also served to increase the power and influence of health workers who act as gatekeepers to knowledge and resources like formula feeding.105

- Research in South Africa indicated that despite IUD contraceptive use being safe for HIV-positive women, some family planning service providers would not administer an IUD because they believed it increased the risk of HIV/STI infection. This highlights the need for, and perhaps lack of, refresher training amongst counselors and health care workers.106

- Research in Botswana found that counselors had different ideas about what information was crucial to commu-
nicate to HIV-positive pregnant women. When asked what was important, there were a number of varied responses and there was only agreement on two areas: the evaluation of ARV treatment and using condoms. Disturbingly only 30% of the nurses and midwives interviewed thought that PMTCT should be addressed in a counselling session with HIV-positive pregnant women and only 11% thought infant formula should be discussed. While the counselors fared better, there was still reason for concern. While 69% of the counselors thought PMTCT should be addressed only 11% thought infant feeding should be discussed.

- Respondents in a study in Uganda suggested that the trainers responsible for running PMTCT information workshops may not have appropriate training skills and may use language and terminology that is unfamiliar to the target audience who may therefore not understand important aspects of PMTCT.

7.1.4 Inadequate family planning services and counselling

- Research in South Africa suggests that family planning policies may not be adequately sensitive to gender-related issues and that individual women may be overemphasized in comparison to men and to couples.

- Research in South Africa reports inadequate male involvement in family planning. Men are likely to feel intimidated by the large number of women attending regular family planning sites and there is a lack of male-friendly family planning sites and programmes.

- Promising research in Kenya found that the vast majority of HIV-positive women (72%) indicated that they could talk to their male partner/husband about HIV. HIV-negative women were, however, significantly more likely than HIV-positive women to indicate they could talk to their male partner/husband (93%). HIV status, therefore, may have implications for family planning as disclosure of status is needed to initiate a discussion of whether or not to have a child.

- Research in Uganda found that 73% of individuals practicing pregnancy risk behaviour did not want a child and were at a high risk for unwanted pregnancies. 42% of the participants were sexually active and 18% of these participants expressed a desire to have a child.

- Research in Kenya found that most of the participants who had been sexually active in the last month had unmet family planning needs. Research in Uganda and Kenya found the following reasons for wanting to have a child: wanting to leave a lineage, not having either a boy or girl child, not having a child, wanting to add siblings to the family and wanting support in old age. Contraception has been shown to have an impact on the reduction of infant infections. In Kenya men were four times more likely than women to want a child.

- Research in a number of developing countries found that PMTCT sites often miss opportunities to provide clients with family planning services. In Zambia, for example, it was found that while slightly more than half the participants in the study received family planning counselling at their first antenatal visit this decreased to 38% among HIV-positive women and 50% among HIV-negative women at their 6 month postpartum visit.

- Research also found that certain FBOs offering PMTCT services exclude comprehensive family counselling.

- Research in Lusaka found that in many sites 98% of HIV-positive and HIV-negative women believe that HIV-positive women should not have a child.

- Research in a number of developing countries found that in low contraceptive and high HIV prevalence settings the family planning needs of HIV-positive women are dealt with by parallel family planning services, but are often not tailored to meet the needs of HIV-positive women.

107 (Baek, Creek, Jones, Apicella, Redner & Rutenberg, 2009)
108 (Chopra et al., 2005)
109 (IMAU & CDC Uganda, 2009)
110 (UNAIDS, FHI, Department of Health (S.A), 2009)
111 (USAID, FHI & Department of Health (S.A), 2005)
112 (Baek & Rutenberg, 2005)
113 (Nakayiwa, Abang, Packo, Lifshay, Purcell & King, 2006)
114 (Nakayiwa et al., 2006)
115 (Reynolds, Janowitz, Wilcher, & Cates, 2008)
116 (McCarragher, Cuthbertson, Kung’u, Otterness, Johnson & Magiri, 2008)
117 (McCarragher et al., 2008)
118 (Rutenberg & Baek, 2004)
119 (Rutenberg & Baek, 2004)
120 (Rutenberg & Baek, 2004)
121 (Rutenberg & Baek, 2004)
7.1.5 Inadequate integration of services

- PMTCT services like VCT are not routinely offered as part of maternal, newborn and child health (MNCH) services in developing countries, that is, PMTCT and ANC services are not adequately integrated.[122, 123, 124] Even where the services are integrated this does not guarantee that family planning happens.[125] It was found in South Africa, for example, that while facilities were providing routine MNCH services, additional follow-up care including infant testing and AIDS care have not been integrated into primary health care services at the majority of facilities.[126]

- Research in South Africa illustrates that PMTCT programmes are often integrated into health care systems that are already understaffed and over pressurized and as a result there are delays in aspects of implementation and in the training process.[127]

- Although there is agreement in South Africa about the need to integrate family planning into PMTCT services due to the urgent need to deal with the family planning needs of HIV-positive pregnant women, there is no agreement on the level of integration required. Service providers have argued that integration requires additional training on the integrated service delivery. Achieving adequate integration of family planning and HIV/AIDS services will involve a number of operational changes including role definition, allocation of time and developing an appropriate referral system.[128]

7.1.6 Poor referral links

- Poor referrals within the health care system and between clinics have a negative impact on follow up visits[129] and on the continuity of care between the different facilities.[130]

- Geographical constraints often undermine the effectiveness of models such as the family oriented approach to PMTCT. For example, while it is possible to reach partners and children living together, it might not be possible to reach a child who is not living with their biological family but with an extended family member.[131]

- In many rural areas there are shortages of telephones and health care workers often resort to communication by sending letters through public transport, which is not reliable.[132] Poor communication between clinics impedes responses to emergency situations, complicates ongoing management, and limits important exchanges of information and referrals between sites.[133]

7.1.7 Lack of communication within the health care system

- Poor communication of PMTCT related policies to relevant health care workers will have a serious impact on the success and scaling-up of PMTCT programmes.[134, 135, 136, 137] In South Africa, for example, research reports that while family planning and HIV/AIDS policies are communicated through workshops, training and meetings, some non-governmental service providers stated that they accidentally discover them or download them from the internet. This suggests that the private and NGO sector, which services 25% of health service users in the country are often excluded from policy training programmes.[138]

- Most PMTCT programmes have also focused almost entirely on PMTCT interventions, while fewer programmes have focused on primary prevention and the prevention of unintended pregnancies. It is suggested that this is partly due to the lack of clear policy and operational guidance on how these issues can be implemented within the context of HIV/AIDS.[139]
• A combination of fear and misinterpretation of UNAIDS/WHO/UNICEF guidelines on infant feeding practices for PMTCT has led to reduced support of breastfeeding despite evidence of its usefulness.\(^{140}\)

• A lack of up-to-date information results in health workers giving poor advice and counselling on important PMTCT practices like exclusive breastfeeding.\(^{141}\)

• Health care workers report that they do not have guidelines to share with mothers to support them in their feeding choices.\(^{142}\)

• A resistance to meaningful collaboration between TBA’s and medically trained health care workers is problematic in contexts where a large number of births take place in TBA sites.\(^{143}\)

7.1.8 Poverty and infrastructure

• A lack of money in low income areas prevent follow-up visits, for example in contexts where transport is needed to reach health care sites, people may not have the money to pay for transport.\(^{144}-^{146}\)

• Clients across sub-Saharan Africa may have to walk considerable distances to clinics due to a lack of money for transportation and the distance between sites.\(^{148}\) In a study in the Eastern Cape (South Africa) it was found that the average time it took a woman to reach the clinic was over an hour.\(^{149}\)

• Financial constraints will often inhibit a woman’s ability to rapidly cease breastfeeding, because she will not have the money to purchase formula feed to replace breast milk, in contexts like Malawi,\(^{150}\) or if a clinic should run out of formula feed, which has been known to happen in the South African context.\(^{151}\) Mothers may not have the finance to continue purchasing formula feed after 6 months when the government stops providing free formula as is the case in South Africa.

• Poor access to government grants denies women in many resource poor contexts the resources to attend clinic follow-up sessions.\(^{152}\)

• Poor transport infrastructure inhibits the up-take of services as people are unable to get to relevant treatment sites.\(^{153}-^{156}\)

• A lack of telephones in rural areas impacts on referrals and general PMTCT delivery. A lack of telecommunications means that health care workers are not able to communicate with each other directly.\(^{157}-^{158}\)

• A situational analysis of PMTCT services in the Eastern Cape found that in rural, underdeveloped areas there may only be one main road, while remaining roads are made of gravel or dirt. These are difficult to cross during rainy seasons. Under such circumstances reaching the clinic may be difficult or impossible.\(^{159}\)

• Research in the Eastern Cape also found that the scattering of villages, lack of transport networks and poor signage made giving and following directions to clinics difficult or impossible.\(^{160}\)

7.1.9 Overlooking the needs of youth

• In South Africa research has indicated that the reproductive needs of youth are not being adequately addressed in family planning counselling. High levels of teenage pregnancies despite educational campaigns and the availability of condoms confirmed for many of the participants that HIV/AIDS had not affected the reproductive behaviour and choices of youth.\(^{161}\)

\(^{140}\) (Ogudele & Coulter, 2003)

\(^{141}\) (Cooadja & Bland, 2007)

\(^{142}\) (de Paoli et al., 2008)

\(^{143}\) (Manzi et al., 2005)

\(^{144}\) (Kagwe, 2008)

\(^{145}\) (Skinner et al., 2003)

\(^{146}\) (Tearfund, 2008)

\(^{147}\) (Jones et al., 2005)

\(^{148}\) (WHO & UNICEF, 2007)

\(^{149}\) (Peltzer et al., 2007)

\(^{150}\) (de Paoli et al., 2007)

\(^{151}\) (Manzi et al., 2005)

\(^{152}\) (Jones et al., 2005)

\(^{153}\) (Kagwe, 2008)

\(^{154}\) (Tearfund, 2008)

\(^{155}\) (Skinner et al., 2005)

\(^{156}\) (Tleber, Jackson, Loveday, Matizirofa, Mbombo, DoHerty, Wigtan, Treger & Chopra, 2007)

\(^{157}\) (Peltzer et al., 2007)

\(^{158}\) (Skinner, Mfecane, Gumede, Hend & Davids, 2005)

\(^{159}\) (Skinner et al., 2003)

\(^{160}\) (Skinner et al., 2003)

\(^{161}\) (USAID et al., 2005)
• In Tanzania school pupils’ knowledge about safe motherhood and MTCT is low, which indicates that there is a lack of interventions addressing reproduction at the teenage level. Many of the participants believed that complications during pregnancy and childbirth were due to pregnancy taboos and a result of not adhering to traditions. Knowledge about birth preparedness, risk factors and postpartum care was very low.162

• In South Africa research has found that rural adolescents are less likely than their urban counterparts to successfully implement most PMTCT related practices. It was also found that HIV stigma, family decision making and cultural norms surrounding infant feeding hampered these adolescent mothers’ attempts to PMTCT.163

7.1.10 Cultural factors

• Research in the Eastern Cape (South Africa) indicates that men play a limited role during their partner’s pregnancy and birth and few attend clinic visits with their female partners, which has serious implications for women who will not attend PMTCT services without the consent of their partner.164

• The phrase PMTCT implies that it is the woman’s primary responsibility to prevent her infant from being infected through MTCT, which undermines efforts to increase male involvement in PMTCT.165

• South African research suggests that traditional birth attendants (TBAs) may not be skilled in PMTCT birthing practices and there is no standardization for TBA training.166 A large number of births across Africa are not attended by medically (and PMTCT) qualified health professionals,167 and many occur at TBA sites as found in Malawi.168

• South African research found that in some cultures it is considered inappropriate for women to disclose their pregnancy to their mother-in-law until the pregnancy shows,169 and research in Lesotho found that there is a general taboo around public acknowledgement of pregnancy.170

• Cultural taboos around talking about sex, impact on the uptake of certain PMTCT services,171 for example, this will inhibit family planning or safer sex discussions.

• Culturally accepted practices around infant feeding may make it very difficult for a woman to adhere to PMTCT feeding options. For example, in contexts where mixed feeding is an accepted practice, rapid cessation of breastfeeding is difficult for mothers to do.172 In Lesotho, for example, it is the man who decides on how long a child should be breastfed and in some contexts this can be as long as 2 years173 and in other settings, Tanzanian families place pressure on women to introduce food to her infant.174 In South Africa young mothers are highly likely to be pressurized by family regarding her infant feeding choices.175

• Social expectations regarding a woman’s child-bearing role influence decisions on childbearing. Pressure from male partners/husbands, family and the wider community can override an HIV-positive woman’s decision not to have a child.176

• In Botswana and South Africa research has illustrated that gender power imbalances have an effect on women’s ability to negotiate condom use with their male partners.177

7.2 Community barriers

7.2.1 Cultural Factors

The many barriers listed in the previous section (Societal barriers – immediately above) also pertain to the community level.

162 Mushi, Mpembeni & Jahn, 2007
163 Varga & Brooks, 2008
164 Skinner et al., 2003
165 Thorsen et al., 2008
166 Skinner et al., 2003
167 WHO, 2007
168 Manzi et al., 2005
169 (Skinner et al., 2003)
170 (Towle & Lende, 2008)
171 (Zambia Central Board of Health, 2004)
172 (Thorsen et al., 2008)
173 (Towle & Lende, 2008)
174 (Burke, 2004)
175 (Thairu, Peltro, Rollins, Bland, Ntshangase, 2005)
176 (London et al., 2008)
177 (Langen, 2005)
7.2.2 The perception of poor social support

- If social support from the general community is perceived to be low this will have a negative impact on the uptake of PMTCT services and adherence to treatment regimens.\(^{178,179}\)
- A women who fears a negative reaction from members of her community for rapidly ceasing exclusive breastfeeding at six months, may choose to carry on breastfeeding even if she is in the position to cease breastfeeding.\(^{180}\)
- Research in rural Burkina Faso has demonstrated that women who perceived a positive attitude from their community were significantly more likely to participate in counselling.\(^{181}\)

7.3 Social network barriers

7.3.1 Stigma

- Women may not access PMTCT services due to a fear of stigmatization\(^{182}\) as actively participating in a PMTCT programme or following specific recommendations makes women’s HIV status public.\(^{183,184}\)
- In contexts where HIV is associated with ‘promiscuous’ behaviour, as is the case in many sub-Saharan African countries, women may be reluctant to test because their partners may end up questioning their faithfulness and because they fear negative reactions from their partners and discrimination from the wider community.\(^{185,186,187}\)
- In contexts of stigma, women have difficulty with disclosure of their status.\(^{189}\) Research in Soweto (South Africa) found that stigma has not diminished and that women fail to disclose to their partners because they fear rejection from both their partner and their families.\(^{190}\) Amongst 31 female disclosure experiences in Johannesburg (South Africa) 91.5% of the participants had told at least one person (usually a partner) voluntarily and within a week of receiving their HIV-positive test results. These primary disclosures were associated with positive responses and experiences. On the other hand, secondary disclosure, which was more often involuntary, was more likely to lead to rejection, stigma and withholding of financial support. This research confirms the influence socio-cultural norms have on disclosure experiences, sometimes creating a safe space for disclosure while at other times making disclosure a risky and difficult experience.\(^{191}\) Research in Botswana also indicates that women fail to disclose to their husbands because of contexts of stigma.\(^{192}\)

7.3.2 Gender related issues and male partner/husband support

- Women in many African countries and other resource poor settings report fears of discrimination, abandonment, rejection, divorce and or physical violence as reasons for not wanting to disclose their positive status to their male partners/husbands.\(^{193,194,195,196,197,198}\) Research in South Africa found that women do not disclose their status because of fear of abandonment and discrimination, even though findings suggest that there are often fewer consequences than expected.\(^{199}\)
- In many developing countries women are often not in the position to make independent choices about their

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178 (Kagee, 2008)
179 (Perez et al., 2008)
180 (Thorsen et al., 2008)
181 (Sarker et al., 2007)
182 (Skinner et al., 2003)
183 (Thorsen et al., 2008)
184 (Kebaabetswe, 2007)
185 (WHO & UNICEF, 2007)
186 (Mlay, Lungina, & Becker, 2008)
187 (Tongwe-Gold, 2009)
188 (Dahl, Mellhammar, Bajunirwe, Bjorkman, 2008)
189 (Rigard, 2005)
190 (Garson, 2005)
191 (Varga, Sherman & Jones, 2006)
192 (Eide, Myhre, Lindbaek, Sundby, Arimi & Thor, 2006)
193 (WHO & UNICEF, 2007)
194 (Zambia Central Board of Health, 2004)
195 (Mlay, Lungina, & Becker, 2008)
196 (Tongwe-Gold, 2009)
197 (Tearfund, 2008)
198 (King, Katuntu, Lifshay, Packel, Batamwita, Nakayiwa, Abang, Bbirye, Lindkvist, Johansson, Mermin & Bunnell, 2008)
199 (Visser, Neufeld, de Villiers, Makin, & Forsyth, 2008)
own health or that of their babies and it is therefore often impossible for women to access PMTCT services without disclosing their status to their partners/husbands.\textsuperscript{200}

- In Nigeria women have reported a number of practices from male partners that inhibit safe motherhood: physical violence, delaying access to obstetric care, encouraging heavy labour to induce birth, unwillingness to use family planning, withholding financial help, and blaming women for complications in pregnancy.\textsuperscript{201}

- Research in Tanzania showed that HIV-positive women whose partners attended VCT were three times more likely to use Nevirapine prophylaxis and six times more likely to adhere to the infant feeding method they selected.\textsuperscript{202} These findings suggest that if a male partner does not know his HIV status or about PMTCT, a woman is less likely to adhere to PMTCT strategies or engage in PMTCT programmes.\textsuperscript{203}

- It has been found that if a male partner disagrees with his female partner’s decision to test she is not likely to test.\textsuperscript{204} The need to discuss whether to test or not with their partner is also a factor that leads to test refusal.\textsuperscript{205}

- Research showed that women who believed their partners/husbands would accompany them to the antenatal clinic and expressed confidence in the fact that they would disclose their status to their partners were significantly more likely to want to get tested. Research in Botswana found that lack of male support prevented women from participating in PMTCT programmes.\textsuperscript{206}

- The majority of South African men do not involve themselves actively in reproductive health care and are not typically involved in consulting with their partners around family planning or antenatal issues.\textsuperscript{207}

- Research in South Africa indicated high levels of anger amongst women at the perceived denial of men of their responsibilities in PMTCT.\textsuperscript{208}

- Research in Uganda indicates that the up-take of VCT is relatively good amongst pregnant women, but not among their male partners/husbands.\textsuperscript{209}

- Childrearing in many African countries, like Malawi, is viewed as being primarily the work of women, a view that is likely to prevent men from accessing PMTCT services or attending visits with their female partners, in turn inhibiting family oriented PMTCT models.\textsuperscript{210,211}

- Research in Johannesburg (South Africa) indicates that male partners/husbands may not see the need for continual follow up visits if their female partner has not disclosed to them.\textsuperscript{212}

7.4 Individual barriers

7.4.1 Lack of awareness and knowledge

- A lack of awareness and knowledge about HIV/AIDS and MTCT in the general population is an ongoing concern. Research in the Eastern Cape in South Africa indicated that knowledge levels about PMTCT are low not only among women and mothers, but also amongst mothers-in-law and male partners/husbands.\textsuperscript{213}

- A national survey in South Africa in 2002 found that 46.8\% percent of respondents demonstrated incorrect or uncertain knowledge about breastfeeding. It also found that respondents had either incorrect knowledge of, or were uncertain about, the causal relationship between HIV and AIDS.\textsuperscript{214}

- A national survey in South Africa in 2005 found that 31.9\% of 12-14 year olds and 23.5\% of individuals 50 years of age or older answered ‘no’ or ‘do not know’ when asked if HIV could be transmitted from mother to child. It also found that 18.7\% of young people between the ages of 12-14 and 11.2\% of adults over the age of 50 years did not understand the sexually transmitted nature of HIV.\textsuperscript{215}

\textsuperscript{200} (Medley, Garcia-Moreno, Gill, & Maman, 2004)\textsuperscript{201} (Adeseye & Chiwuzie, 2007)\textsuperscript{202} (Msuya et al., 2008)\textsuperscript{203} (Kebaabetswe, 2007)\textsuperscript{204} (Sarker et al., 2007)\textsuperscript{205} (Dahl et al., 2008)\textsuperscript{206} (Baiden, Remes, Baiden, Williams, Hodgson & Boelaert, 2005)\textsuperscript{207} (Mullick, Kunene, Wanjiru, 2005)\textsuperscript{208} (Garson, 2005)\textsuperscript{209} (Kizito, Woodburn, Kesande, Ameke, Nabulime, Mugwanga, Grosskurth & Elliott, 2008)\textsuperscript{210} (Tongwe-Gold, 2009)\textsuperscript{211} (Tadesse, Muula, & Misiri, 2004)\textsuperscript{212} (Jones, et al., 2005)\textsuperscript{213} (Peltzer et al., 2007)\textsuperscript{214} (Shisana et al., 2002)\textsuperscript{215} (Shisana et al., 2005)
• Research in the Western Cape (South Africa) found that participants had high levels of knowledge about the transmission of HIV and correctly knew that MTCT was preventable. Only 11% of these participants however, were able to explain exclusive breastfeeding or mixed feeding correctly.216

• A study across South Africa in 2005 found 78.6% of males and 79% of females were aware of a place nearby to get a test. A lack of awareness of available PMTCT-related facilities and services will impact negatively on the uptake of PMTCT services.217,218

• The study also found, however, that 66% of adults and youth believed that they would not get infected. 69.7% of the respondents had not been tested and the primary reason for this was the belief that they were either not positive or not at risk.219

• South African research reports gaps in mothers’ knowledge about PMTCT strategies like exclusive breastfeeding. For example, they received limited advice on how to cease breastfeeding rapidly, showed little understanding about the rationale for rapid cessation and the dangers of continued breastfeeding and they also demonstrated no awareness of risks involved in replacement feeding.220

The literature is confusing around breastfeeding. There is a considerable amount of literature arguing strongly for exclusive breastfeeding for six months while other literature argue for the use of replacement feeding as it is less risky.221 It is suggested that the avoidance of infant feeding in counselling might reflect this confusion about breastfeeding.222 Research in the Western Cape (South Africa) found that the terms that are supposed to be used in counselling about infant feeding, including exclusive breastfeeding, mixed feeding and cup feeding, were not defined correctly by the majority of women. This suggests that not enough emphasis is placed on communicating the different feeding options that are available to women.223

• Research in Burkina Faso found that a lack of understanding about the testing procedure has been found to inhibit people from testing for HIV.224

• Research in Lesotho found that VCT is inhibited by the perceptions individuals have about possible treatment options.225

7.4.2 Confusion and dilemmas around infant feeding options

• An important and recurring finding in the review of the literature is that around the infant feeding practices of HIV-positive mothers. Under the headings ‘poor quality of counselling and information’ and ‘lack of awareness and knowledge’ frequent reference was made to the confusion that exists around the issue of infant feeding and PMTCT.

• According to the South African policy on PMTCT infant feeding counselling should take into consideration the specific circumstances of each pregnant woman or mother so that an appropriate infant feeding choice is made. The AFASS (acceptability, feasibility, affordability, safety and sustainability) criteria should be used to help the woman to decide on an appropriate feeding practice. The recommended feeding options for the first six-months are exclusive breastfeeding or exclusive formula feeding.226 In a study in Tshwane, Pretoria (South Africa), 74% of the women planned to formula feed despite the fact that only 30% of these women had access to piped water, that the median per capita income amongst the households was R320 and that 76% of the women were unemployed. The study stated that the large majority of the women in the study were influenced to formula feed by the counselling they received, suggesting that the AFASS criteria are not being used to assist women in this area to make appropriate infant feeding choices.227

• In the case of pregnant women and mothers who choose to formula feed the South African policy states that formula should be given to the mother for free for a pe-
period of six months.\textsuperscript{228} The implication is that mothers (or their families) will have to purchase formula feed after the 6-month allocation of free formula. In the case of breastfeeding the policy states that HIV-negative babies should be exclusively breastfed for a period 6 months followed by rapid cessation. If the infant subsequently tests negative and there is no food security the policy states that exclusive breastfeeding should continue until the AFASS criteria are met or when the child reaches the age of 1.\textsuperscript{229} WHO also recommends cessation of breastfeeding at 6 months and the continuation of breastfeeding in cases where replacement feeding is not feasible because of, for example, financial constraints or lack of access to clean water.\textsuperscript{230} This approach is further supported by leading South African scientists.\textsuperscript{231}

- The review of the literature highlights a level of confusion around infant feeding and breastfeeding in particular. The discussion confirms that programme managers, counselors and pregnant women continue to be confused and suggests that even at the level of scientific debate a certain level of polarization between those practitioners who believe in avoidance of all breastfeeding among HIV infected women, versus those who acknowledge the importance of the counselling approach to help women choose the most appropriate feeding option continues to exist. The low levels of knowledge and awareness of infant feeding options reported in the research confirms that there is a need for clarity on the issue. Counselors either avoid the topic in counselling sessions or push women in a particular direction and as a result women are given inadequate knowledge to make an appropriate infant feeding choice. There is clearly a need for scientists and practitioners to work together to develop clear guidelines and a consistent message based on scientific evidence that is contextualized within the cultural norm and household setting.

7.4.3 PMTCT practices that are perceived as discriminatory

- HIV testing is a practice that is generally associated with high-risk groups. Active, opt-in counselling and testing is likely to be avoided by pregnant women who may not identify with high-risk groups, or fear being associated with a high-risk group. \textsuperscript{232}

- Exclusive breastfeeding for the first six months of an infant’s life may not be in line with general breastfeeding practices nor with cultural norms and complying with this practice, therefore, often makes it impossible for women to hide their status, a major concern for women within a highly stigmatized context. \textsuperscript{233}

- In contexts of economic constraints and food insecurity, receiving food parcels, for example, after PMTCT visits is likely to lead to assumptions of an HIV status by other community members. In such contexts, women run the risk of being stigmatized and resented at the same time. The matter is further complicated by attempts to hide these incentives to protect an HIV-positive woman’s right to privacy. Such attempts on the part of programme providers may be misunderstood as colluding with the idea that being HIV-positive should be kept a secret.\textsuperscript{234} In a study in South Africa high levels of stigma towards people with HIV, and in particular mothers accessing free formula, forced mothers to hide their formula feed.\textsuperscript{235}

- Home visits by PMTCT programmes are likely to expose a woman’s HIV status who then risks becoming the object of gossip by surrounding community members.\textsuperscript{236 237}

7.4.4 Psychological barriers

- Fear of death, fear of HIV testing and results and fear of reactions to a positive status are reported psychological barriers to PMTCT services like VCT and disclosure of status. \textsuperscript{238 239 240 241 242 243}

\textsuperscript{228} (Department of Health (S.A), 2009)
\textsuperscript{229} (Department of Health (S.A), 2008)
\textsuperscript{230} (de Paoli et al., 2008)
\textsuperscript{231} (Coovadia & Bland, 2007)
\textsuperscript{232} (Thorsen, et al. 2008)
\textsuperscript{233} (Thorsen et al., 2008)
\textsuperscript{234} (Thorsen et al., 2008)
\textsuperscript{235} ( DoHerty et al., 2006)
\textsuperscript{236} (Thorsen et al., 2008)
\textsuperscript{237} (Eide et al., 2006)
\textsuperscript{238} (Peltzer et al., 2007)
\textsuperscript{239} (Burke, 2004)
\textsuperscript{240} (DoHerty et al., 2005)
\textsuperscript{241} (Dahl et al., 2008)
\textsuperscript{242} (King et al., 2008)
\textsuperscript{243} (Kebabetswe, 2007)
• Denial of HIV status and a sense of hopelessness are additional psychological barriers. 244
• Shame has also been reported as a reason for not returning for follow up visits. 245

8. Key participants to be reached through communication strategies

The discussion of the barriers that impede the success of PMTCT programmes highlights that a number of key participants, rather than just HIV-positive pregnant women or mothers, should be the focus of PMTCT communication strategies. This is in line with the model of communication for social change, which highlights the role of dialogue and collective action to bring about a set of shared objectives. From such a perspective it is not appropriate to identify individuals to be targeted as though they are objects of change waiting to be fed information. Emphasis should rather be placed on developing relationships among relevant participants, who through cooperative action are able to bring about relevant change at both individual and social levels.246

The aim of communication should be to connect and mobilize people around a common cause.247 Within the context of PMTCT the following participants should be connected through participatory activities and dialogue to develop an integrated and consolidated approach to strengthening PMTCT programmes. A communication strategy that builds synergy and collaboration can position the PMTCT programme on a stronger structural footing.

8.1 Societal participants

8.1.1 Health care workers in rural and urban sites

This should include the full range of health workers identified across the literature discussed above, for example: HIV managers, programme directors, administrative staff, Doctors, nurses, lay counselors, full-time counselors, supervisors and mentors.

Communication occurs at two interrelated levels with these participants. Firstly, they are actively involved in communicating important PMTCT information to programme clients. The literature has shown how health worker attitudes and interactions and their levels of knowledge can become barriers that impede the success of PMTCT programmes. Secondly, these participants are themselves in need of up-to-date information and ongoing training to ensure that they provide quality information and advice to their clients in a non-judgmental and non-discriminatory way.248

8.1.2 Representatives from various clinics, hospital sites and services

The discussion of the literature suggests programme managers, clinic managers and health care workers need to consult with each other.

The literature discussed above shows that a lack of communication between different treatment sites and a lack of integration of various services (ANC and family planning with PMTCT) inhibit the success of PMTCT services. This indicates that there is an urgent need to bring representatives from the different sites and service areas together to participate in the development of communication strategies that will allow for consistent, integrated and comprehensive treatment of clients across sites and services.

8.1.3 Relevant government departments and policy makers

The discussion of structural barriers in the literature indicates that various departments need to be engaged around PMTCT strategies, for example: The Department of Health and relevant sub-directorates within the HIV and AIDS division, the Department of Communication, the Department of Social Development and the Department of Transport.

244 (Tlerebe et al., 2007)
245 (Painter et al., 2004)
246 (Figueroa et al., 2006)
247 (Stackpool-Moore, 2006)
248 (PAH0, WHO, UNICEF, CENSIDA, & Mexico, 2002)
Communication for social change recognizes that there is an intimate link between individual and social change.\(^{249}\) The literature has shown that a number of contextual factors act as barriers to the implementation of PMTCT programmes. Poor health care infrastructure, staff shortages, a lack of telecommunications, poor access to government grants and poor transport networks have all been identified as impeding the success of programmes. Linkages with government partners are therefore crucial in order to create channels for governments to respond to these important social issues.\(^{250}\) Communication with various government departments can contribute towards securing appropriate levels of government expenditure\(^{251}\) on PMTCT programmes. Further, the Department of Health is responsible for the development of policies that guide the implementation of PMTCT programmes. Communication channels between the Department of Health and various health workers need to be encouraged and strengthened to ensure that they are informed about policy changes and relevant guidelines for the PMTCT. Involving the Government is recognition that communication is not just the task of outreach campaigns, but that communication has various social and political sources that need to be integrated into a comprehensive strategy.\(^{252}\)

Research on family planning in South Africa also highlights the lack of guidelines for interdepartmental collaboration in policy execution. For example, while condoms may be promoted by the Department of Health they are not promoted by the Department of Education.\(^{253}\)

8.2 Community participants

8.2.1 Community outreach workers

The literature discussed identifies a number of individuals involved in community outreach that need to be engaged with. Examples here include: Support group leaders, mentors, peer educators. A perceived lack of community support, limited support from male partners/husbands, and high levels of stigmatization are factors that will have a negative impact on women’s abilities to adhere to PMTCT components such as exclusive breastfeeding for six months and attending follow-up sessions at clinics regularly. Community outreach workers such as support group leaders, home-based mentors and peer educators play a crucial role in communicating essential information within a context of care and support. These volunteers are in need of up-to-date information, resources and training\(^{254}\) to ensure that they are able to provide accurate information and psycho-social support.

8.2.2 Community organizations

The literature highlights the potential value of engaging with FBOs, NGOs, CBOs, women’s organizations (including organizations that work around gender violence) and men’s organizations. Community-based organizations are able to communicate important information through already established social networks and assist in overcoming some of the problems of inadequate transport infrastructure\(^{255}\) by offering necessary services in decentralized ways. Despite these advantages they can become a barrier to effective PMTCT strategies. For example, FBO’s might not provide comprehensive family planning because of its beliefs about sexual behaviour. Youth may not be taught about contraceptives and unmarried discordant couples may not be given safer sex options to ensure that the HIV-negative partner is not infected or to avoid an unintended pregnancy. So while community organizations can facilitate communication through already existing networks, they are also in need of up-to-date information and training to ensure that an ideological agenda is not put before a preventative agenda.\(^{256}\)

8.3 Social networks

8.3.1 Influential community members

\(^{249}\) (Vincent, 2006)  
\(^{250}\) (Vincent, 2006)  
\(^{251}\) (Vincent, 2006)  
\(^{252}\) (Shisana et al., 2008)  
\(^{253}\) (UNAIDS et al., 2005)  
\(^{254}\) (Vincent, 2006)  
\(^{255}\) (Vincent, 2006)  
\(^{256}\) (Vincent, 2006)
The literature discussed above highlights the importance of engaging key community members in PMTCT communication. Examples here include: Spiritual leaders, community leaders, respected elders, TBA’s.

The literature highlights that there are a number of cultural factors that can impact negatively on PMTCT programmes. Cultural beliefs about infant feeding and child bearing, about the role of men in child rearing and taboos around talking about sexuality all have the potential of undermining the success of preventative measures. In addition, stigma continues to perpetuate fear and discrimination in contexts where HIV/AIDS is linked with high-risk groups and behaviours. Spiritual leaders, community leaders, traditional leaders, traditional healers and TBA’s are important sources of social communication.257 It is important to partner with these individuals, to equip them to actively communicate information that contributes to a supportive and enabling context for PMTCT and that works towards normalizing HIV/AIDS. This supportive context will make it much easier to adhere to PMTCT practices that would otherwise be seen as alien to a particular community.258 Engagement of influential community members also ensures that communication occurs from within existing social networks, rather than being imposed from without and is sensitive to cultural beliefs. These members will require information and supportive training to ensure that they communicate accurate information and work towards developing social norms that will facilitate the PMTCT.

8.3.2 HIV-positive women’s families

The literature discussed above highlights the importance of engaging with the extended family, children, family-in-law, male partner/husband and supportive friends of HIV-positive women who are pregnant or are mothers.

The literature shows that many women are reluctant to test or to disclose their status because they fear rejection from their male partner/husband, their extended family and friends. The research also shows that women are more likely to adhere to PMTCT strategies if they have the support of their male partners/husbands in particular. It is therefore crucial for PMTCT programmes to create communication networks throughout the family system rather than focusing their communication on the mother alone. The family health model, which focuses on the entire family rather than just the mother, is one way in which these supportive links can be developed within family units.260 261 262 Communication between women and their male partners/husbands will contribute significantly to women’s uptake of and adherence to PMTCT services and interventions. Further, men, in particular, are in need of information about PMTCT interventions like exclusive breastfeeding to foster support for PMTCT interventions that their female partner may have to adopt.

8.4 Individual participants

8.4.1 HIV-positive men and women (rural and urban)

The literature discussed above highlights the importance of a social network of support for infected women who may be pregnant or wanting to have a child and therefore highlights the importance of targeting both HIV-positive men and HIV-positive women who are pregnant or who are not pregnant.

HIV-positive women who are pregnant and women who are of a child bearing age are often considered to be the ‘primary targets’ of PMTCT communication strategies. While a pregnant mother may transmit HIV to her child vertically if she does not adopt PMTCT practices the literature as a whole suggests that she, alone, should not be the primary target of PMTCT information. HIV-positive mothers need to be supported to seek PMTCT services and to adopt PMTCT practices by creating a social network of support.263 It is particularly important to involve the male partner/husband as he himself may be in need of treatment and can

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257 (Shisana et al., 2005)
258 (PAHO et al., 2002)
259 (Scalway, 2002)
260 (USAID no date)
261 (Horizons, 2009)
262 (Tongwe-Gold, 2009)
263 (DoHerty et al., 2003)
be instrumental in encouraging his female partner to seek appropriate PMTCT services. This should extend in an integrated fashion to the broader family (see below).

8.4.2 HIV-negative women and men (rural and urban)

The literature discussed above highlights the importance of avoiding primary infection and unintended pregnancies amongst men and women of a reproductive age, male and female adolescents, and older men and women. Engaging with these groups also ensures a wider network of social support for HIV-positive women.

Primary prevention of HIV transmission is an important component of PMTCT services and youth need to be addressed around prevention measures. Although negative women and men (both young and older) may not be seen as an important target for information on PMTCT programmes they do in fact play a crucial role. One study found that there was a positive correlation between women who had been exposed to HIV education at school and HIV knowledge when tested at an antenatal clinic. This highlights that HIV prevention education is important at the high school level and may increase the chances of a women seeking out PMTCT services when she does fall pregnant. Other studies have also highlighted the importance of communicating MTCT and PMTCT information to youth at school level. Other research has found that youth can be important advocates for PMTCT in their family if they are knowledgeable about it. There are other studies, which highlight the importance of educating the general population about PMTCT to harness greater support for mothers having to adopt PMTCT practices. Older women who may provide support for young mothers are therefore also in need of information about PMTCT. The literature highlights that people of all ages and from all localities need to be included in communication strategies as there tends to be poor programme reach amongst people who are 50 years or older and an urban bias with poor reach in rural areas.

9. Key PMTCT message themes to be communicated

Embedded in the literature are a number of key message themes that should be the focus of PMTCT communication strategies. The importance of bringing people together to mobilize them in cooperative social action around the cause of PMTCT highlights that all the message themes should, with minor exceptions, be communicated to all of the key participants to be reached.

The following message themes have emerged from the literature:

9.1 Societal level

9.1.1 Caring, non-judgmental and non-discriminatory attitudes and actions

This message should be communicated widely but, more specifically, to health care workers who have in some contexts been reported to delay or even prevent HIV-positive clients from receiving necessary medical care. It has also been reported that in some contexts health-workers, fearing infection from treating an infected woman, send the woman away from hospitals to be delivered by a TBA. It is important to communicate to health care workers the extent of the influence they have on the decisions that pregnant women and mothers make. Two-thirds of the research participants from an informal settlement in the Western Cape (South Africa) reported that the health care worker had advised them to formula feed. These women had not received information about the different feeding options. Other studies have found that health workers influenced 80% of the women’s feeding choices. This suggests biased

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264 (PEPFAR, 2004)
265 (Gupta et al., 2007)
266 (Shetty et al., 2008)
267 (UNICEF, 2002)
268 (Eide et al., 2006)
269 (Almoroth, Dinh Quang, This Thug Hou & Williams, 2008)
270 (Shisana et al., 2005)
271 (Skinner et al., 2003)
272 (Moore, 2003)
273 (Moore, 2003)
274 (Petrie et al., 2007)
and subjective counselling, leaning in the direction of formula feeding. 275

9.1.2 Sexual and reproductive rights of HIV-positive women

The literature points out that the South African health system is one of the most coercive systems, where women are often forced into complying with medically accepted advice. It is essential that the general public and health workers are aware of the rights of HIV-positive pregnant women and HIV-positive women who are not pregnant, especially their sexual and reproductive rights. 276 277 278 279 280 281 282 283 284

9.1.3 Importance of family planning

Family planning options are important to discuss with HIV-positive women and their male partners/husbands so as to avoid unintended pregnancies and to ensure that those who do want to have children are advised appropriately. Research confirms that there are couples practicing high pregnancy risk behaviour who do not want a child 285 and that the importance of dual protection 286 needs to be communicated to avoid both unintended pregnancies and HIV infection. 287 Research confirms that there is an unmet demand for family planning information 288 289 and that counselors need to be trained to be sensitive to the needs of HIV-positive women and to respect her right to make an informed decision about having a child or not and the desire to involve their partner in the decision making process. 290 Counselors also need to be trained to make referrals to family planning services and the counselors should themselves be trained to inform women about family planning options. 291 There is also a need to provide youth with friendly comprehensive sexual and reproductive health education. Youth have a right to comprehensive and unbiased information whether it be through sexuality and HIV education programmes or whether it is through family planning or sexual health clinics. 292

9.1.4 Testing approaches for pregnant mothers

There are a number of debates in the literature around various testing models to increase the uptake of PMTCT services. These various models need to be investigated and debated by relevant policy makers and programme managers (with other relevant stakeholders) and the decisions communicated unambiguously and consistently to relevant health care workers. ‘Op-out’ models have been found to increase the uptake of services and therefore challenge the accepted practice of active voluntary ‘opt-in’ testing. 293 There are debates about the ethics and possibility of mandatory testing in countries like Botswana 294 that may need to be engaged with in other countries at some point.

9.1.5 Importance of a family centered model for health 295

The literature confirms that women are more likely to adhere to PMTCT practices in contexts of familial support. The family health model for PMTCT should be communicated to all PMTCT sites. This model focuses not only on the mother, but other members of the family including the male partner/husband. This ensures greater male involvement in PMTCT. 296

\[275\text{ (Petrie et al., 2007)}\]
\[276\text{ (Seidel, 2000)}\]
\[277\text{ (Cooper, 2008)}\]
\[278\text{ (Kgwele, 2008)}\]
\[279\text{ (Farlane, 2008)}\]
\[280\text{ (Sorgie & Crankshaw, 2008)}\]
\[281\text{ (Stevens, 2008)}\]
\[282\text{ (UNICEF, 2009)}\]
\[283\text{ (Pillsbury & Mayer, 2005)}\]
\[284\text{ (Byakuzwe, Jones, Starrs & Sorkin, 2008)}\]
\[285\text{ (Nakayiwa et al., 2006)}\]
\[286\text{ (USAID et al., 2006)}\]
\[287\text{ (Mahendra, Mudoi, Oinam, Pakkela, Sarna & Panda, 2007)}\]
\[288\text{ (Rutenberg & Baek, 2004)}\]
\[289\text{ (McCarraher et al., 2008)}\]
\[290\text{ (Rutenberg & Baek, 2004)}\]
\[291\text{ (Mahendra et al., 2006)}\]
\[292\text{ (International HIV/AIDS Alliance, 2009)}\]
\[293\text{ (Nuwagaba-Biribonwoha, Mayon-White, Okong, & Carpenter, 2007)}\]
\[294\text{ (Clark, 2006)}\]
\[295\text{ (Horizons, 2009)}\]
\[296\text{ (Sonke Gender Justice Project, 2008)}\]
9.1.6 Importance of on-going support for mothers

Research has shown that mothers who are regularly informed on feeding practices and supported tend to report higher levels of optimism than those who do not receive on-going information and support. It was found that the counselor also reported higher levels of optimism by providing the regular information and support. This highlights the importance of communicating the need for ongoing support from counselors, health professionals, male partners/husbands and peer mentors/educators.

9.1.7 On-going training of health care workers to ensure quality services

Up-to-date information has to be channeled to relevant participants. Ongoing, onsite training, mentoring and supervision are essential to ensure that information reaches relevant participants.

9.1.8 Integrated ANC, PMTCT, postnatal care and family planning services

The literature highlights the importance of integrating services that, in combination, can contribute to a decrease in MTCT. These include ANC, PMTCT and family planning services. It is important to highlight that meeting the contraceptive needs of HIV-positive women requires that health workers and counselors are trained to seek out and understand the fertility preferences of these women and to counsel them effectively on their reproductive choices. Informed choice counselling is essential and care needs to be taken not to coerce HIV-positive women into particular reproductive decisions.

9.1.9 Information on feeding options and need for counselling

The literature discussed has confirmed that there is currently substantial confusion and low levels of knowledge about the significance of different infant feeding options. In particular the knowledge levels on the importance of exclusive breastfeeding tend to be low. Information imparted must be clear, unequivocal and up-to-date. The literature also confirms the need for ‘objective’ counselling that assesses the suitability of the different feeding options for each mother and the importance of providing information that will empower mothers to make an informed choice about a feasible and sustainable feeding option.

There is also a need for policy information to be communicated to all relevant programme directors and health care workers. There is an urgent need for scientists and practitioners to engage with each other and to come up with appropriate recommendations and clear and consistent messages around infant feeding options. A recent WHO technical consultation, for example, ended its considerations with the recommendation that there should be a revitalization of breastfeeding promotion and support even in areas with HIV prevalence. Researchers are also arguing for the importance of considering the appropriateness of formula feeding in contexts of poverty. It is also clear that all counselling on infant feeding options should be contextualized to the particular socio-cultural circumstances of the individual mother.

9.1.10 Up-to-date information about programme implementation

Important data needs to be communicated to the programme managers and other relevant participants. Relevant information includes, inter alia, PMTCT coverage per area.
the mortality rate and cause of death in these areas, the 
number of people receiving antenatal and postnatal care, 
the number of people being tested and the number of ex-
tended family members being tested. This information has, 
in the literature, been termed ‘information for action’ as it is 
on the basis of this information that necessary steps can 
be taken to improve programme success.\textsuperscript{308} It will also 
be important to document HIV-free survival of children 
born to HIV infected mothers and share this information 
with managers of PMTCT programmes and those in-
volved in direct service delivery. The value and importance 
of facility level data for programme management and 
for reinforcing health worker practice is often neglected. 
This undermines data quality but also disconnects health 
workers from any sense of achievement and alignment with 
programme goals. Data provides feedback to staff on the 
outcome of their work and motivates them to take respon-
sibility for the functioning of programmes.\textsuperscript{309}

9.1.11 Relevant policies and changes in 
policies

One of the barriers to effective implementation of PMTCT 
is the lack of communication of new policy decisions and 
changes in policy to relevant managers and health care 
workers. It is, however, important for the general public to 
be informed about current policy. This information is cru-
cial to the delivery of effective and up-to-date PMTCT ser-
vices and the promotion of informed access to services.\textsuperscript{310}

9.1.12 Socio-economic and infrastructure 
constraints on PMTCT uptake\textsuperscript{311}

It is important to communicate to the relevant participants 
that there are major 
socio-economic constraints that limit the ability of wom-
en to access and adhere to PMTCT services and practices 
like regular-follow up visits. The literature has shown that 
in certain contexts, particularly rural areas, poor telecom-

unications, poor transport infrastructure and the inability 
to access grants make it impossible for women to benefit 
from PMTCT services. Programme managers need to 
better understand the social circumstances of mothers.\textsuperscript{312}

9.1.13 The importance of partnering with 
relevant NGO’s\textsuperscript{313 314 315 316 317}

Where there are limited service sites NGO’s can play a cru-
cial role in communicating essential information about 
PMTCT and offering certain PMTCT services; for example, 
offering counselling and testing.\textsuperscript{308} \textsuperscript{318} 
This requires in-
creased collaboration and communication between Gov-
ernment and NGOs. Opportunities exist for creative col-
laboration between the public health sector, facilities, local 
communities and service users in overcoming social and 
structural barriers to programme implementation and 
maintenance.

9.2 Community level

9.2.1 Beliefs around reproduction, 
childbirth and childrearing\textsuperscript{320}

The literature shows that there are a number of cultural, 
traditional and religious beliefs that are likely to act as barri-
ers to the uptake of PMTCT services. Men play a significant 
role in decision making and traditional feeding practices 
and childbearing practices can run counter to the advice of 
PMTCT services. This highlights that, firstly, information 
needs to be communicated to clients in a way that is sen-
sitive to cultural beliefs and practices\textsuperscript{314} and, secondly, that 
these cultural practices should be engaged with and debated 
at a wider level within relevant spaces. For example, spiri-
tual leaders and community leaders can challenge the idea that it is only women who are responsible for PMTCT. This is in line with the principles of communication for social change that works towards taking debate and dialogue beyond behaviour to social norms and culture to create a supportive environment for health enabling decisions.

9.3 Social networks level

9.3.1 Importance of male support and engagement

It is important to communicate that women would like their male partners/husbands to know the results of their test. A study in Ghana, for example, indicated that 92.6% of women would like their male partner/husband to know the results of their tests. It is particularly important to communicate to women that despite fears of abandonment, violence and divorce there are research findings that show that there are far fewer adverse consequences than expected after disclosure to a male partner/husband. It is also important to inform health professionals that women adhere to treatment plans more if they have the support of their male partner/husband. Research in Kenya found that involving men in a pilot PMTCT programme led to a significant increase in the number of men who made use of the VCT services. Research in KwaZulu-Natal (South Africa) found that men had shown a desire to be involved in antenatal care, but did not feel skilled to do so. This highlights the importance of engaging with men around their supportive roles. There should also be some discussion around the terminology of PMTCT and emphasis should be placed on the idea that just because vertical transmission occurs between the mother and child, it should not be the sole responsibility of the mother to prevent transmission. For example, India makes use of the term PPTCT (Prevention of Parent to Child Transmission of HIV) to emphasise the role of the parents rather than just the mother.

9.3.2 Disclosure skills

The literature confirms that women who disclose their HIV-positive status to their husbands are far more likely to seek out PMTCT services and to adopt and adhere to PMTCT practices. Disclosure is also very important for discordant couples so that decisions can be made on how to ensure that the uninfected partner is not infected. Counselling should communicate skills and advice on disclosure.

9.3.3 Gender equity and women’s rights

The literature shows that there are a number of complex issues around gender that can impede the success of PMTCT programmes. Women are often dependent on their partners and without their permission are not likely to test or to access PMTCT services. Women in relationships characterized by unequal power relations are less likely to be able to negotiate the use of condoms. There is a need to ensure that messages about the rights of women and the importance of gender equity be integrated into PMTCT communication strategies. This is particularly important in a context where there are high levels of violence against women.

9.4 Individual level

9.4.1 Key components for prevention at an individual level

It is important to communicate the importance of early ANC visits, the different treatment options for PMTCT, the obstetric (OB) practices that can reduce the chances
of MTCT and the importance of a skilled TBA if a woman chooses to have her child outside of the formal health care sector. It is also important to communicate about birthing preparedness to ensure that appropriate actions are taken for PMTCT. The importance of a continuum of care and ongoing follow-up visits for mother and child need to be communicated and the need for follow-up visits with both the mother and the father of a newborn child. Messages about OB practices, for example, should not just be channeled towards mothers-to-be, but to families and the public to create wider social awareness about PMTCT.

9.4.2 Accurate facts about HIV/AIDS, MTCT and the PMTCT

The statistics discussed under the heading ‘lack of knowledge and awareness’, under ‘barriers to PMTCT’, confirms that although many people may have some general knowledge about HIV/AIDS they tend to have very limited knowledge about MTCT and the PMTCT, which can act as a barrier to PMTCT programmes. It is essential that all relevant participants are equipped with this information and that the general awareness of HIV/AIDS and PMTCT is increased widely. The discussion of the literature above identifies the following specific areas around which information needs to be communicated:

- MTCT transmission routes.
- Infant feeding options including exclusive breastfeeding, exclusive formula feeding and mixed feeding.
- Early cessation of breastfeeding.
- Formula feeding and related terminology.
- The causal link between HIV and AIDS.
- The sexually transmitted nature of HIV/AIDS.
- The risk of infection.
- The various PMTCT strategies.
- The availability and location of PMTCT services.
- VCT and the testing procedure.
- Treatment options.

9.4.3 Importance of knowing your status

This is particularly important for the primary prevention of infections, but essential for pregnant women or couples wanting to have a baby. The benefits of HIV testing, information about the testing procedure and the location of testing service needs to be communicated. Research has shown that women who knew their status were more likely to modify risky behaviours and were likely to change these behaviours out of concern for infant health and transmitting the virus to others. This highlights that alongside communication on the importance of testing, the specific benefits of testing for the well-being of one’s infant should be communicated. Research found that male participation in VCT was low for partners of both HIV-positive and negative women.

10. Best practices

The following broad contextual factors have been identified in the field of HIV/AIDS communication and also specifically from PMTCT communication approaches, as contributing towards planning and implementing successful HIV/AIDS communication campaigns:

- A relatively free and open media.
- An active civil society.
- An engaged political leadership.
- A critical analysis of the epidemic, which moved beyond sexual behaviour to explore relevant contextual factors,
including gender issues, discrimination and poverty that contribute to the spread of HIV.

- Open dialogue through personal communication networks.
- Harnessing local expertise.
- A multi-sectoral response.

In 2002 a Communication for Development Roundtable came to the disturbing conclusion that despite evidence that highlights the effectiveness of responses that prioritize collaborative and community participation, communication responses to HIV/AIDS are too often driven by donor demands, tend to be short-term, narrowly focused and largely uncoordinated. Participants at the round table were concerned with the fact that externally conceived and vertically imposed processes characterize communication responses to the HIV/AIDS epidemic. 352

A 10-year (1998-2007) systematic review of HIV/AIDS mass communication campaigns confirms that there is still a strong preference for communication campaigns based on behaviour change theories. The review reports on a shift from raising awareness to changing behaviour, but makes no comment on the need for campaigns to focus on social transformation to create supportive contexts for behaviour change. 353 The systematic review also gives the impression that publications based on social change and participatory approaches, tend not to meet the inclusion criteria for such reviews by virtue of their design and/or analysis. For example, a recent review of community-based-initiatives directed at youth found that only 8 of the 96 studies fulfilled 3 or more of the inclusion criteria.354 We argue that the integrative approaches to communication should be as rigorously evaluated as the less multi-dimensional behaviour change approaches, as it is the rigor of the evaluation methodologies rather than the qualities of the programmeme evaluated that excludes them from consideration in meta-analyses.

The roundtable concluded that there is a need to work within the UNAIDS framework that identifies five contextual domains on which communication strategies should focus:355

- Government policy.
- Socio-economic status.
- Culture.
- Gender relations.
- Spirituality.

The roundtable further recognised the value of the communication for social change approach and in conclusion made the following two recommendations regarding communication in the context of HIV/AIDS:356

- Challenge donors and international organizations to recognise the importance of social change communication over and above behaviour change strategies.
- Community ownership, participation and debate need to ensure that local community agendas are placed above those of donors and international organizations.

A UNICEF analysis document identified the following aspects of better practices in PMTCT communication strategies in Zambia, Rwanda, Thailand, India, Nigeria and South Africa. It was highlighted that due to a number of barriers there was no one country that met all the criteria for better practice in PMTCT communication, but by identifying those aspects of better practice an overall better practice strategy can be developed. The following aspects were identified:357

- Community-based PMTCT research: Identifying, through community-based research, potential barriers to PMTCT services and addressing them before offering PMTCT services. This may be done using innovative research methods like narrative workshops, to identify the contextual factors that either promote or inhibit the uptake of PMTCT services. Research findings are used as the foundation on which communication strategies are designed.
- Community participation: The development of communication strategies needs to encourage high levels of community participation and should include various stakeholders including: traditional healers, home-based care givers, lay counselors, care and support groups,

352 (Scalway, 2002)
353 (Noar, Palmgreen, Chabot, Dobransky, Zimmerman, 2009)
354 (World Bank, 2009)
355 (Scalway, 2002)
356 (Scalway, 2002)
357 (UNICEF, 2002)
men’s groups, women’s groups, and youth groups.

- **Team counselling and a caring atmosphere**: A compassionate and welcoming environment and quality individual and group counselling (maintained through a peer review process, ongoing training, management and supervision/) enhance people’s experiences of and desire to access PMTCT services.

- **Counselling training**: Ongoing training improves counselor confidence and job satisfaction, which in turn increases PMTCT programme interest and uptake.

- **Community preparedness**: Inclusion of community preparedness activities to introduce and sensitize communities to the benefits of various PMTCT services.

- **Youth advisory groups**: Youth advisory groups are included to ensure that PMTCT communication interventions are interesting and appropriately focused at youth. Some areas have made use of youth camps to ensure that at least one youth per household is informed about HIV/AIDS/PMTCT information. These youth act as PMTCT advocates within their families.

- **Consistent PMTCT messages**: This highlights the importance of evidence-based, clear and consistent messages around various aspects of PMTCT including infant feeding options.

- **Improving attitudes of health workers**: Introspective sessions have been built into some training programmes to encourage health workers to explore how they feel about treating HIV-positive clients and why they feel this way. This contributes towards creating a less stigmatizing and discriminatory environment for clients.

- **Community dialogue**: Community partnerships foster dialogue and collaboration within the community. Community members identify positive aspects of their community and how existing social problems are successfully dealt with. The community receives accurate information about HIV/AIDS and PMTCT and is mobilized to create more caring and supportive environments.

- **Overall planning for PMTCT communication**: Community-based qualitative and quantitative research is used as the foundation for the development of tailored PMTCT communication strategies.

- **Communication teams**: A multi-sector, team approach is used to ensure communication activities are implemented appropriately and in a timely manner. These teams include a number of stakeholders, including members from various community organizations, PWHA, religious leaders, local opinion leaders and members of the private sector.

- **An integration of services**: A key global lesson is the importance of integrating PMTCT into routine ANC service delivery.

## 11. Strategies for strengthening PMTCT

### 11.1 Societal level

#### 11.1.1 Media communication strategies

While a large portion of this review has dealt with interpersonal and community communication, less has been said about the role that media can play in promoting PMTCT. Most South Africans access mass communication media a few days or more a week. Research in 2005 found that in South Africa exposure to radio is the highest, followed by television, newspapers and magazines. Further research confirmed that television reaches the greatest number of South Africans followed by national radio, local radio, community radio and local community events. The research explored the impact of 19 AIDS communication programmes in South Africa. The reached ranged from 4% for participation in the government’s Khomanani campaign and The Journey community radio drama to a high of 65% for the television drama Soul City. Mass media is, therefore, an important vehicle through which important PMTCT information can be channeled.

A qualitative analysis of HIV/AIDS media coverage shows that newspapers in South Africa can be used more effectively to communicate information about HIV/AIDS related issues. Newspapers tend to deliver responses that are based largely on occurrence of events and the sources of these articles tend to be politicians, bureaucrats and civil society leaders. There is less emphasis placed on finding

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358 (Shisana et al., 2005)
359 (Kincaid, Parker, Schierhout, Connolly, Pham, 2008.)
local stories or linking national, provincial and local issues and rural areas receive less coverage. Only 38% of the articles provided some factual knowledge around HIV/AIDS. Newspapers can clearly play a much more constructive role in communicating important information about PMTCT and the experiences of people living with HIV/AIDS, which will serve to increase awareness and help to decrease stigma and discrimination.

There is, however, reason to be cautious when using mass media as it also has the potential, unless carefully and critically thought through, to reproduce problematic understandings or representations. For example, a discourse analysis of South African newspaper articles on HIV/AIDS found that black African parents and families were problematically portrayed as failing their moral duties towards children, while middle class individuals were portrayed as going beyond their moral duty in the context of HIV/AIDS. Other research has found that the media can be responsible for contributing towards stigma, by for example, making a link between formula feed and being HIV-positive. The media needs to be actively involved in challenging potentially harmful norms rather than reproducing them. There has been a call, for example, for the media to ensure that HIV information and education is more inclusive of and aimed at young men and should aim at disrupting various elements of masculinity that could increase young men’s risk of HIV infection.

Research in South Africa has confirmed that national level mass media HIV/AIDS communication programmes have an indirect influence on HIV status through their effect on several HIV prevention behaviours. This finding challenges the commonly held belief that prevention campaigns are not working in South Africa. There is clearly a need to move HIV/AIDS communication into the public arena in South Africa to increase awareness of HIV/AIDS and PMTCT and reduce stigma.

### 11.1.2 Recommendations

#### Stigma reduction: implications for communication strategies

The literature highlights that stigma undermines the effectiveness of PMTCT programmes. The literature also, disturbingly, points out that few campaigns that have attempted to address stigma have been successful. Despite this finding, it is suggested that it is important to continue to work towards breaking the silence around HIV/AIDS. To do this effectively it is necessary to broaden discussions around HIV/AIDS. Communication needs to move beyond the personal sphere into the interpersonal and public arena to assist in breaking down stigma and discrimination.

The relevance of this statement is confirmed by local research that found that while a number of South Africans are reached by national HIV/AIDS campaigns, they tend to have poor reach amongst those who are 50 or older and are primarily run in urban areas. A number of South Africans report that their information in fact comes from interpersonal communication and community activities rather than campaigns. It was also found that family and friends were sources of information. There is clearly a need to move HIV/AIDS communication into the public arena in South Africa to increase awareness of HIV/AIDS and PMTCT and reduce stigma.

#### Addressing gender equality

Gender relations are difficult to address through interventions and can only be adequately addressed through a combination of communication processes and simultaneous advocacy and social mobilization. The literature highlights that unless gender equality is integrated into PMTCT programme design, issues such as gender inequity will continue to undermine the effective of PMTCT programmes.

The following suggestions have been made on how to address gender equality through communication and social mobilization within the context of HIV/AIDS and PMTCT:

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360 (Spurr, 2005)
361 (Meintjies & Bray, 2005)
362 (Scalway, 2001)
363 (Kincaid & Parker, 2005)
364 (Vincent, 2006)
365 (Vincent, 2006)
366 (Shisana et al., 2005)
367 (Vincent, 2006)
• Work at creating a supportive social environment for the rights of women and girls is essential for improved PMTCT success. This can be achieved by ensuring that females stay in school and receive a quality education, that women are protected from violence and other forms of abuse, that women are not exploited or discriminated against on the basis of their gender and involving young men and male partners/husbands in child care and in ensuring the PMTCT.368

• Make use of existing programmemes and interventions that inform men and women, young and older, about gender related issues, including rights. For example, there are a number of manuals that have been developed that can be adapted for the South African context. Two potentially useful manuals are ‘Working with young women: Empowerment, rights and health’369 and ‘Young men and HIV prevention: A toolkit for prevention’.370

Improved health systems and integrating services

The literature has highlighted a number of systemic factors that are likely to impede the effective delivery of PMTCT programmemes. Integrating health services increases opportunities for the communication of important HIV/AIDS and PMTCT information to a larger number of people who access health services. The integration of services is also likely to encourage participation as routine links to a number of integrated services is less stigmatizing than being referred to one specific service that is clearly HIV/AIDS related.371 An overburdened health care system is also likely to impact on the quality and availability of services. The literature has highlighted how a lack of staff and insufficient treatment sites has prevented people from accessing PMTCT services. Unless these factors are dealt with, the effectiveness of PMTCT services is likely to be undermined.

The following recommendations emerge largely from the literature that identifies and explores barriers to PMTCT programmemes:

• Develop a trained lay counselor network to increase the take up of services like VCT that are often compromised due to a lack of staff.372

• Improved clinic infrastructure (confidential spaces), working conditions, the provision of sufficient equipment and the involvement of staff in decision making processes is crucial to staff retention and efficient programme implementation.373

• Communication channels need to be streamlined to ensure that all policy decisions and clinical protocols are communicated in a timely manner to all relevant health professionals.374 375

• A decentralized approach is important to decrease the number of women who are lost to follow-up due to the fact that they cannot reach treatment sites.376

• Provide 4x4 vehicles, off-road motorcycles and cell phones in areas with poor transport infrastructure and telecommunications have been suggested to improve PMTCT implementation in certain, largely rural, contexts.377

• Develop a continuum of care within the health care system378 and strengthen referral systems within health care sites and between different services.379

• Explore opt-out counselling in antenatal clinics to increase access to and use of PMTCT services380

• Develop male friendly counselling outside of antenatal clinics. Although PMTCT programmemes are important entry points for male involvement in PMTCT the traditional clinic-based approach to harnessing their support and engagement has reached few men.381

• Integrate PMTCT, VCT, ANC and family planning services. Research showed that integration of family planning and VCT services does not necessarily compromise service quality, and that there were in fact financial savings.382 The integration of interventions also serves to reduce stigma and discrimination as a person is not expected to move to different sites or labeled rooms and

368 (UNICEF, 2009)
369 (Promundo, no date)
370 (Ricardo, Barker, Nascimento & Segundo, 2007)
371 (Vincent, 2006)
372 (McKee et al., 2004)
373 (Delvaux et al., 2008)
374 (WHO & UNICEF, 2007)
375 (DoHerty et al., 2003)
376 (Perez et al., 2004)
377 (Skinner et al. 2003)
378 (UNICEF, 2009)
379 (Stevens, 2008)
380 (Spensly et al., 1999)
381 (Msuya et al., 2008)
382 (Family Health Institute, 2007)
also promotes the right to services and increases access to services.383

- Offer training on the integration of family planning and HIV/AIDS related issues.384
- Increase the availability of male friendly health clinics. Clinics that extend opening times to accommodate men who work and clinics that employ male staff have shown some success in increasing the number of men who access VCT.385

11.2 Community level

11.2.1 Media communication strategies

In line with the principles of communication for social change, it is essential to ensure that communication campaigns involve existing community networks and relevant stakeholders. Community involvement ensures internally driven change rather than change that is imposed from the outside by, for example, funders.386 Community dialogue is also a critical element of communication for social change as it is effective dialogue that is said to lead to collective action and relevant social change.387

Research has found that strategies like discussion forums, community discussions, radio listening clubs and awareness training have helped reduce stigma by promoting discussion and awareness of the reality of HIV-positive people’s lives388 and PMTCT programmees have identified media briefs and working with local radio stations and television shows as part of their PMTCT communication strategies.389 390 There are a number of existing guidelines on how to plan and deliver media broadcasts. One such guide ‘Soap operas for social change to prevent HIV/AIDS: A training guide for journalists’ provides guidelines on developing edutainment dramas for HIV prevention amongst young women and girls.391

As pointed out earlier – Newspapers can clearly play a much more constructive role in communicating important information about PMTCT and the experiences of people living with HIV/AIDS, which will serve to increase awareness and help to decrease stigma and discrimination. Community newspapers are very useful communication tools – not only as a source of information, but also as a mirror reflecting community life and values.

An innovative intervention called ‘Women Connect!’ is an example of how developing skills in using media and information communication technology can lead to increased access to health rights information for women, both young and older. This programmeme resulted in a number of innovative media projects including radio broadcasts on family planning, media campaigns on avoiding teenage pregnancies, newsletters and training manuals.392

Some may argue that the use of media and advance technology may not be feasible in a resource constrained setting. There is, however, evidence that carefully planned, low cost broadcasts can be used effectively in resource constrained setting to reach a number of people effectively with HIV/AIDS related media.393

11.2.2 Recommendations

The following recommendations around community level communication strategies have emerged, largely through the literature that has highlighted existing barriers to PMTCT implementation:

- Adopt successful programmees like the Baby Friendly Hospital and community Initiatives to contribute to the increase in understanding of the importance of exclusive breastfeeding.394
- Select and train appropriate peer counselors who have been found to contribute significantly to improved breastfeeding strategies (for example, adherence to exclusive breastfeeding) by providing ongoing support to mothers and providing counselling to extended family

383 (International HIV/AIDS Alliance, 2009)
384 (UNAIDS, 2005)
385 (Sonke Gender Justice Project, 2008)
386 (Programme for Appropriate Technology in Health (PATH), 2006)
387 (Figueroa et al., 2002)
388 (Vincent, 2006)
389 (Zambia Central Board of Health, 2004)
390 (IMAU & CDC Uganda, 2003)
391 (Barker & Sabido, 2005)
392 (Pillsbury & Mayer, 2005)
393 (Myhre & Flora, 2000)
394 (Coovadia & Bland, 2007)
Peer education in antenatal clinics has, for example, been found to feasible, acceptable and sustainable.\(^{395,396}\) Peer education in antenatal clinics has, for example, been found to feasible, acceptable and sustainable.\(^{397}\)

- **Develop mother-to-mother support programmes.** There is research that shows the effectiveness of community based interventions like the mother-to-mother (m2m) programmes,\(^{398}\) where HIV-positive mothers are used as mentors to support other similar women. This programme had a substantial impact on PMTCT, with reports of increased interaction by the mothers and a reduction in the number of HIV-positive children born. It also led to an increase in the number of women who disclosed to their partners and family.\(^{399}\) The m2m programme is based on two main assumptions, firstly, that peer support is an effective model of communication and empowerment and, secondly, that mothers themselves are the best vehicles to provide support to other mothers. Mentors engage in various activities including providing health talks, providing individual and group education and regular support meeting. They are also involved in community outreach programmes that assist mothers in decisions around disclosure and treatment. There was a significant increase in disclosure, treatment and the number of women reporting an exclusive feeding practice. The general well-being of the women who participated was significantly greater than those who did not.\(^{400}\) A similar (pre-existing) programme to m2m called mothers-to-mothers-to-be (m2m2b) involved training recently delivered HIV-positive mothers to share their personal experiences to encourage adherence to treatment, infant feeding and to increase the uptake of PMTCT services.\(^{401}\)

- **Develop interventions aimed at increasing men’s awareness of PMTCT.** Research found that a community intervention that included inviting men to the local clinic for VCT, focusing education at men and providing support groups for women resulted in an increase in spousal communication about PMTCT, in the number of male partners who attended VCT and in the disclosure of results by both partners.\(^{402}\)

- **Conduct community preparedness activities with male leaders and opinion leaders.** Research found that these preparedness activities lead to an increase in the uptake of testing by men when the service was made available.\(^{403}\)

- **Encourage key community members to communicate information about and encourage support of PMTCT, for example, community leaders and spiritual leaders.\(^{404}\)**

- **Develop PMTCT support groups to provide support to newly diagnosed mothers and on an ongoing basis.\(^{405}\)**

- **Develop male-sensitive support groups where men can get support in dealing with issues such as disclosure.\(^{406}\)**

- **Intensive community awareness campaigns on HIV/AIDS and MTCT and related services have been found to increase acceptance of testing and counselling.**\(^{407}\) These awareness campaigns should work towards normalizing HIV and testing in the wider community, which will in turn help to reduce the social stigma that threatens to undermine the success of preventative programmes.\(^{408}\)

- **Use cultural and community events to communicate HIV/AIDS and PMTCT information to the wider community, for example, public meetings, seminars, prayers and wedding celebrations.\(^{409}\)**

- **Use recreational spaces and events to communicate HIV/AIDS and PMTCT information to the wider community, for example, drama, sporting events, market days, existing television and radio shows and home visits.**\(^{410}\) Interactive theater is an example of using drama to encourage community dialogue around HIV/AIDS. It encourages audience participation and discussion.\(^{411}\)

- **Use the ministerial Izimbizo\(^{412}\) to be conducted by the**

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395: (Haider, Kabir, & Huttly, 2000)
396: (Khan, 2007a)
397: (Shetty et al., 2008)
398: (Scorgie & Crankshaw, 2008)
399: (Mothers2Mothers, 2007)
400: (Khan, 2007b)
401: (Moore, 2003)
402: (Moore, 2003)
403: (Sonke Gender Justice Project, 2008)
404: (IMAU & CDC Uganda, 2003)
405: (Moore, 2003)
406: (Sonke Gender Justice Project, 2008)
407: (Perez et al., 2004)
408: (Thorsen et al. 2008)
409: (IMAU & CDC Uganda, 2003)
410: (IMAU & CDC Uganda, 2003)
411: (Programme for Appropriate Technology in Health (PATH), 2006)
412: (Department of Health (S.A), 2009)
Department of Health to raise concerns at the highest political levels and needs regarding PMTCT implementation. This is an especially important forum for community mobilization and advocacy.

- Develop community activities that can be used to increase understanding of and change harmful social, cultural and gendered norms that act as barriers to PMTCT programmes.413
- Develop partnerships with NGOs and other CBOs who can, through their existing networks, alleviate some of the burden on the health care system414 415 and offer services in under-resourced contexts.416
- Develop community capacity by educating various community stakeholders in PMTCT (community leaders, men and women’s groups, spiritual leaders, youth groups, traditional healers, TBAs).417
- Select and train appropriate HIV-positive people as Network Support Agents (NSA). Agents deployed in health facilities have been found to increase linkages between communities, support groups, and other PMTCT related services at the health care and community level. These agents also meet with support groups and people in their homes where they provide counselling and information and make appropriate referrals to services including VCT, PMTCT and family planning. They were also involved in facilitating general community awareness and advocating for accessible and quality services.418

11.3 Social network level

11.3.1 Media communication strategies

Research in South Africa has confirmed that national level mass media HIV/AIDS communication programmes have an indirect influence on HIV status through their effect on several HIV prevention behaviours. This finding challenges the commonly held belief that prevention campaigns are not working in South Africa.419 There is clearly a need to look into the possibility of using mass media communication to support PMTCT interpersonal and community communication strategies.

Radio programmes have, for example, been shown to be effective in changing attitudes towards family planning and increasing spousal communication about family planning.420

And network and dialogue with community elders and leaders to access existing structures and relevant social networks that can support the implementation of PMTCT programmes.421

11.3.2 Recommendations

- Invest in the mother-to-mother plus programme or an adaptation thereof which is essentially a family focused health model that has been found to be successful in enrolling HIV-positive women, partners and children in HIV/AIDS and PMTCT activities. A multi-disciplinary team including physicians, nurses, midwives, counselors, outreach workers, pharmacy personnel has led to remarkable levels client retention.422 This is also an innovative way of involving male partners in the PMTCT process.423
- Research from South Africa highlights the importance of ensuring that family planning addresses gender issues and works at increasing male involvement. One strategy is to engage in a renewed focus on couple counselling.424
- Make use of appropriate communication approaches that encourage men and women to talk about issues like sexuality and gender norms and practices that are potentially harmful to woman.425
- Young men and male partners/husbands should be encouraged to take part in child care and in ensuring the PMTCT.426

413 (International HIV/AIDS Alliance, 2009)
414 (Msuya et al., 2008)
415 (Nair & Campbell, 2008)
416 (Skinner et al., 2001)
417 (Skinner et al., 2001)
418 (International HIV/AIDS Alliance, 2009)
419 (Kincaid & Parker, 2005)
420 (Boulay, Storey, & Sood, 2002)
421 (Skinner et al., 2003)
422 (Tongwe-Gold et al., 2009)
423 (USAID, 2005)
424 (UNAIDS, FHI & Department of Health (S.A), 2005)
425 (Vincent, 2006)
426 (UNICEF, 2009)
11.4 Individual level

11.4.1 Media communication strategies

The Baby Friendly Hospital is a very successful programme that contributes to an increase in understanding of the importance of exclusive breastfeeding. 427

As pointed out in the social network level above, there is clearly a need to look into the possibility of using mass media communication to support PMTCT interpersonal and community communication strategies.

Interpersonal communication within the context of PMTCT largely refers to the communication that occurs through the one-on-one interactions between clients and health care professionals during consultations and through the process of counselling. Research highlights that poor quality counselling and poor attitudes of counselors and health care providers can become a barrier to successful PMTCT implementation.

PMTCT counselling can be seen as a particularly complex form of counselling as it often involves sensitive issues like parenthood, the possible death of an infant, difficult decisions about whether to conceive or not, the negotiation of normative behaviours including infant feeding and childbearing, negotiating safer sex and relationship dynamics and living with an infant who tests HIV-positive postnatally. VCT is, for example, considered to be the cornerstone of most PMTCT services as it is through this process that women find out their status and are encouraged to enroll in a PMTCT programme if they test positive. Giving advice and counselling around PMTCT services and decisions requires very specific training in both communication skills and in the content that will be communicated.

11.4.2 Recommendations

The following specific recommendations have been made, primarily in the research that has identified and explored the barriers to PMTCT, to improve the quality of counselling and interactions:

- Key selection criteria should be used to select appropriate people for PMTCT counselling. 429 430
- Build on existing resources to develop a standardized counselling training programme that can be adapted for different health professionals in line with their specific job descriptions and most importantly to ensure that all partners are using the same training programmes.
- Train counselors and other relevant health workers to communicate information in a non-prescriptive and coercive way. They should be taught to encourage dialogue and debate around relevant issues (including socio-cultural and psycho-social dimensions) and should encourage their clients to ask questions and empower them to make informed choices rather than enforced ones. 431
- Counselling skills should be integrated into the entire health team and all health professionals could be encouraged to be trained in PMTCT by making it a condition for re-registration with their respective Health Board. 432

The following content areas have been identified as relevant for various aspects of PMTCT counselling and should be integrated appropriately into training that is specific to the different types of counselling (VCT, ANC, postnatal, family planning) and supportive dialogue:

- The importance and benefits of women disclosing their status to their male partners/husbands and skills for disclosure. 433 434 Counselling sessions have been found to be successful in helping women disclose their HIV status to their male partner/husband and to encourage him to test. 435 The research finding that there are far fewer adverse consequences than expected when a woman discloses her HIV status to her male partner/husband should be communicated to counselors. 436
- Gender-based violence. Research has found that a range

427 (Coovadia & Bland, 2007)
428 (McKee, Bertrand & Becker-Benton, 2004)
429 (McKee et al., 2004)
430 (UNICEF, 2002)
431 (McKee et al., 2004)
432 (McKee et al., 2004)
433 (DoHerty et al., 2003)
434 (WHO & UNICEF, 2007)
435 (Msuya et al., 2008)
436 (Mahendra et al., 2007)
437 (Visser et al., 2008)
of men’s violent behaviours, including sexual violence, increases the risk of HIV infection and has a number of other impacts on a women’s health. Counselors and other health care providers should receive training on how to deal with such issues.438

- Skills for couple counselling.439

- VCT, which is considered to be an essential element of PMTCT services,440 and the entry point to PMTCT services.441

- Women’s rights442 and more specifically, reproductive and sexual rights. Research has found that health care workers often react negatively to women who become pregnant.443 444

- Up-to-date, consistent and accurate infant feeding information445 446 447

- Family planning that emphasizes the importance of dual protection to prevent pregnancies and (re)infection448 449 and appropriate advice and information for those who desire pregnancy.450 Family planning counselors should be trained to support HIV-positive women in achieving their preferred sexual and reproductive health goals rather than imposing a particular position.451

- The impact of stigma and discrimination on the success of PMTCT programmes.

- Sensitization workshops that encourage counselors to explore their own attitudes and judgments towards their clients are important for reducing stigma and discrimination during counselling and consultative processes.452

12. The current status of the literature and recommended areas for further research

Currently the literature appears to be focused around particular aspects of PMTCT. A large body of the literature, for example, focuses on the issue of counselling and testing. This is an important area of research and deliberation as research across South Africa in 2005 indicated that those who knew their status (positive or negative) were more likely to use a condom with their partner than those who did not know their status. It further found that those who individuals who knew their HIV-positive status tended to use condoms more than those individuals who knew they were negative.446 This highlights that counselling and testing is an important primary prevention intervention and there is a need for continued efforts to encourage counselling and testing.

A considerable amount of the literature focused on barriers inhibiting the success of PMTCT programmes. These barriers exist at the individual level (for example, a lack of knowledge), the community level (for example, cultural practices and beliefs) and the structural level (for example, a lack of adequate health care infrastructure). The range of barriers discussed in the literature highlights the importance of a communication response that ensures that there is a balance between communication focused at the individual level and communication and efforts focused at bringing about social transformation, that is, community oriented behaviour change.452

There is a considerable body of scientific research emerging around the issue of infant feeding. The research reported on in this review confirms that infant feeding is a contentious and confusing issue that is having a significant impact at grassroots level. Exclusive breastfeeding is currently receiving considerable attention as new research findings emerge in support of this as a feasible and sustainable feeding practice in resource poor contexts. There is the further risk that the needs of women who choose to formula feed or for a medical reason have to formula feed will be

438 (Sonke Gender Justice Programme, 2008)
439 (Msuya et al., 2005)
440 (Moore, 2003)
441 (UNAIDS, 2002)
442 (Scorgie & Crankshaw, 2008)
443 (McCarraher et al., 2008)
444 (London et al., 2005)
445 (DoHerty et al., 2003)
446 (Coovadia & Bland, 2007)
447 (de Paoli et al., 2008)
448 (Mahendra et al., 2007)
449 (Moore, 2003)
450 (Sable, Libbus, Jackson, & Hausler, 2008)
451 (Baek & Rutenberg, 2005)
452 (Moore, 2003).
overlooked in the research arena.

Another area that is receiving considerable interest is that of family planning, with a particular focus on the reproductive rights of HIV-positive women. The review suggests that the family planning needs of many HIV-positive and HIV-negative individuals go unmet and that HIV-positive women run the risk of discrimination if they choose to have a child.

The family centered approach to health was a reoccurring theme in the literature, but has not, alongside the reproductive needs of youth, couple counselling and testing and disclosure, received adequate attention.

The following recommended research areas have emerged from the review of the literature as a whole:

- The attitudes and beliefs of men and women about male involvement in family planning and PMTCT.
- The various psychological barriers to PMTCT.
- Cultural and gendered beliefs and practices around childbearing and childrearing.
- HIV/AIDS and PMTCT knowledge of HIV-positive and HIV-negative men and women, male and female youth and health care workers.
- The attitudes of HIV-positive and HIV-negative men and women and health care workers towards HIV-positive mothers who choose to have children.
- The fertility desires and contraceptive practices of HIV-positive and HIV-negative men and women.
- The family planning and PMTCT needs of young men and women of a childrearing age.
- The experiences of mothers who choose to breastfeed or formula feed respectively. In particular the coping strategies of women who manage to adhere to one particular approach exclusively.
- Infant feeding attitudes, beliefs and influences and the mechanisms through which young females learn about infant feeding.
- Infant feeding practices.
- Male attitudes and behaviours that either prevent or promote safe motherhood.
- How family planning services can become more user friendly.
- The level of HIV/AIDS related stigma and discrimination.
- The impact of gender-based violence on PMTCT.
- Male attitudes towards counselling and testing.
- The existence of couple-friendly counselling and the feasibility of introducing more couple-friendly counselling into PMTCT programmemes.
- Ways of increasing perceptions of risks.
- Cultural and gendered beliefs and attitudes towards disclosing HIV status and pregnancy.
- The experiences of HIV-positive women who have disclosed to their partners.
- The quality of VCT and the reasons why people in general do not agree to be tested.
- The mechanisms through which policy is communicated to relevant programmemes managers, health care works and between government departments.
- The mechanisms through which referrals are made between different service providers.
- The level of integration of PMTCT services with other relevant services including new born and child health, treatment, family planning, ANC, counselling and testing.
- The extent to which the family centered model to health is being implemented and the possibility of scaling-up this model.
- The challenges and successes of current PMTCT programmemes.
- The possibility of integrating lay counselors, community health workers and PLWHAs more formally into PMTCT programmemes.
- The views and experiences of those accessing various PMTCT services.
- The current status of counselling training and curriculum development.
- The various infant feeding options including current scientific findings.
- Ways in which mass media can be used to communicate important PMTCT information and increased male support.
• Ways in which community communication strategies can be improved on to ensure that important information reaches a wide variety of people.
• The various sources from which people find out information about PMTCT and PMTCT services.
• Current level of support for HIV-positive men and women.
• The feasibility and possibility of partnering with various NGOs, FBOs and CBOs to improve the availability and uptake of various PMTCT services and to alleviate some of the work-load stress of health care workers.

13. Conclusion

The review of the barriers to PMTCT implementation suggests that an effective PMTCT communication strategy needs to take into consideration three critical elements that characterize the field of HIV/AIDS and PMTCT in an African context.
• There are a range of very specific behaviours that need to occur at the individual level to prevent PMTCT.
• There are a number of cultural and relational dynamics that impact on the effectiveness of PMTCT programmes.
• PMTCT programmes are weakened by wider contextual factors that include social norms, policy related decisions and the quality of the health care system.

In such a context the use of communication strategies driven solely by behaviour theories are neither appropriate nor ethical. The literature confirms that what is needed is an integrated communication strategy that recognises the social complexity of HIV/AIDS and PMTCT.455

The review of the literature of PMTCT in largely under-resourced contexts confirms that the most appropriate communication strategy for effective PMTCT communication is one based on the model and assumptions of communication for social change. This is an integrated model of communication that promotes collective discussion and debate and individual reflection and change, while also recognizing the importance of addressing the complex set of social, cultural, economic and political factors that serve to undermine PMTCT intervention strategies.456 457

The review of the literature confirms that there are a number of barriers that are preventing the successful implementation of PMTCT programmes and that there are critical implications for the design of effective PMTCT communication strategies. The review as a whole recognises that:
• There are a number of key participants that need to be included in the design and implementation of PMTCT communication strategies. Emphasis should be placed on developing an integrated social network of relevant participants who, through participatory activities and dialogue, can engage in the process of developing an appropriate, integrated and synergized communication strategy.
• Pregnant women and mothers should not be the sole focus of communication campaigns. It is clear from the review that unless there is a social network of support, PMTCT programmes are not likely to be effective. Communication needs to be focused at a number of participants to enable a supportive, integrated and pro-active response to the challenges of PMTCT implementation.
• Communication programmes should be focused at all age groups, both genders and should be included in both rural and urban spaces. There is currently a bias towards pregnant women and urban spaces.
• Communication will only be effective in bringing about appropriate behaviour change at the individual level if it occurs within, and supports the development of, a supportive and health enabling context. There is, therefore, a need to work within a human rights framework (with particular emphasis on the reproductive and sexual rights of women), to strengthen the health care system, integrate services within the health care system and address the impact of stigma, discrimination and gender inequity if mothers are expected to enroll in, and stay enrolled in, PMTCT programmes. This highlights the importance of communication with, and between, relevant Government Departments and community based organizations.

455 (Vincent, 2006)
456 (Vincent, 2006)
457 (Scalway, 2002)
• Communication campaigns should invest in strengthening interpersonal, community and mass media communication strategies in a way that ensures integrated and consistent PMTCT communication.

• Communication strategies should be based on the findings of up-to-date participatory research.

The recently released Department of Health Strategic Plan (2009/10-2011/12)458 supports the overall findings of this review and is likely to bolster the effectiveness of PMTCT communication campaigns. The plan demonstrates support for the revival of constructive grass roots level participation in health service delivery. The Department’s Policy and Guidelines for the Implementation of the PMTCT programmeme (2008) also lends support to the design and implementation of an effective communication strategy and further confirms the findings of this review that recognises the role of leadership, partnership and the importance of creating supportive social environments to strengthen the PMTCT programmeme.

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458 (Department of Health (S.A), 2009)
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